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In memory of my mother-in-law, Ruth Medernach.

And in memory of Jonathan Barry Forman—
gentleman, scholar, friend.

"That is no country for old men."

—W.B. Yeats, *Sailing to Byzantium*

"Sir, you are old. Nature in you stands on the very verge of its confines . . . being weak, seem so."

—William Shakespeare, *King Lear*, Act II, Scene 4

" . . . the test of a civilization is the way that it cares for its helpless members."

—Pearl Buck

Introduction

If we judge our society by the care it provides its most vulnerable members, we must find it wanting in some respects. This study finds that much is amiss with the provision and financing of long-term care for elderly people in the United States with respect to both institutional care in nursing homes and care provided in the home.

In the United States, long-term care is provided in congregate facilities and in homes. Home care is by provided by individuals sponsored under home- and community-based service (HCBS) programs financed by Medicaid, a government program financed by the federal government and the states, and by caregivers, many of whom are relatives of the persons being cared for and most of whom are unpaid. The number of elderly persons being cared for at home was estimated in 2019–2020 to be 52.0 million, dwarfing the 2.9 million at congregate facilities.

There are three types of congregate facilities in the United States: nursing homes, which typically offer only semiprivate accommodation (two to a room); assisted living facilities (ALFs), which provide separate apartments for their residents; and continuing care retirement communities (CCRCs), which provide apartments and homes for their residents. ALFs and CCRCs cater to an affluent clientele. Nursing home care is financed largely by Medicaid; however, Medicaid does not finance room and board at ALFs, and plays no role in the financing of CCRCs.

This study identifies six major weaknesses with the current U.S. system:

1) Long-term care coverage is severely limited by the stringent asset and income tests that Medicaid requires for eligibility for nursing homes and HCBS. As a result, the United States does not compare well with other countries in its coverage of the elderly infirm or of their caregivers.

2) Despite their outsized role, caregivers of the elderly at home receive little governmental support.

3) Basic information on some institutions or parts of the long-term care system is not always timely or comprehensive.
4) Medicaid is complex and hard to understand. Many Americans think long-term care is financed by Medicare, which covers only short-term stays. This lack of understanding could leave them unprepared to deal with Medicaid's stringent eligibility tests if and when they confront the issue of financing long-term care.
5) Incentives to rectify shortcomings in the care provided by congregate facilities, especially nursing homes, may be inadequate.
6) The low wages for paid caregivers are a matter of concern.

The chapters that follow in this book assess long-term care in all its aspects, not just institutional care. Chapter 1 discusses how the emergence of nursing homes in the 1930s replaced the poorhouses that had previously housed the indigent elderly. It then addresses the introduction of Medicaid in 1965 and its initial bias toward nursing homes as opposed to care at home. It provides a discussion about the advent of HCBS and the growth of ALFs and CCRCs. Chapter 1 also includes a section on paid caregivers.

Chapter 2 considers the financial arrangements governing the provision of long-term care. In particular, the section on Medicaid explains how the federal government interacts with the states to finance both institutionally based care and HCBS, and the criteria that determine eligibility for Medicaid and share of the costs that it covers. The chapter also discusses the anemic market for private long-term care insurance.

Chapter 3 provides a comparative analysis of long-term care in member countries of the Organisation for Economic Co-operation and Development (OECD). It briefly describes the various models of provision of long-term care and provides thumbnail sketches of the way long-term care is delivered and financed in Canada and in Germany, a country that has been cited as a possible model for the United

States. The Canadian system also has some features that, if adopted, might increase the coverage and also the public financing of long-term care in the United States. The comparative analysis of Chapter 3 is not flattering to the U.S. system.

Chapter 4 addresses the impact of the pandemic on nursing homes in the United States and includes some comparison with Canada, Germany, and the United Kingdom, three other countries for which data are readily available. The losses in U.S. nursing homes before the roll-out of vaccination programs in the winter and spring of 2021 were staggering, and were higher than those of the comparator countries, particularly Canada and Germany.

Finally, Chapter 5 sets out a benchmark for a good system. It compares the U.S. system to it and, as this chapter has already highlighted, finds that the current system falls short of the proposed benchmark in important respects. Chapter 5 concludes by offering three possible directions for reform that are progressively more ambitious but also more politically contentious.

Chapter 1

A Brief History of Long-Term Care

The modern history of long-term care in the United States begins with the establishment of nursing homes as distinct institutions in the 1930s.[1] The next major development was the advent of public support for home- and community-based services (HCBS) in the 1970s. Recent decades have seen the rise in popularity of assisted living facilities (ALFs), which, unlike nursing homes, are typically private pay. Continuing care retirement communities (CCRCs), which, like ALFs, cater to relatively affluent elder Americans began to flourish in the 1970s, and their numbers have grown substantially since then.

The regulatory role of states and the federal government is greatest for nursing homes and HCBS, but it is more limited for ALFs and more limited still for CCRCs. Reflecting this difference in the degree of regulatory oversight, the information available on nursing home residents and the quality of the care they receive is far greater than that on the residents in ALFs and CCRCs. The most recent development in long-term care has been moves by several states toward implementing their own programs of long-term care; Washington State, for example, has introduced a system that is complementary to Medicaid.

Studies of long-term care typically focus on the care that is paid for at least partially by Medicaid, whether provided at nursing homes or through the community. However, these studies are limited by the fact that the number of elderly and disabled Americans who are cared for at home by their families dwarfs the number of elderly Americans living in one of the three types of congregate institutions (see Table 1.1).

Although some of the elderly living at home with family benefit from Medicaid-financed services, caregivers who are relatives

Table 1.1 Residents in Long-Term Care Institutions and Persons Cared for at Home

	Nursing homes	Assisted living facilities (ALFs)	Continuing care retirement communities (CCRCs)	Persons cared for at home
Year reported	2019	2019	2020	2020
Residents	1,246,000	812,000	800,000	52,000,000

NOTE: Some of these statistics are quite uncertain. ALFs do not routinely report resident numbers to their state. The CCRC figure is an educated guess, and the figure for persons being cared for at home is based on a survey.

SOURCE: Nursing homes: Kaiser Family Foundation (2020); ALFs: National Center for Health Statistics (2019) Table VIII; CCRCs: Various sources; Persons cared for at home: AARP (2020a) and author's estimate.

and most other caregivers are almost all unpaid. The total number of caregivers of adults aged 50 years or older in 2019 has been estimated to be as large as 42 million, and the number of adults they care for exceeds that number—an estimated 52 million, a number that is projected to be about 20 times the number in nursing homes, ALFs, and CCRCs combined.[2] Typically, the care recipient is a parent of the caregiver with an average age of 75. Some 45 percent of care recipients are estimated to have multiple health conditions or disabilities (AARP 2020a).[3]

The number of elderly Americans cared for at home is certain to have grown in 2020–2021 in response to the fear of contracting COVID-19 in congregate or institutional settings, especially nursing homes, where occupancy fell by 16 percent between January 2020 and January 2021 (Cottle 2021a). The aging of the baby boom generation will continue to have the same effect. This chapter does not directly address the history of stay-at-home care, but it is important to be mindful of the huge role it plays in long-term care. The next chapter will address the broader economic and financial implications of unpaid caregiving.

THE ESTABLISHMENT OF NURSING HOMES

Before the Social Security Act (SSA) of 1935, most disabled or ill elderly who were not cared for at home were lodged in county- or city-run poorhouses, where conditions were often frightful. A few may have had the comparatively good fortune of living in homes that were established for their religious sect or ethnic community, although even here conditions might be far from luxurious. As Smith and Feng (2010, p. 2) put it, "Long-term care was, in essence, the last holdover of the Elizabethan poor-law approach."[4]

The Old Age Assistance program of the SSA led to the creation of the private nursing home industry by providing funds to states that established residences specifically for the elderly poor while prohibiting funding for residents in poorhouses, a policy that emptied out the poorhouses, at least of their elderly residents. In 1950, the funds from Old Age Assistance began to be paid directly to the nursing homes themselves, rather than to their residents, and nursing homes had to be certified by their state to be eligible for funding.[5] In the mid-1950s, the Hill-Burton Act provided some funding for the construction of nursing homes.[6]

In 1965, Medicare and Medicaid were passed as amendments to the SSA. Medicare, in addition to providing health insurance for Americans aged 65+, covers nursing home stays for short-term or acute care. Medicaid covers long-term stays and unlike Medicare is jointly funded by the federal government and the states. Initially, Medicaid covered only the indigent, blind, and disabled. In addition to being poor, those elderly who were not blind or disabled had to demonstrate a need for assistance with at least one of the activities of daily living (ADLs).[7] In this respect, it might be said that Medicaid was perpetuating the poorhouse approach to the care of the elderly.

Medicaid's provisions are extremely complex. They vary not only from one state to another, but within states depending on the programs offered. In addition to institutional services, the states are

obliged to offer certain home health services to qualifying state residents—namely, part-time or occasional nursing services; home health aide services; and medical supplies, equipment, and appliances suitable for use in the home to qualifying Americans aged 65 or older (Watts et al. 2020).[8]

Other services may be provided at the option of the individual state, and the same state may have different programs covering essentially the same services. As will be explained in greater detail in Chapter 2, Medicaid's coverage was subsequently expanded by the addition of two pathways to the original pathway established by the Johnson administration. The complexity of Medicaid's provisions may partly explain why many Americans believe that long-term care is covered by Medicare, when actually that program covers only short-term postsurgical stays and the like.

Medicaid's initial bias in favor of institutions and against community-based care has been interpreted as an effort to avoid policies that would entail moral hazard, since a genuine need for home care is harder to monitor and ascertain than the need for institutionalized care (Smith and Feng 2010).[9]

THE CURRENT REGULATORY FRAMEWORK FOR NURSING HOMES

The subsequent history of the Medicaid program has been marked by a series of legislative acts to toughen the oversight and improve the standard of care in nursing homes. These acts at times have been enacted in response to publicly voiced concern over the quality of care in the homes. In 1968, the Department of Health, Education and Welfare (subsequently renamed the Department of Health and Human Services), which had assumed overall responsibility for Medicaid's administration, was authorized to set standardized regulations for care and withhold funding from homes that failed to achieve the stipulated standards of care.[10] The Nursing Home Reform Act of 1987 strength-

ened federal standards, inspections, and enforcement provisions; set uniform standards for nursing homes funded by either Medicare and Medicaid; required comprehensive resident assessments; set minimal requirements for licensed nursing staff; and required inspections to focus on care outcomes.

The Affordable Care Act of 2010 included requirements for facility quality assurance, performance improvement programs, and compliance and ethics programs. In 2016, the Obama administration acted to implement these requirements and introduced revamped standards for the assessment of the quality of care of nursing home residents, including those related to infection control, facility assessment, and emergency preparedness. Among other reforms, the 2016 regulations also revised provisions to give more attention to person-centered care (i.e., care that is more tailored to individual residents) and the reporting of abuse and neglect. Additionally, the 2016 regulations added a new section on behavioral health services and required staff competency vetting to determine staffing sufficiency as well as new staff training requirements. The regulations were implemented in three phases between 2016 and 2019 (Musumeci and Chidambaram 2020).

The current regulatory framework requires states to oblige certified nursing homes to provide them with a very substantial amount of information annually on the condition of nursing home residents and the quality of care they receive, in addition to data on the number of beds, residents, and ownership status and size of homes. Nursing homes must also provide data on the number of their residents unable to perform any one or more of the six ADLs, as well as data on basic indicators of health and well-being, such as the incidence of incontinence, pain, and pressure ulcers (bed sores). This information is passed on to the federal government and is published by various agencies.[11]

Improving both the quality of information regarding various dimensions of the quality of care in nursing homes and the effectiveness of measures to rectify problems once they are found has been an ongoing challenge since the beginning of federal and state oversight.

Over the years, several legislative initiatives whose goals included these basic objectives have failed to pass through Congress.[12]

A Summary of Annually Reported Informational Requirements for Nursing Homes with Some Basic Data

Ownership categories, funding of care, and resident population: In 2015–2016, of the nation's 15,600 nursing homes, 69 percent were for-profit, 23 percent were nonprofit private, and 7 percent were publicly owned (National Center for Health Statistics [NCHS] 2019). These shares have not varied enormously in the past 20 years. The nation's 1.4 million nursing home residents as of the 2016 count had declined to 1.2 million as of 2019, according to the Kaiser Family Foundation (2020). Of the total number of residents, 62 percent were funded by Medicaid, 14 percent by Medicare (for short-term stays), and 25 percent by private or other sources (Harrington et al. 2018). As Chapter 4 notes, the number of residents has fallen substantially since 2016 both because of the deaths caused by the COVID-19 pandemic and decisions by potential residents and their families to opt for home care or assisted living.

Quality of care: Nursing homes are required to report shortcomings over a comprehensive list of indicators of the quality of care, considering both the frequency and the severity of the problem. A finding of a specific problem is known as a health deficiency. Over the 2005–2014 period, the most cited health deficiencies pertained to food sanitation, accident prevention, overall quality of care, and infection control (CMS 2015).[13] Depending on the severity and prevalence of deficiencies, a nursing home may lose its state certification. The imposition of such a draconian penalty is rare. In addition to health deficiencies, nursing homes are required to report instances of abuse by nursing home aides, be it physical, mental, or emotional.

A recent report from the Government Accountability Office (GAO 2020) that analyzed data from the Centers for Medicare & Medic-

aid Services (CMS) for 2013–2017 found that 82 percent of nursing homes had been cited for an infection control deficiency. About half of these were cited for one or more consecutive years during this period. However, only 1 percent of the deficiencies were found to be severe, in the sense of posing immediate harm to one or more residents.[14] Another GAO report (2019) on instances of abuse in the same period found that although the incidence was low at the beginning of the period under study, it rose dramatically over the five years. The report also found that information on the type of abuse or its perpetrator was not readily available; therefore, it is fair to conclude that although reporting of health deficiencies is adequate, follow-up appears to be lacking, and the situation for abuse is likely much worse.

THE ADVENT OF HOME- AND COMMUNITY-BASED SERVICES

In the 1970s, efforts began to authorize the use of federal funds for noninstitutional HCBS. In 1970, Medicaid funds could be used for the first time to finance noninstitutional care for the elderly with functional disabilities if those deficiencies would qualify them for nursing home residence (Iezzoni, Gallopyn, and Scales 2019). The SSA was amended to permit federal grants to states for social services programs such as homemaker services, adult day care, and health support.[15] In 1975, amendments to the SSA created Title XX, which consolidated federal assistance to states for social services into a single grant, giving states more flexibility in the allocation of the funds across different programs under the general rubric of HCBS while requiring states to prevent or reduce inappropriate institutional care by providing for these at-home services.

Potential problems with moral hazard aside, home care should in principle impose less of a burden on public finances than institutionalized care, because the beneficiaries of home care remain in

their homes, sparing the federal government and the states the cost of lodging and feeding them. One study has found that states with established HCBS programs achieved lower costs than other states (Kaye, LaPlante, and Harrington 2009). Medicaid expenditure on HCBS began to grow significantly in the 1980s, but waiting lists for the optional HCBS that states offer have lengthened because states can limit the number of persons eligible for the programs offered.[16]

The Americans with Disabilities Act, enacted in 1990, emphasized the importance of integrating people with disabilities into the community and ending exclusion and segregation. Another step was the creation of the Money Follows the Person demonstration program, which aimed to support state efforts to rebalance their long-term services and supports system to emphasize HCBS by giving individuals a choice of where they live and receive services. From the program's authorization in 2005 until 2021, states transitioned more than 100,000 people to community living, amounting to about 7 percent of the number of nursing home residents as of 2008. About one-third of those transitioned were elderly persons; the rest were disabled younger persons. In addition to its obvious benefits for the individuals who returned to the community, the program has saved Medicaid money (Gottlich 2021).

The Affordable Care Act provided additional choices to states aimed at encouraging the improvement of their long-term care infrastructures and expanding HCBS. Its provisions included an extension of the Money Follows the Person program. In addition, for the five-year period beginning January 1, 2014, states were required to apply spousal impoverishment standards—which had been introduced earlier to avoid the impoverishment of the spouses of persons needing institutionalized care—in determining eligibility for married Medicaid applicants receiving HCBS. Prior to this, these standards were applied only to the spouses of nursing home residents.[17]

The number of elderly Americans benefiting from adult day service centers, which is one component of HCBS, was about 300,000 in 2016 (NCHS 2019), with Medicaid financing about two-thirds of

the total cost. By way of comparison, home health agencies—which numbered 12,200 in 2015–2016, and which are almost entirely financed by private health and/or long-term care insurance—had about 4.5 million users in 2016 as measured by the number of patients discharged in that year (NCHS 2019). A substantial share of expenditure on HCBS goes to paying for home visits by doctors and other medical personnel, as well as visits by aides who assist with ADLs. As of fiscal year 2018 (fiscal years end on September 30 of the year stated), the states provided HCBS to about 620,000 elderly persons under their basic Medicaid obligation. An additional 4.2 million benefited from optional programs (Watts, Musumeci, and Chidambaram 2020).[18] With the increased emphasis on HCBS, the share of Medicaid's budget going to institutional care has declined; spending on HCBS surpassed spending on institutional care for the first time in 2013. In 2016, it comprised 57 percent of total Medicaid Long-Term Services and Supports spending (Watts, Musumeci, and Chidambaram 2020).

In addition to paying for in-home visits by doctors and other providers of medical services, a state's Medicaid program may also pay for the services of certain family and non-family members who assist Medicaid-eligible persons with ADLs. In most states, spouses of eligible persons may not be employed in this capacity, but divorced spouses may. Rates of remuneration vary from state to state but are generally at the minimum wage level. Data on the relative roles of paid and unpaid caregivers are not readily available, although it appears that the great majority of these caregivers' time is unpaid (AARP 2020a).[19]

A discussion of HCBS should not conclude without a reference to the Programs for All-Inclusive Care for the Elderly (PACE). PACE began as a single center in San Francisco's Chinatown in the early 1970s aimed at providing home services to older adults who qualified for institutional care but with adequate care could avoid being institutionalized. The original day care center began receiving Medicaid payments in 1974. Under the program, each participant benefits from

care by a multidisciplinary team. The PACE model gradually spread across the country, with each organization acting as a separate nonprofit covering a particular geographical area at a single physical site. In 1990, the first PACE programs received Medicare and Medicaid waivers to operate. By 2019, 130 PACE organizations were operational in 31 states and were serving over 50,000 participants (National Pace Association, n.d.). A fixed sum is paid for each participant, which allows participants to benefit from services not covered under Medicaid's fee-for-service approach. PACE is an optional program under Medicaid: that is, states are not required to offer it.

ASSISTED LIVING FACILITIES

The total number of ALFs in the United States as of 2019 is estimated to be nearly 29,000, with a capacity of about one million beds and number of residents about 812,000 (NCHS 2019). The average number of residents per facility was 28, compared with 86 at the nation's nursing homes. Some 57 percent of the nation's ALFs are chain-affiliated (i.e., related to a group of facilities under the same ownership) (NCHS 2019).

Assisted living centers cater to more affluent elderly people than nursing homes do and are intended for those elderly who want the privacy of their own apartment but typically cannot perform all the ADLs. Apartment units normally have a small kitchen area with a fridge and a microwave for snacks and reheated meals, but meals are usually served in a communal dining room. The residents in ALFs do tend to need less assistance with the ADLs than nursing home residents, and many residents in ALFs may be quite mobile. For example, in 2015–2016, only one in five residents in ALFs and similar residential care communities needed assistance with eating, compared with 6 in 10 nursing home residents. Ninety percent or more of nursing home residents needed assistance with one or more of the other ADLs, compared with 40–60 percent of residents in ALFs and

other care communities. However, ALFs usually also include what is known as a memory unit for residents suffering from Alzheimer's or other dementias, and some 42 percent of residents were diagnosed with one of these conditions, not far below the 48 percent of nursing home residents with that diagnosis (NCHS 2019).

Although residents in ALFs have more living space than the typical nursing home resident, ALFs are less expensive than nursing homes. In 2020, the nationwide median annual cost of a private one-bedroom unit in an ALF was estimated to be $48,000, compared to about $93,000 for a semiprivate unit in a nursing home (American Health Care Association/National Center for Assisted Living 2021). The ALF estimate, however, does not include charges for such extra services as the supply and monitoring of medications, which can exceed $1,000 per month.

A comparison of the make-up of the labor force at ALFs and nursing homes may help explain part of the difference in the cost of the two types of institutions. At nursing homes, nurses at all levels of training accounted in 2016 for 34 percent of the full-time equivalent labor force; at ALFs they make up 16 percent (NCHS 2019, Table VI). Aides, mostly unskilled and low-paid, account for a correspondingly higher percentage of the full-time equivalent labor force at ALFs. The average hourly wage earned by certified nursing assistants is about $14 (Bureau of Labor Statistics 2021). Cottle (2021b) implies that this rate is on a par with the wage paid by Chipotle, the fast-food chain, and it is certainly less than what a nurse would receive.

Similar to the regulation of nursing homes, the regulation of ALFs is split between the federal and state governments. The federal government's involvement is exercised through Medicaid. Although Medicaid does not cover room and board, it may cover personal care services for residents who would be eligible for Medicaid were they eligible for Medicaid coverage in a nursing home.

Ideally, Medicaid should ensure that the elderly and disabled receive care in the setting most appropriate for their needs. An estimated 48 percent of ALFs are Medicaid-certified to be home and

community-based service providers, and about 17 percent of ALF residents rely on Medicaid to cover some aspect of the cost of their daily care. Although most states offer Medicaid coverage of assisted living services, each state administers its Medicaid programs and has some latitude in the programs it will cover, so that beneficiary eligibility criteria and provider participation range from very limited to robust. In any case, Medicaid does not cover room and board, so it plays a relatively minor role in paying for part of the total cost of residence at an ALF, with less than one in five residents at ALFs being covered even in part by Medicaid in 2016. As a result, ALFs will be beyond the means of most elderly Americans.

The financial arrangements of ALF residents are comparatively straightforward. A new resident enters into a rental agreement with the facility, with a term that is typically month to month. However, residents typically have no legal protection from a decision by the facility not to renew an expiring lease, and there are no limits on rate increases. In practice, it is likely that the lease of a resident will be renewed unless the ALF decides that it is no longer capable of caring for that resident because of a deterioration in their medical condition.

As we shall see in Chapter 4, the greater privacy that residents at ALFs enjoy has held down substantially the total deaths caused by the COVID-19 pandemic in these facilities compared to nursing homes. However, a full picture has yet to emerge because, as of mid-2020, the latest date for which data are available, less than half of the states were reporting COVID-19-related deaths in ALFs.

CONTINUING CARE RETIREMENT COMMUNITIES

In the early 1980s, when the first thorough analysis of CCRCs was published (Winklevoss and Powell 1984), there were about 275 such facilities in the country, with about 70,000 residents. Industry sources have reported that the precursors to these communities date back to the early twentieth century, when religious and other

groups established them for their members, who typically financed their membership by selling their homes (GAO 2010). The number of CCRCs has now grown to nearly 2,000, and the number of their residents is believed to number about 600,000 (AARP 2019). As their name suggests, CCRCs provide residents with services that range from separate apartments or stand-alone dwellings with community amenities, often quite luxurious, for those residents who live independently, to assisted living facilities for members needing help with one or more of the ADLs, to the services of a nursing home. The basic appeal of a CCRC is precisely that residents can in principle be assured of exactly the level of care they need without having to move elsewhere. Consequently, stays at CCRCs may be quite long in comparison with ALFs, particularly if the resident of an ALF is deemed to require care that the facility is incapable of providing.

One issue that crops up with any attempt to study or report on CCRCs is the paucity of basic data on their operations. Even the figure just given for the total number of their residents is an educated guess. The lack of data is most likely due to the fact that there is no federal regulatory framework, and that only 38 states have imposed a regulatory framework of any kind on them. The absence of data may be of less importance than it would be for nursing homes because residents at CCRCs are more affluent than the general population in their age group, are in better health, and are likely better able to advocate for themselves. Nonetheless, CCRCs involve some potentially serious financial risks for their residents.

Most CCRCs have three basic payment arrangements, plus a pay-as-you-go rental arrangement. These arrangements each involve a large entrance fee plus an ongoing monthly fee. The difference among them depends on the treatment of health-related expenditure. The largest up-front fee applies when the monthly fee is not affected by the level of health care the resident needs. Once a person becomes a member of a CCRC requiring an up-front payment, she cannot be asked to leave if her health deteriorates, although depending on the contract she signed upon entering the community, her monthly fee may rise.

In 2019, the entry fee for the CCRCs that have one, which represent close to two-thirds of the total, was an estimated $329,000, plus a monthly maintenance or service fee of $2,000–$4,000. The monthly rent for the remaining CCRCs was estimated at about $3,000–$6,000 (AARP 2019).

The financial arrangements of CCRCs are complex, essentially because by accepting someone as a member, the CCRC is committing to ensure care at an appropriate standard for the rest of the member's life. It is thus taking on a complex contingent liability, because neither a resident's length of life nor the quality of care he may need is predictable. The implications of this commitment and the regulatory challenges it poses are explored further in Chapter 2.

THE LONG-TERM CARE PAID LABOR FORCE

The provision of long-term care is a labor-intensive business. According to the Bureau of Labor Statistics (BLS) Division of Occupational Employment Statistics, in May 2020 some 4.6 million persons were employed as direct care workers in nursing homes, other congregate settings, and in the provision of care in community centers and homes. Direct care workers, as the language suggests, provide basic care to elderly and disabled persons in the performance of the basic ADLs as well as other duties. They are normally classified in one of three occupational groups: home health aides, personal care aides, and nursing assistants.[20] There is, however, considerable overlap in their duties. They work in one of three settings: private homes; congregate settings, including ALFs and group houses; and nursing homes (see Table 1.2).

Nursing assistants, most of whom work in nursing homes, assist residents with ADLs but may also perform basic clinical duties (like monitoring blood pressure) under the supervision of a nurse. Home health aides and personal care aides work in the home, community centers, and the other congregate settings noted. The sector also

Table 1.2 The Direct Care Workforce in 2020 (in thousands)

Home care workers	2,400
Residential care aides	675
Nursing assistants in nursing homes	527
Subtotal	3,602
Direct care workers in other industries	998
Total	4,600

SOURCE: PHI (2021).

employs professionally certified staff, of which the largest single occupational group would be registered and practical nurses, as well as doctors and nonmedical professional staff, such as accountants and business analysts.

The three groups are quite similar in their demography: the vast majority are women and persons of color (see Table 1.3). In addition, about 15 percent are non-U.S. citizens (PHI 2021). Hourly wages are low, and median annual incomes are very low compared with average median incomes for the nation's workforce. Part of the reason for this is that many direct care workers work less than a 35-hour week, which makes them part time. Surveys imply that the typical

Table 1.3 Basic Characteristics of the Direct Care Workforce, 2020

	Home care workers	Residential care aides	Nursing home assistants
Number (000s)	2,400	675	527
Demographic (% of total workforce)			
Women	86	81	91
Persons of color	63	53	58
With at least one minor child	23	26	31
Median age	47	37	38
Economic (% of total workforce)			
Working part time	42	23	24
Share without health insurance	17	17	13
Median hourly wage ($)	12.98	13.45	14.48
Median annual income ($)	18,100	22,200	24,200

SOURCE: PHI (2021).

reason for this is "noneconomic," such as poor health or the need to look after children. Home care workers stand out from the other two groups in two respects: their median age is distinctly higher, as is the share who work part time (see Table 1.3). The higher share of home care workers on part-time schedules helps explain the gap between their annual income and that of the other two groups. The educational attainment of the three groups is similar: about half have no more than high school education.

It is important to note that the estimate of the number of home care workers shown in Tables 1.2 and 1.3 does not include home care workers who are directly employed by the "consumer"—the recipient of the care under Medicaid's consumer-directed programs. PHI, an advocacy group for direct care workers and the source for the data shown in Tables 1.2 and 1.3, estimates that these workers may number 1.2 million, but recognizes that the indirect source of its estimate makes it uncertain (PHI 2021).

In light of the low average incomes of direct care workers, it is not surprising that all three classes tend to reply on public assistance in one form or another (see Table 1.4). That reliance does vary somewhat across the three groups, but for all three it is significant. Equally striking is the share of direct care workers who are members of a household that lives below two times the poverty line. Moreover,

Table 1.4 Indicators of Poverty in the Direct Care Workforce, 2020 (% of group population)

	Home care workers	Residential care aides	Nursing home assistants
Living in a household with income:			
1) Below the poverty line	16	13	12
2) Below 2x the poverty line	45	40	41
Receiving some form of public assistance[a]	53	38	34

[a] Medicaid, food, and nutrition (e.g., Supplemental Nutrition Assistance Program or cash).

SOURCE: PHI (2021).

more than 1 in 10 households with a direct care worker live below the poverty line (Table 1.4).

A recent issue brief from the Kaiser Family Foundation (Musumeci, Amula, and Rudowitz 2021) goes beyond the numbers to address the difficulties encountered by both the direct workforce and unpaid family workers. The brief reports on the results of a focus group exercise organized by the Kaiser Family Foundation in the summer of 2021. By its nature, a focus group exercise cannot be deemed to be representative of whole populations. Nonetheless, the sentiments and views reported in this brief are similar to those reported by other sources, including PHI (2020).

Unsurprisingly, direct care workers believe that they are underpaid for the physical and mental demands of their work, although at the same time they take pride in the work they do. Shift workers complain of unpredictable changes in their hours, which were aggravated by the pandemic. Some members of the groups reported that, while they received training at the employer's expense, they did not benefit from wage increases as a result, nor was there any kind of career ladder.[21]

Medicaid payments to nursing homes and to those home care workers who are paid by Medicaid's HCBS programs appear to put a ceiling on the wages that their direct care workers receive. In spite of reported labor shortages, there has been no increase in real wages, which have in fact declined.[22] The demand for home care workers is expected to grow more rapidly than the demand for personal care and nursing aides, in part because of the momentum of the aging in place movement, which has been given a boost by the impact of the pandemic on the perceived attractiveness of nursing homes.[23] Whether this will lead to any increase in the wages of home care workers is uncertain.

THE DEPARTMENT OF VETERANS AFFAIRS' LONG-TERM CARE PROGRAM

The Department of Veterans Affairs (VA) has its own program of long-term care for qualifying veterans.[24] In addition to a retirement pension payable after 20 years of service, there are three classes of benefit for older veterans: the VA Pension, the Aid and Assistance Benefit, and the Housebound Benefit. They have a common service requirement, as well as a common limit on net worth, which in 2021 was $130,773. The VA's measure of net worth includes a measure of income that consists of salary and related compensation, Social Security benefits, and any other pension benefits. The value of a permanent residence, one vehicle, and certain other real assets that are part of a house are excluded from the limit. A three-year look-back period applies to discourage transfers of assets within three years of an application for benefits.

To qualify for a VA Pension, a veteran must satisfy one of the following four criteria: 1) be age 65 or older; 2) have a total and permanent disability; 3) be a patient in a nursing home receiving skilled nursing care; or 4) receive Social Security Disability Insurance or Supplemental Security Income (SSI).

The value of the VA pension is determined by the difference between the maximum annual pension rate (MAPR), which is set by Congress, and countable income, from which nonreimbursable medical expenses may be deducted. The MAPR depends on the number of a veteran's dependents and his or her marital status. Through November 30, 2021, the MAPR for a single veteran was $13,931, and for a married vet or a vet with one dependent, $18,243. The actual payment, which is made monthly, cannot exceed the MAPR, and is reduced to zero if countable income exceeds the MAPR. In 2017, it is estimated that 637,000 vets were receiving the VA pension for at least one month of that year, with a median monthly payment of $1,087 (Giefer and Loveless 2021).

The Aid and Assistance Benefit is made to veterans who require the services of a paid caregiver for ADLs, are bedridden, live in a nursing home and are physically or mentally incapacitated, or have significantly poor eyesight. The Housebound Benefit is made to veterans who have significant difficulty leaving their residence because of a permanent disability. Each of these benefits has a MAPR, which is higher than the VA benefit. For a single vet with no dependents the combined VA and Aid and Assistance Benefit was $23,238; for a married vet or a vet with a single dependent, the benefit was $27,549. The Housebound Benefit falls between the VA benefit and the combined benefit.

RECENT DEVELOPMENTS IN THE PROVISION OF LONG-TERM CARE AT THE STATE LEVEL

In recent years, six states have explored the idea of a program that would provide their residents with some or all the services that Medicaid now provides. Washington State, in fact, has implemented such a program. In 2019, Washington's state legislature passed a program that provides qualifying residents up to $100 per day in support for up to one year, or a total lifetime maximum of $36,500 as a bridge to support from Medicaid. Washington's program does not require that residents meet the income and asset tests that Medicaid imposes, which are described in Chapter 2. Medical grounds for eligibility are the same as those that apply with the state's Medicaid program. The program is financed by a payroll tax of 0.58 percent on all employees including the self-employed. In addition to helping residents aged 65 and older, the program reduces the cost to the state of its share of Medicaid expenses that it would otherwise incur. The program is vested and requires a certain period of contributions, among other conditions, before a resident may become eligible. Full program implementation is scheduled to begin in January 2025, with premium

collection beginning in January 2022. Washington State's program will ease both the burden of those of its residents who require either institutional or home-based care, as well as the burden of Medicaid on the state's finances.

The other five states (California, Hawaii, Maine, Michigan, and Minnesota) are still developing their policies. Hawaii, the furthest along of the five, has reached what has been described as the pre-operational stage (Cohen et al. 2020). Taken as a group, these states are relatively progressive in the sense that their social policy programs tend to be better developed than those of many other states. It is uncertain whether other states will follow their example.[25]

Notes

1. This chapter draws heavily on Kaiser Family Foundation (2015), as well as the other sources noted. This account is not exhaustive, but rather seeks to highlight the thrust of legislative initiatives to establish and broaden the coverage and the quality of long-term care. Private long-term care insurance, which can pay for either institutional or at-home care is discussed in Chapter 2. As a historical aside, the origin of organized social welfare programs can be found in the pension program established for Civil War veterans in the 1870s. In the 1880s, the administration of the program was moved to Washington's magnificent Pension Building, which is now home to the National Building Museum. Lepore (2018), however, traces the dawn of organized social welfare even further back, to the establishment of support by states of the Confederacy for the widows of Confederate soldiers.
2. An estimated 76 percent of caregivers of adults are responsible for one person, with 24 percent caring for two or more (AARP 2020a). The calculation presented in the text assumes that the 24 percent who care for more than one care for exactly two adults.
3. AARP (2020a) presents survey results for caregiving in general. AARP (2020b) addresses caregiving for adults aged 50+. The two publications report the same figures for recipients of care aged 50+.
4. According to Smith and Feng (2010), roughly 2 percent of the elderly population were housed in either local poorhouses or state psychiatric hospitals prior to the establishment of the SSA. As of 2016, the share of the population aged 65+ who resided in nursing homes is estimated to have been about 2.5 percent. The figures are not strictly comparable,

because the figure for nursing homes does not include elderly persons in long-term psychiatric facilities.

The Poor Relief Act of 1601, passed by the English parliament during the reign of Elizabeth I, provided that local authorities (parishes) were to care for the aged, the blind, and those unable to work in an almshouse or a poor house.

5. Private boarding houses tended to reemerge as for-profit nursing homes—a sector that continues even today to serve a larger proportion of the poor elderly population than do nonprofit homes (Smith and Feng 2010).
6. In his classic work *Asylums*, Goffman (1961) includes homes for the aged among what he terms "total institutions." Although his examples are mainly drawn from mental hospitals and prisons, his characterization of a total or closed institution: regimentation, tight scheduling, and doing the same thing every day with the same people in the same places, is unsettling in the way it pinpoints key features of nursing homes then and now.
7. The six ADLs are 1) bathing, 2) toileting, 3) eating, 4) transferring in and out of bed, 5) being mobile, and 6) dressing and undressing.
8. States have the option of offering the following additional home health services: physical therapy, occupational therapy, and speech pathology and audiology services.
9. Strictly speaking, moral hazard may not be the most accurate term. It normally refers to the tendency for insurance of a contingency to encourage behavior that makes the contingency more likely. For example, moral hazard occurs with life insurance if insured persons take up hang gliding or engage in other risky behavior. Here it is essentially referring to the possibility that persons who do not really qualify for home care may falsely claim that they do—that is, dishonesty.
10. In the 1980s, some states made their Medicaid nursing home eligibility and screening policies more stringent to reduce demand for beds. At least 30 states instituted formal preadmission screening programs for Medicaid nursing home placements in the 1980s to ensure that services were needed; this became mandatory with the adoption of the 1987 Omnibus Budget Reconciliation Act (OBRA) nursing home reform legislation (Harrington et al. 1992).
11. These agencies include MACPAC (Medicaid and CHIP Payment and Access Commission), CMS (Centers for Medicare & Medicaid Services), and the NCHS.
12. In particular, the 1988 Long-Term Care (LTC) Assistance Act, the 1988 Life-Care LTC Protection Acts, the 1990 Pepper recommendations, and the 1993 Clinton Health Security Act never made it out of Congress. The Community Living Assistance Services and Supports program

was passed as part of the Affordable Care Act. It was designed to be a publicly administered voluntary program of long-term insurance, but doubts about its financial viability contributed to opposition leading to its repeal in 2013.

13. National Center for Health Statistics (2019) appears to have the most comprehensive data on the number of nursing homes by type of ownership, beds, and the survey information discussed in the previous section. The latest years for which data are available are 2015–2016, although data on the number of residents through 2019 is available from other sources. The Nursing Home Data Compendium (2015) covers the 2005–2014 period (see CMS 2015).
14. Infection prevention and control deficiencies cited by surveys can include situations where nursing home staff did not regularly use proper hand hygiene or failed to implement preventive measures during an infectious disease outbreak, such as isolating sick residents and using masks and other personal protective equipment to control the spread of infection.
15. In 1965, Congress had already passed the Older Americans Act (OAA) in response to concerns about a lack of community social services for older persons. The original legislation established authority for grants to states for community planning and social services, research and development projects, and personnel training in the field of aging. The law also established the Administration on Aging (AOA) to administer the newly created grant programs and to serve as the federal focal point on matters concerning older persons. Today the OAA is considered an important albeit not the only institution for the organization and delivery of social and nutrition services to this group and their caregivers. The OAA also promotes community service employment for poor older Americans; training, research, and demonstration activities in the field of aging; and activities that protect the rights of the vulnerable elderly (Administration for Community Living, n.d.). The act was last reauthorized in 2020.
16. Gleckman (2020) argues that a large number of people are in nursing homes because they cannot obtain the home-based services they need from their state, not that they really need the services provided by a nursing home.
17. Spousal impoverishment safeguards are explained in Chapter 2, on Medicaid financing.
18. The figure for the total number of persons benefiting from optional programs reflects some double-counting, because one person may be receiving benefits under a state program and a Medicaid waiver program.

19. The role of family caregivers is uncertain. Many states, under the Home and Community Based Services State Plan Option allow relatives to be hired by the care recipient. However, only 14 states allow a spouse as caregiver, so that usually an adult child would be paid by Medicaid, if at all. These plans are entitlement plans, meaning that any recipient of care is in principle eligible. Another program, the Community First Choice Program, allows persons who need nursing-home levels of care to get that care at home. Some nine states have adopted this program. Two other programs for consumer-directed care—HCBS Medicaid Waivers and Section 1115 Demonstration Waivers—exist, but these give the states the right to restrict the number of recipients and the relationship of the family caregiver as well as the area of the state in which the program is available.
20. Personal care aides provide other household assistance and assistance to individuals who want to remain a part of their communities. Home health aides (and in some cases, nursing assistants) may perform certain clinical tasks under the supervision, which may be remote, of a licensed professional.
21. The training might be online or in-person and included topics such as safe lifting practices, allergy management, and tracheotomy and gastrointestinal tube care (for nursing aides).
22. The median nominal wage per hour for direct care workers increased from $12.56 to $13.56 between 2010 and 2020, or by 8 percent. Consumer prices actually increased by 17.2 percent (PHI 2021).
23. The aging in place movement has as its principal goal keeping people in their own homes and out of congregate institutions for as long as possible.
24. This section is based on A Place for Mom (n.d.), and Department of Veteran Affairs (n.d., 2021).
25. The vesting and residency requirements of Washington's program would discourage in-migration of non-state residents seeking to benefit from the new program.

Chapter 2
How Care Is Financed

MEDICAID

Medicaid is a program for poor, or relatively poor, elderly (aged 65+ years) and disabled Americans.[1] It is financed jointly by the federal government and the states from general tax revenues, and in this respect differs radically from Medicare, which is financed by payroll taxes, levies by the federal government on taxpayer incomes exceeding certain thresholds, and the premiums paid by persons aged 65+. This chapter's principal focus is on Medicaid's role in the financing of long-term care for people aged 65+, but although persons benefiting from long-term care services and supports amounted to just 5.5 percent of Medicaid beneficiaries in fiscal year 2019, they accounted for close to one-third of Medicaid expenditure (Rudowitz et al. 2021).

Medicaid provides a guarantee of federal payments to match state expenditure and is open-ended in the sense that it has no preset limit; that is, any person who satisfies the eligibility requirements set by the federal government—or, in the case of certain services, by the states that have opted to provide the services—is covered. With Medicare and Social Security, however, the rules that determine eligibility are the same nationwide. With Medicaid, although states are required to offer certain services to be eligible for federal support, the rules for other services may vary from state to state, even within a state, and are determined by the states themselves. Much of the complexity of Medicaid's financial arrangements stems from its joint ownership by the two levels of government and by the critical role played by means-testing in determining eligibility. Means-testing plays no role in either Medicare or Social Security.[2]

The share of a state's Medicaid expenditure paid by the federal government varies according to a formula under which the share var-

ies with a state's relative per capita income. The minimum share is 50 percent of combined federal and state expenditure, and the maximum is 77 percent as of 2021.[3] The minimum a state receives from the federal government is thus one dollar for each dollar the state itself spends. The share paid by the federal government applies to both the programs that the state is obliged to provide (nursing homes and that part of HCBS that is required under Medicaid's terms, as discussed in Chapter 1), as well as optional HCBS programs. The federal-state sharing arrangement has led some of its critics to argue that the states effectively overspend, on the grounds that the marginal benefit of extra expenditure to a state is less than its total marginal cost. These critics contend that a block grant arrangement—where the federal government pays each state a lump sum—would be preferable, because any expansion of benefits beyond the block grant would be entirely financed by the state.[4] However, growing income inequality, which is linked to worsening health as well as increasing health costs, have undoubtedly pressured states to spend more on Medicaid.

Medicaid provides special match rates for the Affordable Care Act's Medicaid expansion, and for administration and other services. A state may also receive a higher percentage for certain services or populations. Medicaid also provides disproportionate share hospital payments to hospitals serving many Medicaid and uninsured patients.[5] The Medicaid expansion that took place under the Affordable Care Act is financed primarily with federal dollars and accounts for a relatively small share of total Medicaid spending. As of April 2021, 12 states continued to opt out of the expansion of Medicaid under the Affordable Care Act, despite the small share of the additional cost they bear.

Notwithstanding Medicaid's cost-sharing arrangements, state spending on Medicaid as a whole amounted to about $225 billion in FY 2019, which is a sizeable share of state tax revenues. In an effort to reduce the burden that their share of the cost of Medicaid entails, states have reduced the coverage of HCBS programs or reduced expenditure per capita on these programs and the services they are

obliged to provide under Medicaid. Enrollment tends to increase during recessions, when states' revenues are declining and tends not to reverse that increase with economic recovery, which adds to the pressure on states to hold down expenditure per capita.

ELIGIBILITY FOR MEDICAID'S INSTITUTIONAL AND HCBS COVERAGE[6]

The share of the population that is eligible for Medicaid has grown substantially in recent years. Originally, its coverage was restricted to aged, disabled, and blind persons who had qualified for SSI, which was 74 percent of the federal poverty line. The growth in coverage reflects both the inclusion of additional elements of the population and the adoption of less restrictive but certainly not generous means tests. In the 38 states and D.C. that have now opted to participate in the Affordable Care Act's expansion of Medicaid in 2015, virtually all state residents whose incomes do not exceed $17,775 per year as of 2021 (which was 138 percent of the federal poverty level for a single person) are covered at the state's option.

Medicaid relies on an income test as well as an asset test to determine eligibility for both health care and long-term care.[7] The income and asset limits included in the original legislation apply to what is known as the Aged, Blind, and Disabled pathway, which covers the original group to be eligible for Medicaid. The original income limit equaled 74 percent of the federal poverty line, but some states have the option to increase the limit up to 100 percent. The income test excludes income from government programs, as well as a small part of earned income.[8] As of 2018, the monthly income limit for all 50 states and D.C. ranged from $528 in Connecticut to $1,164 in Hawaii for an individual, with a median value of $750, and from $696 to $1,578 for a couple, with a median value of $1,125. In about half of the states, the limit for a single person fell to between $700 and $800 (Musumeci, Chidambaram, and O'Malley Watts 2019).[9]

The asset limit for an individual ranged from $1,500 in New Hampshire to $7,560 in Arkansas, and for a couple, from $1,500 in New Hampshire to $11,340 in Arkansas. Most states impose a limit of $2,000 for individuals and $3,000 for couples. The limits appear to be low, but they exclude the value of an applicant's primary residence (up to a value of $560,000, or as much as $840,000 at the option of the state), one automobile, and personal property and household belongings.[10] These exclusions effectively make the asset test a limit on financial assets, not real assets, for most older Americans. The treatment of retirement plan balances under the asset test varies from state to state: a few states exclude them entirely. Warshawsky and Marchand (2017) estimate that in 2010, some 71 percent of retirement plan assets were countable toward Medicaid asset tests.

For older Americans in need of long-term care, two other pathways to Medicaid eligibility are available that broaden the program's coverage considerably. The first of these is the special income rule, under which 42 states and D.C. have chosen to increase the income limit to three times the standard payment for the SSI, or three times $794 or $2,382 per month in 2021. An asset test that for most states is similar to the test for the Aged, Blind, and Disabled pathway also applies.[11] The income limit of the special income rule is considerably higher than the limit applying under the original program and also higher than the limit that may be applied by states that opted for the Affordable Care Act's expansion of coverage, and three of every four Americans aged 65 years and older are residents in states that offer this pathway.[12]

The second pathway of eligibility is the medically needy pathway, which provides some coverage for applicants whose medical expenses take up a large share of their income. Thirty-four states have opted for this program, 26 of which have chosen also to apply the special income pathway.[13] Its income test is based on a monthly income limit that each state sets. Applicants whose income exceeds that limit are not eligible through this pathway unless they are able to show that they have incurred medical expenses that equal or exceed

the difference between their current monthly income and their state's monthly limit over a stipulated period that ranges from one to six months, depending on the state.[14] Monthly income limits for an individual in 2018 ranged from $100 in Louisiana to $1,041 in Vermont. The median value for an individual was $488. Limits for a couple ranged from $192 in Louisiana to $1,372 in Illinois. The median for a couple was $559.

The application of this rule is complex, and an example of how it might be applied may be helpful. Consider an individual applicant with a monthly income of $2,800 and who is a resident of West Virginia, where the monthly income limit is $200 and the budgetary period is six months. The applicant would have to incur $15,600, or ($2,800 – $200) × 6 in medical expenditures to be eligible for Medicaid's coverage on additional expenditures for the remainder of the budgetary period. To take another example, suppose an individual has a monthly income of $6,500 in a state with a monthly income limit of $500. With a budgetary period of six months, the individual must incur medical expenses of $36,000, or (6 × $6,000), before Medicaid would cover excess expenditures for the remainder of the budgetary period. Once that period ends, the whole procedure must begin again. This second example makes clear that the relief the medically needy pathway offers drops significantly with increases in income.

Any American who satisfies the asset test and whose income falls below the limits set by the original Medicaid program or the special income test is effectively insured by Medicaid against the risk of requiring long-term care. The fact that many older Americans can expect to rely on financing from Medicaid should they need long-term care conceivably may reduce the incentive they have to save for their declining years. Nonetheless, nursing home residents are expected to contribute most of their income to defraying the costs incurred on their behalf before Medicaid kicks in.[15] They are allowed only a small personal allowance. If only a little money is remaining after the nursing home takes its share, the sharing rule may be inflicting hardship. How much discretionary income a nursing home

resident would require over and above what is needed to cover food, other basic living expenses, and the cost of care is an important issue. In the case of a nursing home resident with a spouse, rules are in place to avoid the spouse's impoverishment because of large long-term-care expenditures on behalf of his or her chronically ill spouse.

The financial arrangements for Medicaid's coverage of long-term care differ substantially from those of Medicare's coverage of short-term illness or disability. All Americans aged 65 or older who qualify for Social Security and pay their share of the payroll taxes that finance it and Medicare are eligible for Medicare. Medicare Part A, which covers hospitalization, is normally free of charge. Part B, which covers the fees of doctors and other health care providers, requires a premium that varies with income. Part C, which is known as Medicare Advantage, provides coverage through HMOs and several other vehicles, and can substitute for Medicare Parts A and B. Part D is a prescription drug program provided by private plans. It includes a catastrophic coverage limit. Mackenzie (2020) offers a summary description of the whole program.

Unlike the risk of exposure to health care costs of Americans aged 65 or older, the degree of exposure to long-term care risk depends on income and the state of residence. Older Americans whose incomes are below the SSI limit and who satisfy the asset test are covered. In addition, older Americans are covered if they are a resident in one of the 42 states or D.C. that have adopted the special income pathway, have an income less than three times the SSI limit, and satisfy the asset test. In the remaining eight states, the medically needy pathway also may provide relief to some, but the asset test may require a substantial spend-down.[16]

Of the 43 states (including D.C. among the 43) that do grant eligibility through the special income pathway, only 26 also offer eligibility through the medically needy pathway. Older Americans in the other 17 states with relatively high incomes, and without private long-term care insurance, must rely entirely on their own resources to pay for long-term care (Table 2.1).

Table 2.1 Number of States with the Special Income Pathway and/or the Medically Needy Pathway[a]

States offering both pathways	26
States offering only the special income pathway	17
States offering the medically needy pathway	8
Total, including D.C.	51

[a] All states and D.C. offer at least one of these two pathways.

SOURCE: Musumeci, Chidambaram, and O'Malley Watts (2019) and author's calculations.

Relying on Medicaid rather than taking out private long-term care insurance makes some sense for older Americans with modest incomes. Note, however, that while relying on private long-term care insurance requires the payment of premiums typically starting some and often many years before need, private insurance normally pays all or at least much of the expenses of long-term care once care begins, and long-term care policyholders would have more choice regarding care either in a congregate setting or at home than they typically would under Medicaid. Older people with private long-term care insurance would be much more likely to afford residing at an ALF than the typical person without that insurance.

If older Americans cannot qualify for long-term care benefits under Medicaid and lack private long-term care insurance, what expenses would they face? A 2017 study finds that the probability that one or both members of a healthy 65-year-old couple will move to a nursing home at some point in their remaining lifetime is 78 percent; the probability of visits by a home health aide is 63 percent; and the probability of residing in an assisted living facility is 29 percent (Crook and Sutedja 2017).[17] Despite the likelihood that older Americans will need some kind of long-term care, the median duration of a nursing home stay was estimated to be only 9 months. The median duration of home health visits and residence in ALFs was 14 months. A more recent study finds that the probability of a 65-year-old in 2020 developing a disability severe enough to require long-term care is 56 percent (Favreault and Dey 2021).

With the median annual cost of a nursing home stay in 2020 at about $93,000, the cost of long stays becomes prohibitive.[18] The chances that a nursing home stay lasts for more than one year has been estimated at 32 percent for at least one member of a healthy 65-year-old couple; the probability of a stay of more than three years has been estimated at 8 percent (Crook and Sutedja 2017). The odds that an older American who does not qualify for Medicaid will incur substantial expenses for long-term care are not negligible, but neither are they large. Comparing the contingencies covered by auto and long-term care insurance, it is highly unlikely that Americans can pass through life without having to deal with an auto accident of some degree of seriousness, and consequently most people have at least an intuitive understanding of the benefits of auto insurance.[19] The probability of requiring long-term care is lower than that of a serious car crash or car theft, however. As a result, wishful thinking may lead many people to underestimate their exposure to the latter contingency, or to expect that family members will be able to care for them, without considering the emotional and financial burden that home care can involve.

The older Americans who are most exposed to the risk of long-term care expenses are those who live in the 17 states that do not offer eligibility through the medically needy pathway, and whose incomes exceed the limit of three times SSI. Residents in these states who are 65 years or older account for about 30 percent of the national total. Assuming, perhaps conservatively, that no more than 50 percent of the elder population fails this test (i.e., that one in two has income more than three times the SSI limit), it would amount to about 14 percent of the population age 65 years and older. The asset test, however, also must be met. If it cannot, then candidates for long-term care must spend down those of their assets that are deemed to be countable for the purposes of the asset test or protect them by establishing a trust.[20]

ACTUARIAL AND FINANCIAL ASPECTS OF CONTINUING CARE RETIREMENT FACILITIES

Viewed from the economic point of view, the basic feature of a CCRC is that it is a risk-sharing arrangement, one that entails obvious risks for both parties.[21] Prospective residents in CCRCs, as well as CCRCs themselves, confront longevity risk—the unpredictability of lifespans. Both parties may also confront investment risk, the risk of an uncertain rate of return on their reserves. The degree of both longevity and investment risk depends on the nature of the contract between the two parties.

Longevity risk is a basic risk for the CCRC (i.e., the owner or owners) and for prospective residents, who have greater life expectancies than the general population. In part, this reflects the fact that CCRC residents are wealthier than the general population, and there is a positive relationship between wealth and longevity.[22] A further influence is adverse selection—persons interested in joining a CCRC are likely to believe that they will live there for many years, particularly if the move requires that they sell a home in which they have lived for many years, which is not an easy step for many older people to make. It is also argued that the community aspect of living in a CCRC promotes longevity.

In addition to longevity (or mortality) risk, there is also morbidity risk—the risk that a resident may need to move to the assisted living or nursing care component of the community, which increases the costs for the CCRC. It is important to distinguish between the risk of a temporary transfer to the nursing home component and a permanent transfer, that is, one that lasts until the death of the resident.

As Chapter 1 explains, the typical CCRC contract involves a large entry fee with continuing monthly payments until the death of the resident, or both residents if a couple. A prospective resident may have a choice between several combinations of entry fee and monthly payment. With the largest entry fee, there is no increase in the monthly

fee in the event of a transfer to the nursing component. Residents may also be offered a trade-off, where in return for a smaller entry fee, they accept the risk that their monthly fee may increase in the event of a transfer. Not all CCRCs offer the intermediate step of assisted living between independent living and the nursing home component, and some limit the number of days that may be spent in nursing at an unchanged monthly fee. A rental arrangement is also possible, where there is no sizeable up-front entry fee.[23]

With the large entry fee, the CCRC is taking on the risk that its earnings and the fee itself will not cover the expenses of a very long-lived resident, or one who will require many years of nursing-level care. Contracts typically provide for the partial or total reimbursement of the entry fee if the new resident dies within some stipulated period after entering the community. However, once that period has elapsed, no refund is possible. In addition, contracts will typically provide for periodic adjustments in monthly fees to reflect increases in the cost of providing a given level of service.

Without having precise numbers for entry fees and monthly payments, it is impossible to draw hard and fast conclusions about the advantages and disadvantages of different contracts for prospective residents and owners. If, however, we compare two basic versions of a CCRC contract—one with a large entry fee and one with a smaller entry fee, and correspondingly smaller and larger monthly fees—we may draw some qualitative conclusions. The large entry fee contract may seem more attractive to residents who worry about their ability to afford an increase in monthly fees in the event of serious illness or who have enough of a nest egg that paying the larger entry fee will not unduly deplete their reserves. Residents choosing a smaller entry fee also incur the risk that the return on their reserves may be disappointing.

From the CCRC's perspective, the contract with the larger entry fee may look attractive if it thinks that residents overestimate their own longevity. There is also the advantage of getting the money up front and avoiding the complications that arise if a resident cannot pay

the monthly fee.[24] However, in agreeing to the contract with the large entry fee, a CCRC is more exposed to the consequence of an extended stay in the nursing home component of the facility.[25] Another potential risk for the CCRC is a decline in new entrants, which some connected with the industry have noted can occur with declines in the market for residential real estate, because the sale of a household's principal residence often provides the money for the entrance fee.

Regulatory Issues

As of 2018, only 38 states had any kind of regulatory framework for CCRCs (Breeding 2018), the same number as GAO (2010) reported. The remaining states and D.C. had none. Broadly speaking there are two distinct aspects to the regulation of CCRCs: the regulation of their role as providers of health care, which pertains mainly to their assisted living and nursing home components, and their financial regulation. All 38 states regulate the provision of health care in tandem with the federal government (as do all the states and D.C.). In Maryland, for example, the CCRC regulatory function is the responsibility of the Department of Aging. The department's website notes that only part of the contractual arrangements of CCRCs are subject to regulatory law. On its website, the department "urges anyone who is considering moving into a CCRC to consult with an attorney and a financial advisor familiar with these types of agreements before signing any documents."[26] This is certainly good advice, but one wonders if it is enough.

It appears that the 38 states that regulate CCRCs do require that they provide basic financial accounting statements, such as a statement of assets and financial liabilities, as well as income and expenses. The former would include a valuation of the CCRC's real property with an estimate of depreciation, as well as financial assets and any debt. A basic income statement would include among its elements on the income side monthly fees paid by residents, in addition to payments for other amenities like cable, internet, and dining subscriptions.

Breeding (2018) notes that the mandatory requirements and degree of oversight among the 38 states can vary substantially. North Carolina requires annual audited financial statements with disclosure statements. Operating reserves must be maintained at 50 percent or more of forecasted operating revenue for the next 12 months, although this ratio may drop to 25 percent for CCRCs with occupancy rates of 90 percent or higher. Breeding also notes that no CCRC in North Carolina has gone bankrupt to date. Some states are said to have less stringent reporting requirements, and apparently some have more.

The GAO (2010) report was based on a study of CCRCs in eight of the country's most populous states.[27] It found that only three of them required actuarial valuations.[28] A financial statement of assets and liabilities can make a CCRC appear to be in good financial condition when it is seriously undercapitalized. A periodic actuarial valuation of a CCRC's contingent liabilities is needed for a comprehensive evaluation of its true financial condition. Quite apart from these actuarial issues, there have also been some cases of misappropriation of financial assets.

PRIVATE LONG-TERM CARE INSURANCE

The market for private long-term care insurance has seen better days.[29] Its origins date from the early 1990s, and by 2000 about 100 insurance companies were in the market. However, their numbers began to shrink subsequently (Cohen 2019). According to Cohen (2019), the number of active claims in 2019 was about 300,000, and there were about seven million policies.

In its current form, a policy for private long-term care insurance stipulates a maximum lifetime benefit payout and a typically maximum payout period as well as a maximum daily payout, which may vary depending on whether the policyholder lives in a congregate setting like a private nursing home or an ALF or lives at home and receives trained care. Home caregivers are typically provided through

an agency that the insurance company has vetted. The insurance company pays the agency on behalf of the policyholder and the agency pays the caregiver and is responsible for withholding payroll and income taxes. Caregivers who perform basic tasks typically receive a modest wage.[30] Some policies may also pay family caregivers a modest stipend.

Long-term care insurance issuers are subject to regulation at the state level. States require that once a policy has been issued it may not be revoked unless the policyholder is unable to pay the premium, which is normally due annually. The premium is supposed to be set so that, taking account of the reserves that will accrue on premiums, it will not need to be adjusted, apart from changes that the regulating state deems are necessary given changes in underwriting costs. In their adjudication of requests for premium increases from insurance companies, states are expected to strike a balance between the interests of the policy issuer and policyholders.

Premiums increase with the age at which the insurance is contracted. The younger the age, the longer will be the expected period that elapses before a claim is activated, because the need for long-term care insurance increases with age, and because with an increase in the interval between the start of coverage and the activation of a claim the longer the period over which reserves can accumulate. The level at which a premium is set is also a function of lapse rates, and the younger the age at which coverage begins, the greater the chances that it will be allowed to lapse.

To trigger a claim, a policyholder must demonstrate to the insurer that he or she is unable to carry out a number of the six ADLs—usually two—or display a significant degree of cognitive decline.[31] This assessment is necessary to deal with the problems of moral hazard, which we touched on in Chapter 1 in the discussion of publicly provided long-term care, and adverse selection. Moral hazard can crop up with long-term care insurance when the policyholder exaggerates or falsifies a claim of inability to perform ADLs. Adverse selection, the tendency for an insurance arrangement to attract clients who are

more likely than the average person to need the insurance, is also a feature of this market and contributes to the gap observed between the premium for a group policy and an individual policy, the former being less susceptible to adverse selection than the latter.

There are several reasons for the decline in this market. Insurers underestimated the longevity of claimants and overestimated lapse rates, and did not foresee the rate at which the cost of care increased. The general decline in interest rates that has taken place over the past 20 years has required an increased buildup in reserves to offset a given liability. These developments have increased break-even premia and reduced demand. An NAIC study (Nordman 2016) found that the average income of new policyholders had increased substantially since the early 2000s. The American Association for Long-Term Care Insurance (2021) reports that in 2021, a select policy with a lifetime maximum of $165,000 would cost a 60-year-old woman $1,900 and a 60-year-old man $1,175. If the maximum benefit of the policy increases by 3 percent per year, premiums would be $4,300 and $3,525, respectively. These figures are high enough to deter many middle-income households from acquiring a policy given the uncertainty surrounding the eventual need for long-term care and the age at which care would be needed.

Price is not the only influence on demand for private long-term care insurance, however. Both Medicaid and private long-term care insurance provide protection against catastrophic loss entailed by a long period of care, although Medicaid is subject to the stringent means-testing previously described, and private long-term care insurance is not. Self-insurance against such a contingency is possible only for the rich. Consequently, private long-term care insurance and the publicly provided benefit may compete with one another.[32] But private insurance has clear advantages over Medicaid, most notably, the protection of assets and income from means-testing, the choice of facility if institutionalized care is required, and perhaps also the quality of care at home. However, ignorance about the costs of Medicaid also plays a role. Many Americans believe that Medicare, not Medicaid,

covers long-term care, and many are unaware of the stringent eligibility requirements that Medicaid imposes, especially on those who have not protected their assets by establishing a trust.[33] Greater awareness of the advantage of private insurance as well as a greater awareness of the real risk of one day needing long-term care would undoubtedly increase demand for it. However, it is easy for people in their fifties and sixties to downplay that risk because of its uncertain timing and the fact that the risk increases with age. A further inhibiting influence on demand may be the unpredictability of premium increases.

Private long-term care insurance could cover more U.S. households than it does. One promising development has been the emergence of so-called combination products, such as the life care annuity, whose payout increases if the policyholder demonstrates a need for long-term care. The product reduces underwriting costs because its potential clientele have shorter life expectancies than traditional annuitants. The market might also grow if private insurance could take the form of a "front-end" product that covered the first two years or so of need before Medicaid kicked in. This would reduce its cost. However, the cost of traditional private insurance policies and the existence of a public option are obstacles to the development of a larger market for them.

UNPAID CAREGIVERS

As emphasized in Chapter 1, the number of older Americans in need of assistance with one or more of the ADLs, living at home, and being helped by a relative or in some cases someone from outside the family dwarfs the number living in congregate settings. These caregivers should not be confused with either the health care workers who come to the homes of elderly persons in need of assistance with ADLs or instrumental ADLs or those who provide the more specialized services provided under Medicaid's HCBS programs.

As noted, above, Medicaid does pay some of the relatives and others who provide basic care, but the terms vary considerably from state to state, and it is extremely difficult to know how many of the huge number of the nation's caregivers receive any money at all. In fact, the AARP studies of home care already cited (AARP 2020a,b) effectively assumes that all home caregivers are unpaid.

That there are so many unpaid caregivers raises difficult economic, financial, political, administrative, and moral or social issues. These issues intertwine and overlap, and it is not easy to pull them apart to analyze. However, it is worth trying to do so. Our discussion begins with the moral aspects of the issue. Unpaid caregivers shoulder an obvious economic and psychological burden. Studies by AARP have repeatedly found that the great majority of caregivers also work for pay outside the home and come from all age classes. The time they spend as caregivers reduces the hours that those of them who are potential labor force participants can work for pay outside the home, and the hours they can devote to other productive activities within the home, such as meal preparation and supervising homework—or simply relaxing, which of course is also true of caregivers who have retired themselves.

This economic cost caregivers and their families bear raises the question of whether society at large—that is, the taxpayer—should compensate them for looking after their older and infirm relations.[34] Doing so would of course require an increase in taxes and/or a reduction in other public expenditure programs, and many observers might argue that the benefit of the activity of caregivers does not accrue to society at large but to the families of the people being cared for. But the same argument might be advanced to oppose taxes that finance education or child care for low-income families, if one argues that these taxes benefit only families with school-aged children, not older families.[35] In addition, caring for persons aged 65 or older must reduce the demand for beds at nursing homes, which does reduce the general tax burden. Caregiving also reduces the time that givers can devote to their own children, and to furthering their own education.

This may impose a cost on society. More generally, if we accept that society at large has a moral obligation to provide some support for the disabled elderly, then we also effectively assume a responsibility of not allowing an undue share of that burden to fall on their caregivers. This is a moral or an ethical judgment and not a statement that can be refuted by evidence. By this point the reader will have realized that it is a judgment the author shares.

Caregiving has an obvious economic cost, what economists call its opportunity cost—caregivers could be doing something else productive with their time. AARP has published a regular series of studies that address the issue of what it has aptly termed "valuing the invaluable." These studies make calculations of the economic cost of the time spent by caregivers, which can serve as a basis for calculating what a public policy of remunerating them would cost the public purse. The latest of the AARP studies is based on four different sources, with various estimates of the number of caregivers, the average number of hours they work, and the average wage that should apply to their work (Reinhard et al. 2019). The AARP's weighted analysis of these studies yields a total wage bill or cost of $370 billion, which is about 2 percent of 2017 nominal GDP, the year for which the data was collected.[36]

In macroeconomic terms this is not a tiny sum. It would require a substantial increase in the national tax burden to finance it—at the federal level, if the benefit were paid by the federal government, which would mark a shift away from the traditional sharing of costs by Medicaid programs, the tax burden would have to increase by over 10 percent of all federal tax revenues, including the payroll taxes that finance Social Security.

Any increase in taxation is politically contentious. The nature of the expenditure this tax increase would be financing also raises administrative issues. In particular, the issue of monitoring the work of caregivers arises. Should caregivers be required to submit a verifiable accounting of the number of hours they put in each week? Although requiring a submission at periodic but not too frequent intervals might

not impose a huge paperwork burden on the caregiver, verifying its accuracy would undoubtedly impose an unrealistic burden on the monitoring agency of the government concerned. One approach that would avoid excessive compliance burdens on caregivers or monitoring costs for government might be to require simply demonstrating that an older family member was in obvious need, perhaps once per year, and was being cared for. No accounting of the number of hours of care provided would be required. Instead, some stipulated number of hours of care might be assumed. This approach would amount to a sort of presumptive assessment of the burden of care, at least in terms of hours, and could make sense from an administrative point of view.

This chapter has covered a broad range of complicated issues. Its basic theme is that the current system of long-term care is both excessively complicated and underfinanced. Its complexity means that its basic features are not well understood either by many persons who will soon need long-term care or by the taxpayer. The lack of financing for care at home is inefficient to the extent that it results in institutionalization that is more costly than care provided at home (Kaye, LaPlante, and Harrington 2009). The lack of financing may be judged as inequitable to the extent that society adopts an ethical standard that older infirm persons deserve an adequate standard of care, whether at home or in an institution.

Notes

1. This section draws largely on Rudowitz et al. (2021).
2. To be eligible for Medicare, a person must have reached the age of 65 and have worked and contributed to Social Security for 40 quarters, regardless of his or her state of residence. To draw a retirement pension, a person must have reached the age of 62. The retirement pension increases with the number of years worked and average wages as calculated by Social Security (actually the 35 years with the highest wages, which are indexed to the economy-wide wage rate for the calculation). The benefit, once elected, is indexed to consumer prices and also increases with the age at which it is elected up to age 70. Some of Social Security's rules are quite complex but they do not vary from state to state.

3. Puerto Rico and other U.S. territories are all subject to a limit on the federal government's share of 50 percent—so there is no adjustment for per capita income—as well as a dollar limit. If the dollar limit is exceeded, the federal government's share automatically drops below 50 percent.
4. A block grant arrangement has its own drawbacks. The amount of the grant would have to be adjusted regularly just to keep up with inflation. In addition, even an inflation-adjusted grant would have to be adjusted to keep up with population growth, which would vary from state to state. Veghte and Bradley (2017) discuss the drawbacks of block grants and per capita block grants.
5. Disproportionate share hospitals (DSH) serve many Medicaid and low-income uninsured patients. States have considerable discretion in determining the payments to each DSH hospital, and federal DSH funds are capped at both the state and the facility level. Payments to DSH hospitals were about 3 percent of Medicaid's total budget in FY 2019.
6. This discussion draws on Mackenzie (2020), which in turn draws on Musumeci, Chidambaram, and O'Malley Watts (2019). It also draws on Skračić, Bond, and Doonan (2020).
7. A certain amount of income is disregarded in applying the income test, which varies from state to state but is usually small.
8. The limits of the income and asset tests and other limits included in this and the next two paragraphs are for the year 2018 and come from Musumeci, Chidambaram, and O'Malley Watts (2019). Higher disregards apply to boarding homes and shared living (i.e., noninstitutional) arrangements.
9. Eight states have elected an option allowing them to use their own income criteria provided these are no more restrictive than what they had in place in 1972.
10. Arizona has no limit on asset holdings for either individuals or couples.
11. The limit is 250 percent of SSI in Delaware. In Missouri, it varies by program. The eight states that have not opted for the special income rule are California, Hawaii, Illinois, Montana, Nebraska, New York, North Carolina, and North Dakota. These states have all opted to participate in the medically needy pathway described next. Massachusetts does not apply the special income rule regarding institutions (e.g., nursing homes) but does apply it for HCBS.
12. In about half of the states, individuals whose income exceeds 300 percent of the SSI can still be eligible for support from Medicaid if they establish what is known as a Miller trust, and they administer through it the income that exceeds 300 percent of the SSI. See Musumeci, Chidambaram, and O'Malley Watts (2019) for additional discussion.
13. All 34 states apply this pathway for pregnant women and children; 32

states apply it for seniors and the disabled (Texas and Tennessee being the exceptions); and 26 states apply it for low-income parents.

14. Eleven states have opted for a budgetary period of one month, and 13 states have opted for six months. In several other states, the limit depends on whether the applicant plans to remain in the community (Musumeci, Chidambaram, and O'Malley Watts 2019, Appendix Table 3).
15. Recipients of community-based services can retain much more of their income because they will be responsible for much more of the basic costs of living, such as lodging, food and clothing.
16. In Massachusetts, as noted, the special income rule covers HCBS but not institutional care.
17. The probabilities add up to more than 100 percent because a couple can experience not just one but two or all three of these outcomes.
18. Genworth (2020) estimates that the median national cost of a semi-private room in a nursing home in 2020 was about $93,000.
19. Belbase, Cen, and Munnell (2021) find that about one in five 65-year-old Americans will not require long-term care at any level of intensity, while about one-quarter will require at least a moderate to high level of care for some years.
20. For a general discussion of estate planning and the role it can play in preserving a family's assets when long-term care becomes necessary, see Correia, Sayre, and Allen (2017).
21. The classic study of CCRC finances and actuarial issues is Winklevoss and Powell (1984). The most comprehensive recent study of CCRC regulatory issues is GAO (2010).
22. Wilkinson and Pickett (2011) present evidence that, even within the Washington, D.C., area, life expectancy rises enormously as one travels from one end of the Red Line of the Metro system to the other.
23. Some observers argue that smaller entry fees are almost always more desirable because most CCRCs do not include in their pricing the benefit of the interest earnings on the entry fee (or the debt service foregone that would otherwise be required without the entry fee). Moreover, entry fees are at-risk investments if the debt a CCRC has incurred is senior to entry fees, which means that the creditors' claims take precedence over the claims of residents. Because the smallest entry fee is no entry fee, some observers argue that pure rental communities are growing in popularity as trust in the entry fee model for financing aging is eroding.
24. In one CCRC with which the author is familiar, there are charitable drives to raise funds for residents who are no longer able to afford their monthly fees. Both better-off residents and outsiders can contribute to these charities. In another there is a tacit understanding that no resident who becomes unable to pay the monthly charge will be asked to leave.

25. To reduce the risk it accepts in taking on a new entrant, a CCRC will require a physical examination as well as evidence of a new entrant's ability to pay the CCRC's monthly fees.
26. https://aging.maryland.gov/Pages/continuing-care-retirement-communities.aspx (accessed July 24, 2022).
27. The eight states are California, Florida, Illinois, New York, Ohio, Pennsylvania, Texas, and Wisconsin.
28. California, New York, and Texas require periodic actuarial studies, but only for those CCRCs that offer contracts that incur long-term liabilities by guaranteeing health care services over the long term.
29. This section of the chapter draws on a comprehensive study by Nordman (2016) under the auspices of the National Association of Insurance Commissioners (NAIC) and the Center for Insurance Policy and Research as well as the other sources cited.
30. One established agency in the Washington, D.C., area pays caregivers who assist its clients with difficulty performing ADLs or with significant cognitive decline an hourly wage of $12.00–$13.00.
31. A standard test of cognitive ability is demonstrating the ability to count backwards from 100 by seven.
32. Brown and Finkelstein (2009) argue that Medicaid has substantially reduced the demand for private insurance.
33. The survey previously noted found that more than 4 in 10 of the general population surveyed, who were aged 50+ years either thought that a public program would pay for most of the cost of six months of long-term care or expressed ignorance (Life Plans 2017). However, the survey also reports a growing awareness that public programs will not step up to the plate.
34. Perhaps it is needless to point out that the same issue arises with caring for young seriously disabled family members, although they number far less than older persons in need of care.
35. Education economists generally agree, however, that schooling at the primary and perhaps the secondary levels has social benefits that go beyond the benefits enjoyed by the students and their families. The benefits at the tertiary level are considered to accrue mainly to the students and their families.
36. The study is based on an estimated nationwide hourly wage of $13.81. The hourly wage estimates by state ranged from $10.57 in Louisiana to $18.01 in Alaska. The figure for the number of caregivers is 41 million, which is based on a weighted average of the survey estimates adjusted to match their demographic composition to eliminate over or undersampling. The calculations assume a 16-hour average work week and a work year of 52 weeks. For further discussion, see Reinhard et al. (2019).

Chapter 3

A Comparative Analysis

Just as health care systems differ enormously across countries, even across the great majority of high-income countries with universal health care, the way in which countries provide long-term care services and supports differs greatly as well. To use Veghte's (2021) terminology, the model that countries follow can be classified as social insurance, universal comprehensive coverage, residual coverage, or a hybrid.

Social insurance is usually financed by payroll taxation, like Social Security in the United States, and its benefits may be limited to contributing workers and their families. In practice, however, coverage is near universal. Universal comprehensive coverage applies to the whole population of a country and is normally financed by the central government's budget. Residual systems are means-tested, and as the term suggests, hybrid systems combine elements of one or more of the first three. Germany and Holland are prime examples of the social insurance model, while the Nordic countries are exemplars of universal comprehensive coverage. The United States and the United Kingdom are both means-tested systems. Veghte (2021) classifies France's system as a hybrid because it is financed by both general revenues and payroll taxes, and because, although its coverage is universal and is not means-tested as such, benefits decline as income increases. Even social insurance systems may have some benefits or services that are means-tested, and coverage may be limited in other ways. For example, room and board in long-term care institutions may not be covered.

A social insurance system can be pay-as-you-go or funded, or somewhere in between. The typical system is pay-as-you-go. With a fully funded system, the contributions of a given age cohort of workers are expected to finance their long-term care needs. When the system is first introduced, it builds up a surplus, at least on paper, because

at its inception contributions far outstrip expenditure.[1] Medicaid is not a funded system. The supplementary system established in Washington State in 2019 and described in Chapter 1 is a funded system.

The role of private long-term care insurance varies across countries, but typically it is a niche market if it exists at all. As Chapter 2 explains, the role of the private long-term care insurance market in the United States is quite limited: as of 2019, outstanding policies amounted to about 7 million, or about 5 percent of the country's labor force, and about 7 percent of the aged 55+ population. Its role in other high-income countries varies. In Germany, some 12 percent of the population has private long-term care insurance, mainly because the federal government puts caps on the amount of support it pays to persons in need of long-term care. However, the government subsidizes the purchase of long-term care insurance to some extent.[2]

Typically, publicly provided long-term care begins with institutional care before extending its reach to home care. This was the case with the Nordic countries, which were the pioneers in universal long-term care. There has been a general tendency across countries—including in the United States, as Chapter 2 notes—to increase the role of care provided in the home while reducing reliance on institutionalized care. With well-designed policies, this development should increase the welfare of care recipients and reduce the burden of long-term care on public finances.

SOME CONSEQUENCES OF THE MEANS-TESTED APPROACH

A comprehensive study from the OECD (Hashiguchi and Nozal 2020) on the cost to households of long-term care and notably of its impact on the risk of declining into what the study calls relative poverty contrasts the workings of long-term care provision in regions or entire OECD member countries, including two U.S. states, Cali-

fornia and Illinois, as well as England (Scotland, Northern Ireland, and Wales are excluded), France, Germany, and Japan. The study estimates the share of the elderly population that would experience *relative* poverty, defined as a level of income below the population-wide median, with and without the country or region's long-term care regime, for differing levels of long-term care needs. The United States does not fare well in this international comparison. In both California and Illinois, Medicaid does not reduce the share of the elderly experiencing relative poverty.[3]

In England, social care is both income- and assets-tested. Minimum allowances guarantee that a share of care recipients' incomes is protected, and care recipients with assets less than £14,250, or about $19,000, as of December 31, 2021, are eligible for public support covering 100 percent of the costs of care. Conversely, older people with assets worth over £23,250 receive no public support. Apart from the minimum income allowance, they must cover the full costs of care (Hashiguchi and Nozal 2020). However, and unlike the U.S. case, the provision of public assistance keeps most older people in need of long-term care from falling into relative poverty.

The OECD study also compares the share of elderly people already living in relative poverty by the study's definition who do not need benefits under their country's system with the share that would decline into relative poverty *if* they needed long-term care at home, even with public benefits. Again, the United States fares poorly by comparison with most other countries, including England.

One basic, if obvious, lesson that may be drawn from these analyses is that the impact of means-testing on disposable income after taking account of the out-of-pocket costs that long-term care support does not cover is that it depends on how stringently the income and asset limits are set, and on their design. The OECD study does, however, argue that countries with comprehensive income and asset means-testing generally do less well at protecting the elderly population at risk for needing long-term care from poverty.

Another notable international comparative statistic is the share of GDP that the major industrial countries (the G-7) spend on long-term care (see Table 3.1). The share of expenditures by Medicaid on both residential and HCBS care was 0.9 percent in the United States in FY 2019, which is lower than the other six countries except Italy (for which the reported year was 2017). This is partly related to the comparatively young demography of the United States as well as the limits imposed by Medicaid on the share of the elderly population that qualifies for public support.

Table 3.1 Long-Term Care Expenditure as a Percentage of GDP, G-7 Countries

	Health component	Social component	Total
Canada	1.3	–	1.3
France	1.3	0.6	1.9
Germany	1.5	0.0	1.5
Italy	0.7	–	0.7
Japan	1.8	–	1.8
United Kingdom[a]	1.2	0.3	1.4
United States	–	–	0.9

[a] Numbers do not sum due to rounding.

SOURCE: OECD (2019) for all countries except the United States. Author's estimate for the United States based on Rudowitz et al. (2021). The U.S. figure is for fiscal year (FY) 2019. The values for the other countries are for 2017. "Health component" refers to institutional care and care related to the activities of daily living (ADLs), whereas "Social component" refers to care related to the instrumental ADLs.

All the major industrial countries are parsimonious compared to the Nordic countries and the Netherlands, all of which have universal coverage. Norway, Denmark, and Holland all spent more than 3 percent of GDP on long-term care in 2017, and Sweden and Finland spent more than 2 percent.

HOW CANADA AND GERMANY ADDRESS THE CHALLENGE OF LONG-TERM CARE

The long-term care systems in Canada and Germany, which are profiled below, are undoubtedly different in important respects from the U.S. system. Of the two, Canada's is the more similar. They are both more expensive than the U.S. system, and reforms to the U.S. system that make it more like either of them would require a significant increase in public financing. That said, neither the Canadian nor the German system is nearly as expensive as the systems in Holland and Scandinavia. Given the probably insurmountable political difficulties that would be encountered in adopting a version of these latter systems, it makes sense to consider the less expensive systems. Moreover, the systems in both countries, especially Germany, have significant advantages over the U.S. system in the way they provide or finance long-term care to their older citizens.

Canada

The Canadian long-term care system does not fit neatly into one of the three classes of universal coverage, social insurance, or means-tested. Coverage is not universal or near-universal, but care is not means-tested either. These features mean that in some respects the Canadian system is closer to the U.S. system than it is to the systems in most European countries, except the United Kingdom. As was the case in the United States until the passage of the Social Security Act in 1935, long-term care in Canada bore the vestiges of the Elizabethan Poor Laws following the end of World War II, which also saw the establishment of a chain of hospitals for war veterans. In Ontario, Canada's largest province, the Homes for the Aged Act passed in 1949 ushered in the entry of the government into the provision of long-term care.[4]

The public sector's role in the provision of long-term care in Canada and in its financing are in some ways similar to those in the

United States, but in others quite different. In Canada, the provision of both health care and long-term care is primarily in the provincial domain. The provinces and the federal government share in financing institutional care, but there is no long-established quantitative rule to determine the relative share that the federal government pays in any province, as is the case with Medicaid, and the provinces, unlike their U.S. state counterparts, pay for the lion's share of care.

The beginning of a major role for the provinces in long-term care was in the mid-1960s, about the same time that the provincial governments under the aegis of the federal government implemented Canada's version of Medicare, which unlike the U.S. system, covers all Canadians, regardless of age. Like the United States, Canada has both public and privately run nursing homes (called long-term care facilities or care homes), but eligibility for residence is not subject to means-testing of either assets or income.[5] The provinces set rates at both classes of institution. However, the care provided by long-term care homes is by no means free. Rather, residents or their families pay a monthly rate that depends on the degree of privacy of the accommodation provided. In Ontario in 2019, these rates were about $1,487 for what is described as basic accommodation; $1,784 for semiprivate; and $2,112 for private (Picard 2021).[6] Similar rates are said to be charged in other provinces. These costs could pose a heavy financial burden on some middle-income Canadian families, although they are heavily subsidized by the provinces. The total cost of operating Canada's nursing homes is more than double what residents and their families pay.

In 2019, nursing homes had some 190,000 residents. Scaling that figure up by a factor of nine—Canada's population is about one-ninth that of the United States—gives a figure of 1.7 million, compared to the U.S. figure of around 1.3 million. About 6 in 10 residents in long-term care homes suffer from some form of dementia, a share similar to that in U.S. nursing homes, and like U.S. nursing homes, a staff of both skilled and unskilled caregivers is needed at all hours. An additional 170,000 Canadians aged 65+ live in other congregate set-

tings, for a total of about 360,000 residents in all congregate settings, which is about 7 percent of Canada's aged 65+ population, compared to about 4 percent in the United States. The cost of these congregate facilities—retirement communities, ALFs, or the Canadian equivalent of CCRCs—is not subsidized.[7]

In addition to the lack of means-testing, another distinguishing feature of the Canadian system is the less important role now played by home-based care in Canada compared with the United States. Despite the costs that residents or their families incur for care in long-term care homes, there is a chronic shortage of beds and hence a wait-list for prospective residents. As of June 2017, Ontario—with a population of about 15 million, or less than 5 percent of the population of the United States—was reporting a wait-list of 32,000 beds. The list continues to grow at an annual rate of 15 percent (Canadian Association for Long Term Care 2020). Scaling Ontario's wait-list figure up to the U.S. population would result in a wait-list equal to about one-half of the number of beds in the United States.[8] The greater role of home-based care in the United States must reflect the fact that Medicaid's stringent means-testing effectively shuts out middle-income families with elderly members who otherwise would be prepared to live in nursing homes. This does not occur in Canada, at least not to the same extent, and raises the basic issue of whether many of the elderly Americans who are taken care of at home might be better cared for in a nursing home, at least in one that maintained a high-quality standard of care.

Some money is available for home care in Canada, but as Picard (2021, pp. 66–67) notes, coverage varies widely across provinces, with some provinces imposing monthly limits on the number of hours of care per care recipient and others a dollar limit. A family wishing to keep an elderly relative who needs substantial skilled care at home must pay for virtually all the care provided itself. These limitations on the available funding for home care must increase the demand for institutionalized care. Nonetheless, the share of Canada's elderly population who are cared for at home is substantially less than that in

the United States. Some 900,000 are estimated to have received home care, compared with over 20 million in the United States (AARP 2020a). Again, if we scale up the Canadian figure by a factor of nine, the number of elderly persons cared for at home is less than one-half the U.S. number.

Germany

The provision of some form of long-term care in Germany, like the old-age pension, can be traced back to Bismarck's efforts to placate working-class unrest in the wake of the German Empire's rapid industrialization in the mid to late nineteenth century.[9] Emanuel (2020) remarks on the relative continuity of German social policy over the subsequent cataclysmic upheavals of the First and Second World Wars and the separation and reunification of East and West Germany. East Germany's system was replaced upon reunification with the system of West Germany.

Contemporary Germany has a social insurance system but one with nearly universal coverage. The German states are not involved in financing the long-term care system. It is financed by a payroll tax that is currently set at 1.525 percent of wages up to a cap of €4.838 (about $5,500) in 2021 matched by an equal contribution from the federal government, and it covers both workers and their dependents.[10] A period of two years of contributions is required before a benefit can be earned, but the system is effectively pay-as-you-go: the payroll tax rate has been increased several times in recent years to maintain a rough balance between current revenues and expenditures. Childless workers pay an extra 0.25 percent of their wages on the assumption that more of the care the average childless worker might need will be borne by the government, and less by his or her family. Able-bodied retirees may also contribute to the system, and the self-employed pay both the worker's and the government's share of the payroll tax, as is the case with Social Security in the United States.

Perhaps the key feature of the German system is that the federal government places fixed limits on the payments it will make to finance long-term care, with specific limits that increase with the degree or amount of care required. There currently are five different levels at which care is deemed to be provided, with a fixed Euro limit paid for each. As a result, any residual or remainder expense is borne by the recipients or their families. For some families, particularly those with a member needing institutional care, this arrangement can entail a significant burden, which is partially alleviated by social assistance from the local community. In 2019, about one-third of residents in long-term care facilities were receiving social assistance. The federal government recently set a limit on the expenditure that families have to bear for the care of their dependent older members. Local communities can require that the children of care recipients reimburse them at least partially for the assistance that local communities pay if the income of children exceeds a certain level, which has increased over the years and is now relatively high. This feature reduces the cost of the social assistance to the local community but must introduce a degree of complexity into the long-term care financing system.

The current system has an obvious benefit for the federal government in that it is not financially open ended. However, this same feature means that unless the payments the federal government makes are adjusted (increased) at reasonably frequent intervals, the burden borne by families will simply increase every year. Under the current policy, the federal government does in fact increase the benefits it pays at each of the five levels of care every three years. The system really requires that a delicate balance be struck between the welfare of families with members needing long-term care and the financial position of the federal government. In the German system, virtually all families with an elderly member being cared for at home are receiving either cash or in-kind benefits (like visits from nurses or other health care providers). Cash benefits may be used to compensate family members for the time they spend as caregivers or to pay

non-family members. This is not the general rule in either Canada or the United States.

One feature of the German system that is not in either the Canadian or the U.S. system is the reliance on immigrants to provide care, typically unskilled care.[11] This reliance has undoubtedly held down costs, but it has also raised concerns about the quality of care. That said, the long-term care industry is not the only sector of the German economy relying on labor from other European Union countries. For those families not depending entirely on outside help, whether from immigrant labor or not, the law requires employers to give caregivers in their employ up to 10 days of mostly paid leave for caregiving. A proposal to substantially increase the generosity of this benefit is under consideration.

LESSONS FOR THE UNITED STATES

The long-term care system in the United States has one clear advantage over that of most other countries, including Germany and Canada: it is less expensive. A possible additional advantage is that the federal government may have more control, albeit indirect, over its costs than other countries do over their costs. Although Medicaid is an entitlement system, one in which states are obliged to provide the statutory level of care for a resident who meets Medicaid's eligibility requirements, the states have some incentive to control costs and can do so by stinting on the quality of care and by limiting the optional services they provide. Apart from its lower costs, however, the U.S. long-term care system does not compare well with that of either Canada or Germany.

Long-term care coverage in both countries, especially Germany, is substantially broader than it is in the United States. In Germany, families providing care do not necessarily have all their costs covered, but home care is much better supported, and family members can be remunerated for their time and effort. In contrast, care by fam-

ily members in the United States is mostly unremunerated. German families are not subject to the stringent means-testing that Medicaid applies, so, while not free, home-based care in Germany is available to middle- and upper-income families.

As already noted, Canada's system has the advantage over the American system in that middle-income families can afford to pay for institutionalized care. That care is both price and quantity rationed, as the long waiting lists imply. The money available for care at home, although it is not means-tested like in the United States, is not plentiful, however. As Chapter 2 discusses, the public financing of home care can raise some thorny administrative issues. Germany appears to have managed this aspect of long-term care better than North America.

Notes

1. The qualification "on paper" is necessary because there is little or no point in establishing a system that builds up a surplus if that surplus simply finances other government expenditures.
2. See Chapter 6 in Emanuel (2020).
3. Neither California nor Illinois apply the special income rule, the second pathway for eligibility for Medicaid. Consequently, no one with an income of more than 138 percent of the federal poverty line qualifies.
4. Previously, some institutional long-term care had been financed by municipalities and charities. The province had also provided some financing, but the 1949 act substantially increased its financial and administrative role (Association of Municipalities of Ontario 2011).
5. Low-income earners can apply for subsidies, but these are available only for basic accommodation, with perhaps three or four beds to a room.
6. These rates are the U.S. dollar equivalent of the Canadian dollar rates reported in Picard (2021, p. 52), converted at the exchange rate of one U.S. dollar equals 1.33 Canadian dollars, prevailing on December 31, 2021.
7. The figures for the number of residents in congregate settings comes from Picard (2021).
8. In this respect, long-term care is like health care in Canada: it is partly rationed by quantity, and not by price. For example, most Americans with insurance in need of hip replacement do not typically have to wait many weeks to schedule an operation. In Canada, unless the case is deemed to be urgent, the wait can be much longer.

9. This section draws heavily on Veghte (2021). Bismarck's social programs were not particularly expensive at their inception. Relatively few Germans survived to the age of 65, when they became entitled to a pension and when disability would have begun to set in with a vengeance.
10. Euros have been converted to dollars at the exchange rate of one Euro equals $1.1371, prevailing on December 31, 2021.
11. A qualification of this remark as it applies to the United States may be needed, in that undocumented immigrants are known to play a significant role in the unskilled workforce in nursing homes.

Chapter 4

The Impact of the COVID-19 Pandemic on Older Americans in Nursing Homes and Other Institutions

The devastating effect that COVID-19 had on the residents in America's nursing homes became apparent even in the early stage of the pandemic. In spring of 2020, news reports began drawing attention to the unusually high death rates occurring in nursing homes. As of April 25, 2021, a couple months after the start of large-scale distribution of vaccines in the United States, an estimated 132,000 nursing home residents had died of COVID-19, or roughly 1 in 10 of the total number of residents (CMS 2021). The exact number may never be known, in part because the reliability of the data differs from state to state. In some states, deaths of caregivers have been confounded with deaths of residents. In addition, the classification of cause of death by coroners' offices was not uniform across the country.

The pandemic has also caused deaths of residents in ALFs. The fatality rate in ALFs appears to be much less than the rate among nursing homes, but the data are less reliable, mainly because of differences among states in reporting requirements. It is uncertain what impact the pandemic has had on residents in CCRCs.

NURSING HOMES

The shocking death toll in U.S. nursing homes is the result of at least five different influences:[1]

1) COVID-19 has disproportionately killed older people, especially the very old (75+). This tendency is evident in the

death rates by age of the population at large. As of May 6, 2021, the total number of deaths attributed to the pandemic was about 576,000 (CDC 2021). Of that number, about 80 percent are estimated to have been aged 65 or older, and most of these deaths were in people aged 75 or older.[2] The disproportionate impact of COVID-19 on the elderly is a global phenomenon. The elderly account for the lion's share of deaths in Canada, Germany, the United Kingdom, and other countries as well. That said, the death rate among Americans aged 65+ who are not living in nursing homes is estimated to be 0.6 percent, which makes it a fraction of the death rate in nursing homes.[3]

2) Unlike ALFs, nursing home residents typically have little privacy. Most share a room with another resident or are housed in dormitory-style quarters. Consequently, infections of all kinds have more opportunity to spread.

3) Caregivers would bring in the diseases from the broader community. As of April 25, 2021, infections among caregivers were estimated to be about 575,000, compared with an estimated total number of caregivers of about 945,000 in 2016 (NCHS 2019). Deaths among caregivers were estimated at about 1,900 (CMS 2021), which—assuming no growth in the number of caregivers in 2016–2019—implies a death rate of about 2 per 1,000. Making the not unreasonable assumption that virtually all caregivers were aged less than 65 years, their rate of death is about five times that of the population at large in this age range, and their rate of infection was about five times that of the overall population.[4]

4) Morbidity (the prevalence of disease and ill health in general) is higher in nursing homes than it is among the general population of the same age.

5) Sanitation standards in many nursing homes, as Chapter 1 discusses, have often been substandard, and the penalties imposed on nursing homes reporting deficiencies in sanitary practices have not been onerous.

The pandemic will almost certainly have a profound impact on the structure of the nursing home industry. The adjustment process has not yet played out, and we cannot draw a firm conclusion on the demand for beds. However, the number of residents is estimated to have dropped by 16 percent between January 2020 and January 2021, or by about 200,000. Demand for beds may never fully recover without the adoption of new policies assuring that adequate sanitation standards will be maintained. In the meantime, potential residents will be seriously considering the options of aging at home and, their financial situation permitting, choosing to move to an ALF. That said, the COVID-19-related deaths in these institutions will have had a depressing effect on demand for apartments at ALFs as well.

On the supply side of the nursing home market, institutions will probably choose to reconfigure their premises to offer their residents more privacy, and in any case may be obliged to do so by changes to the regulations that Medicaid eligibility payment requirements will impose on them. These structural changes will reduce the number of beds a home can offer and will increase their break-even cost per resident. The combined influences of contracting supply and demand (in economists' language, leftward-shifting supply and demand curves) will reduce the number of beds the industry can offer. The impact on the cost to residents is uncertain.

The dissemination of vaccines that began in January 2021 strongly favored the residents in nursing homes, as it should have. By early May 2021, about 1.4 million residents in nursing homes, ALFs, and similar institutions had been fully vaccinated. Death rates in these institutions have dropped by almost 90 percent in 39 reporting states (which include the country's most populous) in the first four months of 2021 (Chidambaram and Garfield 2021). Nonetheless,

COVID-19-related deaths in nursing homes as of early May 2021 were accounting for about 5 percent of nationwide deaths, despite the small share of Americans who reside in these facilities.

The largely successful campaign to vaccinate nursing home residents appears to have effectively ended the devastation the pandemic has wrought among the country's nursing homes, although vaccine hesitancy remains a problem among caregivers, as reflected in the fact that less than half are fully vaccinated. But the COVID-19 pandemic is certainly not going to be the last pandemic that America and the world will face. What happened in the country's nursing homes must never be allowed to happen again. Before turning to the experience in ALFs and CCRCs, we briefly discuss aspects of the international experience of long-term care institutions with the pandemic.

EXPERIENCES IN OTHER COUNTRIES

At least three possible causes of the high death rates in America's nursing homes—age, limited privacy, and comorbidities—will be found in other countries as well. It may be useful to compare the U.S. experience with that of Canada, Germany, and the United Kingdom. In the United Kingdom, residents in care homes, which are similar to U.S. nursing homes, were estimated in 2016 to account for about 4 percent of the population aged 65 years and older, which is about twice as high as the share of nursing homes in the United States. Deaths of residents amounted to about 9 percent of the population of care homes, a figure that is lower than the U.S. share, although obviously still extremely high (see Table 4.1).

In Canada, the death rate of residents in long-term care homes and other institutions for the elderly are estimated to be about 3 percent of the population of these institutions.[5] The share of deaths of residents in the Canadian equivalent of nursing homes in total COVID-19 deaths is estimated to be 69 percent of total deaths (Canadian Institute for Health Information 2021), which is much higher than the share

Table 4.1 Pandemic-Related Nursing Home Deaths in the United States, the United Kingdom, and Canada (March 2020–April 2021)

	United States	United Kingdom	Canada	Germany
Number of nursing home deaths	150,000	41,521	14,739	29,000
Deaths as a share of home residents (%)	11.5	8.8	3.4	3.6
Deaths as a share of 65+ population (%)	0.28	0.35	0.22	0.16
Deaths as a share of national deaths (%)	26.5	27.4	69.0	31.4
Number of nursing home residents	1,300,000	472,562	428,525	800,000
Population aged 65+ (in millions)	54.07	11.81	6.84	18.09
Total COVID-19 deaths	565,000	151,795	21,361	92,271

NOTE: In the United Kingdom, nursing homes are known as care homes; in Canada, as long-term care homes.

SOURCE: Canada: number of long-term care home residents is from 2016 census; figure for long-term care homes includes Canadian equivalent of ALFs; 65+ population is Statistics Canada estimate for July 1, 2020. U.S.: 65+: Census; total and nursing home deaths CDC; nursing home residents based on state figures. U.K.: National Health Service for number of residents; MHA.org.uk for percentage of pop. 65+ in homes. Germany: Population and total deaths: Statista; nursing home residents and deaths: newspaper reports.

in the United States or the United Kingdom, but this simply reflects the much higher death rates in the population at large of these two countries.[6]

The United Kingdom, like the United States, has vaccinated a relatively large share of its older population and especially care home residents. About half the country was partially vaccinated as of early May 2021, and one-quarter was fully vaccinated. In Canada, although elderly people have been favored in the distribution of vaccines, vaccination rates were initially much lower than in the United States, in part because Canada lacks a maker of vaccines. Rates subsequently recovered as the country obtained more vaccines from abroad, and because provincial vaccination campaigns have not encountered the same resistance as they have in the United States. The rate of death

in German nursing homes, based on the available data, appears to be similar to the rate in Canada.[7]

It is impossible to fully understand why the rates of death in nursing homes in the United States and the United Kingdom were so much higher than in Canada and Germany, but two possible influences might have been at work. First, the rate of infection in the general population was much higher in the United States than in other countries, and that was reflected in caregivers' infection rates and death rates.[8] Second, Medicaid's means-tested character probably resulted in U.S. nursing home residents having lower incomes than those in Canada or Germany. To the extent that income correlates with health, it could be inferred that comorbidities played a greater role in the United States than it did in these two countries.

ASSISTED LIVING FACILITIES AND CONTINUING CARE RETIREMENT COMMUNITIES

As Chapter 1 explains, Medicaid requires states to supply substantial information to qualify for eligibility in the program, but the same does not apply to either ALFs or CCRCs. As a result, the information available on the impact of COVID-19 is extremely limited in the case of ALFs and basically nonexistent for CCRCs.

A study by the Kaiser Family Foundation in September 2020 reported data on cumulative infection and death rates in ALFs for 19 states through August 2020. Thirty-one states and D.C. were not reporting cases or deaths in ALFs. Of the 19 reporting states, 10 provided data for both June and August 2020. For the 14 states reporting through August 2020, cumulative deaths were about 2,600 (True et al. 2020). No information for the subsequent period on cases or deaths from these states is readily available.

The available data do not permit a calculation of the number of deaths per ALF resident, although the comparatively low number of deaths for the 14 reporting states, including California, Connecticut,

New York, Pennsylvania, and Texas—states that account for a large share of the population of ALF residents—suggest that it is substantially lower than the rate of death at nursing homes.

Subsequently, New York State began reporting deaths in ALFs, nursing homes, and other facilities at weekly intervals, with cumulative totals. In the first week of March 2021, deaths in ALFs accounted for 5 percent of cumulative total deaths in long-term care institutions of 15,430 (Long-Term Care Community Coalition 2021). Timely and detailed data for other states do not appear to be readily available. If, however, the situation in New York may be taken as representative of the whole country, the conclusion that the death rate among residents in ALFs is much lower than that at nursing homes is reinforced.

The limited data on CCRCs do not allow any firm conclusion to be drawn as to the impact of the pandemic on these facilities. It is likely, however, to have been similar in ALFs, and possibly less given their more spacious living arrangements. That said, CCRCs do include facilities for residents who can no longer care for themselves. To the extent that the living arrangements for these residents are like nursing homes, similar problems may arise.

In sum, we cannot offer a comprehensive explanation of the appallingly high death rates in U.S. nursing homes, but the higher rate of infection in the population at large, which affected the infection and death rates among caregivers, probably played a role. Higher comorbidity may also have contributed. The higher infection rate in the population at large was not within the control of nursing homes, but their response to it was, at least in part.

Notes

1. One very troubling aspect of the COVID-19 pandemic that affects younger survivors is so-called long COVID: the lingering and often debilitating side effects of the disease on survivors. See *The Economist* (2021).
2. The total number of deaths for which age at death is recorded is about 80 percent of the total number of deaths, apparently because the age

at death of about one in five victims of COVID-19 could not be determined or was not recorded.

3. Americans aged 65 and older numbered about 54 million in 2019, according to the American Community Survey. With an estimated 1.3 million nursing home residents in 2019, the number living outside homes was about 53 million. If we assume that nursing home residents are all aged 65+ years, which is a reasonable approximation, COVID-19 related deaths were 0.6 percent of the population aged 65+ outside of nursing homes.
4. The death rate of the population less than 65 years old is estimated to be 0.04 percent.
5. The death rate in Canada is for all congregate facilities, not just for long-term care (nursing) homes. The rate for nursing homes would be higher than the rate shown in Table 4.1 if other congregate facilities were excluded. However, it would remain well below the U.S. rate.
6. The lower death rate at Canadian institutions does not in any way imply that the administration in these places has been satisfactory. Picard (2021) documents some shocking cases of mismanagement and neglect, including some egregious cases of what amounts to malpractice in one long-term care home in Montréal.
7. The figure for Germany shown in Table 4.1 is the sum of estimates for the German states taken from various sources. It should, therefore, be considered as representing only an order of magnitude.
8. The Canadian Institute for Health Information estimates that as of March 2021, about 25 caregivers had died in Canadian facilities. Even adjusted for the difference in population between Canada and the United States, this is a fraction of the number of deaths of caregivers in U.S. nursing homes.

Chapter 5

Recommendations for Policy

When considering policies for improving long-term care in the United States, any set of recommendations must be mindful of what is realistically attainable. Politics is the art of the possible, and as Voltaire observed, the perfect is the enemy of the good. That said, it might be useful to set out what a *good*, if not a perfect, system of long-term care might look like as a benchmark for reform. Setting a benchmark is not the same as establishing an edict that must be met to the letter. It is merely a way of giving reform a coherent and consistent set of objectives and pointing to areas where current practice is too far from the norm to really be acceptable.

With that in mind, this chapter proceeds with a summary account of what the author believes a good long-term care system would look like. It will then draw together the analyses of the chapters that have preceded it and briefly summarize the ways in which current practice meets or falls short of this benchmark. Finally, it will make recommendations to bring current practice closer to the norm described here, setting out three progressively more ambitious approaches to reform.

A THUMBNAIL SKETCH OF A GOOD SYSTEM

A good system should provide at least adequate long-term care to every citizen who needs it, in an appropriate setting.[1] That setting may be an institution, the person's home, or a community care center. The cost of care at home may well be less expensive than institutional care, although this will depend on the level and nature of care that each care recipient needs. Persons suffering from severe dementia, for example, require around-the-clock care, which is much less expen-

sive if provided in a congregate setting than it would be at home. That said, some families may have the means to pay for intensive at-home care and may choose to do so.

Paying for care should not immiserate the care recipient or her family. The burden of good care on the public purse and therefore on the taxpayer should be minimized by ensuring that families that can afford it should pay for all or most of the care, or more generally, that the role of the public support should vary inversely with the income or wealth of the care recipient. Except for the very poor, the care recipient or his family should pay for at least part of his care.

A good system should minimize waste and fraud. To that end, public support of home care as well as institutional care should be adequately monitored, which will require that caregiving institutions provide appropriate and timely information on their activities and their budgets. In addition to adequate information, there must be incentives in place to effectively minimize poor-quality care or dangerous practices, especially in nursing homes. Monitoring care given in the home is likely more costly than monitoring institutional care, because of economies of scale.[2]

Frontline workers, both skilled and less skilled, should be adequately paid, trained, and vetted. The less-skilled workers in nursing homes, who may have the most contact with residents, need to be thoroughly trained in procedures that minimize the risk of exposing residents to infections, and understand the importance of helping more immobile residents to avoid bed sores.

A good system should also be as easy as is feasible given its inherent complexity for its users, actual and potential, to understand. Less misunderstanding of the rules that determine who is eligible for publicly supported care and the terms of those rules will make it easier for everyone to plan for this contingency. Information on publicly provided care should be published at regular and timely intervals.

Finally, any long-term care system involves politically sensitive trade-offs between the cost to the taxpayer, the quality of care, and the financial burden borne by low- and middle-income households.

Making that trade-off as easy as possible for the country's political system to deal with is another critical feature of a good system and will require that the incentives for efficiency and waste minimization be as well designed as possible. It will also require some general acceptance of the need for higher taxes, if higher taxes are needed, to allow the quality and coverage of long-term care to reach a norm.

HOW DOES THE CURRENT SYSTEM COMPARE TO THE BENCHMARK?

Chapter 3 places the U.S. system in the general category of a residual (i.e., means-tested) system. The U.S. system has the undoubted merit of being less expensive than the systems of any other advanced country. However, when compared to the benchmark we have just outlined, it is deficient in some crucial respects. Of particular concern are the following shortcomings:

- **Coverage and means-testing.** Unlike Germany and the Netherlands, where coverage of long-term care is either universal or nearly so, coverage in the United States is quite severely limited by means-testing. The result is that many middle-class families will not be able to avail themselves of it without first spending down their assets or engaging in estate planning (which is not cheap) to protect their assets from encroachment. Even then, they may fail their state's income test. Even in Canada, where coverage of institutional care or care at home is not universal, government subsidies bring institutional care into the reach of most middle-income families. The same is true of the United Kingdom, as the OECD study described in Chapter 3 demonstrates. More generally, the U.S. system can push families to the brink of poverty or require that they care for their infirm elderly at home when institutional care might be superior.

- **Care at home.** Caregivers at home receive little support from the government and as a result are often obliged to forgo remunerated work outside the home. The AARP's surveys report significant levels of burnout and psychological stress.
- **The provision of timely and comprehensive data.** Nursing homes currently provide comprehensive data, but there is an unnecessarily long lag in its dissemination. Data on ALFs is fairly comprehensive in some states, but skimpy or nonexistent in others. It is generally not made available promptly. Data on CCRCs is almost completely lacking. Regular reporting on care at home understandably does not take place, although AARP and others have produced very useful and quite comprehensive surveys of the number of caregivers and their recipients and other relevant information. This disparity in reporting across congregate institutions mainly reflects the fact that Medicaid is jointly financed by the federal government and the states, while ALFs and CCRCs are financed entirely by their residents.
- **Understandability.** No one who has studied or attempted to study Medicaid would seriously argue that its rules are easy to understand. The nature of long-term care would make the rules that applied to its public provision complex regardless of any efforts to simplify them. But the combination of the divided jurisdiction between the federal and state levels of government and the role of means-testing adds layers of complexity. It is no wonder, as Chapter 2 notes, that a large share of Americans over the age of 50 are confused about who pays for what.
- **Incentives to rectify shortcomings in care in congregate facilities.** This is almost certainly a more serious problem in nursing homes than it is in other congregate settings or care at home. Although nursing homes are required to report deficiencies in the care of their residents to their state by Medic-

aid, and appear to do so at the required frequency, sanctions for unhealthy and dangerous practices are rarely invoked. Although the data available on the impact of the pandemic in nursing homes or equivalent facilities in other countries is very limited, what there is makes clear that nursing homes in the United States were shockingly unprepared to deal with the risk of contagion and infection. The difference between the death rates in nursing homes in the United States and those of its northern neighbor is remarkable, despite the inadequacies that have been reported in Canada.

- **Pay and work conditions of unskilled workers at nursing homes.** Unskilled workers at nursing homes are typically paid somewhat less than $15 per hour, the wage seen by many as a minimum living wage. It is questionable whether that rate is high enough to attract the dedicated workers that the job demands.

DIRECTIONS FOR REFORM

This section sets out three possible approaches to reform of the current system that would bring it into closer alignment with the model previously described. The first is the simplest and easiest to implement, at least from a technical point of view. It would maintain the structure of the status quo while addressing at least in part what the author believes are the worst failings of the current system. This first approach, assuming it had political support, would be the quickest reform to implement, but like the more ambitious versions that follow, it would require additional taxes to finance it. The second approach would add some features to the first and would significantly improve it. It would, however, require yet more taxpayer dollars. The third approach would require a root and branch reform of the current system. It would take some time to implement—along with its addi-

tional cost, it would require enormous political will, and a consensus that the current system is simply too broken to be fixed.

The First Approach

The first, simplest, and least costly approach would leave the current financial structure of Medicaid in place. The program would remain jointly financed by the federal government and the states, but it would be made more generous by making the means-testing rules less stringent, both as they apply to custodial care and as they apply to HCBS. This reform would simply bring public support to more middle-class families. How much more generous the program could be would obviously depend on the willingness of taxpayers to pay more for it. To reduce the effect of moral hazard, the program might be redesigned with a sliding scale that would eliminate the strict cut-offs of the current system. The addition of this sliding scale would be more complex than simply raising the asset and income tests.[3] Another reform, albeit one that would require some change in the division of responsibility between the two levels of government, would be to make more uniform the rules that states apply to countable assets, although this might prove to be a bridge too far.

Simply making means-testing less stringent would entail its own complications. The reader will recall that there are three pathways to Medicaid eligibility: the original pathway, with an income ceiling depending on the state of 74 percent or 100 percent of the federal poverty line (which, in the 39 states including D.C. that have accepted the ACA, is now 138 percent); the special income rule, with a ceiling of three times the SSI level; and the medically needy rule, the most complex of the three. Raising the limit of the special income rule, which applies in 42 states and D.C. would be technically straightforward if politically contentious. The original pathway might be adjusted by a multiple of its current level in each state, like 1.25. Adjusting the limits of the medically necessary pathway would be the most complex because of the way the income floor varies from state to state. Similar considerations would apply to the asset ceiling that states impose.

One issue that might arise with this first approach, and which would undoubtedly be politically contentious, is the division of financing between the federal government and the states. Would the rules stay the same—a minimum of a 50 percent share and a maximum of a 77 percent share for the federal government, or would there be substantial pressure for the federal government to pick up more or even all the extra costs that the reform would entail? Even if the federal government agreed to increase its share of total costs, disagreement among the states as to what that increased share should be is quite possible. In sum, even an increase in public support with the basic structure of Medicaid financing left unchanged would entail some technical issues that would need to be worked out, and perhaps more importantly, would be difficult politically.

The Second Approach—The First Approach with an Add-on

The second approach would build on the first by including remuneration for the millions of unpaid relatives and non-family members who care for the elderly infirm in their homes. A system of payments to these caregivers is described in the last section of Chapter 2. Payment based on a strict system of periodic reports on the number of hours spent by caregivers was deemed to be infeasible. Instead, a presumptive system was proposed, where there might be annual inspections of a home where care is being provided and an assumed number of hours of caregiving assessed. This assessment could be based on an evaluation of the needs of the care recipient and the number of persons being cared for in each home. The annual assessment could be requested by the caregiver or his or her representative and need not generate much paperwork. In many cases, only one assessment would be needed, and assessments perhaps would not need to be carried out every year. Remuneration per hour could be some multiple of the state's minimum wage.

Even this simplified system for determining what a caregiver should be paid would pose its own complications. Should the assess-

ment be done by a trained nurse, as is the case with assessments by insurance companies that issue long-term care policies when a policyholder initiates a claim? That would require tens or hundreds of thousands of visits in each state, each costing perhaps three or more hours of a skilled person's time. Or could a system work if it was based on an honor system, where it would be enough to show that an elderly person was living at home and where caregivers made a declaration—which would have to be subject to severe criminal penalties if it proved to be false—that he or she was in fact providing the care they claimed?

Another issue would arise with respect to the income of the family undertaking the care and whether it should be considered in determining the remuneration of caregivers. One way to limit costs would be to place a limit on the income of a caregiving household related to the number of its members. Under a sliding scale approach, the rate of hourly remuneration would be phased out as income per household member increased.[4] A related issue is whether the hourly income rate would be determined by the state or by the federal government. Clearly, the second "add-on" approach would require that additional technical issues be resolved. More importantly, and while there may be no point in stating the obvious, political resistance would be considerable because of its extra cost.

The Third Approach—Root and Branch Reform

The third approach would entail a complete overhaul of the current system. Arguably, it would also require a fundamental change in Americans' attitudes toward their government and its role in the economy. The reader does not need reminding that a policy like Medicare for all has already encountered strong political resistance, and so would the reform of long-term care described here. The third approach is offered not as a realistic reform option, but rather as an ideal that the country might someday wish to pursue. Furthermore, this account does not presume to be a blueprint, ambitious or otherwise, but a mere sketch of the direction of proposed reform. The

reader will recognize that the proposal borrows important elements from the German system described in Chapter 3.

The basic elements of the reform would be universal coverage with safeguards to ensure that households would contribute toward the cost of long-term care according to their means. Universal coverage would either be combined with or entail an end to state-by-state regulations and options. Like Medicare, all states would offer the same coverage. There would be no means-testing, and hence, no need for state-by-state ceilings on income or assets.[5] This aspect of the reform would have the great virtue of making the system less difficult for the average American to understand and navigate.

The program could be financed from general tax revenues (the universal model that Chapter 3 describes) or from an addition to the payroll taxes that now finance Social Security and Medicare (the social insurance model). Moving to a payroll tax system would require some adjustment in the taxes levied by the federal government and the states, because it would relieve states of the need to contribute directly to Medicaid's costs.

Nursing homes and any other congregate institutions would continue to set prices as they currently do under present arrangements and would continue to be reimbursed by state governments. However, the financing source of these payments might change. Under the social insurance approach, the federal government would make payments to the states, which would have to either cede part of their tax base to the federal government or compensate it, at least in part for the extra expenditure it was undertaking. The same change of arrangements would need to apply for HCBS.

Residents in subsidized congregate facilities would be expected to pay the government a charge for their room, board, and maintenance that would be related to their household income. Residents from households below a certain level would pay nothing, and a sliding scale would be established for households at higher levels of income.

Care at home could be provided by paid caregivers or professional staff from outside the home, as it now is, or by family members.

Government could continue to pay caregivers from outside the home under a HCBS program whose elements would apply to the whole country, albeit at rates of remuneration that would vary across states. The government would pay relatives and the other unpaid caregivers who now come to the home of infirm older persons, and as is the case with institutional care, would establish a sliding scale that would apply to the total budget each household could allocate to this type of care, leaving the choice of the source of care in the home up to the household.[6] Caregivers from outside the home would be subject to the same rates of remuneration that now apply. Relatives and other unpaid caregivers would be subject to the presumptive scheme described in Chapter 2.

Medicaid in its present form is largely administered by the states. The federal government has a critical financing role, which as pointed out under this reform, would have to change. It also has an indirect supervisory role of nursing homes, given the reporting requirements it imposes on states for access to Medicaid financing and the penalties it can impose if the standards it sets for nursing homes and other congregate facilities it pays for are not met. A change in financial arrangements might mean that the federal government would lose the leverage it now has to make states impose adequate standards of care. This could be avoided if the states remained responsible for paying nursing homes and were subject to a federal withholding of the funds they would normally get if they failed in their disciplinary role.

The devil is always in the details, and there are a lot of details that this broad-brush presentation of a very fundamental reform has not provided. Moreover, even if the details could all be worked out perfectly, there is the question of what it would cost. As the section on unpaid caregivers discussed, paying these workers at rates that workers in their states receive for similar work would cost about 2 percent of GDP, amounting to about 10 percent of federal government revenues and 6 percent of general government revenues. It is well beyond the scope of this study to estimate the cost of relaxing means-testing: for example, the cost of increasing the ceiling under

the special income pathway from three to four or five times the SSI. But estimates like these would have to be made.

The epigraph from Pearl Buck at the beginning of the book is worth pondering when we reflect on the cost of improving the care that we give to our most vulnerable citizens. Perhaps it would be well worth the high cost. If this study inspires its readers to take Ms. Buck's words seriously, it will have accomplished its basic objective.

Notes

1. This is an ethical judgment, one that cannot be proved or disproved. A libertarian might posit that persons in need of care or their families should be responsible for the costs of that care, regardless of their income or wealth level. The definition of "adequate" is a related but separate issue. We might all agree on the need to support the elderly poor but differ over the quality of that support—the amount of living space they should have, the quality of the food they eat, and so on. In any case, if we believe in a societal obligation to support the elderly disabled and their families, we must reckon with the possible moral hazard that such support could create: the danger that households will not undertake any saving to meet the contingencies of old age.
2. There are economies of scale in the sense that with institutionalized care, those being cared for are under one roof, rather than being separated by possibly long distances.
3. With a sliding scale, the cut-off point of the income test would be raised with the applicant's income.
4. Yet another issue relates to the treatment of household members who are minors—would they count as an adult in numbering the members of a household? Economists have sometimes assumed that minors should be counted for less than one adult, on the grounds that their basic expenditure or consumption needs are less.
5. Some functions of government, notably primary and secondary education and policing, are most efficiently carried out at the regional (i.e., state) and local levels. Medicare, however, is undoubtedly administered more efficiently at the federal level, and there is no obvious reason why its rules should vary from state to state. And if that is true of health care, it should also be true of long-term care. The same is true of Social Security. The country does not have 51 Social Security Administrations. Parenthetically, one might also wonder why it needs 51 separate agencies (the 50 states and D.C.) to administer unemployment insurance.

6. This assumes that care recipients are either in a facility or are being cared for at home. If in each budgetary period a care recipient were receiving care both at an institution and at home, a total budgetary envelop would apply.

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