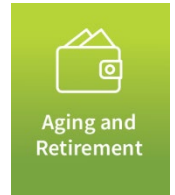


Long-Term Services and Supports: Usage and Payment by Race, Ethnicity and Socioeconomic Factors

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Long-Term Services and Supports: Usage and Payment by Race, Ethnicity and Socioeconomic Factors

An Overview of the System and a Discussion of Existing Disparities

AUTHORS Brian Kaul
Andrew Larocque, ASA, MAA
Patricia Matson, FSA, MAAA
Rebecca Sheppard, FSA, MAAA

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CONTENTS

Executive Summary	4
Section 1: Methods and Approach	7
Section 2: Usage (Need and Utilization) of Long-Term Services and Supports	9
2.1 The Need for Long-Term Services and Supports.....	9
2.2 HCBS Utilization	13
2.2.1 Adult Day Center Demographics.....	15
2.2.2 Paid HelperS for HCBS.....	16
2.3 Facility-Based Care Utilization	16
2.3.1 Residential Care Facilities	17
2.3.2 Assisted Living Facilities.....	18
2.3.3 Nursing Homes.....	18
2.3.4 Preferences by Race and Ethnicity.....	19
2.4 Informal Caregivers.....	20
Section 3: Providers of LTSS	20
Section 4: Financing of Long-Term Services and Supports	22
4.1 Medicaid	23
4.2 Medicare.....	25
4.3 Long-Term Care Insurance.....	26
4.4 Cost of Care.....	27
Section 5: LTSS for Individuals with Disabilities (under age 65)	28
Section 6: Areas for Further Study	29
Section 7: Acknowledgments	30
Appendix A: Select Data Sources	31
National Health Expenditure Data	31
National Health and Aging Trends Study (NHATS)	32
Appendix B: 2019 Per Capita Medicaid Expenditures by State	33
References	35
About The Society of Actuaries Research Institute	39

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An Overview of the System and a Discussion of Existing Disparities

Executive Summary

For individuals who have complex needs because of chronic illness, disability, or aging, long-term services and supports (LTSS) are essential to maintain an optimal quality of life. In the United States, individuals needing LTSS access care, utilize services, and pay for their services in various ways. Medicaid is the largest payer of LTSS, but private insurance, Medicare and other programs are also used in LTSS payments or reimbursements. Outside of formal paid care, a significant portion of LTSS is provided informally through family, friends and communities. While the cost of formal care can be obtained directly through administrative claims and utilization data, the cost of informal care is more difficult to accurately track. We used survey data to provide insight on informal care where available.

In this paper, we explore LTSS in the U.S. and the disparities that exist across race, ethnicity and socioeconomic factors within the current LTSS system. We aim to understand how the need for LTSS, utilization of LTSS and payment for LTSS differ by population cohorts. Our primary focus is disparity by race and ethnicity, but we also consider variation by geography, family structure, age, sex, gender¹, and other socioeconomic factors where possible. During our research, we found limited amounts of data for many of the cohorts we wanted to study. In these instances, we comment on the lack of information and recommend the topic for further data collection and research. We combine findings from prior research, data from original sources such as surveys and other publicly available data, as well as insights from the diverse group of experienced professionals on the Project Oversight Group. This paper expands on existing literature by taking a broad lens in considering all aspects of LTSS utilization and payment while at the same time considering the disparities which exist in the current system. Perhaps the most important contribution of this paper is to highlight the need for additional research to ensure that all individuals are fully represented. We prepared this research to support the needs of actuaries, providers, policymakers and consumer advocates to aid in understanding the current landscape of LTSS and to consider the disparities that exist.

At the time of writing this paper, a global pandemic, commonly referred to as COVID-19, had been underway for several years. When COVID-19 began it had a significant impact on LTSS, especially that provided in nursing homes where a substantial portion of COVID-19 deaths occurred. Elderly adults and individuals with chronic illnesses were among two of the most susceptible groups for COVID-19. The pandemic impacted the delivery of health care as well as social and environmental norms. COVID-19 magnified already existing racial and ethnic disparities in LTSS (Gorges & Konezka, 2021). A full exploration of COVID-19 is outside the scope of this report, but the impact that COVID-19 had on LTSS is noted, where applicable and where data was available, throughout the report.

¹ We use the term “gender” from the NHATS data. However, we note that the survey states “If gender is obvious, code without asking. Otherwise ask: What is your gender? 1= Male 2= Female.” This means that the field may be based on the interviewer’s interpretation and not actually self-reported and that the question asks about gender but records responses in terms of sex.

Key findings from the report are broken into four main categories: need, utilization, payment and specific considerations of LTSS utilizers with disabilities.

Need

Rates for developing severe LTSS needs are similar across races/ethnicities. But less-severe LTSS needs vary by specific chronic illnesses, which vary by race/ethnicity. In addition, varying rates of population growth by race/ethnicity mean that as the population ages, the need for less-severe LTSS will likely vary significantly by race/ethnicity.

Key findings related to the need for LTSS are as follows

- The rates for developing severe LTSS needs are similar across white, Hispanic/Latino and Black/African American adults.
- The aging of the U.S. population will result in an increased need for LTSS services; the expected population growth varies by race and ethnicity and the varying rates of growth will result in a disproportionate increase in the need for LTSS services.
- Individuals with chronic illness have a greater need for LTSS than those without chronic illness; and the distribution of certain significant chronic illnesses varies by race and ethnicity.
- For adults aged 65 and older, we used health status as a proxy for needing LTSS because of aging or chronic illness. Self-reported health status indicates the distribution of health status for Hispanic/Latino adults is skewed toward poor and fair health while the health status for white adults is skewed toward very good and excellent health. Black/African American adults most often report good health.

Utilization

Across races and ethnicities, people strongly prefer home and community-based care rather than facility-based care. But the number of people of color in facilities increased faster than the overall population of people of color, suggesting that people of color have less access than whites to preferred LTSS care options.

Racial segregation in nursing homes has been found to have negative effects on quality for people of color, including lower staff-to-patient ratios and worse end-of-life pain management.

Key findings related to the utilization of LTSS are as follows

- Individuals have a strong preference for home and community-based care rather than facility-based care; this is consistent across all racial and ethnic groups.
- The reported health status of LTSS utilizers is consistently lower for Black/African American and Hispanic/Latino adults than it is for white adults.
- Predictors of facility-based care admission are health need, economic resources and social ties; never married males have the highest admission rates.
- The number of residents who are people of color in nursing homes increased faster than the overall population of people of color; this suggests reduced access to preferred LTSS care options.
- Disparity was found in assisted living facilities; Black/African American adults are underrepresented, and assisted living facilities with memory care licenses (needed for dementia care) are primarily located in affluent and predominantly white communities.
- Racial segregation in nursing homes has been found to have negative effects on quality for people of color; these results include lower ratios of staff to patients and worse end-of-life pain management (Mack, 2020).

Payment

Medicaid is the largest payer of formal care, and it covers proportionally more Black/African American and Hispanic/Latino adults than whites. Historically Medicaid covered only facility-based care, but to address disparities in access and care, many states have expanded Medicaid to include home and community-based care.

LTSS is expensive, and the cost is expected to rise. Many adults are not prepared for future LTSS expenses and do not purchase private insurance to protect themselves from financial risk and ensure access to care.

Under Age 65

Disability rates in 2015 for adults aged 18–64 varied by race/ethnicity: 14% for Black/African Americans, 11% for Non-Hispanic whites, 8% for Hispanic/Latinos and 5% for Asians/Asian Americans.

Medicaid provides the majority of coverage for these individuals, who comprise 11% of Medicaid enrollees but represent 50% of all Medicaid LTSS costs.

Key findings related to payment for LTSS are as follows:

- There are various sources of LTSS funding including government programs, individual out-of-pocket payments, private insurance (not covered by private health insurance) and informal care (typically unpaid).
- Medicaid is the largest payer of formal care.
- Informal care is estimated to be a significant portion of LTSS.
- Initially Medicaid primarily covered LTSS in only an institutional setting but through the implementation of innovation waivers, the provision of home and community-based care through Medicaid is rapidly growing.
- Medicaid covers a larger percentage of Black/African American adults and Hispanic/Latino adults than white adults.
- To address disparity in access to care, many states have expanded Medicaid eligibility and taken initiatives to improve health outcomes for historically marginalized races and ethnicities.
- LTSS care is expensive, and the cost is expected to rise; currently many adults are not prepared for future out-of-pocket LTSS expenses and do not purchase private insurance to protect themselves from financial risk and ensure access to care.

Key findings related to LTSS utilizers with disabilities under age 65 are as follows:

- Individuals with disabilities may have life-long needs for LTSS and their costs tend to be higher than other LTSS utilizers; this creates a significant financial burden for individuals with disabilities and their families.
- Medicaid provides the majority of coverage for these individuals; Medicare also covers a limited amount of LTSS and some individuals with LTSS needs are dually eligible for Medicaid and Medicare.
- Individuals under age 65 with disabilities make up 11% of Medicaid enrollees but represent 50% of all Medicaid LTSS costs.

These findings are discussed in greater detail throughout this paper. Additional resources are noted in the Appendices.



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Section 1: Methods and Approach

The focus of this paper is to assess the disparities by race and ethnicity that exist in the need for, utilization of and payment for LTSS² in the United States. Where available, we explore disparities by geography, wealth, education, family structure, age, sex, gender, and other socioeconomic factors. Findings included in this paper are derived primarily from our review of existing literature. The metrics presented are based on our analysis of existing survey data and other publicly available data. Our research did not include performing our own surveys or collecting data directly.

Our scope is the U.S. LTSS system and includes peer-reviewed journal articles and other resources that discuss LTSS utilization and payment across various population segments. We used multiple data sources provided by the U.S. government including data from the Census Bureau, the Bureau of Labor and the Department of Health and Human Services. The primary survey data that we analyzed were the National Health and Aging Trends Study (NHATS) which is led by Johns Hopkins University Bloomberg School of Public Health and the University of Michigan's Institute for Social Research, with data collection by Westat. We also reviewed data published by Brown University in the LTCFocus data set but ultimately did not include it in the paper as it did not address our specific research questions. While we were able to find data concerning LTSS utilization, payment, or data segmented by race and ethnicity, it was not always possible to find the desired data at the level of detail necessary for our analysis. In these cases, we relied on multiple data sources to draw conclusions and note the assumptions we are making in these conclusions.

We attempted to explore disparities for the following racial and ethnic groups: American Indian/Alaska Native, Asian/Asian American, Black/African American, Hispanic/Latino, Native Hawaiian/Pacific Islander, and white. In many cases we could not find information for each of these racial and ethnic groups. The majority of studies and data sources segmented the data by Black/African American, Hispanic/Latino, and white. Some included data for Asian/Asian American. Only the U.S. Census Bureau information included data for American Indian/Alaska Native and Native Hawaiian/Pacific Islander. NHATS includes American Indian/Alaska Native and Native Hawaiian/Pacific Islander in the sensitive data set but not in the publicly available data set. Some studies included an "other" category to capture racial and ethnic groups that were not explicitly presented while some studies simply did not report data for these groups. Composition of the "other" group can vary by survey source and may not be comparable throughout this paper. Individuals who identify as two or more races are included in the "other" group. The minimal data available for American Indian/Alaska Native, Asian/Asian American, and Native Hawaiian/Pacific Islander is a limitation of this report and area for future research.

In the research articles we reviewed, there is some variation in the terms used for racial and ethnic groups, as shown in Table 1. Throughout this paper, we have replaced the terms as the authors have reported them in their research to be consistent with our terms.

² The term "long-term care" (LTC) is often used interchangeably with LTSS, but we note that LTC is more often used when referring to private insurance coverage, whereas LTSS is more often used in academia and government and to emphasize the broad set of services and supports that may assist individuals with functional limitations.

Table 1
TERMS USED IN REVIEWED RESEARCH FOR RACE AND ETHNICITY

Source	Asian/Asian American	Black/African American	Hispanic/Latino	White
This paper	Asian/Asian American (presented as Asian in figures for a shorter presentation)	Black/African American (presented as Black in figures for a shorter presentation)	Hispanic/Latino (shown as Hisp./Lat. in figures for a shorter presentation)	White
Centers for Disease Control (data summarized from National Health Interview Survey)	Asian, non-Hispanic (in some summaries this cohort is not reported separately but rather grouped as “Other”)	Black, non-Hispanic	Hispanic	White, non-Hispanic
Feng, 2011 Goodman, 2019 Gorges & Konezka, 2021 U.S. Census Bureau Yao, 2018	Asian or Non-Hispanic Asian	Black or Black, non-Hispanic or Non-Hispanic Black or African American	Hispanic or Latino	White or White, non-Hispanic or Non-Hispanic White
London, 2021 Thomeer, 2015	Not reported separately, included in “Other” category	Non-Hispanic Black	Hispanic	Non-Hispanic White
National Health and Aging Trends Survey (non-sensitive data)	NR (Asian or Asian American are grouped with “Other” in the available data; the sensitive data set includes specific race)	Black, non-Hispanic	Hispanic	White, non-Hispanic
Davis, 2017 Estrada, 2021 Gorges, 2019 Johnson, 2016 and 2019 Lee et al, 2021 Leggett, 2022 Riester, 2021 Suntai, 2021 True, 2020	NR	Black or Non-Hispanic Black or Black, non-Hispanic	Hispanic	White or Non-Hispanic White or White, non-Hispanic
Wallace, 1998	NR	African American	Latino	Non-Latino White
Caffrey, 2021	Not reported separately, included in “Another race/ethnicity” category	Non-Hispanic Black	Not reported separately, included in “Another race/ethnicity” category	Non-Hispanic White
Cornell, 2021 Fabius et al, 2021 Morales, 2020	NR	Black	NR	White
Bowblis, 2021 Shippee, 2022	Not reported separately included in “Black, Indigenous, and people of color (BIPOC)”	Not reported separately included in “Black, Indigenous, and people of color (BIPOC)”	Not reported separately included in “Black, Indigenous, and people of color (BIPOC)”	White

NR stands for not reported.

Section 2: Usage (Need and Utilization) of Long-Term Services and Supports

Long-Term Services and Supports (LTSS) refer to a wide range of paid and unpaid medical and personal care assistance and other services to assist individuals with functional limitations. Individuals may need LTSS when they have trouble completing self-care tasks as a result of aging, chronic illness, or disability (Reaves, 2015). LTSS falls into two main categories—home and community-based care services (HCBS) and formal, facility-based care which is also referred to as institutional care. It is important to distinguish LTSS from medical care. LTSS is not curative but rather it is used to help individuals with self-care tasks.

There are a variety of settings for receiving LTSS. Facility-based care includes residential care, assisted living and skilled nursing facilities (SNF). Continuing care retirement communities span all levels of facility-based care, as individuals can access each level of facility-based care depending on their needs. HCBS comprise a range of alternatives to institutional care, such as home care (whether formal or informal), which covers a wide array of health care and personal care services that are performed in an individual's home. HCBS also includes attendance at adult day centers and other community support services, such as transportation and meal programs. While institutional care is often utilized by those with more specialized needs, home care is usually less expensive than institutional care in hospitals or SNF. In this section, we first explore the need for LTSS across race and ethnicity and then discuss utilization by race and ethnicity in these various settings.

2.1 THE NEED FOR LONG-TERM SERVICES AND SUPPORTS

The need for LTSS is generally defined in relation to performance of activities of daily living (ADLs) and instrumental activities of daily living (IADLs). An individual who has limitations performing ADLs or IADLs may require LTSS. Examples of activities of daily living include bathing, grooming, dressing, meal preparation, eating, mobility and medication assistance. IADLs are more complex than ADLs and include tasks like financial management, shopping, driving and care of pets. Individuals may have lifelong limitations with ADLs and IADLs as a result of a disability or may develop limitations over time as a result of aging or chronic illness. In this section we explore LTSS needs because of to aging and chronic illness. Individuals under age 65 with LTSS needs are discussed in Section 4 of this paper as this population has unique needs and considerations.

In a study published by the Urban Institute in 2019 using Health in Retirement Survey (HRS) data from 2014, researchers found that 40% of adults aged 85 and older had severe LTSS needs while only 17% of adults ages 75–84 and 8% of adults ages 65–74 had such need. Severe need was defined as (1) having difficulty with two or more ADLs expected to last at least 90 days or severe cognitive impairment and (2) receiving unpaid care from family or friends or paid LTSS. Seventy percent of adults (64% of males and 75% of females) who survive to age 65 develop severe LTSS needs before they die. By race and ethnicity, the rates for developing severe LTSS needs were 73% for Black/African American adults, 73% for Hispanic/Latino adults and 70% for white adults (Johnson, 2019).

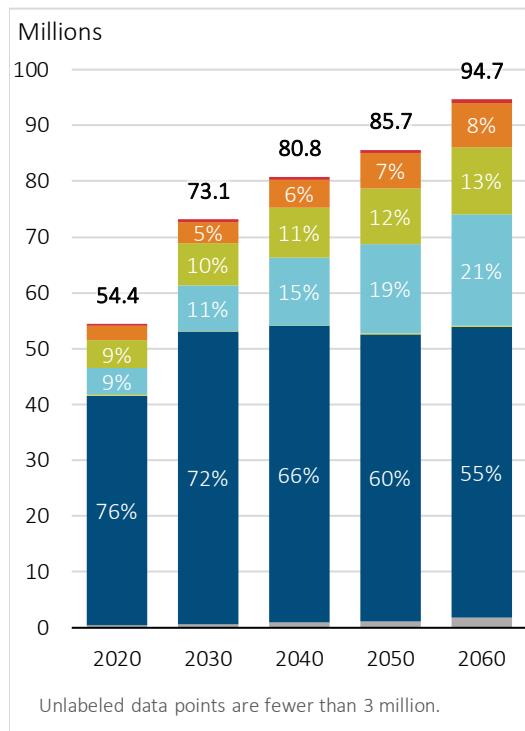
To understand potential LTSS needs because of aging for different races and ethnicities, we reviewed several population estimates. First, we looked at the U.S. adult population aged 65 and older by race and ethnicity from 2016 projected through 2060. Next, we looked at the U.S. adult population aged 85 and older for the same population segments and time periods. We used these distributions to provide context for the quantification of the current and future need for LTSS because of aging by race and ethnicity.

According to the 2020 U.S. census, an estimated 54 million people in the U.S were aged 65 and older and approximately 6 million were aged 85 and older. Projections by the U.S. Census Bureau in their 2017 estimates (the most recent available which are based on the 2010 census) show that by 2060 nearly 95 million people in the U.S will be aged 65 and older, and the population aged 85 and older is expected to grow to approximately 19 million. The expected overall growth rate for the entire U.S. population from 2020 to 2060 is expected to be 22%, while the growth rate in the population aged 65 and older is expected to be 74% over the same time period. The racial and

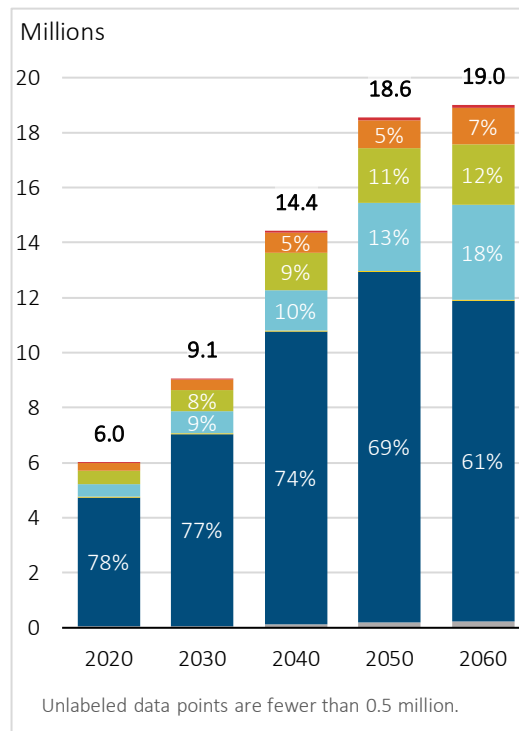
ethnic makeup of the U.S. population aged 65 and older is expected to become more diverse over time. Chart 1 illustrates the population aged 65 and older through 2060 by race and Hispanic/Latino ethnicity. Chart 2 shows the same information for the population aged 85 and older. The U.S. Census Bureau recommends using the latest population estimate in place of the projection when available. Charts 1 and 2 use the 2020 U.S. census population estimate for 2020 and the 2017 projections for years 2030, 2040, 2050 and 2060.

DISTRIBUTION OF U.S. ADULTS BY CALENDAR YEAR AND RACE/ETHNICITY

**Chart 1
AGES 65 AND OLDER**



**Chart 2
AGES 85 AND OLDER**



LEGEND

- AI/AN
- Asian
- Black
- Hisp./Lat.
- NH/PI
- White
- Two or more races

Source: U.S. Census Bureau, Population Division: Washington, DC. 2020 = Annual Estimates of the Resident Population by Sex, Age, Race and Hispanic Origin for the United States: April 1, 2020, to July 1, 2021 (NC-EST2021-ASR6H); Future years = Race and Hispanic Origin by Selected Age Groups: Main Projections Series for the United States, 2017-2060. NH/PI = Native Hawaiian and other Pacific Islander. AI/AN = American Indian and Alaska Native.

Several things are notable from the Charts 1 and 2. There is a significant number of individuals who may need LTSS because of aging in 2020 and this population is expected to increase dramatically. For both the over-65 and over-85 populations, white adults make up the largest percentage of the population in 2020 and in all projected years. When comparing the over-65 and over-85 population, the percentage of white adults is higher in the over-85 group compared to the over-65 group, while the percentage for all other races and ethnicities is lower. From 2020 to 2060, the percentage of Black/African American, Asian/Asian American, and Hispanic/Latino adults is expected to increase, while the percentage of white adults is expected to decrease.

Chronic illness is also a driver of LTSS need as the need for assistance with ADLs increases as the quality of life deteriorates for those with a chronic condition (Maresova, 2019). We considered whether the prevalence of chronic illness varies by race and ethnicity. One study found that Hispanic/Latino older adults and Black/African American older adults had the greatest prevalence of diabetes, while white older adults had the greatest prevalence of cancer and chronic lung disease. Researchers did not find significant differences in the prevalence of an individual having

multiple chronic conditions by race and ethnicity. The study was based on National Health Interview Survey data from 2006 to 2014, and older adults are defined as adults aged 60 to 79. Chronic illness was determined based on the following diseases: diabetes, coronary heart disease, heart attack, angina pectoris, diabetes, emphysema, chronic bronchitis, chronic obstructive pulmonary disease, or cancer (excluding nonmelanoma skin cancer). The study did not include findings for individuals who were Alaska Native, Asian/Asian American, Native Hawaiian, other Pacific Islanders, of another race, or who didn't answer, which is a limitation of the study (Davis, 2017).

Statistics published by the Centers for Disease Control (CDC) using data from the Jan. 2017 through March 2020 National Health and Nutrition Examination Survey show that the age-adjusted (by the CDC) prevalence of diabetes (diagnosed which is self-reported by those who have been told by a doctor or health professional that they had diabetes and undiagnosed which is based on clinical data indicating the potential presence of diabetes in those who did not report a history of diagnosed diabetes) is highest for Black/African American adults followed by Asian/Asian American adults and Hispanic/Latino adults. White adults had the lowest prevalence of diabetes as shown in Table 2.

Table 2
AGE-ADJUSTED PREVALENCE OF DIAGNOSED, UNDIAGNOSED AND TOTAL DIABETES AMONG ADULTS AGED 18 YEARS OR OLDER, UNITED STATES, 2017–2020.

Race/Ethnicity	Diagnosed Diabetes	Undiagnosed Diabetes	Total Diabetes
Asian/Asian American	11.1%	5.4%	16.4%
Black/African American	12.4%	4.4%	16.8%
Hispanic/Latino	13.0%	4.6%	17.6%
White	8.9%	2.3%	11.2%

Source: National Center for Health Statistics. 2017–March 2020 National Health and Nutrition Examination Survey.
<https://www.cdc.gov/diabetes/data/statistics-report/appendix.html#tabs-1-1>

The CDC also published statistics (although these figures are not age-adjusted) regarding coronary heart disease, the most common type of heart disease in the U.S., and for high blood pressure (hypertension), which affects many adults in the U.S. and is a risk factor for heart disease and stroke. As Table 3 shows, the percent of adults with coronary heart disease was highest for white adults (5.6%) and lowest for Hispanic/Latino adults (2.2%). The percent of adults with hypertension is significantly higher for Black/African American adults at 34.9% in 2020 compared to Hispanic/Latino adults, who had the lowest rate at 18.3%. The high rate of hypertension for Black/African American adults puts them at higher risk for complications like heart disease and stroke compared to adults of other races or ethnicities who have lower rates of hypertension. We compared the 2020 statistics (which could potentially be influenced by the COVID-19 pandemic) to the pre-pandemic 2019 statistics and observed that the results were similar.

Table 3
PERCENTAGE OF CORONARY HEART DISEASE AND DIAGNOSED HYPERTENSION FOR ADULTS AGED 18 AND OVER, UNITED STATES, 2019–2020.

Race/Ethnicity	Coronary Heart Disease 2020	Hypertension 2020
Black/African American	4.1%	34.9%
Hispanic/Latino	2.2%	18.3%
White	5.6%	27.9%
Another race	3.5%	22.2%

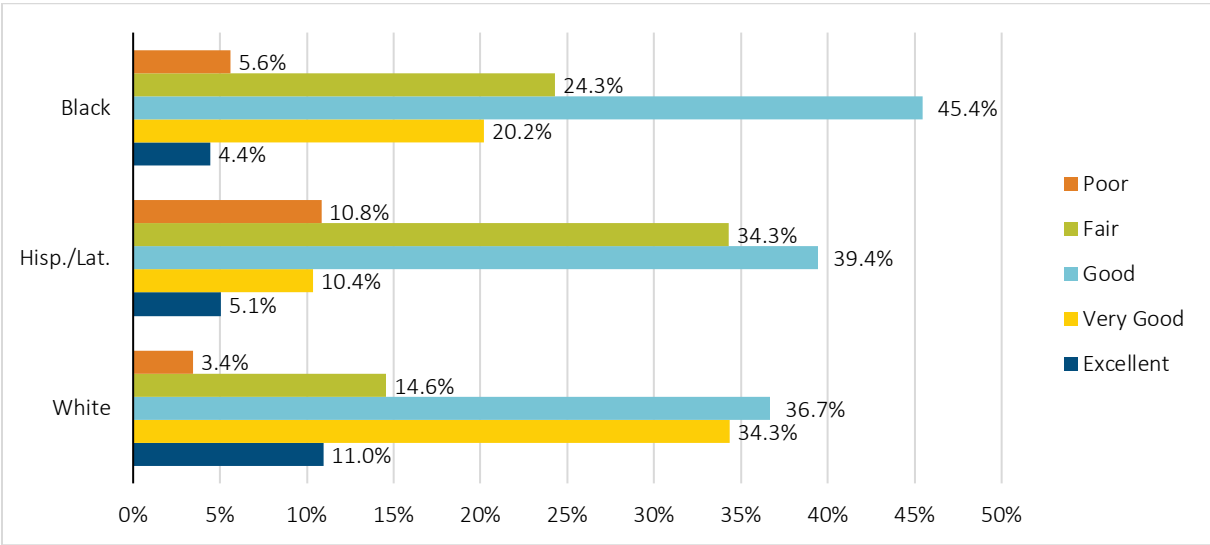
Source: National Center for Health Statistics. Percentage of coronary heart disease for adults aged 18 and over, United States, 2019–2020. Percentage of diagnosed hypertension for adults aged 18 and over, United States, 2019–2020. National Health Interview Survey. Generated interactively: Oct 01, 2022, from https://wwwn.cdc.gov/NHISDataQueryTool/SHS_adult/index.html

We selected the chronic illnesses illustrated in Tables 2 and 3 based on their prevalence in the community and their impact on health that may require LTSS. These statistics show that distribution of chronic illness varies by race and ethnicity.

We also assessed the need for LTSS across race and ethnicities in older adults using data from NHATS which is further described in Appendix A. We note the results from NHATS do not distinguish between individuals who are Alaskan Native, Asian/Asian American, Native Hawaiian, or Pacific Islanders. These races are grouped into one category in the publicly available NHATS data while actual race is included in the restricted/sensitive data set of NHATS. Further, we note that we did not age-adjust the findings (as age is also a restricted/sensitive field) but we did review the distribution of respondents by age band and race/ethnicity and found the distributions to be similar.

Although not a direct measure of disability, we looked at survey responses regarding the participants’ health status to estimate the potential need for LTSS (rather than the utilization of LTSS). Respondents were asked to rate their health status as excellent, very good, good, fair, or poor. Some respondents refused to answer or did not know. We assigned a value of 1 through 5 to each response (excluding those who refused to answer or did not know) with 1 being poor health and 5 being excellent. We averaged the responses by race and ethnicity across each of the survey years from 2015 through 2021. A higher value indicates better health, and a lower value indicates poorer health. We found little variation over time, and we found that Hispanic/Latino adults had the lowest average score (ranging from 2.6 to 2.8), Black/African American adults had a slightly higher average score (ranging from 2.9 to 3.0), and white adults had the highest average health score (ranging from 3.3 to 3.4). In Chart 3 we show the distribution of reported health status for Black/African American, Hispanic/Latino, and white adults. White adults had the highest percent reporting very good (34.3%) and excellent (11%) health. Hispanic/Latino adults had the highest percent reporting poor (10.8%) and fair (34.3%) health. Black/African American adults had the highest percent reporting good (45.4%) health.

Chart 3
SELF-REPORTED HEALTH STATUS OF ADULTS AGED 65 AND OLDER



Authors’ analysis of NHATS data 2021 based on the following scale of self-reported health conditions (1=Poor, 2=Fair, 3=Good, 4=Very Good, 5=Excellent)

With this information in mind, we next explored utilization of various types of LTSS by race and ethnicity. Our findings are presented in the following subsections.

2.2 HCBS UTILIZATION

HCBS are types of person-centered care delivered in the home and communities of patients as the name implies. Although HCBS can include both medical and nonmedical services, nonmedical services are the most common type of HCBS. Nonmedical services include adult day centers, home-delivered meal programs and personal care assistance (dressing, bathing, toileting, eating, transferring to or from a chair or bed). Medical services include skilled nursing care, occupational/physical therapy, pharmacy, and hospice care.

Compared to institutional services, HCBS tends to be more cost effective and culturally responsive. Most older adults prefer to age in place, to live independently and to remain among their family/community as long as possible; they also prefer to avoid formal long-term care when possible (Thomeer 2015). Because HCBS allows participants to minimize formal care and age in place, it promotes greater quality of life over institutional care. Although it is not clear based on analysis of Medicaid and Medicare claims data, if the clinical health outcomes of HCBS participants are better or worse than for those in institutional care HCBS is consistent with a commonly expressed preference to age in place (Gorges, 2019). In an analysis of who provides long-term care, Reaves found that the majority of long-term care delivered in the U.S. is provided by unpaid caregivers—including relatives or friends—in home and community-based settings (Reaves, 2015).

In a study conducted by Fabius and colleagues, they examined the effect of race and gender³ on receiving assistance with daily activities among older adults. They performed a statistical analysis on data from the 2015 NHATS. Their study included Black/African American and white adults aged 65 and older who receive assistance with routine daily activities. The study did not include adults of other races or ethnicities which is a limitation of the study. They note that of all community-dwelling older Medicare beneficiaries, 8.2 million of them receive an average of 36 hours of LTSS per week from caregivers (both paid and unpaid). Assistance includes personal help with daily tasks like self-care (eating/dressing), mobility (getting around the house) and household activities (shopping or meal preparation). Their cross-sectional analysis of older Black/African American and white adults who received HCBS show marked differences in reported health levels by gender and race, but there are significantly fewer substantial differences in care received. Whereas 19.5% of white men and 21.5% of white women who received HCBS reported being of very good or excellent health, only 9.6% of Black/African American men and 9.7% of Black/African American women reported the same. The study found that relative to white men, Black/African American men who receive help are less likely to receive assistance with self-care and mobility activities.

Half of older adults receiving assistance were getting help with self-care tasks, defined as help getting dressed, eating, toileting and bathing. Race and gender differences in this category were generally insignificant, although white men received the most help getting dressed (44.8%), and white women received the least help (37.0%), with Black/African American men and women falling in the middle (39.8% and 40.6%, respectively). White and Black/African American women are more likely to get help with mobility (48.5% and 53.2%, respectively) compared to white or Black/African American men (37.9% and 29.8%). Black/African American women were the most likely to get help with household activities, defined as help shopping or meal preparation (88.4%), and white men were the least likely (69.4%). In this same study, only 8.7% of white men and 13.5% of white women were covered by Medicaid, while 40.3% of Black/African American men and 43.3% of Black/African American women were covered (Fabius et al, 2021). Table 4 summarizes these values.

³ We use the term “gender” from the NHATS data. However, we note that the survey states “If gender is obvious, code without asking. Otherwise ask: What is your gender? 1= Male 2= Female.” This means that the field may be based on the interviewer’s interpretation and not actually self-reported and that the question asks about gender but records responses in terms of sex.

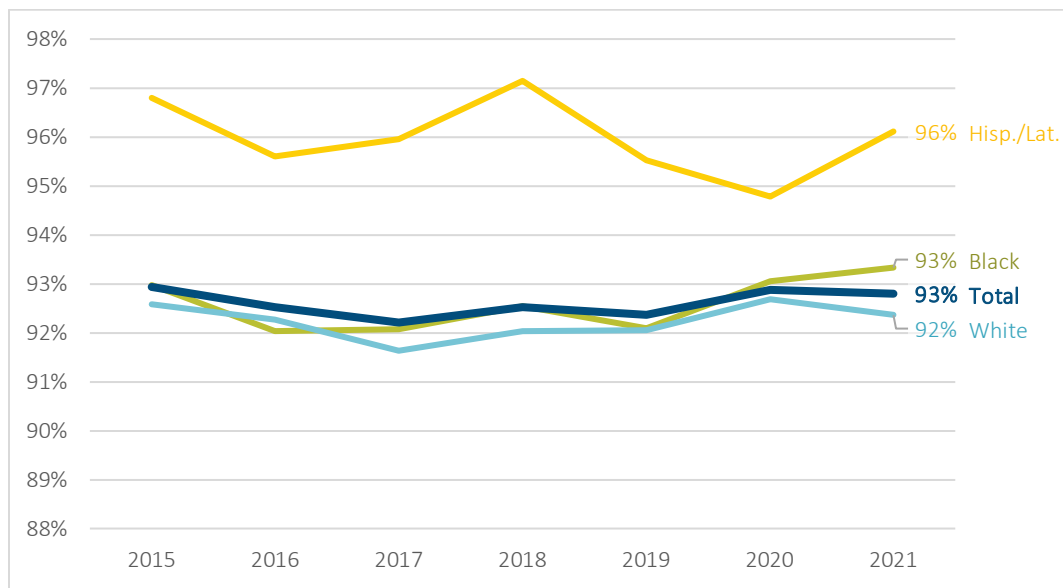
Table 4
METRICS FOR INDIVIDUALS USING HCBS BY BLACK/AFRICAN AMERICAN AND WHITE RACE AND GENDER

Of those using HCBS	Black Men	Black Women	White Men	White Women
Reported being in very good or excellent health	9.6%	9.7%	19.5%	21.5%
Covered by Medicaid	40.3%	43.3%	8.7%	13.5%
Receiving assistance with getting dressed	39.8%	40.6%	48.6%	37.0%
Receiving assistance with household activities	87.5%	88.4%	69.4%	83.6%
Receiving mobility assistance	29.8%	53.2%	37.9%	48.5%

Source: Fabius et al, 2021 summary of NHATS 2015 survey data.

We also reviewed the NHATS data directly, specifically the distribution of adults aged 65 and older living at home or in the community. As shown in Chart 4, this is the majority of respondents. Although there are slight differences over time the percentage is fairly consistent. In 2021, 96% of Hispanic/Latino adults aged 65 and older were living at home or in the community compared to 93% of Black/African American adults and 92% of white adults. This data is not restricted to those who need LTSS service but rather all adults in this age cohort represented by NHATS.

Chart 4
PERCENTAGE OF PEOPLE AGES 65 AND OLDER LIVING AT HOME/IN THE COMMUNITY



Authors' analysis of NHATS data 2015-2021

Although medical care is less common in HCBS, there is some utilization of this service. States can develop home and community-based services waivers (HCBS Waivers or Section 1915 (c) waivers) to meet the needs of people who prefer to get long-term care services and supports in their home or community, rather than in an institutional setting. Prior to the use of Section 1915 (c) waivers for Medicaid, about 5% of Medicaid expenditures from 2011 to 2014 were directed to home-based medical care (HBMC), which are various services provided in an individual's home by a nurse or aide. In a study by Yao and colleagues, they examined the volume of HBMC visits made to frail older adults between 2011 and 2014. Their study looked for disparities in HBMC use by sex, race, ethnicity, frailty-related comorbidity and geography. They created a comorbidity index score that sums the presence or absence of 13 groups of illnesses linked to the need for long-term care. These illnesses included minor or major ambulatory impairment, mental health diagnosis, mental retardation, dementia, sensory or self-care impairment, general symptoms, major chronic diseases, pneumonia, renal disease, or other medical risks. Summed comorbidity scores

were used to create three groups (0–3 low, 4–6 medium, 7+ high). From 2011 to 2014, the use of HBMC among Medicaid beneficiaries with medium comorbidity increased from 8.7% to 10.1%. For those with high comorbidity scores, the rate increased from 14.2% to 15.7%. Black/African American adults were 21% more likely to use HBMC compared to whites, and Asian/Asian American adults were 31% less likely to use HBMC compared to whites. Females were 24% more likely to use HBMC than males, and rural residents were 78% less likely to use HBMC than those in the largest metropolitan areas (Yao, 2018). The impact of Medicaid’s shift to home-based care is discussed further in Section 3.

2.2.1 ADULT DAY CENTER DEMOGRAPHICS

One specific example of community-based LTSS are adult day service centers (ADSC). They are generally open on weekdays and provide long-term and post-acute care services, including structured activities, health monitoring, socialization and assistance with ADLs. Based on data from the 2018 wave of the biennial National Study of Long-Term Care Providers, an estimated 251,000 participants were enrolled in ADSCs in the U.S. (Lendon, 2021). Chart 5 shows the distribution of ADSC utilization by age band and Chart 6 shows the distribution by race and ethnicity.

Most ADSC participants were aged 65 and over (61%); 39% were aged under 65, 42% were aged 65–85, and 19% were aged 85 and over. Most ADSC participants were of a race and ethnicity other than white (55%); 45% were white, 22% were Hispanic/Latino, 17% were Black/African American, and 16% were other races. In addition, almost 6 in 10 participants of ADSCs were female (57%).

Chart 5

DISTRIBUTION OF ADSC USERS BY AGE BAND, 2018

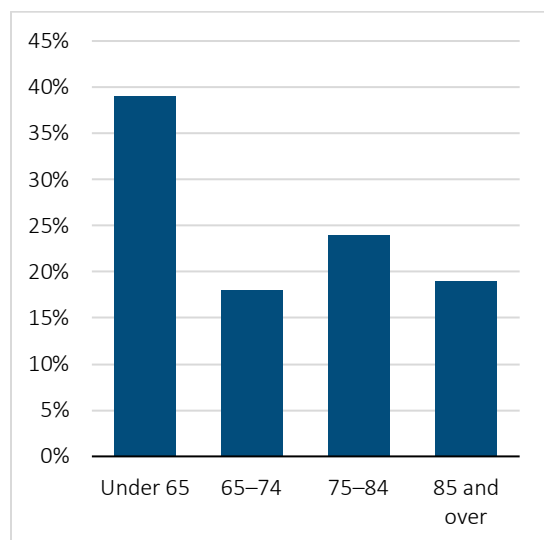
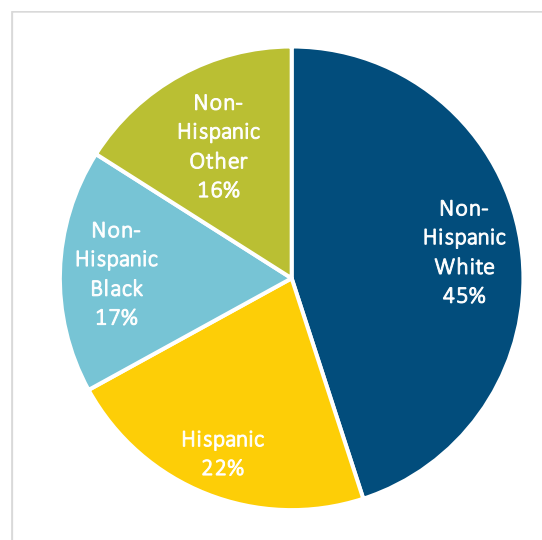


Chart 6

DISTRIBUTION OF ADSC USERS BY RACE/ETHNICITY, 2018



SOURCE: National Center for Health Statistics, National Study of Long-Term Care Providers, 2018 as reported in Lendon, 2021.

ADSC participants needed the most assistance with bathing, walking and dressing. Most participants (64%) needed help with three or more activities related to daily living. Seventy-five percent of participants needed help bathing, 58% needed help walking, 64% needed help dressing, 54% needed help transferring, 53% needed help toileting, and 41% needed help eating. Among ADSC participants, just over half (51%) were diagnosed with high blood pressure and just under a third (30%) were diagnosed with diabetes. Following these diagnoses, the most common chronic conditions among ADSC participants were Alzheimer’s disease or other dementia (28%), intellectual and developmental disability (27%), depression (22%), arthritis (19%), heart disease (13%), osteoporosis (13%), severe mental illness (11%) and COPD (7%) (Lendon, 2021). These statistics were not further segmented by race and

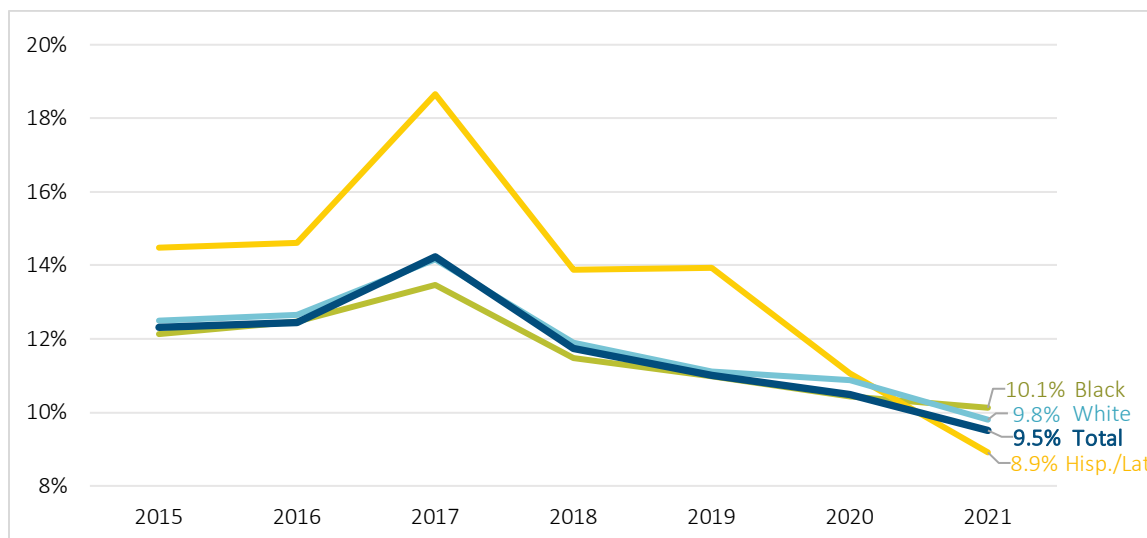
ethnicity but help to describe ADSC participants. As noted above the prevalence of diabetes is highest for Hispanic/Latino adults and the prevalence of high blood pressure is highest for Black/African American adults.

2.2.2 PAID HELPERS FOR HCBS

We reviewed the data reported in NHATS from 2015 through 2021 and found that only a small percentage of respondents had a paid helper for LTSS, ranging from 9% to 19% depending on the year and racial/ethnic group (Chart 7). Over time there has been a general decrease in the percentage with the total percentage dropping from 12% to 10% (aside from a slight uptick reported in 2017). In 2021, the percentages by race and ethnicity were comparable at about 9% to 10%.

Chart 7

PERCENTAGE OF ADULTS AGED 65 AND OLDER WITH PAID HELP FOR LTSS



Authors' analysis of NHATS data 2015-2021

2.3 FACILITY-BASED CARE UTILIZATION

For individuals whose needs are more complex or for whom HCBS is not available, they may rely on facility-based care. Facility-based care provides more comprehensive and formal LTSS. There are multiple types of facilities which can generally be grouped into these categories: residential care facilities, assisted living facilities, nursing homes (also called skilled nursing facilities) and continuing care retirement communities

Assisted living facilities are appropriate for people who need help with daily care, but not as much help as a nursing home provides. Typically, a few “levels of care” are offered, with residents paying more for higher levels of care. Assisted living residents usually live in their own apartments or rooms and share common areas. Such facilities also have medical staff available around the clock, but nursing and medical care usually are not provided on-site.

Nursing homes (NH), also called skilled nursing facilities (SNF), provide a wide range of health and personal care services. Their services focus on medical care more than most assisted living facilities. Rehabilitation services, such as physical, occupational and speech therapy, are also available. Some people stay at a nursing home for a short time after being in the hospital. After they recover, they go home. However, a large number of nursing home residents live there permanently because they have ongoing physical or mental conditions that require constant care and supervision.

Continuing care retirement communities (CCRCs), also called life care communities, offer different levels of service in one location. Often CCRCs require a significant entrance deposit. Many of them offer independent housing (houses or apartments) which is referred to as independent living, assisted living and skilled nursing care all on one campus. Health care services and recreation programs are also provided. People who can no longer live independently move to the assisted living facility or sometimes receive home care in their independent living unit. If necessary, they can enter the CCRC's nursing home.

The three key predictors of facility-based care admission are need (based on health and/or disability), economic resources and social ties (Thomeer, 2015). For example, greater need as a result of poor health or disability can require specialized care, and therefore predicts an increased likelihood of long-term care facility use (Mudrazija, Thomeer, & Angel, 2015). Lack of economic resources is also associated with long-term care facility use, as those financially able to stay at home and receive alternative care (such as HCBS) typically choose to do so (Friedman et al., 2005). Social ties often serve as substitutes for formal care, reducing use of long-term care facilities (Charles & Sevak, 2005). For example, among females, the number of living children, availability of non-spousal help, and even monthly contact with neighbors all decreased the risk of long-term care facility use (Thomeer, 2015). Among males, contact with neighbors does not predict long-term care use, but males who were divorced, widowed, or never married were more likely than continuously married males to enter long-term care facilities, and never married males are at the highest risk of all.

Those who have never married report lower levels of household net worth as compared with those who are currently married or who have previously been married. They are also more likely to live alone and to be childless (Pinquart, 2003). This may weaken the social supports of older, unmarried people. However, in addition to having stronger social ties, partnered adults also report higher incomes and pensions, yet fewer disabilities or chronic conditions compared to unmarried adults (Thomeer, 2015). It is therefore necessary to disaggregate the independent effects of wealth and marital status on long-term care admission. When controlling for economic resources, females are no more likely to enter long-term care facilities if they are married, widowed, divorced, or never married. For males however, marital status exerts an independent effect. When controlling for economic resources, males are more likely to enter long-term care facilities if they have never been married.

Being married does not affect the likelihood that Black/African American adults will use a long-term care facility, suggesting that family, friends, or non-marital partners may serve as functional substitutes for marriage among Black/African American adults (Thomeer, 2015). This has been true for decades, as one study from the 1990s showed that despite having higher levels of need and higher levels of Medicaid, older Black/African American adults have lower rates of nursing home care compared with white adults. Moreover, Black/African American adults also had higher levels of unpaid in-home care despite a lower marriage rate than white adults (Wallace, 1998). This data was available only for Black/African American and white adults, not other races or ethnicities, which is a limitation of this data.

2.3.1 RESIDENTIAL CARE FACILITIES

Residential care communities provide housing for people who cannot live independently, but generally do not need the skilled care found in nursing homes. As reported in a study by Caffrey and colleagues, in 2018, there were an estimated 918,700 people living in residential care communities in the United States. However, as the U.S. population ages, this number is likely to increase to become a substantial proportion of the long-term care population.

In 2018, residents were predominantly female (67%). Eighty-nine percent of residents were white, 6% were Black/African American, and 5% were another race or ethnicity. In addition, the majority of residents (55%) were aged 85 and older, and 26% were aged 75 to 84.

Residential care community residents needed the most assistance with bathing, walking and dressing. Most residents (61%) needed help with three or more activities related to daily living. Seventy-seven percent of residents needed help bathing, 69% needed help walking, 62% needed help dressing, 51% needed help transferring, 49% needed help toileting, and 26% needed help eating.

Among residential care community residents, just over half (55%) were diagnosed with high blood pressure and about a third (34%) were diagnosed with Alzheimer's disease or other dementia. Following these diagnoses, the most common chronic conditions among residential care residents were depression (27%), arthritis (20%), diabetes (20%), heart disease (17%), osteoporosis (12%), chronic obstructive pulmonary disease and allied conditions (11%), stroke (10%) and cancer (9%) (Caffrey, 2021). As noted above, the prevalence of chronic conditions varies by race and ethnicity.

2.3.2 ASSISTED LIVING FACILITIES

Assisted living facilities are like residential care facilities with the primary difference being that the latter tends to serve a small group (generally 20 or fewer individuals). In a 2020 study of 2015 data, researchers found that Black/African American adults aged 65 and older are less likely to move to assisted living and are more likely to move to a nursing home than do white adults aged 65 and older. The study reviewed three types of factors that may impact utilization: predisposing factors, enabling factors and need factors. Predisposing factors were defined as age and gender. Enabling factors were defined as income, housing tenure, Medicaid enrollment and living arrangement, while need factors were defined as ADL limitations, physical capacity, self-rated health and dementia. The study showed that Black/African American -white disparities related to moving to nursing homes are explained by enabling and need factors but Black/African American -white disparities related to moving to assisted living facilities were not explained by these factors (Morales, 2020). One limitation of the study is that it did not include other races, nor did it distinguish an individual's ethnicity.

A separate study published in 2021 also found that Black/African American older adults were underrepresented in assisted living facilities. In addition, the study found that the service provided was not equitable across various communities. Researchers concluded that assisted living facilities with memory care licenses are primarily located in affluent and predominantly white communities (Cornell, 2021). Patients with dementia are more likely to utilize facility care than those without dementia. For example, over 60% of white adults and 55% of Black/African American adults with dementia use facility care while only about 30% of white adults or 15% of Black/African American adults without dementia use facility care (Gorges, 2019). Black/African American and Hispanic/Latino older adults are less likely to utilize assisted living services because the industry is predominantly private-pay, whereas Black/African American and Hispanic/Latino older adults are disproportionately Medicaid recipients. While some states have implemented Medicaid waivers to expand access to assisted living, eligibility remains limited (Shippee et al., 2022). Medicaid is discussed further in Section 3.2.

2.3.3 NURSING HOMES

Nursing homes, or skilled nursing facilities, provide more complex care and more medical care than residential care and assisted living facilities. Researchers at Brown University found that between 1999 and 2008, the number of Hispanic/Latino residents and Asian/Asian American residents in nursing homes increased by 54.9% and 54.1% respectively, whereas the number of Black/African American residents increased by only 10.2%, and the number of white residents actually decreased by 10.8% (Feng, 2011). The studied included only residents aged 65 and older.

A systematic review of publications relating to nursing home racial segregation was conducted by Mack in 2018. Most of the studies documented a negative impact of racial segregation on people in historically marginalized racial groups and facility-level quality outcomes (Mack, 2020). Some of the differences were because of economic factors, as skilled nursing facilities for historically marginalized racial groups have lower ratios of staff to patients. A more

recent study by Estrada found that nursing home residents from historically marginalized racial groups experienced worse pain and symptom management at the end-of-life (Estrada 2021). Both Black/African American and Hispanic/Latino residents are more likely to enter facilities with inspection deficiencies, understaffing problems and a higher likelihood of termination (i.e. the facility shuts down owing to poor finances) compared to white residents. Hispanic/Latino residents on average entered facilities with worse RN-to-total nurse ratios and tended to rely more on Medicaid than white residents. Because Medicaid tends to pay less than other payers, nursing homes may have more or less money to provide high quality care depending on the makeup of their residents. In 2021, Bowblis and colleagues performed an analysis to measure the quality of life for residents in a nursing home, where quality of life was measured as an individual's overall well-being and satisfaction with life while in the facility based on a scale of 0% to 100% with higher values indicating higher quality of life. They found an overall lower quality of life existed among Black/African American, Indigenous and other Persons of Color (BIPOC), 73.2%, when compared to white residents, 79.5%. The overall quality of life score as well as satisfaction scores for facility environment, attention from staff, food enjoyment, engagement and mood were all statistically lower for BIPOC than for white residents (Bowblis et al., 2021).

During the COVID-19 pandemic, nursing homes with higher proportions of people of color had both a higher number of infections as well as a higher number of deaths than those with higher proportions of white residents. One study of 13,312 nursing homes showed that among nursing homes with the lowest proportion of white residents (quintile 1) there was a mean of 5.6 deaths per facility, where the nursing homes with the highest proportion of white residents (quintile 5), there was a mean of 1.7 deaths per facility (Gorges & Konetzka, 2021). Nursing homes in quintile 1 had 3.9 more deaths per facility than quintile 5. This study shows a nearly identical disproportion in the number of infections, with an average of 37.1 cases for quintile 1 and only 12.3 for quintile 5. Therefore, while there was about 1 death for every 7.2 cases in the facilities with the most white residents, there was about 1 death for every 6.6 cases in facilities with the least white residents.

2.3.4 PREFERENCES BY RACE AND ETHNICITY

We also wanted to understand if variation in LTSS utilization could be the result of underlying differences in preferences by race and ethnicity. There was limited data available regarding preferences about preferred site of LTSS care by race and ethnicity therefore we reviewed preferences about end-of-life care. White residents in nursing homes were more likely than residents of color to both complete an advance directive and complete it more quickly. On average, white residents completed advance directives within 21 days of admittance, whereas residents of color completed their directive after an average of 229 days (Estrada 2021). A nationwide analysis of resuscitation choices among nursing home residents revealed that on admission, Black/African American and Hispanic/Latino residents more often assented to future CPR as compared with white residents, who more often assented to a do-not resuscitate status. Similarly, Black/African American residents who initially assented to do-not-resuscitate status were 47.4% more likely than white residents to change that to CPR status upon admission to a nursing home. Hispanic/Latino residents were also more likely than white residents to elect aggressive treatments (Estrada 2021). The study did not distinguish between differences in an individual's preferences compared to differences in an individual's understanding about alternative choices; this is a limitation of the study.

Consistent with this expressed preference for receiving more intensive end-of-life care, Asian/Asian American, Hispanic/Latino and Black/African American residents were more likely than white residents to be hospitalized in the last 90 days before death. Correspondingly, all three groups were more likely than white residents to die in a hospital. However, even in the presence of do-not-hospitalize orders, the probability of end-of-life hospitalization was higher for Black/African American residents with cognitive impairments. In contrast, while results for Hispanic/Latinos were mixed, white nursing home residents were more likely to die in hospice than Black/African American residents (Estrada 2021).

2.4 INFORMAL CAREGIVERS

In a study conducted by Leggett and colleagues, using the 2017 NHATS and National Study of Caregiving, they examined the potential for race-based disparities for informal caregivers, generally family members or close friends. They found that the average age of informal caregivers was 59.6 years old and 63.2% were female. The study looked at the interaction between informal caregivers and providers and found that race and ethnicity did not impact whether an informal caregiver interacted with an LTSS provider. When compared to their white counterparts, the study found that Black/African American informal caregivers were 1.9 times more likely to keep track of medications, 1.8 times more likely to use their own money to pay for the patient's care and 3.5 times more likely to pay the patient's Medicare premiums or copayments. There was a greater likelihood of Hispanic/Latino informal caregivers providing these same tasks than whites; however, the results were not statistically significant (Leggett, 2022).

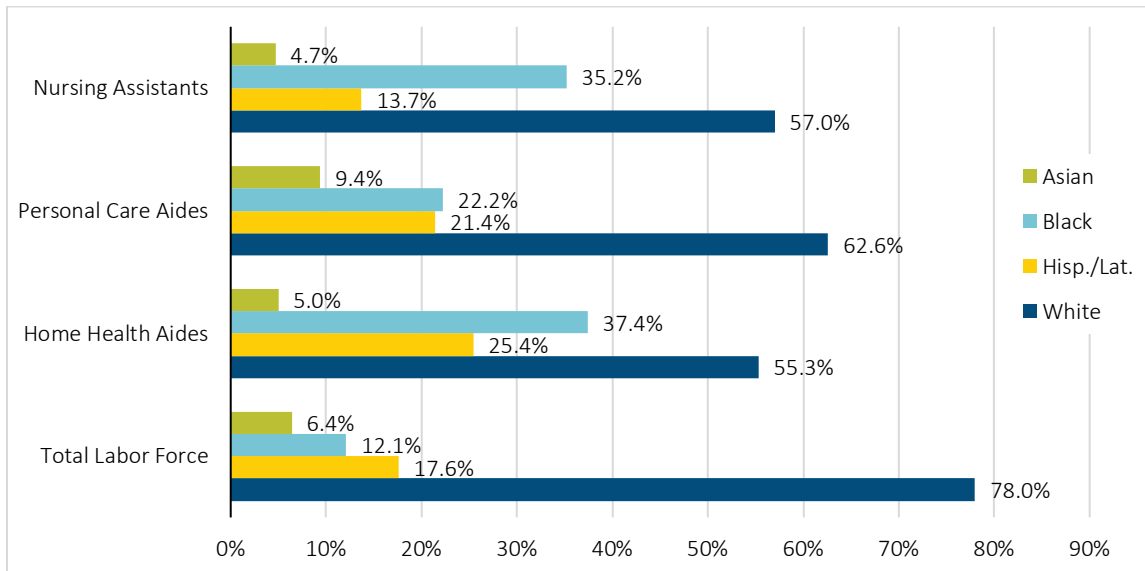
Section 3: Providers of LTSS

While most long-term services and supports are provided by unpaid caregivers such as relatives and friends, understanding key dynamics of LTSS providers is important to understanding utilization of services. There are a number of issues facing LTSS providers that impact the availability and utilization of formal LTSS care. The majority of individuals working for LTSS providers are paraprofessionals such as personal care assistants, home care aides, resident care aides or certified nursing assistants. In a report published by the Centers for Medicare and Medicaid Services Quality, Safety and Oversight Group on January 7, 2022, they state that staffing in nursing homes has a substantial impact on the quality of care and outcomes residents experience. They published annual turnover rates by star rating of the nursing home. The data showed that one-star nursing home rates had annual turnover rates greater than 50% for all nursing staff as well as registered nurses. The annual turnover rates decreased as star rating increased with five-star nursing homes reporting annual turnover rates of approximately 35% for registered nurses and approximately 40% for all nursing staff. One-star nursing homes had an average of 1.4 administrators leave while five-star nursing homes had an average of 0.8 administrators leave. Low wages and limited benefits contribute to high employee turnover in nursing homes, home care agencies and other settings.

In 2018, the long-term care workforce was 82% female, 38% were adults over age 50 and 26% were Black/African American. In addition, 58% earned annual wages less than \$30,000. Fifty-three percent of long-term care workers were aides and personal care workers, 13% were direct contact support workers, 14% were health care providers, 3% were social and behavioral health workers, and 16% were other support workers and managers (True, 2020). Chart 8 illustrates the distribution of the workforce in total and for direct care by race and Hispanic or Latino ethnicity in 2020. Individuals can report more than one race and ethnicity.

Chart 8

PERCENTAGE OF TOTAL EMPLOYED FOR SELECT OCCUPATIONS BY RACE AND ETHNICITY, 2020



Source: U.S. Bureau of Labor Statistics—Labor force characteristics by race and ethnicity, 2020 Table 8. Employed people by detailed occupation, race and Hispanic or Latino ethnicity, 2020 annual averages. Individuals can report more than one race and ethnicity resulting in total percentages greater than 100%.

Although the workforce in total is 78.0% white, the direct care workforce has a higher concentration of Asian/Asian American, Black/African American, and Hispanic/Latino workers. Only 2.7% of whites in the workforce work in health care support occupations compared to 6.8% of Black/African Americans in the workforce. In addition, the median weekly earnings of full-time wage and salary workers by occupation varies by race and Hispanic/Latino ethnicity. In 2020, as reported by the U.S. Bureau of Labor Statistics, the median usual weekly earnings for workers in health care support occupations were \$699 for Asian/Asian American employees, \$616 for white employees, \$580 for Hispanic/Latino employees and \$575 for Black/African American employees..

Beginning in 2020, the COVID-19 pandemic has had a significant impact on long-term care providers. Older adults and individuals with underlying health conditions have been at greater morbidity and mortality risk from the virus. Social distancing to prevent the spread of the virus is difficult in a group setting like nursing homes and assisted living facilities where patients need direct care. The majority of long-term care providers are in close contact with patients. A study published by the Kaiser Family Foundation in April 2020, stated that for LTC workers of color who have frequent contact with patients, they face a higher risk of infection compared to other LTC workers who do not have frequent contact with patients from the virus which may be compounded by their underlying risk. Personal protective equipment is a key component to protecting workers and stopping the spread of the virus. While most facilities were able to provide personal protective equipment during the pandemic, home health care workers were often overlooked and may not have received sufficient personal protective equipment (True, 2020). Although further analysis on the impact of staffing shortages in LTSS is outside the scope of the paper, we note that these shortages have been compounded by economic conditions, the aging population and the COVID-19 pandemic. LTSS providers have a direct impact on the utilization of care and we observed notable differences in providers by race and ethnicity.

Section 4: Financing of Long-Term Services and Supports

Access to LTSS is impacted by ability to pay for these services. In the United States, there are various reimbursement types for LTSS including government programs, individual out-of-pocket payments, private insurance (not covered by traditional major medical health insurance) and informal care (unpaid). While there is limited data on the cost of informal care, since it is not paid for and often not well documented, it has been estimated to be worth \$199 billion to \$470 billion using various assumptions and estimations methods (Upadhyay, 2019). In the absence of more detailed payment data for informal care, this paper focuses on the utilization of informal care (as described in Section 2) rather than the cost. The cost and the value of informal care by race/ethnicity is a recommended area for future research.

Formal care can be covered by government programs, private insurance, out-of-pocket expense, or charitable care (not specifically addressed in this paper). In Chart 9 we summarize spending on LTSS by payer over time using National Health Expenditure data. Chart 10 shows the same information on a per capita basis to normalize for the size of the total population. We include the following categories: Other Health, Residential, and Personal Care (for Medicaid only to account for 1915 (c) waivers), Home Health Care, and Nursing Care Facilities and Continuing Care Retirement Communities. This data includes LTSS for all ages.

Chart 9
AGGREGATE NATIONAL HEALTH EXPENDITURE FOR LTSS BY PAYER FROM 2000 TO 2020

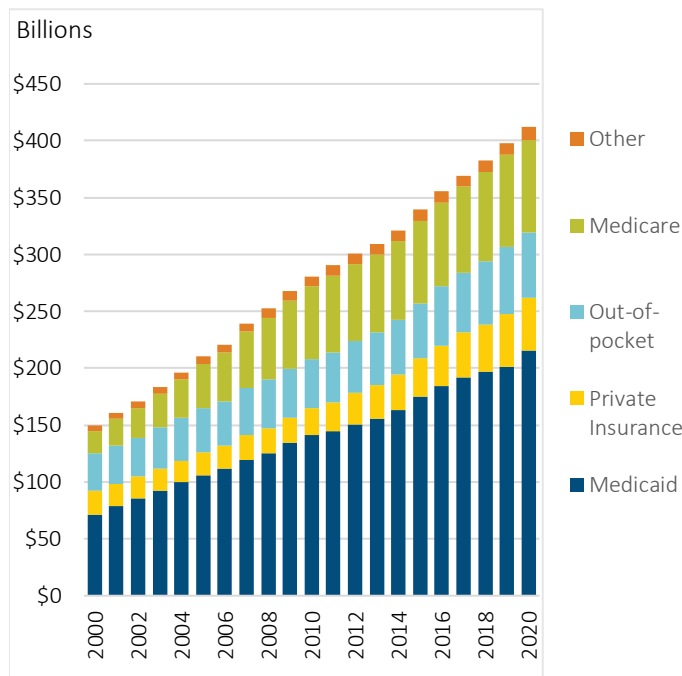
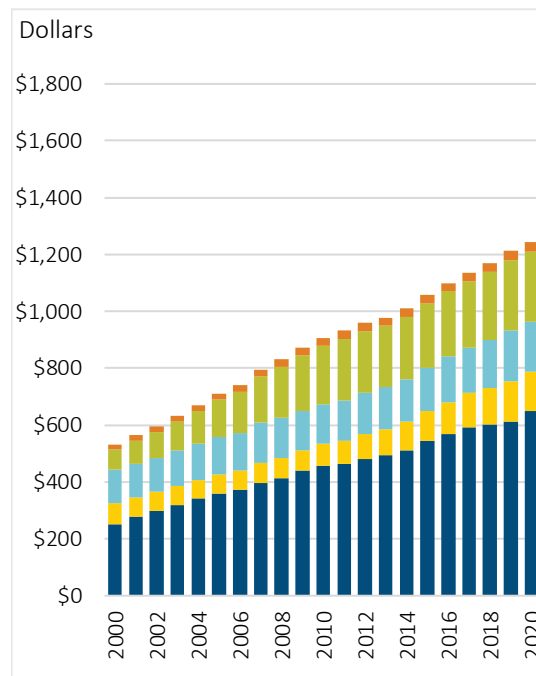


Chart 10
PER CAPITA NATIONAL HEALTH EXPENDITURE FOR LTSS BY PAYER FROM 2000 TO 2020



Source: National Health Expenditure data 2020 from the Centers for Medicare & Medicaid Services (CMS) is part of the Department of Health and Human Services (HHS) in the U.S.

In 2020, out of \$411 billion on national LTSS spending nationally, 52% came from Medicaid, 14% came from out-of-pocket spending, 11% came from private LTSS insurance, and 22% came from other public and private sources including Medicare. The Medicare amounts include the Medicare’s coverage of skilled nursing facilities. These percentages have been fairly stable over time.

Although many individuals who require LTSS are Medicare-eligible, Medicare covers only a portion of LTSS. This is because long-term care is not considered “medical care” based on the definition in federal legislation, and Medicare covers only “medical care.” Medicare covers up to 100 days of nursing home care in an inpatient setting (the individual must require skilled services such as nursing) but coverage ends if an individual needs only “custodial care.” The purpose of LTSS is to help individuals with their daily activities. LTSS is not curative while medical care is designed to be curative. For this reason, LTSS is also generally not covered by private traditional major medical health insurance. Private LTSS coverage is available through long-term care insurance products.

Medicaid finances the majority of LTSS in the country, at 52% of all formal LTSS. However, Medicaid is available only to individuals after they exhaust their other financial resources. Medicaid is jointly funded by state and federal governments, and Medicaid coverage varies significantly by state.

4.1 MEDICAID

Medicaid is a means-tested federal and state program that helps those with limited resources access health care. The program provides health insurance to low-income and disabled people in the U.S. As of April 2022, as reported by Medicaid.gov, Medicaid covers 81.1 million individuals, or about 24% of the country. Medicaid is therefore the largest single source of funding for medical and/or health-related services for low-income Americans. While not initially intended as a primary funder of LTSS, Medicaid now provides more funding for LTSS than any other single source in the U.S., and spending on LTSS now takes up about a third of Medicaid’s expenditures.

At its inception in 1965, Medicaid required states to provide institutional services such as nursing home care, but it gave states no obligation to provide HCBS benefits, home health or private duty nursing (Wenzlow, 2016). As such, Medicaid began with a strong bias toward funding institutional care such as licensed nursing homes over other forms of long-term care, like HCBS. While additional Medicaid legislation in the 1960s and 70s focused on creating standards of care in nursing facilities to curb abuse and neglect, the 1980s and 1990s saw statutory amendments and court decisions that changed both Medicaid LTSS policy as well as Medicaid eligibility. For example, in *Olmstead v. L.C.* (1999), the Supreme Court of the United States ruled that avoidable institutionalization of persons with disabilities violates the Americans with Disabilities Act. In recognition of the near universal preference of elderly individuals to remain at home, Medicaid has therefore shifted its focus from institutional care to instead spend more on HCBS (Upadhyay, 2019). The subsequent share of Medicaid LTSS funding spent on HCBS has increased relative to that spent on institutional care since the early 1980s. Over the past three decades, increased access to Medicaid HCBS has resulted in greater enrollment and spending on these services (Watts, 2018).

Medicaid is working to increase the use of HCBS over facility/institutional care through a variety of initiatives including state waivers. In 1989, for example, only 12% of Medicaid long-term care expenditures were for HCBS relative to 88% for nursing facilities, but by 2019, that figure had increased to 59% (Murray, 2021). Medicaid-eligible individuals who use LTSS are among those with the most disabilities and chronic illnesses of the total Medicaid population. Family involvement in home care significantly decreases inpatient health care utilization along with Medicaid spending on such care and also improves health outcomes, as measured by infection rates, the development of bed sores and shortness of breath (Upadhyay, 2019 via Coe and colleagues).

Table 5
MEDICAID EXPENDITURES PER STATE RESIDENT FOR THE TOP FIVE AND BOTTOM FIVE STATES

State	Rank	Total Medicaid Expenditures per Capita	% of Medicaid Expenditures for LTSS	% of Medicaid Expenditures for HCBS	% of Medicaid Expenditures for Medicaid Waiver 1915 (c)
District of Columbia	1	\$4,098	34%	21%	13%
New York	2	\$2,986	46%	29%	13%
Alaska	3	\$2,866	26%	16%	13%
Vermont	4	\$2,625	34%	23%	0%
Massachusetts	5	\$2,526	40%	29%	10%
Nebraska	43	\$1,107	45%	25%	22%
Georgia	44	\$1,022	29%	15%	12%
South Dakota	45	\$1,016	42%	22%	18%
Wyoming	46	\$1,010	53%	29%	26%
Utah	47	\$850	31%	16%	14%
United States	-	\$1,791	34%	20%	9%

Source: Appendices D and F from Murray, Caitlin, Alena Tourtellotte, Debra Lipson and Andrea Wysocki. "Medicaid Long-Term Services and Supports Annual Expenditures Report: Federal Fiscal Year 2019." Chicago, IL: Mathematica, December 9, 2021. Ranked by Medicaid expenditure per state resident in 2019 (data was not available for California, Delaware, Illinois and Virginia). FFS = fee-for-service

Medicaid spending per capita varies significant by state from less than \$1,000 to over \$4,000 (Table 5). Medicaid spending on LTSS ranges from 18% to 55% of the state's total Medicaid spending across all states included in the data with an average of 34%. Medicaid spending on HCBS ranges from 7% to 37% with an average of 20%. Medicaid Waiver 1915(c), also related to HCBS, makes up 9% of Medicaid spending on average with a range of 0% to 26%.

Medicaid coverage varies by race and ethnicity. As of 2020 by race and ethnicity reported in the Current Population Survey for adults aged 65 or over, Medicaid covered approximately 11.8% of Black/African American adults, 15.3% of Asian/Asian American adults, 14.1% of Hispanic/Latino adults compared to 4.2% of white adults. In addition, direct purchase health insurance (which can be any type of health insurance including LTC or major medical that is purchased directly from a private insurance company or through an exchange) varies by race and ethnicity, 27.1% of white adults have this type of coverage whereas only 10.7% of Black/African American, 13.3% of Asian/Asian American and 11.1% of Hispanic/Latino adults have this coverage. This data is reported by the U.S. Census Bureau based on specific single races (although multiple races can also be selected). Data for Native Americans,⁴ Other Pacific Islanders and those reporting two or more races are not shown separately as single races. Individuals of Hispanic/Latino origin may be of any race but are categorized as Hispanic/Latino in this data.

To address disparity, 35 states have Medicaid initiatives in place to address racial and ethnic disparities in fiscal year 2021 and 2022 (Guth, 2022), and the Affordable Care Act simplified enrollment for Medicaid. In Dec. 2021, federal action was taken to reduce the administrative burden of enrolling in Medicaid and to reverse some policies that may have caused access barriers especially for immigrant families. Work requirement waivers and Medicaid premium requirements above statutory limits were being phased out or have been withdrawn (Guth, 2022).

⁴ Includes American Indians, Alaska Natives and Native Hawaiians

Governments at both the state and federal level have identified racial health equity as a key priority, and a survey asking states about their Medicaid initiatives revealed that most states have one or more Medicaid initiatives aimed at decreasing racial disparity in health outcomes (Gifford et al, 2021). The majority (33 out of 37) of responding states that contract with Medicaid managed care organizations (MCOs) reported using their MCO contracts to help address enrollee social needs both within and outside managed care by focusing on identified social determinants of health. Social determinants of health include food, housing, education, employment, healthy behaviors and personal safety, and they differ by race. MCOs help address these needs by screening enrollees for social or behavioral health needs, providing referrals to social services and partnering with community-based organizations. Twenty responding states reported initiatives to address disparities in specific health outcomes, including maternal and infant health (11 states), behavioral health (7 states), COVID-19 outcomes or vaccinations (6 states), or other specific health outcomes (8 states).

From 2014 to 2021, 32 states (“expansion states”) implemented Medicaid expansion by removing the categorical criteria for childless adults and by expanding income eligibility to 138% of the federal poverty level for non-elderly adults (Lee et al, 2021). In response to this expansion, the federal government reports that as of July 2020, Medicaid enrollments increased by 15.9 million, or 41.7% relative to pre-expansion levels (The White House, 2021).

Expansions have also led to a narrowing of coverage disparities across race and ethnicity. Between 2013 and 2018, for example, there were larger increases in the percentage of the population with insurance coverage (including public and private insurance) for Black/African American and Hispanic/Latino individuals than among white individuals. The observed increases in insurance access were greater in expansion than non-expansion states. Independent studies bear out similar findings, suggesting a 6.5% point decline in uninsured status in expansion states relative to non-expansion states from 2010 to 2017 (Lee et al, 2021). There was a more pronounced effect on Black/African American and Hispanic/Latino individuals (a decrease of 6.7% and 7.0%, respectively) than on white individuals (a decrease of 6.0%), although the difference was minimal.

However, when measuring more specific outcomes in expansion states, such as the decrease in unmet needs or delays for medical care as a result of cost, there were significantly stronger effects on Hispanic/Latino individuals and somewhat so for Black/African American individuals relative to white individuals. For example, in expansion states compared to non-expansion states, 7.4% fewer Hispanic/Latino individuals delayed medical care because of cost, compared to 1.5% fewer Black/African American individuals and 1.2% fewer white individuals. Similarly, 6.4% fewer Hispanic/Latino individuals had unmet needs for medical care because of cost, compared to 2.7% fewer Black/African American individuals and 1.8% fewer white individuals (Lee et al, 2021). Thus, Medicaid expansion was associated with significant decreases in uninsured rates across all racial/ethnic groups and decreased differences across racial/ethnic groups regarding delayed care and unmet need for care. Although these findings are not specific to only LTSS, they show an increase in access to health insurance and an improvement in medical outcomes.

While there may be an improvement in access to medical care as a result of Medicaid expansion, we could not find evidence of the same improvements in access to LTSS. In an issue brief published by Watts and colleagues for the Kaiser Family Foundation, which focused on HCBS, they noted waivers are the main way that states offer HCBS LTSS coverage, and waivers allow states to limit the number of recipients. A majority of states (41) report that they had waiting lists for HCBS waiver coverage in 2018. The average wait time was 43 months for expansion states and 33 months for non-expansion states as of 2018 (Watts, 2021). There was no discussion of the impact of Medicaid expansion on other types of LTSS which is a limitation of this data.

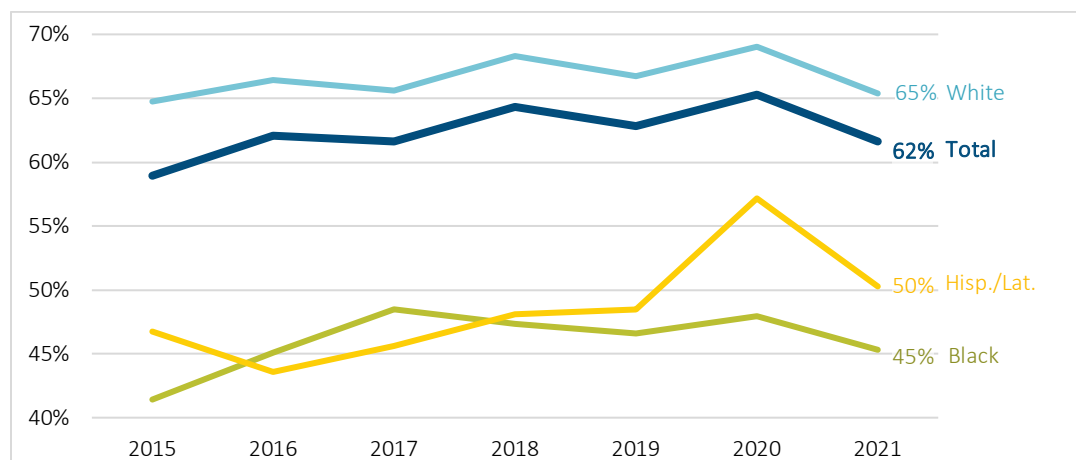
4.2 MEDICARE

As noted above, Medicare provides limited LTSS coverage. Home health services are covered only for beneficiaries who are homebound, and personal care services are not covered by Medicare. Post-acute nursing facility care is covered for up to 100 days following a qualified hospital stay but the individual is responsible for a portion of the

cost (referred to as cost share). Supplemental coverage is available through private insurance to cover this cost share. These private insurance plans are called Medicare Supplement or Medigap. In Chart 11 we show the percentage of individuals by race and ethnicity who carry Medicare Supplement insurance from 2015 through 2021. The data is based on self-reported coverage for a sample of Medicare beneficiaries. In 2021, 65% of white respondents reported having Medicare Supplement while only 50% of Hispanic/Latino respondents and 45% of Black/African American respondents reported having this coverage.

Chart 11

PERCENTAGE OF ADULTS AGED 65 AND OLDER WITH MEDICARE SUPPLEMENT INSURANCE



Authors' analysis of NHATS data 2015–2021

4.3 LONG-TERM CARE INSURANCE

Private long-term care insurance has been available since the 1980s, but enrollment has been declining in the last two decades. The percentage of adults aged 65 and older with private long-term care insurance was 10% in 2002, 12% in 2008 and 11% in 2014. About 13% of white adults aged 65 and older owned policies in 2014; but only about 2% of Hispanic/Latino adults and about 3% of Black/African American adults had long-term care insurance (Johnson, 2016). These proportions are consistent with statistics for 2002 and 2008. In addition to individuals being reluctant to buy coverage for a variety of reasons such as cost, underestimating their risk or overestimating what is covered by public insurance, individuals may also be denied coverage because of health issues (Johnson, 2016). A study by Suntai and colleagues using 2018 NHATS data found a difference by race/ethnicity in advance care planning. The study calculated an “odds ratio” for discussing end-of-life care and medical power of attorney by race/ethnicity. They found that white older adults were nearly twice as likely as Black/African American older adults to discuss both end-of-life care and medical power of attorney. The gap was greater for Hispanic/Latino older adults, as whites were found more than 2.5 times as likely to discuss both end-of-life care and medical power of attorney as Hispanic/Latinos (Suntai, 2021). Although not specific to long-term care insurance, the study results may indicate a difference in preferences by racial/ethnic group.

While a majority of people turning 65 today will need some sort of long-term care, and since not many have the financial resources to pay hundreds of thousands of dollars per year out of pocket, few people purchase LTC insurance to cover this cost (Kallenbach & Chow, 2018). Previous research by the Life Insurance Marketing and Research Association (LIMRA) found that high level premiums deterred middle-market consumers from purchasing LTC insurance, with 4 out of 10 experts agreeing that LTC insurance was a niche product for affluent Americans. As noted earlier, sales of LTC products dropped 83% from 2002 to 2014. Stand-alone LTC product sales continued to fall by double digits every year thereafter, at least through 2017.

Offsetting this decline over the period from 2013 to 2017, there has been some increase in sales of products that combine life insurance with some long-term care coverage: life/critical insurance (CI) which covers some critical illness, life/LTC which combines life and classical long-term care coverage and life/EOB which allows for long-term care that can exceed the death benefit. However, of these combination life products, the products that provide the least LTC coverage have the largest market share, with life/CI making up 54% of combination life products, and life/LTC making up 32% of the market (Terry & Lagonigro, 2021). Even then, companies selling combination life products indicated that 76% of combination LTC products target households making \$100,000 per year or more, with just 8% of the products focusing on families making under \$50,000 (Kallenach & Chow, 2018).

4.4 COST OF CARE

The cost of LTSS is not only driven by facility-based care, even covering the expense of paid home care can be difficult. The Office of the Assistant Secretary for Planning and Evaluation estimated in 2019 that only about one-half of individuals with severe LTSS needs have enough savings to cover paid home care for two years even if they liquidated all their available assets.

Genworth (a private life insurance company that offers long-term care products) publishes an annual survey regarding the cost of care for long-term care. The survey was conducted from June through Nov. 2021 by a Genworth subsidiary. They contacted 67,742 providers by phone and completed 14,698 surveys of nursing homes, assisted living facilities, adult day centers and home care providers. Table 6 illustrates the annual national median cost by type of service for 2004, 2012 and 2021. Cost for long-term care services have been increasing.

Table 6
ANNUAL NATIONAL MEDIAN COST BY TYPE OF SERVICE FOR SELECTED YEARS.

Annual National Median Cost	2004	2012	2021
Homemaker Services	\$38,095	\$41,184	\$59,488
Home Health Aide	\$42,168	\$43,472	\$61,776
Assisted Living Facility Costs	\$28,800	\$39,600	\$54,000
Semi-Private Room	n/a	n/a	\$94,900
Private Room Nursing Home Costs	\$65,185	\$81,030	\$108,405

Source: Genworth 2021 cost of care survey.

Genworth reported that the main driver of increases in cost is that demand continues to grow, and the supply of long-term care providers is not keeping pace. They attribute this to a high turnover rate among long-term care workers, an insufficient supply of professionals and the effect of the COVID-19 pandemic on staffing.

Genworth also provides cost of care data by state. In 2021, the annual cost of a private room in a nursing home was \$378,140 in Alaska, the highest cost state, followed by \$182,044 in Connecticut, the second highest cost state. 28 states were above the national median of \$108,405. The lowest costs were \$73,000 in Oklahoma; \$72,719 in Louisiana; and \$71,175 in Missouri. Assisted living facility annual costs ranged from \$83,730 in District of Columbia to \$36,000 in Missouri with 22 states above the national median of \$54,000. Annual costs for a home health aide ranged from \$82,940 in Minnesota to \$42,900 in West Virginia with 30 states above the national median of \$61,776. The costs by state vary significantly.

Section 5: LTSS for Individuals with Disabilities (under age 65)

As discussed in Section 2, the need for LTSS is based on an individual's limitations with performing ADLs. While there are many different definitions for the disabled, the Americans with Disabilities Act defines it as "a physical or mental impairment that substantially limits one or more major life activities" or "being regarded as having such an impairment." With limitations on performing ADLs, many individuals with disabilities utilize LTSS. In 2016, 11 million U.S. adults aged 25 to 54 were found to have at least one of six disabilities defined as having difficulty with the following: vision, hearing, the ability to walk or climb stairs, cognition (remembering, concentrating, or making decisions), self-care (dressing or bathing) and independent living (doing errands alone such as visiting a doctor's office or shopping) (Ross et al., 2018). When analyzing disability rates in the American Community Survey across race and ethnicity, Goodman and her colleagues observed disability rates in 2015 among working age 18–64 adults were 14% for Black/African Americans, 11% for Non-Hispanic whites, 8% for Hispanic/Latinos and 5% for Asians/Asian Americans (Goodman, 2019).

Depending on meeting certain eligibility criteria, individuals with disabilities are eligible for coverage through either Medicaid or Medicare. According to the 2017 Actuarial Report on the Financial Outlook for Medicaid, there were 10.6 million people with disabilities covered by Medicaid and 8.9 million people with disabilities covered by Medicare. Individuals who are covered by Medicare and Medicaid are referred to as "dual eligibles." As reported by Medicare Payment Advisory Commission (MedPAC) in June 2019, LTSS accounts for approximately 80% of Medicaid spending on dual eligibles. Care for these individuals is not well coordinated because of the challenge of dealing with two complex programs. In addition, while managed care plans exist for both Medicaid and Medicare they are often not coordinated (MedPac, 2019). One option for integrating care is a Program of All Inclusive Care for the Elderly (PACE). Another option is Dual Special Needs Plans.

Expectations are that Medicaid spending for long-term care will grow by 3.1% on average from 2018 through 2027, increasing from \$116.5 billion in 2017 to \$158.2 billion in 2027. The majority of long-term care services in the Medicaid program are utilized by aged enrollees and people with disabilities. The expected growth is not only because of increasing utilization of services for both the Aged and disabled, but also because of growth in enrollment for these enrollees (Truffer, 2018). A recent study of 2019 Medicaid LTSS spending found that the under 65 Disabled enrollees were 11% of total Medicaid enrollees, but represented 50% of all Medicaid LTSS costs (Chidambaram, 2022). When looking at total costs per enrollee for the same period, the same researchers found that per enrollee costs for the disabled, \$19,520, were five times greater than that of children and nonelderly adults who were not disabled, \$3,247. Additionally, the researchers found that among the state waivers discussed in section 3.1, people with intellectual and developmental disabilities represented less than half of the waiver enrollment but accounted for more than two-thirds of waiver spending, which represented nearly \$40 billion based on Fiscal Year 2020 spending for the Medicaid program.

Individuals with disabilities utilizing LTSS have specific needs and concerns that should be considered in addition to those LTSS utilizers because of age and chronic illness (discussed in Section 2.1).

Section 6: Areas for Further Study

Using data and projections from the U.S. Census Bureau, the Bureau of Labor, and the Department of Health and Human Services, as well as survey data from the National Health and Aging Trends Study (NHATS), we have seen that in the coming decades, the number of people over the age of 65 will increase significantly from 54 million to around 95 million by 2060, with a correspondingly large increase in the need for LTSS. Over this time, the percentage of older Americans who are Black/African American, Asian/Asian American, and Hispanic American is projected to increase as compared to the percentage of older Americans who are white, indicating that future needs in LTSS will increase at a faster rate in those groups.

These trends highlight the need to understand differences in LTSS need across groups, as well as the drivers of ongoing disparities in access to appropriate LTSS, such as sources of funding. For example, individuals of Hispanic ethnicity tend to report lower levels of health compared to Black/African American or white individuals, indicating a possible higher unmet need for LTSS. Another example is that Black/African American and Hispanic/Latino older adults are less likely to utilize assisted living services where the industry is predominantly private-pay, and Black/African American and Hispanic/Latino older adults are disproportionately Medicaid recipients.

There are two major gaps in the current literature that prevent us from making strong conclusions regarding disparities across racial or demographic groups. The first relates to the granularity of the data available. Specifically, most studies on race/ethnicity in LTSS fail to make more granular distinctions between racial groups than Black/African American, Hispanic/Latino and white, leaving limited data regarding Asians/Asian Americans, American Indians, Alaskan Natives, Native Hawaiians, Pacific Islanders, and individuals of more than one race. Collecting future data at a more granular level could allow future researchers to study disparities in access to LTSS specific to those groups, where at present that is not possible. Related to this concern, we found limited research looking at multiple demographic factors simultaneously and little data that normalized for one demographic factor in order to look at other demographic factors in isolation. Therefore, additional research by a wide range of demographic factors that impact LTSS is needed. These factors include geography, wealth, education, family structure, age, sex, and other socioeconomic factors.

The second primary limitation involves the difficulty in measuring the gaps in LTSS care (i.e., the difference between need and utilization). Presently, there is no standardized measure for a gap between need and utilization in the current literature, so we have to infer the gap based on proxy variables for need and actual utilization. However, even if researchers had solid data on the gaps between need (as defined by ADLs, for example) and utilization across groups, the existing literature has not resolved the degree to which differences in cultural preferences may influence individual choices regarding LTSS care. Prior to developing a means of controlling for differences in LTSS preferences, it would be difficult to determine the degree to which LTSS gaps were attributable to differences in access vs differences in preferences.

In addition, the cost and the value of informal care by race/ethnicity is a recommended area for future research.



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Section 7: Acknowledgments

The researchers' deepest gratitude goes to those without whose efforts this project could not have come to fruition: the Project Oversight Group and others for their diligent work advising throughout the project and reviewing and editing this report for accuracy and relevance.

Project Oversight Group members

Jonathan Applewhite, FSA, MAAA

John Cutler

Jo-Ann Davis-Valz, ASA, MAAA

Robert Eaton, FSA, MAAA

Alexandra Fernandez

Robert Gomez, FSA, CERA, MAAA

Sam Gutterman, FSA, CERA, FCA, FCAS, HONFIA, MAAA

Nick Johnson, FSA, MAAA

Andrew Melnyk, PhD

Mitchell Momanyi, FSA, MAAA

At the Society of Actuaries Research Institute:

Lisa Schilling, FSA, EA, FCA, MAAA, Senior Research Actuary

Appendix A: Select Data Sources

This appendix provides a summary of various publicly available data sources related to Long-Term Services and Support that are used in this report. Below is a brief background on the organization, a summary of the content of the data, frequency of the data refreshes and other key information.

NATIONAL HEALTH EXPENDITURE DATA

Link: [National Health Expenditure Data | CMS](#)

The Centers for Medicare & Medicaid Services (CMS) is part of the Department of Health and Human Services (HHS) in the U.S. CMS publishes National Health Expenditure (NHE) data annually. The National Health Expenditure Accounts (NHEA) measure annual U.S. expenditures for health care goods and services, public health activities, government administration, the net cost of health insurance and investment related to health care. The data are presented by type of service, sources of funding and type of sponsor. Three primary characteristics of the NHEA are:

- Comprehensive – contains all the main components of the health care system with a unified mutually exclusive and exhaustive structure
- Multidimensional – includes information on payers of expenditures not just total expenditures
- Consistent – common set of definitions that allow comparisons among categories and over time

The NHEA can be used to study health care expenditures as a proportion of Gross Domestic Product (GDP), by payer or program (such as Medicare or Medicaid), by type of goods and services, by type of sponsor (business, households, government, etc.). The NHEA include health spending by age and gender and by state. The data underlying the NHEA comes from various sources including survey data, Medicare and Medicaid data and other sources. In addition to the historical health spending data, NHEA projections are also available which begin with historical trends and incorporate assumptions about demographic and economic factors, as well as inflation rates.

The NHE data is also adjusted for price inflation of medical goods and services. Health spending is influenced by changes in technology, demographics, service intensity, utilization of health care services per person and price inflation. In order to study growth factors other than price inflation, the NHE data is deflated by applying a selected index (which varies by type of good/service) to the actual data to remove the impact of price inflation.

The main categories of the NHEA are listed below:

- Personal Health Care (PHC) expenditures represent all revenue received by health care providers and retail establishments for medical goods and services as well as all non-patient and non-operating revenue, grants, subsidies and philanthropy received by health care providers. PHC includes:
 - Hospital Care
 - Professional Services
 - Other Health, Residential and Personal Care
 - Home Health Care
 - Nursing Care Facilities and Continuing Care Retirement Communities
 - Retail Outlet Sales of Medical Products
- Health Consumption Expenditures (HCE) represent spending for all medical care rendered during the year, and is the sum of PHC, government public health activity, and government administration and the net cost of health insurance. In addition to PHC, HCE includes:
 - Administration and the Net Cost of Health Insurance—the administrative cost of running various government health care programs, and for private insurers, the net cost represents the difference between premiums earned and the claims or losses incurred for which insurers are liable.

- Government Public Health Activities—spending by governments to organize and deliver health services and to prevent or control health problems.
- National Health Expenditures (NHE) equals HCE plus investment, or the sum of medical sector purchases of structures and equipment and expenditures for noncommercial medical research. In addition to HCE, NHE includes:
 - Investment—spending for noncommercial biomedical research and expenditures by health care establishments on structures and equipment.

The main payers included in the NHE data are listed below:

- Out-of-Pocket
- Private Health Insurance
- Other Private Revenues
- Medicare
- Medicaid
- Other Payers

For additional details, see the National Health Expenditure Accounts: Methodology Paper, 2020 available at the link provided above.

NATIONAL HEALTH AND AGING TRENDS STUDY (NHATS)

Link: [National Health and Aging Trends Study \(NHATS\) | NHATS](#)

The Division of Behavioral and Social Research (BSR) sponsors the National Health and Aging Trends Study (NHATS). BSR is a division of the National Institute on Aging (NIA). NIA is one of the 27 Institutes and Centers of the National Institute of Health (NIH) which is part of the Department of Health and Human Services (HHS) in the U.S. NHATS is led by Johns Hopkins University Bloomberg School of Public Health and the University of Michigan's Institute for Social Research, with data collection by Westat.

NHATS collects data from a nationally representative sample of Medicare beneficiaries ages 65 and older. Annual, in-person interviews collected detailed information on the disablement process and its consequences. The sample is refreshed periodically so that researchers may study national-level disability trends as well as individual trajectories. Replenishment of the sample to maintain its ability to represent the older Medicare population was undertaken in 2015.

Detailed information is collected on participants' physical and cognitive capacity, how activities of daily life are carried out, the social, physical and technological environment, and participation in valued activities. A series of performance-based tests provides complimentary measures of physical and cognitive capacity. In addition, information is obtained on living arrangements, economic status and well-being, and aspects of early life. For those who die between rounds, the Last Month of Life interview collects details on place and quality of end-of-life care and daily activities since the prior interview.

This summary information was taken directly from the NHATS website. Additional details can be found at the link provided above.

Appendix B: 2019 Per Capita Medicaid Expenditures by State

Table B.1 shows the 2019 Medicaid expenditure data by state broken out by LTSS expenditure as well as Waiver 1915 (c) expenditures. The table also shows HCBS expenditures as a percentage of total LTSS expenditures for fee-for-service (FFS) and managed Medicaid separately. The data comes from Appendices D and F from Murray, Caitlin, Alena Tourtellotte, Debra Lipson and Andrea Wysocki. “Medicaid Long-Term Services and Supports Annual Expenditures Report: Federal Fiscal Year 2019.” Chicago, IL: Mathematica, December 9, 2021.

Table B.1
MEDICAID EXPENDITURE BY STATE

State	Rank	Medicaid Expenditures per Capita	% of Medicaid Expenditures for LTSS	% of Medicaid Expenditures for HCBS	% of Medicaid Expenditures for Medicaid Waiver 1915(c)
District of Columbia	1	\$4,098	34%	21%	13%
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Vermont	4	\$2,625	34%	23%	0%
Massachusetts	5	\$2,526	40%	29%	10%
New Mexico	6	\$2,510	20%	15%	8%
Pennsylvania	7	\$2,506	43%	28%	17%
Louisiana	8	\$2,504	20%	7%	5%
Rhode Island	9	\$2,441	28%	14%	9%
Connecticut	10	\$2,291	43%	24%	18%
Kentucky	11	\$2,285	22%	10%	9%
Arkansas	12	\$2,268	24%	11%	4%
Minnesota	13	\$2,256	49%	37%	21%
Oregon	14	\$2,235	32%	26%	1%
West Virginia	15	\$2,191	37%	15%	11%
Maine	16	\$2,133	44%	28%	19%
Ohio	17	\$2,007	38%	21%	16%
Maryland	18	\$1,940	32%	20%	10%
Mississippi	19	\$1,850	30%	10%	9%
Indiana	20	\$1,848	36%	13%	10%
Michigan	21	\$1,828	21%	8%	3%
Arizona	22	\$1,809	18%	14%	0%
New Jersey	23	\$1,791	33%	16%	10%
Montana	24	\$1,738	27%	15%	8%
Washington	25	\$1,724	30%	22%	6%
Missouri	26	\$1,716	35%	21%	11%
Iowa	27	\$1,648	37%	20%	1%
Colorado	28	\$1,598	35%	25%	15%
Wisconsin	29	\$1,569	46%	35%	8%
Hawaii	30	\$1,539	26%	13%	7%
North Dakota	31	\$1,527	55%	24%	19%
Tennessee	32	\$1,478	26%	13%	7%
New Hampshire	33	\$1,460	43%	20%	17%

State	Rank	Medicaid Expenditures per Capita	% of Medicaid Expenditures for LTSS	% of Medicaid Expenditures for HCBS	% of Medicaid Expenditures for Medicaid Waiver 1915(c)
Texas	34	\$1,380	29%	18%	3%
North Carolina	35	\$1,296	26%	15%	2%
Nevada	36	\$1,292	22%	13%	4%
Kansas	37	\$1,236	49%	35%	0%
South Carolina	38	\$1,225	28%	14%	11%
Oklahoma	39	\$1,203	29%	14%	10%
Alabama	40	\$1,199	31%	13%	7%
Idaho	41	\$1,199	38%	22%	17%
Florida	42	\$1,135	30%	11%	5%
Nebraska	43	\$1,107	45%	25%	22%
Georgia	44	\$1,022	29%	15%	12%
South Dakota	45	\$1,016	42%	22%	18%
Wyoming	46	\$1,010	53%	29%	26%
Utah	47	\$850	31%	16%	14%
California	NA	NA	NA	NA	NA
Delaware	NA	NA	NA	NA	NA
Illinois	NA	NA	NA	NA	NA
Virginia	NA	NA	NA	NA	NA
United States	NA	\$1,791	34%	20%	9%

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Society of Actuaries Research Institute
475 N. Martingale Road, Suite 600
Schaumburg, Illinois 60173
www.SOA.org