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LONG-TERM CARE IN THE UNITED STATES

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ABSTRACT

The population of the United States, as with the rest of the world, is aging rapidly, with the most rapid growth occurring among the age 85 and older population, those who rely most on long-term care. In this chapter, we review the delivery and financing of long-term care in the U.S. We show that the resources of most elderly in the U.S. are insufficient to finance these ongoing long-term care needs and the public sector finances the majority of long-term care spending. At the same time, informal care plays a critical role, with the elderly at every age and every disability level receiving informal care more frequently than formal care. Indeed, when properly valued, informal care accounts for more than one-third of the nearly 2 percent of U.S. GDP devoted to long-term care.

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The population of the United States, as with the rest of the world, is aging rapidly. Although by most measures, the United States is "younger" than many countries in this volume, it faces the highest per capita health care costs in the world (OECD, 2022). Furthermore, the most rapid growth in the older population in the United States is among those ages 85 or older, the group for whom health care costs are the greatest and who are most likely in need of long-term care (CMS, 2014). Figure 1 shows the rising share of the population ages 65 or older while Figure 2 highlights the fact that the most rapid growth is among those ages 85 or older. Seen another way, in 2020, in only three of the 51 U.S. states (and District of Colombia) was more than one-fifth of the population above age 65. By 2050, the number of such states is projected to be 43.[2]

Population aging has a variety of implications for economic activity and for government finances, affecting issues ranging from labor force productivity to public pensions to the costs of treating expensive acute disease. But one of the most important issues is the cost of long-term care: the costs of providing for those elderly who face limitations in caring for themselves. Nearly 30 percent of those ages 65 or older, and 60 percent of those age 85 or older, report at least some limitation in their ability to conduct daily activities. In coming decades, as an increasing share of the population is above age 65 and the "oldest old" (those aged 85+) comprise a rising share of the elderly, the greater prevalence of limitations in daily activities will mean increased care needs for the population.

While the types of long-term care needed and associated expenses run the gamut, here we follow past practices and organize our discussion around two main categories of care: institutional care in nursing homes (or skilled nursing facilities) and home care. In 2018 spending for nursing

[2] Calculations derived by applying estimated national population growth by age group from Ortman, et al. (2014) to population levels by age observed in the 2018 American Communities Survey.

homes totaled approximately $171 billion while home care costs totaled $108 billion. As large as these expenditures are, they ignore an equally important cost of care, that being the implicit cost of informal care provided by millions of Americans to their elderly relatives and friends. A proper accounting of costs must include these costs as well.

In this chapter, we provide an overview of the long-term care system in the U.S. The core data that we use for this exercise are drawn from the Health and Retirement Study (HRS). The HRS is a nationally representative panel study of individuals ages 50 or older and their spouses or partners. The survey collects detailed information on the health, economic well-being, and family structure of its respondents, making possible a thorough analysis of aging and long-term care in the United States.[3]

Our analysis proceeds in three steps. First, we explore the impact of functional limitations on the financial well-being of the elderly. In doing so we focus on the well-known measures of limitations, limitations with respect to Activities of Daily Living (ADLs, activities such as toileting and bathing) as well as limitations with respect to Instrumental Activities of Daily Living (IADLs, activities such as cooking or shopping). We show that those who are older and in worse health have fewer financial resources as measured in several dimensions. We also show, unsurprisingly, that the intensity of care rises sharply with age and with the number of limitations. Finally, we document that the resources of most elderly in the U.S. are insufficient to finance these ongoing long-term care needs. It is clear that without public assistance, the elderly in the U.S. would be largely unable to finance the long-term care that they are now receiving.

[3] At times we supplement these data with information obtained from other sources.

We then turn to a discussion of how long-term care is provided in the U.S. We document the division in financing between public and private sources, including the presence of a small private long-term care insurance market. We then show the distribution of care across types by age and degree of limitation, highlighting the growing use of both formal home care and nursing homes as individuals age and become more disabled. We discuss the workforce engaged in long-term care, focusing on their low level of pay.

Finally, we return to undertake a full calculation of the cost of long-term care for the elderly in the United States – including the costs of informal care. We use alternative methods of valuing the time spent in informal care to show that the costs of informal care are enormous, amounting to 27-40 percent of the total cost of long-term care in the U.S. In total, spending on long term care for the elderly amounts to almost 2% of US GDP when these informal care costs are incorporated.

Part I: Aging, Disability and Well-Being

Sample and Definitions

The primary data for our analyses come from the Health and Retirement Study. The first interview wave of the HRS was administered in 1992 to a sample of individuals born between 1931-1941 and their spouses or partners; interviews for this cohort have been repeated every two years. A second cohort of older Americans, those born before 1924 or earlier, was begun in 1993 with a follow-up survey administered in 1995. This second cohort was merged with the original sample in 1998 and two new cohorts were added at this time – one to fill-in the missing interim birth years (1924-1930) and the second to refresh the sample with a younger cohort (1942-1947). Since 1998, new cohorts spanning ages 51-56 have been added every six years to keep the sample approximately population representative of the older US population ages 50 or older. The HRS

collects information from respondents across a variety of topics, ranging from demographics and family structure to income and wealth to health and long-term care needs.

We use data from the 2018 survey and limit our analysis to those ages 65 or older in that year. Although the HRS does not include nursing home residents in its initial sampling frame, it does follow panel members who were previously living in the community into nursing homes. Our data thus do not include information on individuals who were living in a nursing home prior to the age at which they first entered the survey,[4] but such individuals constitute a very small fraction of nursing home residents. We are therefore able to conduct most of our analyses on all elderly individuals, both community-dwelling and in institutions.[5]

The key measures of health used in our analysis are based on reported functional limitations. These limitations include limitations related to Activities of Daily Living (ADLs) and to Instrumental Activities of Daily Living (IADLs). We use six ADL measures: dressing, bathing, eating, toileting, getting in and out of bed, and walking across a room. We also use five IADLs measures: using a telephone, cooking a hot meal, shopping for groceries, taking medications as prescribed, and managing money. For each of these 11 items, the survey asks respondents whether they have difficulty with the activity due to a health or memory problem that they expect to last more than 3 months. If they answer in the affirmative, we consider them impaired.

Aging, Disability and Well Being

[4] Respondents in the oldest cohort were 70 years old or older when they entered the survey so that cohort is missing many in that age range who were in a nursing home. However, because our analyses are based on data 25 years after that cohort was first interviewed, there are likely to be few such individuals in the sample

[5] We exclude the non-elderly in nursing homes. In 2018, only 16.9 percent of nursing home residents were under age 65 and almost half of these residents were short-stay residents, staying only temporarily for post-acute care and primarily residing in the community (Sengupta et al., 2022).

Table 1 shows the distribution of limitations by age. The majority of those ages 65 or older have no limitations, while 9 percent of the sample has no ADL limitations but at least one IADL limitation, and 20 percent has a limitation with respect to at least one ADL. Among the oldest old (those ages 85 or older) 40 percent are free from any limitation, 18 percent have no ADL limitations but at least one IADL limitation, and just over 40 percent have at least one ADL limitation.

Table 2 illustrates the frequency of the various types of IADL and ADL limitations, both unconditionally and conditional on having difficulty with at least one such activity. For those with one or more IADLs, difficulty shopping for groceries is the most commonly reported problem, followed by managing money. For those with one or more ADL limitation, difficulty getting dressed is the most frequently reported, although taking a bath is the most common limitation among those aged 85+.

We further explore the relationship between limitations and well-being in Table 3, which reports the emotional and physical health status of the respondent by age and degree of limitation. We include measures of subjective health status, retirement satisfaction, and self-reported feelings of being depressed. Among those 65 or older, 73 percent of the full sample reports themselves to be in good or better physical health while unsurprisingly, just 30 percent of those with 3 or more limitations do so. The differences are less stark for retirement satisfaction, but particularly strong with regard to feeling depressed, with just 10 percent of the elderly but 30 percent of those with 3 or more limitations reportedly feeling depressed much time. In every case, those who are older and more disabled are faring less well.

Financial Resources

To explore the potential financial implications of age and disability, Tables 4 and 5 show the distribution of income and wealth by age category and the distribution of income by degree of limitation. We use the RAND-HRS imputed values for total household wealth and total household income, normalizing each measure using the OECD equivalence scale for comparison across other chapters in this volume.[6]

Both the income and wealth distributions are quite skewed with the mean values substantially higher than the medians. Because most of those in this age group are no longer working and thus have zero earnings, the distribution of income is less wide and less skewed than that for wealth. We also note slight differences by age, with lower income and wealth among the older cohort. The differences are less than one might imagine because of selection in who among the 65 or older population survives to age 85. The similarity across the age bands is most pronounced at the upper portions of the distributions, and average wealth is actually higher for those aged 85 or older, wherein selection dominates cohort differences in lifetime earnings.

There are, however, enormous disparities in income by the degree of limitation. To illustrate the pattern, panel 1 of Table 5 divides the sample by income and by number of limitations. Each column sums to 100 percent, showing the distribution of income among those with the corresponding number of limitations. For example, among those with 3 or more ADLs, 40 percent have incomes below the median, while only 7.3 percent have incomes greater than twice median

[6] A household is defined as the respondent and their spouse / partner (if any), so the equivalence scale simply involves dividing income and wealth of two-person households by 1.5. Total income consists of earnings, pension income, business income, government transfers (including Social Security), and an "other income" category. It does not include withdrawals from retirement accounts or cash transfers from family members. Total household wealth includes the value of a home and other real estate, retirement accounts, vehicles, financial wealth (including assets in defined contribution retirement plans, e.g., 401ks and IRAs), and an "other wealth" category, net of mortgages and other debt. It does not include estimated defined benefit pension wealth.

income. There is a clear negative correlation between the degree of limitations and income. When looking at the lowest limitation category (those with no ADLs or IADLs), only 14 percent of the sample have incomes below 50 percent of the median while 21 percent have incomes above twice the median. More generally, the share of people with less than 50 people of the median income is rising consistently with the number of limitations, while the share whose incomes are in categories greater than the median is declining.

A similar pattern emerges in Panel 2 of Table 5, which examines the relationship between wealth and limitations. As before, limitations are negatively correlated with wealth – 63 percent of those with three or more ADL limitations have wealth below 50 percent of median wealth, while only 17 percent have wealth greater than twice the median. In contrast, only 29 percent of those with no ADL or IADL limitations have wealth below 50 percent of the median, while 39 percent have wealth greater than twice the median. Thus, the need for care appears to be greatest among those least able to afford that care.

Care Received

With this understanding of the prevalence of long-term care need and its association with well-being and economic resources, we next examine the use of various types of long-term care. Because questions about the receipt of home care in the HRS are only asked if someone reports *difficulty* with at least one of the 11 ADL/IADLs, some forms of home care may be missed if they are not provided in conjunction with help with an ADL/IADL. This care could include, for example, care focused on monitoring vital signs, dispensing medications and injections, physical therapy or rehabilitation, and wound care, provided that the respondent can manage the listed ADLs and IADLs themselves. We expect that the majority of such care would be temporary in nature and not truly long-term care as such.

For each person who reports difficulty with an ADL or IADL in the survey, a follow-up question is asked about whether anyone ever helps them with that activity and if so, who helps them. After going through all 11 activities, the respondent is asked to report their relationship to each helper, whether the helper was paid, and the total number of care hours of care this helper provided in the last month. Helpers can be professional caregivers or relatives or friends of the respondent such as a spouse or child. We provide summary figures here and explore the nature of long-term care received in more detail in Part 2.

Table 6 shows the distribution of weekly hours of care received for both formal and informal care. The median number of hours of care received is 13, but the mean is 30 hours and 10 percent of the population receives well over 100 hours. Care needs are only somewhat higher for the oldest old, conditional on receiving home care. The median number of hours of care for this group is 14, the mean is 39 and the top 10 percent of the distribution receives 114 or more hours of care.

Much of this care is provided informally by family members. Just two percent of our sample receives some formal home care compared to 12 percent who receive informal care. Formal care is expensive, with the median cost of home care workers at roughly $23 (Genworth, 2019), while informal care can represent a substantial burden for caregivers taking both an emotional and physical toll. We discuss these costs more below.

The primary alternative to home care is nursing home care. While nursing home residence is far less common than home care, and typically less preferred by the individual, it is often the only alternative—particularly when around the clock care is needed. Nursing homes are also very expensive. The median annual cost of a private nursing home room in 2019 was $102,000 (Genworth, 2019), although in contrast to the measure of the cost of home care, the cost of nursing

home care includes room and board as well as any assistance with long-term care needs. While many nursing home stays are of short duration, data from 2018 indicate that 56 percent of nursing home residents had stays of over 100 days and the average length of stay was 485 days (Sengupta et al., 2022). With respect to the HRS sample, Table 7 shows that just over 10 percent of those currently in nursing homes have been there for fewer than 100 days, with the average and median length of stay of over 450 days. (Note that these statistics are not completed stays, but rather stays in progress at the time of the 2018 HRS interview.)

As is clear, the cost of any type of care is sizeable and this burden is readily apparent when comparing these costs to the financial resources of the elderly. The average recipient of formal home care receives 30 hours of care per week; over a full year, these costs would total over $35,000. This amount is greater than the incomes of one-half of the individuals in our sample, and more than the net wealth of roughly one-fifth of respondents.

Nursing homes are even more unaffordable; the median annual cost of a private nursing home room is greater than the incomes of almost 90 percent of the elderly and greater than nearly 95 percent of those 85 or older. In fact, the median price of a nursing home is greater than the total wealth of approximately one-third of the elderly, and two years in a nursing home would exhaust the wealth of almost one-half of this population. While we expect the elderly to be spending down assets in retirement, even when drawing on wealth, few in the sample have the resources needed to support a long-term nursing home stay. Moreover, as we documented, those with the greatest need for long-term care in activities of daily living are also those with the most limited resources to purchase this care.

It is clear from this discussion that the current distribution of long-term care receipt, or anything like it, would be unaffordable if paid out-of-pocket. This leads naturally to the question

of how long-term care is financed. We therefor turn next to an examination of the long-term care system in the United States, discussing the ways in which public programs and informal care may shield the elderly from bearing the full cost of care and quantifying the total cost of these supports and what those costs might amount to for the country as a whole.

Part II: Long-Term Care System in the U.S.

Formal long-term care costs comprise a rapidly growing portion of the U.S. health care system, rising from less than 1 percent of GDP in 1990 to more than 1.5 percent by 2011 (Figure 3). However, since that time, costs have been relatively flat in terms of percent of GDP as state and federal governments worked to find less costly pathways to care.

Despite the dramatic cost of long-term care, particularly relative to the resources of most elderly, few individuals have private long-term care insurance. Instead, much of the cost is borne by government programs. Figure 4 shows how this expense is shared across various financing sources. Even absent the existence of a true national long-term care insurance program, the public sector is the primary payer for long-term care. The two main public programs that cover such care are Medicare and Medicaid. Together these two programs pay for 63 percent of formal long-term care costs, while 19 percent of costs are paid for out-of-pocket and only 10 percent are paid for by private insurance.

Public Insurance: Medicare and Medicaid

Medicare is the universal health insurance program that covers both the elderly and disabled populations, with those age 65 or older comprising 86 percent of the enrolled population and incurring 79 percent of the program costs (MedPAC, 2021). This federally administered program is financed by both a dedicated payroll tax and by general government funds. However,

Medicare coverage of long-term care is limited to those needs that are is "medically necessary," rather than simple assistance with ADLs or custodial care; coverage of nursing home care is limited to 100 days, with individuals shouldering a substantial copayment on the portion of the stay beyond 20 days.[7] Essentially, Medicare long-term care is targeted to acute care and not chronic illnesses; much of the spending, for example, is on post-hospital care.

The second public health insurance program, Medicaid, is targeted at low-income individuals and does provide assistance with limitations in daily living. The program provides coverage for eligible elderly individuals as well as for families with children and for the disabled, with again, the majority of benefits going to elderly enrollees. It is financed jointly by the federal and state governments but administered by the individual states. While the federal government specifies certain parameters of the program, eligibility criteria for long-term care—including income limits, asset limits, and care needs -- vary by state. For single individuals, income limits in many states are currently just over $2500 ($2533) per month,[8] while asset limits are typically $2000 (several important items, most notably, an owner-occupied home, are excluded from the valuation of assets). Elderly individuals who have incomes above the Medicaid limit may qualify for Medicaid coverage if they have sufficiently high medical expenses that they "spend down" their incomes below a "medically needy" level. The existence of medically needy programs and the eligibility guidelines vary significantly across states.

While Medicare coverage is limited in the number of days of care that can be covered and requires that care be medically necessary, Medicaid will provide indefinite coverage for a variety

[7] Because Medicare provides limited coverage of what we think of as long-term care (e.g. assistance with ADLs or IADLs) in the statistics below, we exclude these short term stays in nursing homes.
[8] See American Council on Aging (2021) for additional information on state income eligibility requirements.

of needs, including custodial care. As with income and asset limits, states differ in the types of services they cover, particularly regarding home care. Although Medicaid guarantees nursing home care for those who qualify on health and income grounds, home care is not guaranteed and there are often waiting lists for the receipt of such care. In recent decades, the federal government has allowed states to expand Medicaid coverage of home care, expansions that in many instances are authorized through "waiver" programs under which the state applies for coverage of additional services and the federal government shares in the cost. The goal of these programs is to provide services that can reduce institutionalization and allow elderly individuals to remain in the community. These services can include items such as adult day care or respite care, meals, or transportation assistance. Figure 5 shows the shift in Medicaid expenses from institutional to homecare, with spending on home and community-based services now responsible for over half of Medicaid's long-term care spending.

Figure 6 illustrates the further division of financing by formal home care versus nursing home care. Medicare is by far the largest source of financing of home care, paying for almost half of the total costs of formal home care, while Medicaid covers approximately 30 percent. individuals shoulder only a relatively small fraction of total costs at 10%. However, it is important to remember that much of the care covered by Medicare is short-term and associated with an acute event.

In contrast to home care, the cost of nursing home care is financed relatively equally by Medicare and Medicaid—each responsible for close to 30 percent of total costs. Private expenditures, either private insurance or individual out-of-pocket payments, are each responsible for less than one-eight of the total. Although again, the coverage by Medicare is short-term while Medicaid covers a large proportion of truly long-term care. Consistent with that fact, the majority

of nursing home residents have their costs covered by Medicaid rather than Medicare or are paying for their stays from private resources. A report from the Kaiser Family Foundation found that the share of nursing home residents receiving Medicaid coverage averaged 62 percent across states but ranged from a high of 80 percent in the District of Columbia, to a low of 48 percent in Iowa.[9] Medicaid thus plays a critical role, both in paying for long-term care among low-income and low-wealth elderly and in providing a safety net for those who exhaust their resources to purchase formal care.

Private Insurance

As noted above, there is a relatively small market for private long-term care insurance; 15 percent of the elderly have such private insurance (Table 8), and only 12 percent of the cost of nursing home care is financed by such insurance. The characteristics of those holding private insurance are shown in Table 9. Those with private insurance are wealthier and have higher income than those without, but they do not appear to be in significantly worse health. As Finkelstein and McGarry (2006) document, this pattern arises from two offsetting forms of selection in the market. Those purchasing private insurance include both those who expect to use more care than average (adverse selection) and those who are particularly risk averse – the latter population is healthier on average, and thus "positively selected".

Some in the group without private insurance coverage may lack any sort of coverage and will need to cover such expenses with their own funds. However, others are likely to have sufficiently low income and assets that they are (or would likely become) eligible for Medicaid if they should need long-term care.

[9] Kaiser Family Foundation (2017).

The lack of a more robust private insurance market has been attributed to numerous factors including a misunderstanding of Medicare coverage, suspicions regarding whether insurance companies will agree to pay for covered care if it is needed, the solvency of such companies, the high cost of policies, and the risk of future premium increases (Brown et al. 2012). Over time there has been considerable consolidation in the industry as many insurance providers have dropped out of the market and benefits from private plans often fall short of full insurance with a limited amount per day, a limited number of days/years, and little inflation protection.

In an effort to encourage the private market to develop further, state and federal governments have provided various tax incentives for the purchase of policies in general and for partnership plans which allow individuals to leverage public and private support. Premiums for "qualified" long-term care insurance policies are considered medical expenses and may be tax deductible.[10] Partnership plans are long-term care insurance plans that are tied to state Medicaid plans. Individuals who purchase such policies may qualify for Medicaid coverage despite having assets above the Medicaid limits. This practice allows individuals to preserve a certain amount of assets, typically equivalent to the amount paid for by the private long-term care insurance policy, and receive Medicaid funding of long-term care when (and if) long-term care costs exceed the policy limits.[11] The private coverage reduces the state's Medicaid spending because the initial costs of stays are paid for privately and allows individuals to retain resources should they exit long-term care or wish to reserve some funds for other purposes (for example, leaving an

[10] Medical expenses are tax deductible from federal income tax if they total more than 7.5 percent of an individual's adjusted gross income, so such deductibility is unlikely to be helpful to relatively healthy individuals. States too may offer some deductibility of premiums.

[11] States have set minimum coverage requirement. For example, New York State requires a minimum of three years of private coverage and a given amount of coverage per day, the latter of which increases with inflation.

inheritance to children). Costa-Font and Raut (2021) find that these policies do increase the purchase of long-term care insurance and decrease Medicaid uptake.

Long-Term Care Receipt

As noted earlier, the need for long-term care is pervasive among the elderly yet such care is expensive. In Table 10 we illustrate the fraction of elderly receiving care by age and health categories. Seventeen percent of all those in our full sample (including people with no ADL/IADL limitations) are receiving some sort of assistance, whether in a nursing home or at home, the latter including both formal and informal care. Here we see a stark difference by age, with 41 percent of the oldest old receiving assistance. However, once we condition on the number of limitations, the distributions are similar: 64 percent of those 65 or older with two ADL limitations receive help while 78 percent of those 85 or older do. Similarly, for those with 3 or more limitations, the comparable figures are 84 and 88 percent. These latter numbers also suggest that a significant fraction of those with a large number of limitations are not receiving assistance, though some of this may be due to underreporting of care and to differences in the severity of what constitutes a limitation.

Figure 7 considers the types of care received for those who do receive care. We consider four types of care: long-term nursing home care, formal home care only, informal home care only, and both formal and informal home care. We exclude from this figure those receiving 100 or fewer days of nursing home care. Short stays like these are typically covered by Medicare and are to enable an individual to leave a hospital more quickly after an acute event, and thus not what we generally think of as long-term care. We define formal home care as paid help with ADLs/IADLs from a non-relative or friend, and informal home care as either unpaid help with ADLs/IADLs or paid help with these activities from a relative.

The majority of elderly care recipients, 69 percent (57 percent among the oldest-old) receive only informal home care, while just 5 percent receive only formal home care. The share in a nursing home and the share receiving both formal and informal care are similar at 13 percent. Among the oldest old, the shares in a nursing home or receiving both formal and informal home care are each approximately 50 percent larger than for the entire 65 or older needy population.

Figure 8 presents a useful way to illustrate how the types of care received vary with health limitations, first for all elderly, then for the oldest old. The X-axis documents the number of limitations, while the Y-axis shows the percentage of individuals receiving each type of care. As the elderly become more limited in their health, the odds of using only informal care fall – dramatically so once elders have more than 2 ADLs. But even among those with 3 or more ADLs, roughly half the population receives only informal care, likely indicating a significant burden on family caregivers. Both nursing home care and the use of a mix of formal and informal care rise with the number of ADLs. As with Figure 7, the results for the oldest old are similar. These figures illustrate the crucial role that informal care plays in the lives of the elderly in the United States – even among the oldest and most impaired individuals. In fact, the fraction of individuals receiving only informal care, regardless of age or the number of limitations, is consistently greater than that receiving all other types of care combined. We later return to what this care means to family members.

Table 11 shows the distribution of formal and informal hours of care by age. As noted earlier, the distributions of hours of care for both formal and informal care are relatively skewed—the median number of formal hours is 14 while the mean is 28. For informal care, these numbers are 9 and 26. Those who are 85 years old or older receive more of each type of care, with the difference between all elderly and the oldest more notable for formal than for informal care.

Overall, the receipt of long-term care is increasing substantially with both age and limitations. Moreover, the mode of care shifts from informal to formal care as limitations increase. We next turn to more detailed discussions of the formal and informal care sectors.

Formal Long-Term Care Supply

Formal long-term care in the United States is supplied by both nursing homes and formal home care workers. There are over 15,000 nursing homes in the U.S., containing almost 1.7 million beds (Table 12). With 50 million individuals ages 65 or older, that amounts to three beds per 100 elderly persons and about 25 beds per 100 persons ages 85 or older. Approximately 80 percent of these beds are occupied at any point in time. We mentioned previously the substantial shift that has occurred over the past few years from institutional-based care to home care years, and that shift is reflected in falling occupancy rates from over 90% percent in 1993 (DuNah et al., 1995) to under 80% in 2018 (Table 12).

As shown in Table 13, there is significant variation in nursing home occupancy and capacity across the U.S., suggesting that the difficulty in finding appropriate care may also vary. The nursing home occupancy rates varies from 62 to 92 percent while the number of beds per 100 elderly residents similarly varies from 0.9 to 6.2.

In addition to cost concerns, a major criticism of the nursing home industry in the United States is the quality of care, and statistics back-up these critiques. In 2016, nearly 45 percent of facilities were cited as deficient in infection control, 40 percent were lacking in food sanitation, 34 percent in the general quality of care, and 25 percent cited for the unnecessary use of drugs (Harrington et al., 2018). A variety of factors, ranging from payer mix to staffing levels, have been shown to be correlated with quality of care (Weech-Maldonado et al., 2019; Grabowski &

Chen, 2015). Of particular interest has been the relationship between the for-profit status of nursing homes and the quality of care. A recent influential study found that nursing home mortality is significantly higher for those institutions owned by large private companies while non-profit nursing homes typically fare better on this measure (Gupta et al, 2021; GAO, 2020).

Formal home care is delivered both by agencies specializing in this business as well as by independent caregivers hired directly by care recipients. Data on the latter form of care is limited, but in some states Medicaid waiver programs allow individuals to choose between personal care aides working for an agency or those working independently (Spetz et al, 2019). In 2017 almost 5 million people were cared for by home care workers from approximately 11,500 agencies. Over 80 percent of these agencies are for-profit, although many of their patients are covered by Medicare or Medicaid which have strict limits on rates and the number and type of visits. As is consistent with the large number of agencies, most agencies are relatively small, with 43 percent providing care to fewer than 100 people per year. At the other end of the distribution, 33 of agencies each provided care for 300 or more patients. The services provided in the formal home care sector vary widely and include nursing care (administering medication, monitoring vital signs), therapeutic services (rehabilitation after surgery), personal care (typically help with ADLs), and homemaking services (help with IADLs). However, there is considerable overlap in the provision of these services with home health aides often providing more than one type of care.

Payment for these formal home care services depends upon patient characteristics and needs. As discussed earlier, Medicare covers skilled nursing care at home in both a post-acute and long-term context, but only for set periods of time after which the need for care is reassessed. Notably, it does not cover personal/custodial care unless such care is in conjunction with needed skilled care. Conversely, Medicaid will cover personal and custodial care as well as nursing care

and household services and, as noted earlier, through recent waiver programs, can provide additional services such as meals and transportation to help individuals remain in the community.

Both nursing homes and home health care agencies employ workers with varying levels of skills—with employees classified as aides, licensed practical nurses, registered nurses and social workers. (Absent from this discussion are non-patient facing employees like janitorial staff or office managers.) The least skilled workers are typically termed nurses' aides. This position requires no formal education and a minimal level of training, although requirements vary across states. Table 14 provides some descriptive information on the distribution of required training hours. Thirty-three states require just 75 hours of training for a nurses' aide (less than two weeks of full-time work) and 72 percent of the elderly population live in one of these states. Another 11 states require somewhere between 75 and 120 hours, and just seven states require 120 hours or more.

Further up the skill ladder are licensed practical nurses (LPNs) and registered nurses (RNs). To be certified as an LPN one typically must have a full year of specialized schooling, while RNs are required to hold a four-year nursing degree. Finally, a small share of long-term care workers are licensed social workers; these workers are typically required a graduate degree (a Master of Social Work or MSW) in addition to four years of college. Licensed social workers do not directly provide care but help in the coordination of care.

As shown in Figure 9, the prevalence of various types of workers differs substantially by type of long-term care. At home health agencies, the majority of the workers are highly skilled registered nurses, and roughly one-quarter are nurses' aides. But in nursing homes, almost two-thirds of workers are nursing aides, while only 12 percent are registered nurses.

These differences in skill levels are reflected in the amounts earned by long-term care workers (Table 15). Wages for nursing assistants average only $12-$13/hour, a figure below the average wage in the United States for those with less than a high school degree. Indeed, average earnings for a nurse's aide are not very far above the U.S. poverty line for a family of four, and median earnings are below it. In contrast, registered nurses earn $29 per hour on average, an amount approximately equal to the mean wage for all hourly workers in the United States, but well below the wages earned by those with a college degree or more. Earnings for LPNs lie between these nursing aids and registered nurses.

Who are the Caregivers?

As emphasized earlier, home care for the elderly can be provided either by formal (paid) caregivers or informal (unpaid) caregivers, or both. Table 16 shows the population of helpers of each type constructed from data from the HRS and using population weights to inflate the number to national totals. We estimate that there are 1.9 million people in the United States providing formal help with ADLs or IADLs to those ages 65 or older; 800,000 of these 1.9 million are providing help to those 85 years old or older. This amounts to 3.7 helpers per 100 persons ages 65 or older, and 12.6 per 100 persons ages 85 or older. A much larger population of individuals provide informal care. In 2018 approximately 10.6 million people were providing informal care to the elderly, and of these 30 percent were providing care to those 85 years old or older.

Figure 10 shows the demographic characteristics of formal and informal caregivers. Formal home care workers are overwhelmingly female; only 12 percent of paid home care work is delivered by men. Informal home care has a similar gender bias, but it is much less pronounced, with fully one-third of informal home care delivered by men (a figure that remains roughly the same when excluding care from spouses). The gender distribution in the provision of informal care

differs by type of care with men more likely to help with IADLS than ADLs. With respect to the age of caregivers, formal home care is largely provided by working age individuals, with 85 percent of formal caregivers less than 60 years old and 60 percent younger than age 50. In contrast, informal home care is delivered primarily by older individuals; more than three-quarters of formal home care is delivered by those ages 50 or greater as one would expect, with adult children providing care for elderly parents who would likely be in their late 70s or 80s when they needed care, and spouses caring for each other.

Formal home care providers have little schooling, with almost one-fifth having no high school degree and only one-tenth having a college degree. In contrast, informal home care is provided by a much more highly educated population. Formal caregivers are also more racially diverse than informal caregivers, with approximately two-thirds being non-white (or Hispanic) compared to only one-third of informal caregivers. This distribution reflects that fact that informal caregivers are typically drawn from the ranks of those with sufficient resources to provide care—either those who have flexibility on their jobs, or the financial capacity to reduce labor market effort (Fahle and McGarry, 2022). The formal caregiving workforce draws heavily on immigrants, with approximately one-third of formal caregivers being immigrants to the United States compared to only 14 percent of the overall population (Pew Research Center, 2020).

Figure 11 shows the relationship of informal caregivers to the care recipient. Roughly one-third of informal care is delivered by spouses. The second most common relationship for caregivers is daughters, who provide more than one-quarter of informal care; sons provide only half as large a share.

Part III: The Cost of Long-Term Care

As noted earlier, expenditures on long-term care comprise a sizeable share of total health care spending in the United States. Table 17 summarizes these total costs. In 2019, total spending for the 1.1 million nursing home residents aged 65+ was approximately $142 billion. Spending on formal health home care is 60 percent as large, despite there being more than three-times as many users. Note, however, that embedded in the figures for nursing home expenditures are the costs of room and board; absent this component, costs would be lower. Importantly, these figures do not include Medicaid spending on home-and-community-based services through waiver programs (HCBS), which we exclude because we focus on long-term care for the elderly and a large portion of HCBS recipients are under age 65. For example, only about 30% of Section 1915(c) waiver spending, which makes up approximately 60 percent of total Medicaid home care spending, is directed toward programs targeting the elderly and those with physical disabilities (Kaiser Family Foundation, 2020).

Because most home care is provided informally, typically by relatives, a proper accounting of the total cost of long-term care in the economy should include the opportunity cost of their time as well. Valuing the opportunity cost of informal caregivers raises a number of difficult issues and requires numerous assumptions. In the simplest model, with perfectly competitive labor markets and market wages equal to the value of leisure, the value of time spent in informal care would be the foregone wage. If high potential wage individuals choose to provide informal care themselves rather than purchase such care, it is either because they receive sufficient utility from the provision of care, or because the care they provide is of sufficiently higher quality relative to what is available in the formal market to justify the "cost."

In such a model with the value of leisure equal to the foregone wage, the value of an hour of care provided by those who are not employed would be equal to the wage that they would receive if they were to enter the labor market, as it would be for those who are employed. In practice, however, retired individuals often do not have work opportunities that are equal to their value of leisure, which is why retirement is marked by a complete, rather than gradual, exit from work. It is also hard to value the potential wage for workers who are very old and/or have been retired for many years.

We therefore consider two options for valuing hours of informal care. In each case, we begin by estimating the probability the caregiver is working and by imputing an hourly wage. We then multiply the probability of working by the imputed wage, and then again by the number of hours of care provided. We add to that the product of the probability of not working, the imputed value of leisure hours, and the hours of care provided.

Value of care = (Prob of working) x (Imputed wage) x (hours of care) + (1-Prob of working) x (value of leisure time) x (hours of care)

The two options differ in how we value leisure time. In the first option ("low valuation") we value this non-labor market time zero meaning that the value of care is just: (Prob of working) x (Imputed wage) x (hours of care) as the second term in the equation has a value of zero. In the second option ("high valuation"), we value non-labor market hours as the replacement cost of care—that being the average wage for home care workers. Thus, the value of care is that from the "low valuation" + (1-Prob of working) x ($25) x (hours of care)

We impute the probability of working and the wage rate as follows: For each caregiver, we have information on a set of characteristics including whether they are paid for care, their

gender, and the census region in which the care recipient lives (presumed to be the same for the caregiver). For children, spouses, and other household members, we also know the caregiver's educational attainment, age, race/ethnicity, and marital status. Using data from the 2018 American Community Survey, we then use regression analyses to estimate the predicted probability of working and the predicted wage conditional on working for each caregiver using the set of characteristics that are available for the HRS caregivers.

The results of our estimations are shown in table 18 with the low valuation estimate being $86 billion and the high valuation being $151 billion. We note that these valuations are substantially below what has been frequently used in the literature in which all hours of care are valued at the median or mean wage rate for a caregiver. Were we to use this straightforward calculation with the mean wage rate of $12.32, our value for informal care would be just over $100 billion. We can combine this result with the previous data on formal long-term care spending for the elderly to estimate the distribution of long-term care costs across public and private sources. Two-thirds of the cost of nursing home care is publicly financed the remainder being paid for from private sources (private insurance or out-of-pocket spending), while four-fifths of the cost of formal home care is publicly financed. In addition to this formal cost, we assume that the full cost of informal care is privately financed. The resulting distribution of spending is shown for both of our valuation methods in Table 19. Even in the low valuation method we find that the majority of long- term care "costs" are accounted for by informal care. At the higher valuation for informal care, we find that almost than 60 percent of costs are informal or privately paid. Moreover, under the high valuation scenario, informal care costs are higher than the cost of either nursing home or formal home care, comprising approximately 40 percent of all costs.

Part IV: Conclusions

To anyone with experience arranging care for an elderly family member, the dramatic costs of such care comes as no surprise. The median cost of a year in a private nursing home room in the United States is over $108,000, and a year of formal home care can easily exceed $30,000 at just a total of four hours of care per day. While individuals bear much of this cost through out-of-pocket spending, the largest private cost is through the informal provision of home care for elderly relatives. And combining the two, we estimate national expenses on long-term care for the elderly in 2018 of $382 billion.

One dimension in which the United States differs from other countries is the mechanism for paying for the formal portion of this care. While many countries have specific public insurance programs for the provision of long-term care--programs that are typically paid for by dedicated taxes--the majority of long-term care in the United States is paid for by programs established to provide health care coverage more generally and extended to long-term care in only certain cases—either temporary care or through means-tested programs. Yet despite the lack of a specific long-term care program, the majority of formal long-term care in the United State is in fact financed by the government, with individuals shouldering about 19 percent out of pocket.

However, this fact can be deceiving in that the elderly often rely on informal support from family members, a burden that falls primarily on women. Our estimates suggest that the imputed costs of such care are far larger than those paid for either nursing home or formal home care. This burden exists not just in the United States, but around the world as estimates in other chapters in this volume demonstrate.

As significant as these costs are, and as much as families struggle with finding or providing appropriate care, the difficulty is likely to increase in the coming years as the population continues to age. Not only is the number of elderly individuals growing rapidly but the greatest rate of

increase is among the oldest old, ages at which care is typically the most intensive. While the demand for long-term care is increasing, the population of individuals able to provide that care is decreasing in relative terms due to lower fertility and increased labor force participation among women.

Dealing with these issues on not just a national, but on a worldwide level, is paramount. There is much to be learned by comparing the long-term care infrastructures across countries, and future advances in medical science and in technology provide hope for improvements in the long-term care landscape. While the situation in the United States provides evidence on how private insurance systems might be structured and more recently, in understanding how non-medical forms of assistance might be used to reduce the reliance on institutional spending, the United States in turn can learn from other nations how a national public insurance system might best be employed and the advantages and pitfalls associated with such a mechanism.

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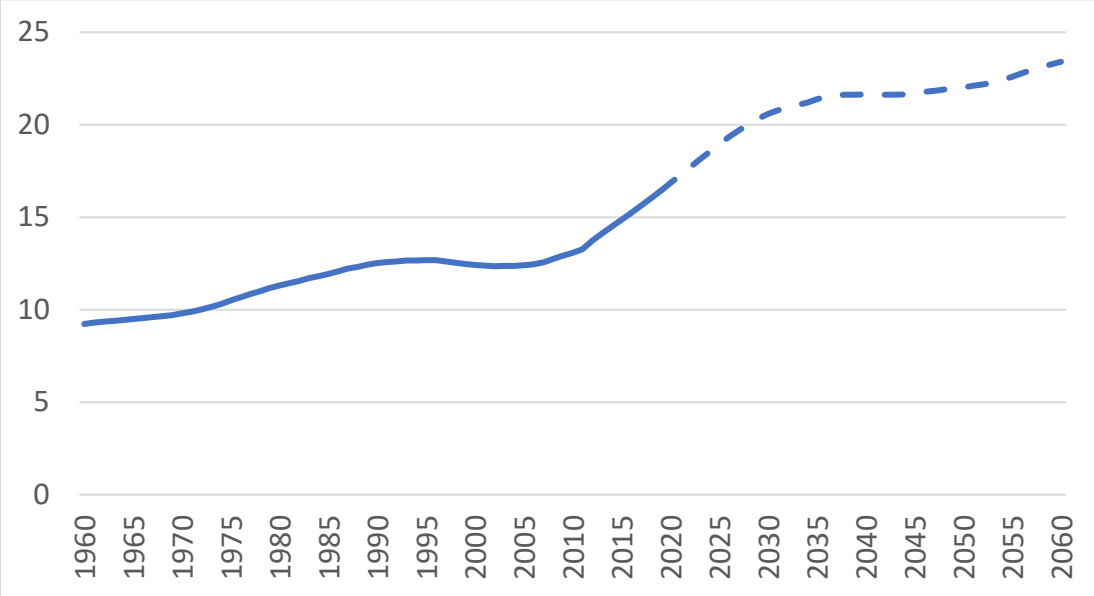
Tables and Figures

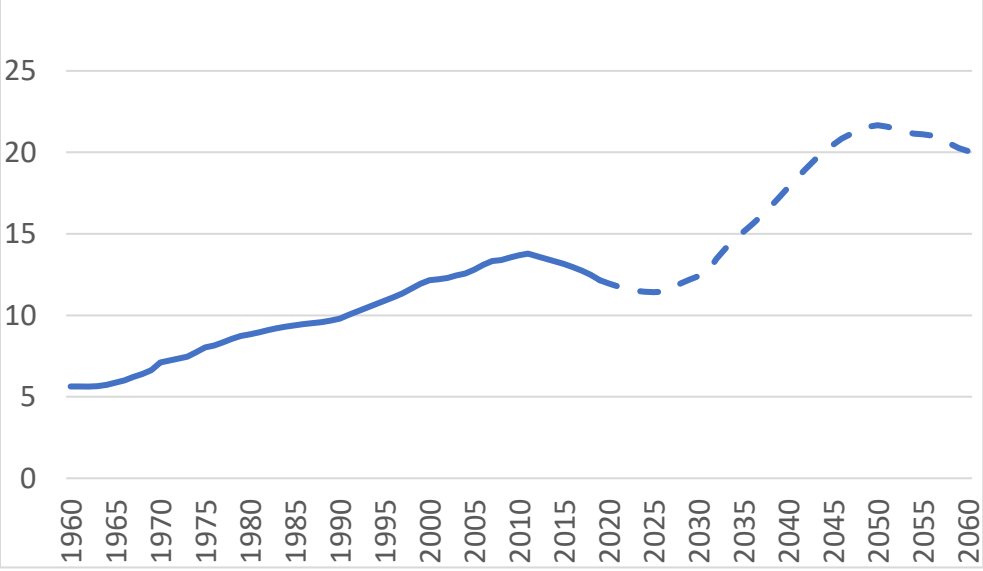
Part I: Aging, Disability, and Well-Being

Figure 1: Percentage of population ages 65 or older
US, 1960-2060.



Source: OECD Population Projections (2022).

Figure 2: Percentage of 65+ population that is age 85 or older.
US, 1960-2060.



Source: OECD Population Projections (2022).

Table 1: Share with ADLs by Age
US, 2018.

	65+	85+
0 ADLs & 0 IADLs	0.710	0.399
0 ADLs & 1+ IADLs	0.089	0.176
1 ADL	0.083	0.144
2 ADLs	0.040	0.086
3 ADLs	0.028	0.058
4 ADLs	0.014	0.026
5 ADLs	0.016	0.043
6 ADLs	0.020	0.070
Any ADLs	0.201	0.425
Any IADLs	0.214	0.515
Observations	*8970*	*1322*

Source: Data are from the RAND-HRS (2018). Weights are used to include individuals in nursing homes. ADLs include walking across room, dressing, bathing, eating, going to bed, and using the toilet. IADLs include using a telephone, managing money, taking medications as prescribed, shopping for groceries, and cooking a hot meal. Individuals that report not doing these activities are also included as having difficulty with them.

Table 2: Distribution of Limitations with Specific ADLs/IADLs
US, 2018.

	65+ All	65+ Conditional	85+ All	85+ Conditional
Panel 1- IADLs:				
IADL – Use a Phone	0.062	0.288	0.205	0.398
IADL – Manage Money	0.110	0.513	0.314	0.609
IADL – Take Meds as Prescr.	0.044	0.205	0.135	0.262
IADL – Shop for Groceries	0.132	0.615	0.361	0.701
IADL – Prepare a Meal	0.116	0.544	0.348	0.676
Observations	8970	2195	1322	662
Panel 2- ADLs:				
ADL – Use the Toilet	0.073	0.363	0.162	0.381
ADL – Get Dressed	0.116	0.578	0.238	0.560
ADL – Take a Bath	0.093	0.465	0.264	0.623
ADL – Walk Across a Room	0.095	0.472	0.250	0.588
ADL – Eat	0.047	0.236	0.146	0.345
ADL – Get In/Out of Bed	0.076	0.379	0.162	0.380
Observations	8970	2033	1322	557

Source: Data are from the RAND-HRS (2018). Weights are used to include individuals in nursing homes. Column 1 shows the share of the sample that report having difficulty with each activity, while Column 2 shows the share of people with at least 1 IADL (panel 1) or at least 1 ADL (panel 2) who report having difficulty with each activity. Individuals that report not doing these activities are also included as having difficulty with them.

Table 3: Well-Being for those 65+ and 85+ by ADL Limitations.
US. 2018.

	65+	65+, 3+ Lims	85+	85+ 3+ Lims
Reports good or better health status	0.73	0.30	0.63	0.41
Very satisfied with retirement	0.55	0.33	0.55	0.43
Depressed Much of Time	0.10	0.29	0.12	0.19
Observations	8970	1353	1322	460

Notes: Data are from the RAND-HRS (2018). Our Limitations Index runs from 0-12 and is the number of ADLs/IADLs that are either difficult or not done from eating, bathing, dressing, using the toilet, walking across a room, and getting in/out of bed (ADLs) + using a telephone, managing money, taking medications as prescribed, shopping for groceries, and cooking a hot meal (IADLs). Because retirement satisfaction is only asked of those who are retired, the sample is restricted to those who are retired. The survey asks whether respondents have felt depressed much of the time over the last week. The poverty measure is produced by RAND to include income from all household members. Combined respondents/nursing home weights from RAND-HRS are used in all calculations.

Table 4: Income and Wealth Distribution
US, 2018.

	Income		Wealth	
	65+	85+	65+	85+
5th Percentile	9,000	7,000	0	0
10th Percentile	13,000	11,000	2,000	0
25th Percentile	21,000	17,000	57,000	37,000
50th Percentile	35,000	25,000	217,000	166,000
75th Percentile	58,000	43,000	618,000	535,000
90th Percentile	93,000	68,000	1,345,000	1,358,000
95th Percentile	130,000	93,000	2,204,000	2,109,000
Mean	52,000	42,000	612,000	615,000
Observations	*8,971*	*1,323*	*8,971*	*1,323*

Notes: Data are from the RAND-HRS and HRS Core (2018). Weights are used to include individuals in nursing homes. All income estimates are post-tax. We use the NBER's Taxsim program to estimate post-tax income based on family characteristics and each household's income sources. All values are adjusted to July 2019 dollars.

Table 5: Income and Wealth Distribution by Limitations for 65+ Population US, 2018.

	0 ADLs & 0 IADLs	0 ADLs & 1+ IADLs	1 ADL	2 ADLs	3+ ADLs	Total
Panel 1: Income						
<50% Median HH Income	0.142	0.204	0.256	0.353	0.404	0.186
50-100% Median HH Income	0.296	0.375	0.363	0.334	0.344	0.314
100-150% Median HH Income	0.221	0.185	0.204	0.127	0.127	0.205
150-200% Median HH Income	0.135	0.094	0.086	0.089	0.052	0.119
200%+ Median HH Income	0.206	0.142	0.090	0.098	0.073	0.176
Total	0.710	0.089	0.083	0.040	0.077	.
Observations	6043	894	841	415	777	8970
Panel 2: Wealth						
<50% Median HH Wealth	0.287	0.414	0.461	0.555	0.625	0.349
50-100% Median HH Wealth	0.157	0.142	0.163	0.120	0.102	0.151
100-150% Median HH Wealth	0.094	0.104	0.104	0.075	0.055	0.092
150-200% Median HH Wealth	0.076	0.063	0.062	0.047	0.047	0.071
200%+ Median HH Wealth	0.386	0.277	0.210	0.204	0.171	0.338
Total	0.710	0.089	0.083	0.040	0.077	.
Observations	6043	894	841	415	777	8970

Notes: Data are from the RAND-HRS and HRS Core (2018). HRS household income estimates are post-tax, estimated using Taxsim based upon household characteristics and income components, and includes only respondent and spouse income. Our ADL Index runs from 0-6 and is the number of ADLs that are either difficult or not done from eating, bathing, dressing, using the toilet, walking across a room, and getting in/out of bed. IADLs include using a telephone, managing money, taking medications as prescribed, shopping for groceries, and cooking a hot meal. Each cell reports the share of respondents in the respective ADL category who are in that row's income group. Combined respondents/nursing home weights are used in all HRS Core calculations. The median household income and wealth are for the 65+ population, calculated in the HRS. The median is roughly $35,000 per year for income and $217,000 for wealth when adjusted to 2019 dollars.

Table 6: Distribution of Hours of Help Received per Week
US, 2018.

	65+	85+
5th Percentile	1	1
10th Percentile	1	1
25th Percentile	3	4
50th Percentile	13	14
75th Percentile	36	57
90th Percentile	107	114
95th Percentile	116	128
Mean	30	39
1 Hour per Day or Less	0.39	0.35
5 Hour per Day or More	0.26	0.33
Observations	*1410*	*389*

*Notes: Health and Retirement Study (HRS), 2018. Respondent weights are used for all calculations. Nursing home residents are automatically excluded from all calculations. Hours include both formal and informal care received from helpers who assist with ADLs, IADLs, and managing money because of a health problem. Hours of help from each helper are limited to 16 hours per day to allow for 8 hours of rest. Respondents could provide the number of days either overall in the last month, per week, or as every day. In the 1st case, the days per month was divided by 4.35 (365/7*12).*

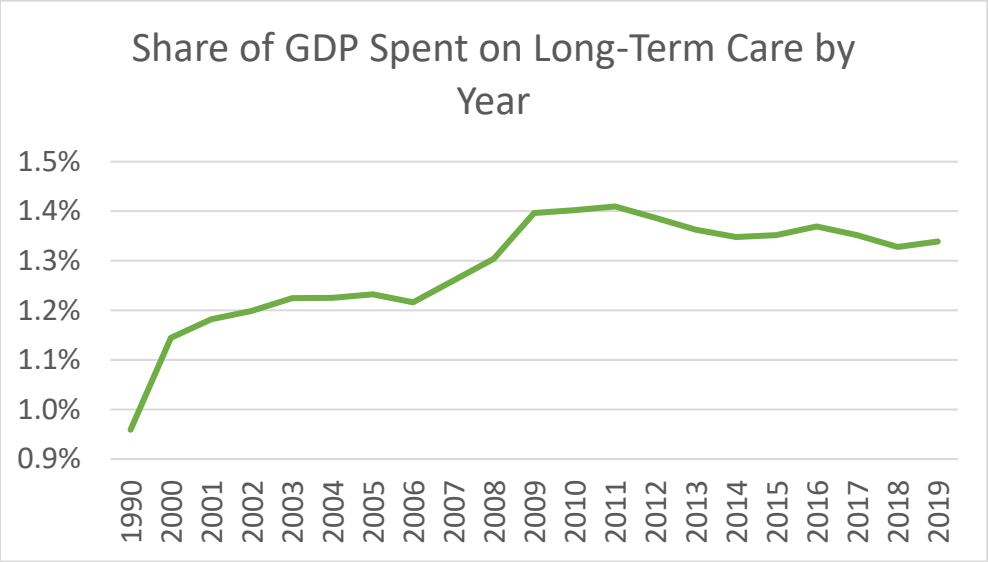
Table 7: Distribution of Nursing Home Stay Lengths
US, 2018.

Average # Days since Entry	474
Median # Days since Entry	456
10^{th} Percentile # Days since Entry	120
90^{th} Percentile # Days since Entry	792
Share in N.H. 2+ Years	0.136
Observations	*155*

Notes: Health and Retirement Study (HRS), 2018. Respondent weights are used for all calculations. We use the RAND nursing home residence and duration variables but exclude those who report being in a nursing home but are given a respondent weight by the HRS rather than a nursing home resident weight, as these individuals were identified by the HRS as living in a different type of residential care setting.

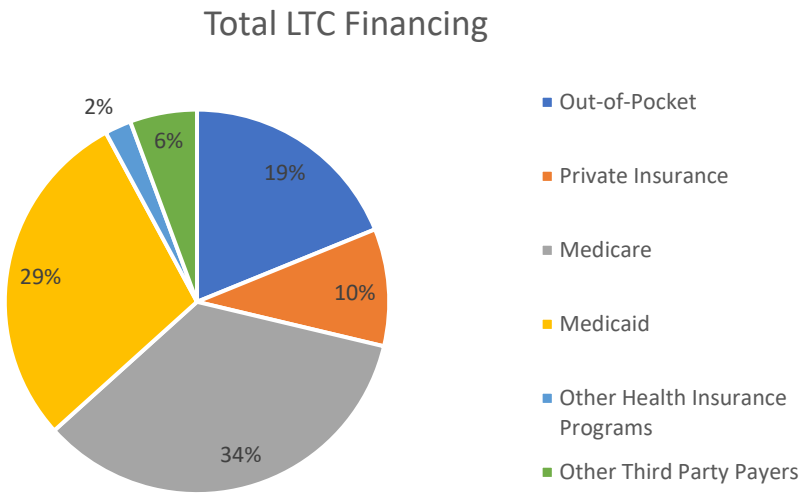
Part II: Long-Term Care System in the U.S.

Figure 3: Share of GDP spent on long-term care
US, 1990-2019.



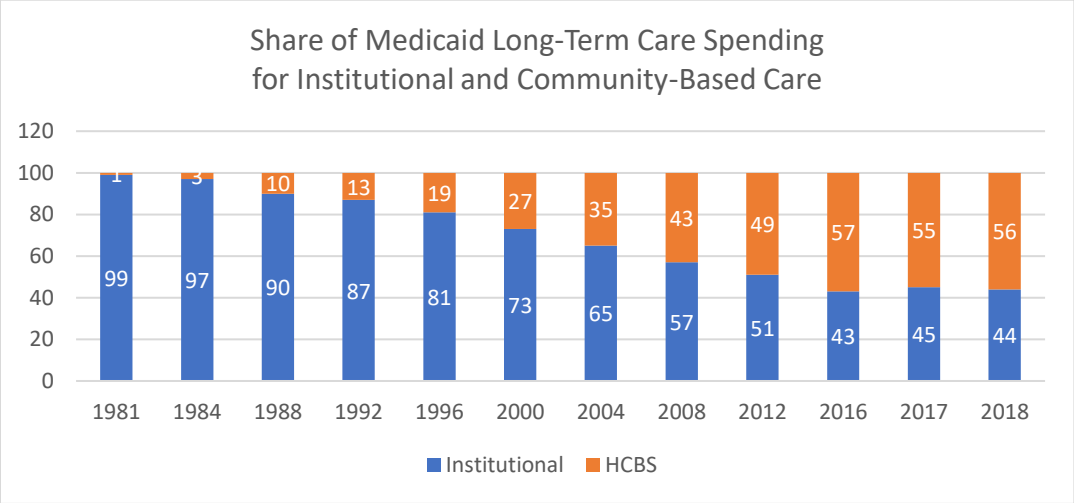
Sources: Centers for Medicare and Medicaid (CMS) National Health Expenditures data; St. Louis FRED Annual GDP data. In this figure, long-term care includes total spending on home health care, and nursing care facilities and continuing care retirement communities.

Figure 4: Percent of LTC Financing by Source
US, 2018.



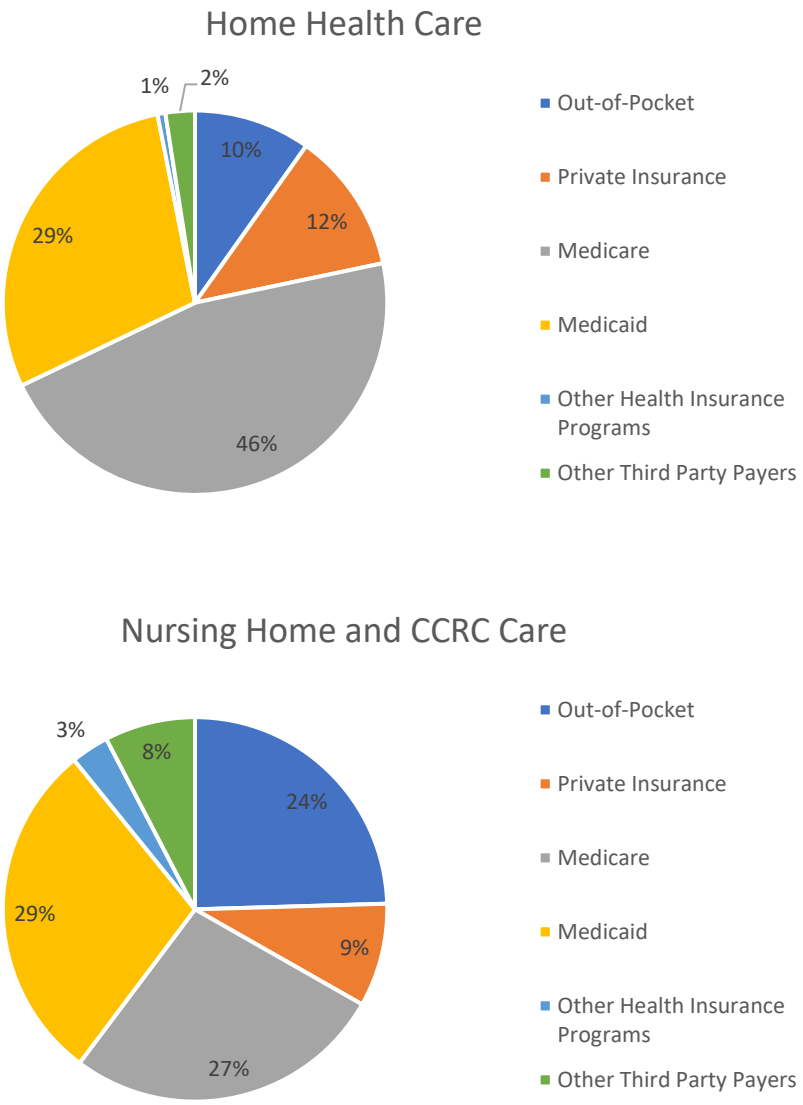
Source: Data are for the year 2018. Centers for Medicare and Medicaid (CMS) National Health Expenditures data. In this figure, long-term care includes total spending on home health care, and nursing care facilities and continuing care retirement communities. Spending is adjusted by the share of recipients who are under 65 from Sengupta et al. (2022), with the assumption that all of the under 65 recipients are receiving funding from sources other than Medicare, which is not adjusted.

Figure 5: Medicaid spending on institutional care has been gradually replaced by spending on community-based care.
US. 1981-2018.



Sources: Eiken et al. (2018) for data from 2016 and before and Murray et al. (2021) for 2017-2018.

Figure 6. Percent spent on home health care and nursing care facilities, by source of funds. US, 2018



Note: Data are for the year 2018. Centers for Medicare and Medicaid (CMS) National Health Expenditures data. Nursing home care includes nursing home facilities and continuing care retirement communities (CCRC). Spending is adjusted by the share of recipients who are under 65, with the assumption that all of the under 65 recipients are receiving funding from sources other than Medicare, which is not adjusted.

Table 8: Population with LTC Insurance
US, 2018.

	65 Plus	85 Plus
Population with LTC Insurance	7,700,000	900,000
Share of 65+/85+ Population	(0.146)	(0.141)
Observations	*1244*	*186*

Notes: RAND-HRS and Health and Retirement Study (HRS), 2018. Combined nursing home/respondent weights from RAND are used for all calculations. All types of long-term care insurance, regardless of whether it covers home care, nursing home care, or both, are counted for the insured indicator.

Table 9: Characteristics by LTC Insurance
US, 2018.

	65+ Insured	65+ Uninsured	85+ Insured	85+ Uninsured
Total Household Wealth - Mean	1,408,000	733,000	881,000	709,000
Total Household Wealth - Median	657,000	239,000	504,000	163,000
Total Household Income - Mean	72,000	49,000	52,000	40,000
Total Household Income - Median	49,000	33,000	37,000	24,000
In Nursing Home (> 100 days)	0.02	0.02	0.08	0.08
Any Home Care Last 2 Yrs	0.13	0.11	0.23	0.25
Live with Spouse or Partner	0.65	0.58	0.32	0.28
Formal Help with ADL/IADLs	0.01	0.02	0.03	0.07
Informal Help with ADL/IADLs	0.10	0.13	0.23	0.26
Observations	*1244*	*7726*	*186*	*1136*

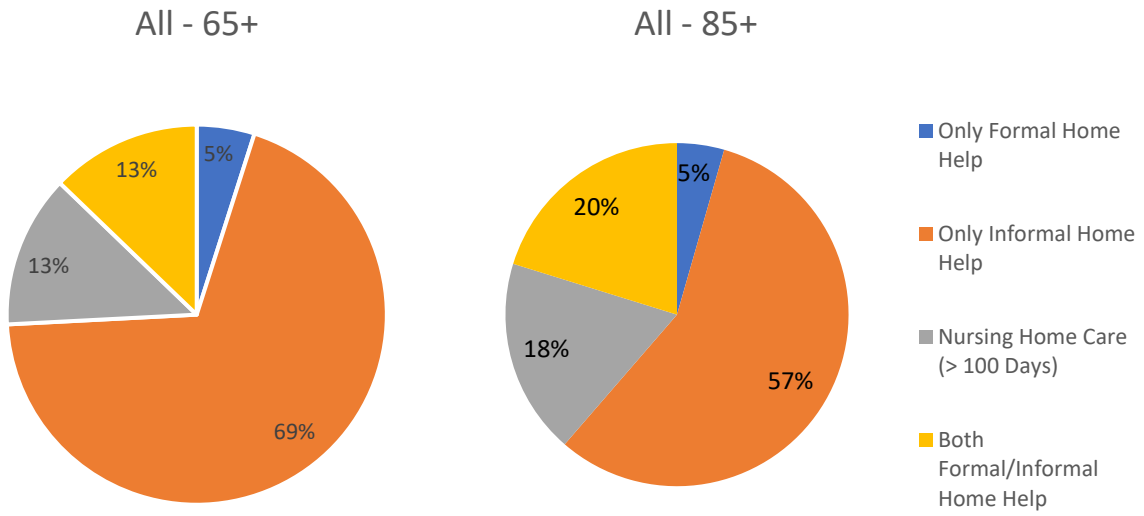
Notes: RAND-HRS and Health and Retirement Study (HRS), 2018. Combined nursing home/respondent weights are used for all calculations. All calculations are in 2019 dollars and income is post-tax, estimated using Taxsim. All types of long-term care insurance, regardless of whether it covers home care, nursing home care, or both, are counted for the insured indicator. All variables (income, wealth, types of help) are defined as they were in previous tables.

Table 10: Any Care by Age and ADL
US, 2018.

	65 Plus	85 Plus
Full Sample	0.17	0.41
0 ADLs, 1+ IADL	0.45	0.50
1 ADL	0.39	0.54
2 ADL	0.64	0.78
3+ ADL	0.84	0.88
Observations	8970	1322

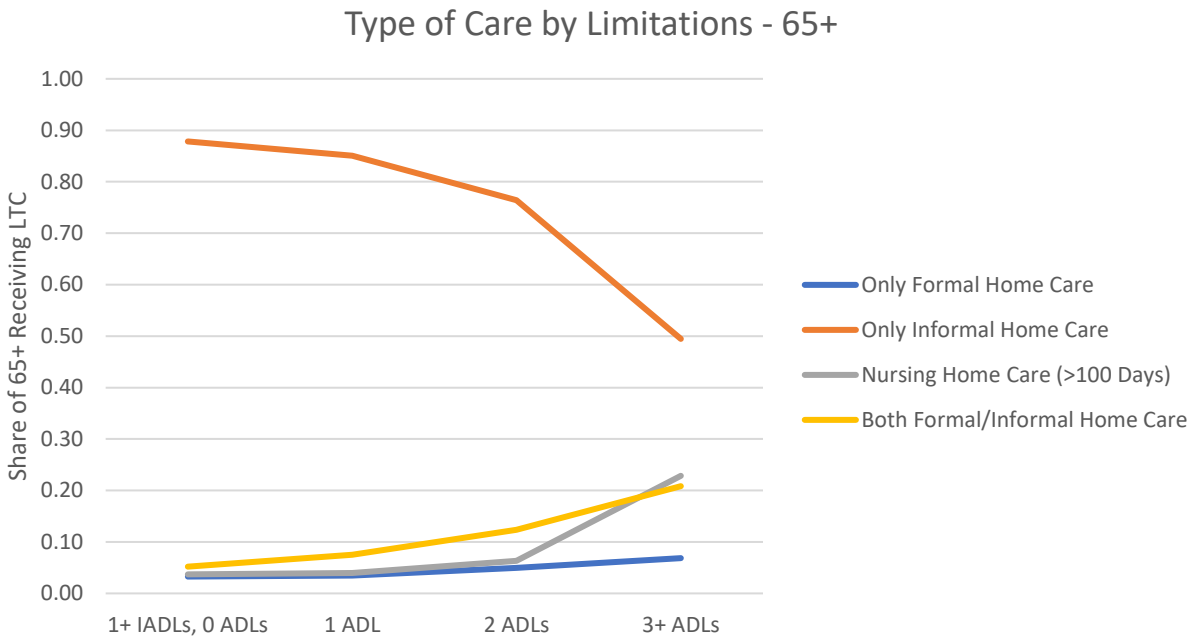
Notes: Health and Retirement Study (HRS), 2018. Respondent weights are used for all calculations. The care variable is defined as either being in a nursing home for more than 100 days or having received either formal or informal home help with ADLs, IADLs, or managing money because of a health condition in the last 30 days. We use the RAND nursing home residence and duration variables but exclude those who report being in a nursing home but are given a respondent weight by the HRS rather than a nursing home resident weight, as these individuals were identified by the HRS as living in a different type of residential care setting.

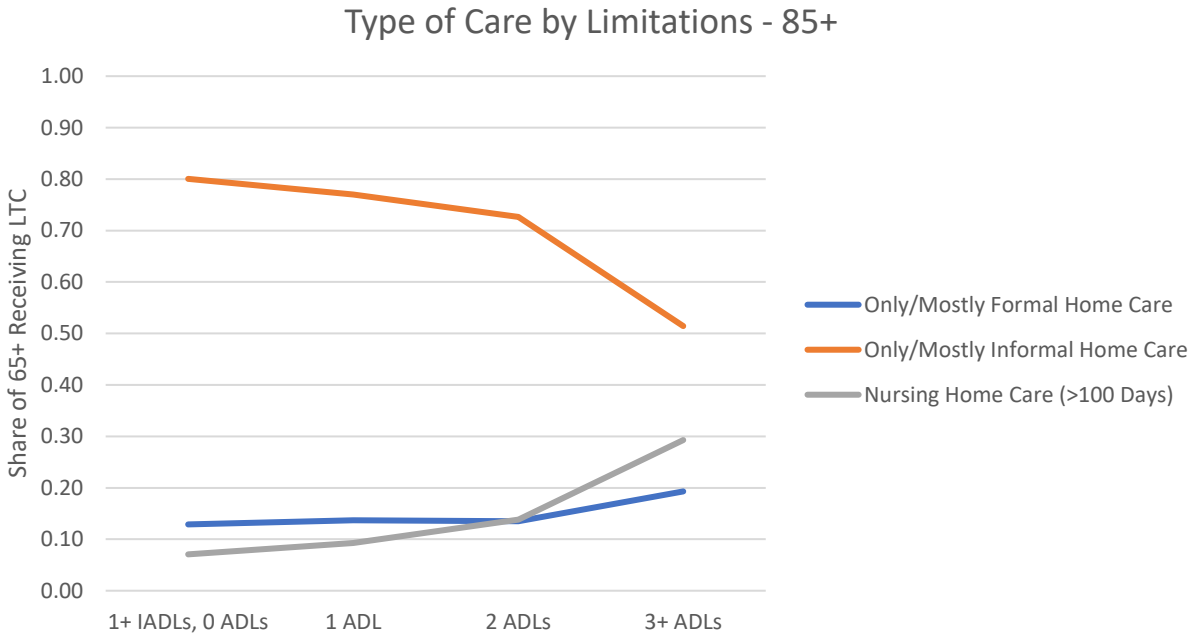
Figure 7: Type of Care Received by Age.
US, 2018.



Notes: Health and Retirement Study (HRS), 2018. Respondent weights are used for all calculations. Some respondents do not report the type of at-home help they receive from some helpers. If this is the case for all of their helpers, they are omitted from these figures. We use the RAND nursing home residence and duration variables but exclude those who report being in a nursing home but are given a respondent weight by the HRS rather than a nursing home resident weight, as these individuals were identified by the HRS as living in a different type of residential care setting. Informal help is defined as help provided without pay or by a paid relative, while formal help is paid help by a non-relative. Help can be with ADLs, IADLs, or managing money due to a health problem.

Figure 8: Type of Care Received by Age and Limitations.
US, 2018.





Notes: Health and Retirement Study (HRS), 2018. Respondent weights are used for all calculations. Some respondents do not report the type of at-home help they receive from some helpers. If this is the case for all of their helpers, they are omitted from these figures. We use the RAND nursing home residence and duration variables but exclude those who report being in a nursing home but are given a respondent weight by the HRS rather than a nursing home resident weight, as these individuals were identified by the HRS as living in a different type of residential care setting. Informal help is defined as help provided without pay or by a paid relative, while formal help is paid help by a non-relative. Help can be with ADLs, IADLs, or managing money due to a health problem. ADLs and IADLs are defined as before. Due to sample size restrictions, we report only/mostly formal and informal home care for the 85+ population, where people who receive both types are assigned to the type from which they receive the most hours.

Table 11: Distribution of Weekly Hours Received by Type
US, 2018.

	65+		85+	
	Formal	Informal	Formal	Informal
5th Percentile	1	0	1	1
10th Percentile	1	1	2	1
25th Percentile	4	3	6	3
50th Percentile	14	9	26	11
75th Percentile	41	32	55	36
90th Percentile	83	86	110	110
95th Percentile	110	114	114	114
Mean	28	26	38	29
Observations	*268*	*1350*	*106*	*375*

*Notes: Health and Retirement Study (HRS), 2018. Respondent weights are used for all population estimate calculations. Nursing home residents are automatically excluded from all calculations. Hours include care received from helpers who assist with ADLs, IADLs, and managing money because of a health problem. Hours of help from each helper are limited to 16 hours per day to allow for 8 hours of rest. Respondents could provide the number of days either overall in the last month, per week, or as every day. In the 1st case, the days per month was divided by 4.35 (365/7*12). Informal help is defined as help provided without pay or by a paid relative, while formal help is paid help by a non-relative.*

Table 12: Absolute number of nursing homes, beds, and occupancy rate.
US. 2018.

	US, 2018
Nursing homes	15,600
Beds	1,655,400
Pop 65+	52,350,000
Beds per pop 65+	0.03
Pop 85+	6,540,000
Beds per pop 85+	0.25
Nursing home residents	1,320,000
Occupancy rate	79.8%
Nursing home employment	1,630,000

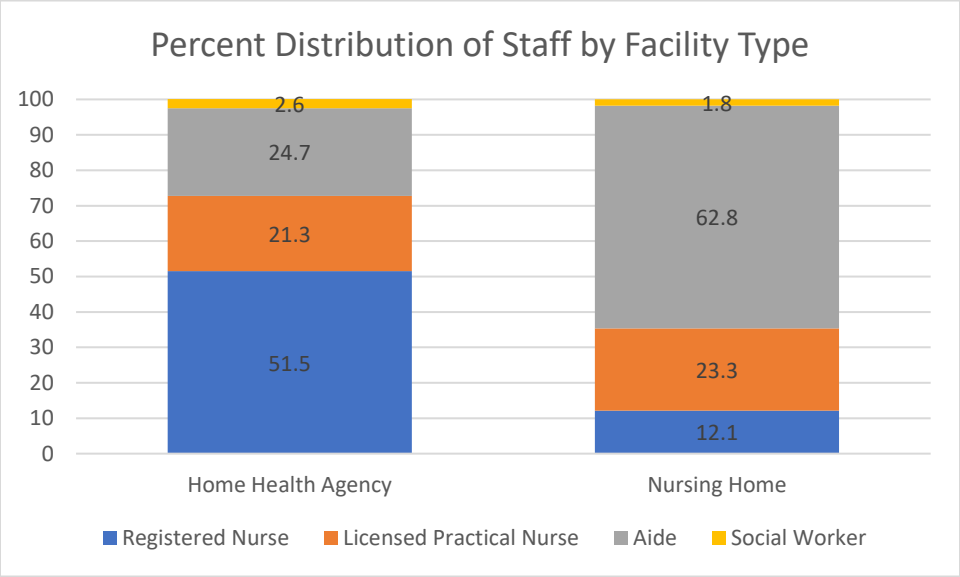
Source: Nursing home resident and bed data are from Sengupta et al. (2022), employment data are from the Census Bureau (2021), and the population data are from the OECD. Occupancy rate is defined as the number of residents divided by the number of beds. Nursing home residents are counted as a point in time estimate in the third quarter of 2018.

Table 13: Distribution of nursing homes occupancy rate and beds across states. US, 2016 & 2019.

Percentile	Occupancy rate (%) - 2019	Nursing home beds per one hundred 65+ - 2016
5%	65	1.60
10%	68	1.97
20%	73	2.40
50%	82	3.41
80%	86	5.01
90%	88	5.50
95%	90	5.75
Min	62	0.89
Max	92	6.20

Source: Beds data comes from CDC NCHS (2017). Occupancy rate from Kaiser Family Foundation (2022).

Figure 9. Percent distribution of nurses, aides, and social workers at care facilities. US, 2018.



Data is from Sengupta et al. (2022).

Table 14: Training requirements for formal home care workers.
US. 2016.

Minimum training hours required by state	# states	Population aged 65+ living in states with corresponding minimum training hours	Share of US population aged 65+
75 hours	33	35,288,595	72%
76-119 hours	11	5,114,669	10%
120+ hours	7	8,798,807	18%

Source: Paraprofessional Healthcare Institute (2016).

Table 15. Pay for full-time care workers at nursing facilities and in home health care.
US, 2018.

Occupation titles	*Mean hourly wage*	*Median hourly wage*	*Annual mean wage*	*Annual median wage*
Panel 1: Nursing Home Industry				
Nursing Assistants	13.47	12.81	29,000	25,000
Licensed Practical Nurses	20.94	20.46	47,000	42,000
Registered Nurses	28.69	28.07	63,000	61,000
Panel 2: Home Health Care Industry				
Nursing Assistants & Home Health Aides	12.32	11.48	28,000	24,000
Licensed Practical Nurses	18.29	17.97	41,000	40,000
Registered Nurses	29.30	29.39	66,000	61,000
Panel 3: All Industries				
All Workers	28.74	21.29	64,000	46,000
No High School Degree	15.67	13.97	36,000	30,000
No College Degree	19.97	17.47	46,000	37,000
College Degree or More	37.80	31.61	93,000	70,000
Average Minimum Wage in 2018	8.89	8.40		
Poverty Line for a family of 4)			25,600	

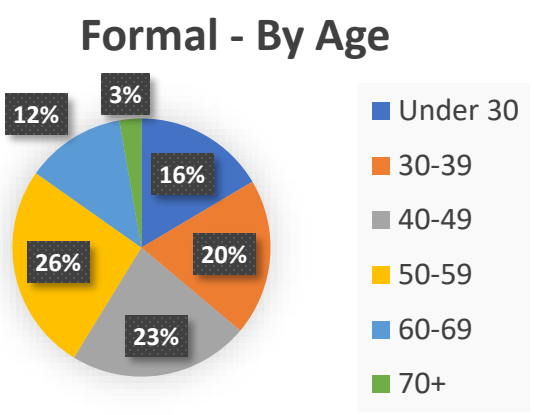
All wage calculations are made using the 2018 ACS, but dollar denominated values are in 2019 dollars The occupation and industry variables are used to identify those working as RNs, LPNs, and CNAs. Because the wage/salary income is reported annually, hourly wages are estimated by dividing the annual totals by the product of usual hours per week and weeks worked in the last year. Because this measure can be noisy for those working part-time, we restrict the sample to those working more than 30 hours per week and more than 40 weeks in the last year. Wages by for each group (row) are also winsorized at the 5^{th} and 95^{th} percentiles. In ACS person weights are used in all calculations. Minimum wage data for states was collected from the Department of Labor and is for 2018. Calculations are weighted by the 18–64-year-old populations of each state, estimated from the American Community Survey 2018.

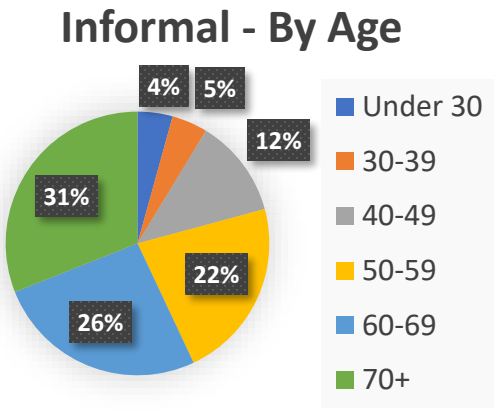
Table 16: Home Care Provision – Population Estimates
US, 2018.

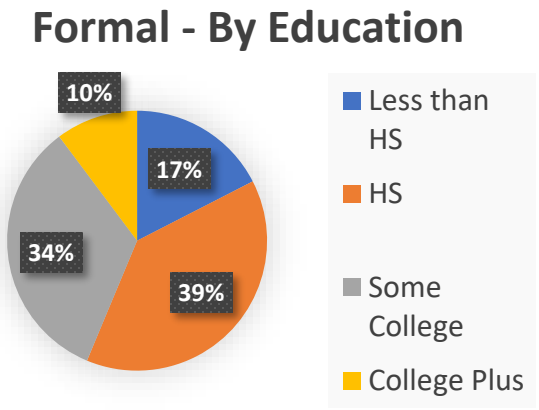
	65 Plus	85 Plus
Formal Helpers - ADL/IADLs	1,900,000	800,000
Relative to 65+/85+ Population	(0.037)	(0.126)
Relative to 18-64 Population	(0.010)	(0.004)
Informal Helpers - ADL/IADLs	10,600,000	3,100,000
Relative to 65+/85+ Population	(0.200)	(0.490)
Relative to 18-64 Population	(0.052)	(0.016)
All Helpers - ADL/IADLs	12,500,000	3,900,000
Relative to 65+/85+ Population	(0.237)	(0.618)
Relative to 18-64 Population	(0.062)	(0.020)
Observations	*2,684*	*823*

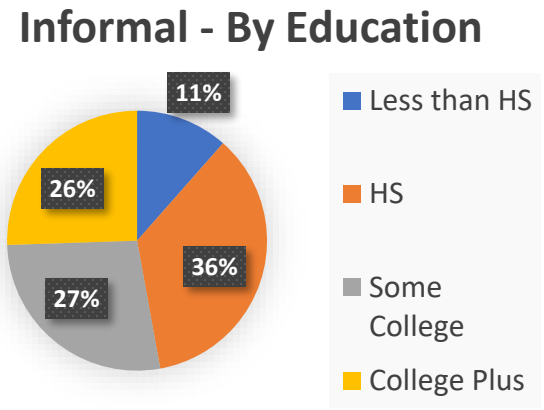
Notes: Health and Retirement Study (HRS), 2018. Respondent weights are used for all population estimate calculations. Those providing help to nursing home residents are automatically excluded from all calculations. ADLs and IADLs are defined as before. Informal help is defined as help provided without pay or by a paid relative, while formal help is paid help by a non-relative.

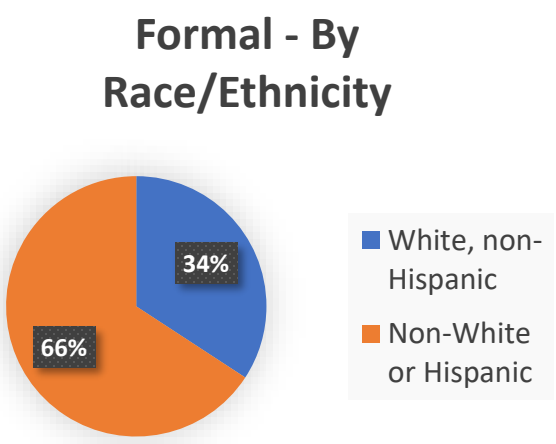
Figure 10: Demographic composition of Formal and Informal Caregivers. US, 2018.

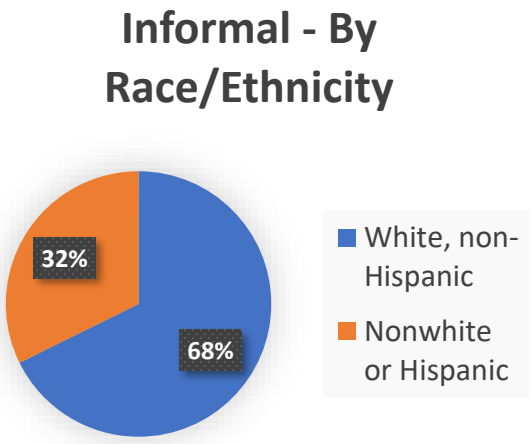


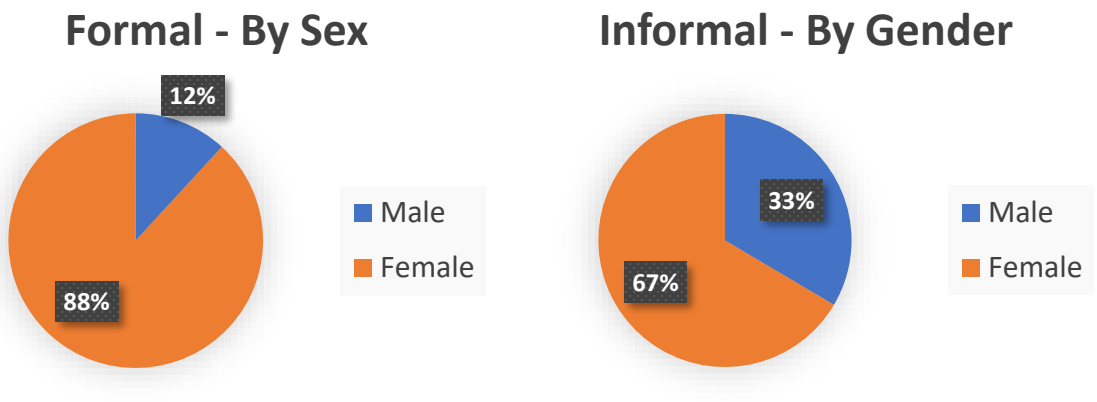








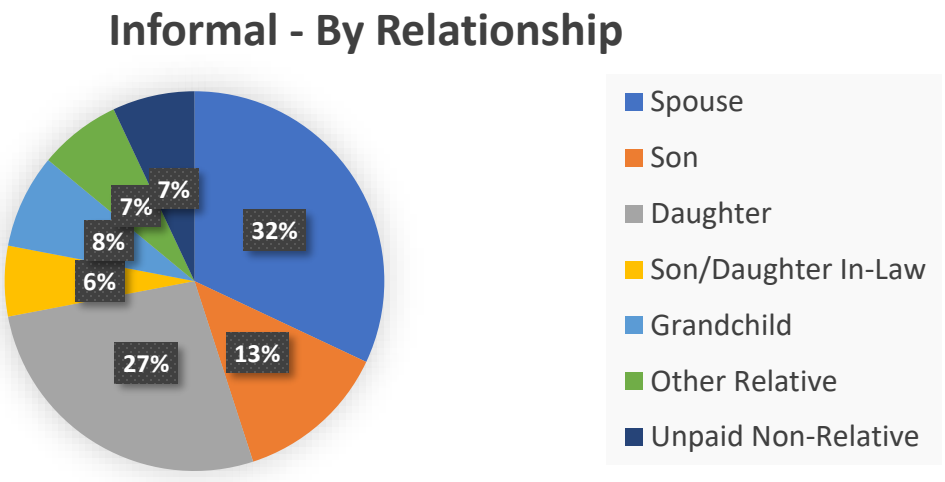




Data on formal caregivers is from the 2018 American Community Survey, restricting to full-time home health, personal care, and nursing aides in the home care industry and using person weights in generating estimates. Informal care data comes from RAND-HRS and HRS Core Helper data, with respondent weights for the person being helped used in all calculations. Those recorded as helping individuals in nursing homes are excluded. Age and race are provided for spouse, children, and household member helpers. The RAND version of the HRS was used for spouses and the RAND family file for children and other household members. Education is provided for spouses and children helpers. The RAND version of the HRS was used for spouses and the RAND family file for children. Sex and relationship are provided for all helpers in the HRS Core Helper file. Data is for help in 2018, though some family file variables were collected in prior waves. All samples are restricted to informal helpers, defined as those providing unpaid help or paid help to a relative. Age, race, and education are restricted to the helpers for whom we have data.

Figure 11: Informal Caregivers by Relationship to Care Recipient.

US, 2018.



Data on informal caregivers comes from the HRS Core Helper file, with respondent weights for the person being helped used in all calculations. Those recorded as helping individuals in nursing homes are excluded. The helper relationship is provided for all helpers in the HRS Core Helper file. Data is for help in 2018. The sample is restricted to informal helpers, defined as those providing unpaid help or paid help to a relative.

Part III: The Cost of Long-Term Care

Table 17: Formal care costs, annual
US, 2018.

Types	Number of users	Total spending (billion $)
Nursing home	1,100,000	142
Home health agency	4,100,000	89

Source: Number of users for formal care come from NCHS 2017-2018 Vital and health statistics (Sengupta et al., 2022). Total spending on formal care come from CMS National Health Expenditure tables. Spending for nursing homes includes continuing care retirement communities, while number of users does not. Both the number of users and spending are multiplied by 1 – proportion of users under age 65 (17% of both HHA and nursing home users are under 65, per Sengupta et al., 2022). Note that the number of users for nursing homes is a point in time estimate while home health agency users is for the full year in 2017.

Table 18: Informal Care Valuation
US, 2018.

	I	**II**
Valuation (billions of $s)	86.3	150.8
Total Hours Informal Help (billions)	8.35	8.35
Probability of Working	0.480	0.480
Predicted Wage * Probability of Working	10.34	
Predicted Wage if Working	25.47	
Observations	1960	1960

Notes: Column I values predicted working hours at the predicted wage, and predicted non-working hours at $0. Column II values predicted working hours at the predicted wage and predicted non-working hours at the average home health aide wage of $12.32 per hour from ACS 2018. Respondent Weights from the HRS are used in all calculations. Valuations are done at the helper level, with predicted wages and probabilities of work calculated separately for the sample broken into 3 main groups - 1) Spouses, Children, and Household Members, 2) Household Members missing education data, and 3) other helpers. Group 1 valuations used ACS data for 4 education categories, 4 regions, 6 age groups, sex, marital status, and white vs non-white to separately predict the probability of work and the wage conditional on working. Group 2 valuations used ACS data for 9 Census Divisions, 6 age groups, sex, marital status, and white vs non-white to separately predict the probability of work and the wage conditional on working. Group 3 valuations used ACS data for 9 Census Divisions and sex to separately predict the probability of work and the wage conditional on working. Some individuals were missing one of the variables used for their group. Their probability of work and wages were predicted using ACS data that excluded the variable(s) they were missing. Hourly wages in the ACS were top-coded to $100. Nursing home residents were excluded from the analysis and only hours for those helping with ADLs were included. Informal care from paid relatives is also excluded, since this has already been compensated. Valuation and hours are in billions. All dollar amounts are in 2019 dollars.

Table 19: Total Costs by Type of Care and Source
US, 2018.

Care Type	Source	Cost I		Cost II	
		2019 $s	% GDP	2019 $s	% GDP
Nursing Home	Public	95	0.5%	95	0.5%
	Private	47	0.2%	47	0.2%
	All	142	0.7%	142	0.7%
Home Care	Public	70	0.3%	70	0.3%
	Private	19	0.1%	19	0.1%
	All	89	0.4%	89	0.4%
Informal Care	Private	86	0.4%	151	0.7%
Total	Public	165	0.8%	165	0.8%
	Private	152	0.8%	217	1.0%
	All	317	1.6%	382	1.8%

Total spending in 2018 on formal care come from CMS National Health Expenditure tables. Spending for nursing homes includes continuing care retirement communities, while number of users does not. Both the number of users and spending are multiplied by 1 – proportion of users under age 65 (17% of both HHA and nursing home users are under 65, per Sengupta et al., 2022). The informal care costs correspond to columns I and 2 of Table 2.C.2. The NHE categories of other health insurance programs and other third party payers are included in the public category. All dollars are reported in 2019 terms.