



Aging in Place

The Economic and Fiscal Value of
Home and Community-Based Services

JANUARY 2022

Florida
TaxWatch





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Dear Fellow Taxpayer,

Florida has long been viewed as a prime destination to age and retire, providing many older residents with unrivaled amenities and quality of life. By the end of this current decade, it is expected that close to one in every four Floridians will be over the age of 65 as the Baby Boomer population progressively retires and many individuals from other states move to the Sunshine State. Although the rapid rise in an older population will bring substantial economic benefits to Florida, there will also be a subsequent rise in demand for long-term health care supports and services.

Ensuring that Florida's seniors can receive top-quality care while also improving overall satisfaction, autonomy, and dignity is of paramount importance for the state. Identifying a cost-effective way to achieve this goal is an added priority for policymakers since long-term care has historically been very expensive. The COVID-19 pandemic illuminated the need to consider the physical safety of the state's most vulnerable, who have succumbed to the virus at alarming rates over the past two years. Together these challenges present a dire need for long-term care solutions that enhance access, promote physical safety, control costs, and improve quality outcomes.

Home and community-based services have become an ideal way to address the aforementioned challenges facing Florida in the future. Not only have these home and community settings been shown to drastically improve quality of life outcomes among individuals, but there are also tremendous fiscal savings that can be realized for Florida's taxpayers. Oftentimes overlooked, there is an added benefit for the millions of families that provide uncompensated medical and personal care to loved ones without much recognition or reimbursement.

Florida TaxWatch undertakes this independent research project to analyze the potential health, economic, and fiscal benefits accruing to elderly individuals, their families, and the state of Florida from providing home and community-based services. The report details some of the prominent continuum of care options that exist in Florida, highlighting the role of public funding and quality outcomes. The report then discusses the value that can be derived from expanding home and community-based long-term care.

We look forward to discussing our findings and recommendations with policymakers during the 2022 legislative session and beyond.

Sincerely,

A handwritten signature in black ink that reads "Dominic M. Calabro".

Dominic M. Calabro
President & Chief Executive Officer

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Executive Summary

Florida is facing a demographic transformation that will see the state's 65 and older population grow by more than 50 percent over the next two decades—a trend that will outpace most of the nation and only grow over time as additional individuals relocate to Florida. The future of Florida's aging population will undoubtedly affect economic growth and fiscal sustainability. Currently, older Floridians supply more than \$505 billion in annual economic activity and support some 6.3 million jobs. Alongside expected economic benefits, a rapidly aging population will increase the demand for long-term services and supports in Florida, inevitably raising financial costs in the process.

A variety of continuum of care options currently exist to meet the evolving healthcare needs of elderly Floridians as they age. Assisted living facilities (ALFs) encourage social interaction and provide care and services to seniors who cannot live independently. Nursing homes deliver more intensive medical care to patients with a range of functional and mental disabilities requiring 24/7 supervision but not hospitalization. Home and community-based services (HCBS) provide seniors the opportunity to receive health and personal care services in their own homes through aging in place methods.

Even though different formal care options exist for elderly residents, restricting factors such as waitlists, excessive expenses, and budget constraints can limit access to care. As a result, family caregivers serve a crucial, yet often overlooked, role in the state's long-term care system. Some 2.9 million family caregivers in Florida spend an average of 23.7 hours per week providing care for family members without receiving compensation. The amount of services provided equates to 2.4 billion hours of unpaid care, totaling \$31 billion in economic costs and foregone earnings each year.

Given the long-term nature of the different care options, paying for these programs can quickly become expensive. Total U.S. spending on long-term services and supports reached \$426.1 billion in 2019. Public sources paid for a majority of this total spending, with Medicaid comprising the largest source of funding at around \$182.8 billion, 43 percent of the nation's total. In the absence of public programs, individuals and their families often resort to out-of-pocket spending, which can quickly deplete family resources.

When analyzing the breakdown of Medicaid long-term care expenditures in Florida, more expenditures are directed toward institutional settings than home and community settings. Florida Medicaid expenditures for institutional settings rose from \$3.3 billion to \$4.3 billion between 2013 and 2018. For home and community settings, total spending rose from \$1.8 billion to \$2.5 billion over the same period. According to the latest available data, the state of Florida only allocates around 37.1 percent of total long-term care spending to HCBS.

Measuring quality is essential given the significant public investment in long-term services and supports. Arriving at an agreed-upon definition of what constitutes quality, however, proves difficult due to the various settings where services are provided. Nursing homes have a long history with quality of care measures but do not readily incorporate quality of life metrics. For HCBS, cross-state variation in waiver programs creates conceptual and practical challenges for measuring quality.

As the state of Florida emerges from the COVID-19 pandemic and confronts the impending aging population, it has become increasingly critical to promote safe, cost-effective, and quality-oriented methods of meeting the rising healthcare needs of older Floridians. Home and community-based services offer policymakers a way to maximize positive health outcomes and minimize taxpayer costs while ensuring dignity in aging.

Florida TaxWatch analyzed the potential safety benefits, fiscal savings, and quality outcomes from expanding HCBS and found the following:

- Home and community-based settings are a safer alternative to minimize physical risk. Between March and July 2020, **only two percent of HCBS residents nationwide contracted COVID-19** compared to nursing homes (37 percent) and assisted living facilities (14 percent).
- When considering actual mortality, **death rates among HCBS residents nationwide were less than one percent** between March and July 2020, compared to nursing homes (11 percent) and assisted living facilities (five percent).
- The cost of providing care in a home setting rather than in a residential setting would potentially generate more than **\$745 million in fiscal savings annually**, before adjusting for inflation.
- Assuming the current waitlist of Florida's state-funded HCBS program (e.g., Community Care for the Elderly Program), **a one percentage point decrease in the waitlist** would generate **\$63.7 million in cost savings for Florida's taxpayers**.
- Addressing uncompensated care among informal family caregivers could yield **more than \$30 billion in annual economic benefits** by reducing extra medical expenses and foregone earnings.
- Past empirical studies show that individuals who transitioned from institutional to home settings reported significant improvements in quality of life and care. **Overall life satisfaction rose 16.9 percentage points in the first year** among patients, and **satisfaction with care and living arrangements rose by 11.7 and 30.5 percentage points, respectively**.
- Among transitioned patients, there was a statistically significant **reduction in re-institutionalization within 180 days** and a **lower risk of hospitalization**.

Efforts by the federal government to enhance and expand HCBS provision across the nation—primarily through the American Rescue Plan Act (ARPA)—constitute a valuable step in addressing the long-term care needs of the future. Florida is set to receive more than \$1.1 billion in enhanced federal funds to develop and/or expand HCBS programs; however, the state's proposed spending plan does not address the waitlists for elderly populations or uncompensated care among family caregivers.

To yield the greatest return on investment for incoming federal funds, and to expand the value of HCBS, Florida TaxWatch recommends the following to policymakers:

- Expand the use of HCBS by reducing waitlists to state-funded HCBS programs (e.g., the Community Care for the Elderly or Home Care for the Elderly) and by improving access through the Medicaid 1915(b)/1915(c) waiver.
- Identify and standardize quality measures for HCBS that incorporate metrics involving both quality of life and quality of care. Ensure such quality metrics are readily available to families and potential long-term care recipients.
- Conduct empirical studies to measure the direct relationship between HCBS usage and quality outcomes.
- Recognize and support the role that family caregivers serve in providing long-term care to family members. Integrate informal caregiving into any comprehensive plan to improve HCBS usage in Florida.

Given the expected growth in Florida's elderly population, expanding the amount of available resources across the continuum of care will prove imperative for Florida's future growth and prosperity.

Introduction

The demographic transformation of the U.S. is underway and accelerating at a quickening pace. As of the most recent U.S. Census estimates in 2020, there are around 54.1 million individuals over the age of 65 in America, representing 16.5 percent of the nation's total population.¹ Over the next four decades—between 2020 and 2060—the number of adults older than 65 is expected to climb by 75 percent from 54.1 million to 94.7 million people.² Along the way, the nation will reach several demographic milestones. The year 2030 will signal a demographic turning point as all Baby Boomers will be older than 65, meaning one in every five Americans will be of retirement age.³ A few years later, those over 65 are projected to outnumber children under 18 for the first time in U.S. history.⁴

Mirroring the nation's demographic trends, Florida will likewise experience rapid growth in its 65 and over population. Based on projections, Florida's elderly population will increase from about 4.4 million in 2020 to more than 6.7 million by 2040.⁵ Even though the state's overall population is expected to grow 22.0 percent over the two decades, Florida's 65 and older population is anticipated to outpace the state average and grow by 52.1 percent over the same period.⁶ More than any other age group, older Floridians will represent the largest category of population growth in the decades ahead.⁷ Furthermore, due to constant inbound migration from other states, especially among retirees, Florida ranks second in the U.S. for the percent of the population over 65—a trend and ranking that will only grow over time as additional individuals age and relocate to Florida.⁸

The future implications of Florida's rapidly aging population are numerous and diverse, affecting all levels of government and the state's economy. Older Floridians contribute more than 48 percent—or \$505 billion—of the state's total Gross Domestic Product (GDP), interact with more than 6.3 million jobs, and generate close to \$35 billion in state and local taxes annually.⁹ As such, any demographic changes would inevitably affect Florida's economic growth and fiscal sustainability. Perhaps most obvious and well-studied, the healthcare field will witness some of the most consequential outcomes. An aging population will increase the demand for long-term services and supports (LTSS) dealing with chronic conditions, physical or cognitive impairments, and basic daily assistance. Not only will an older population require different forms of healthcare services, but the financial cost to meet these needs will rise in tandem.

Long-term impacts stemming from an aging demographic were well-known before COVID-19. The pandemic, however, added a new element for consideration by elevating the physical dimension of care for LTSS. The proximity between patients at various residential settings led to higher risks of infection and subsequent mortality. Based on federal and state data, more than 186,000 LTSS residents and staff around the nation have died due to COVID-19.¹⁰ In Florida specifically, there have been around 11,500 deaths in LTSS facilities, comprising 31 percent of the state's total deaths due to COVID-19.¹¹ Compounding the issue even more, the mortality figures do not account for the added psychological and emotional trauma of social isolation that many residents have had to endure throughout the pandemic. Even though the physical risks primarily affect the vulnerable residents, there are additional harms to family members and the community.

1 U.S. Census Bureau, 2019 American Community Survey (ACS) 1-Year Estimates, Accessed on Oct. 7, 2021.

2 U.S. Census Bureau, "Demographic Turning Points for the United States: Population Projections for 2020 to 2060," Feb. 2020.

3 Note: According to the Social Security Administration (SSA), depending on the year in which an individual was born, the full (normal) retirement age to claim full benefits differs. For Baby Boomers born between 1946 and 1964, the full retirement ranges from 66 to 67. In certain U.S. Census Bureau publications, however, age 65 is still used as a relative benchmark for retirement age.

4 U.S. Census Bureau, "Older People Projected to Outnumber Children for First Time in U.S. History," Mar. 13, 2018.

5 Florida Demographic Estimating Conference, March 2021 and the University of Florida, Bureau of Economic and Business Research, Florida Population Studies, Bulletin 190, June 2021.

6 Ibid.

7 The Florida Legislature Office of Economic and Demographic Research, Presentation: Florida's Economic Future & Impact of Aging, Mar. 17, 2014.

8 Kaiser Family Foundation (KFF), Population Distribution by Age: Table for 2019, Accessed on Oct. 7, 2021. Note: Maine is the number one state in the nation for percent of residents over the age of 65.

9 AARP, The Longevity Economy Outlook: Florida, Oct. 2020.

10 Kaiser Family Foundation (KFF), State COVID-19 Data and Policy Actions: COVID-19 Long-Term Care Facilities, Oct. 2021. Accessed Oct. 8, 2021.

11 Ibid.

The convergence of an aging population, its economic and fiscal effects, and the pandemic’s spotlight on physical risk has created a renewed sense of urgency for pursuing safe and cost-efficient methods to ensure Florida is meeting the LTSS needs of its oldest residents and will continue to meet them in the foreseeable future. Home and community-based services (HCBS) offer Florida policymakers, communities, and families a unique opportunity to innovate and address these short-run and long-term challenges with an acute focus on access to care, cost-efficiency, and quality outcomes. Florida TaxWatch undertakes this report to review the continuum of care options available for Florida’s oldest residents, explore the importance of funding and quality, and analyze the value of expanding HCBS throughout the state.

Continuum of Care Options

Continuum of care refers to a comprehensive approach to providing continual care that adjusts to the evolving healthcare needs of elderly individuals as they age. As individuals grow older, the specific healthcare services needed and the setting in which they receive the assistance may differ depending on the progression of chronic conditions and other physical or cognitive ailments. For example, the medical needs of an independent-living individual who needs personal care help are vastly different from those of a nursing home resident who struggles with severe dementia. As a result, continuum of care options seek to provide the most appropriate treatment at the time and ensure the variety and intensity of care rises in conjunction with patients as they continue to age. Even though there is a variety of different continuum of care options for individuals and their families, several options are highlighted in this section.

Nursing Homes

Nursing homes—also known as skilled nursing facilities—are designed to serve individuals who require full-time medical supervision and possess a range of functional disabilities, mental conditions, or chronic illnesses.¹² These facilities often provide the highest level of medical care available to seniors who do not require hospitalization but need advanced medical assistance. As a result of the heightened need for specialized care, nursing homes have medically certified professional staff on site to provide 24-hour service. Nursing homes provide various medical and personal care services, including but not limited to:

- Palliative and preventative long-term care, including infectious disease control;
- Rehabilitative services involving speech, occupational, physical, or cognitive therapy;
- Prescription medication administration;
- Provision of daily meals;
- Emergency or routine dental services; and
- Assistance with activities of daily living (ADLs), including feeding, dressing, toileting, and bathing.¹³

Across the U.S., there are roughly 15,500 nursing homes with approximately 1.3 million residents—84 percent are over the age of 65 and two-thirds are women.¹⁴ Most adults who reside in nursing homes often suffer from multiple comorbidities, especially dementia, and require advanced nursing care throughout the day. Due to the intensity of services involved, nursing home costs are often expensive for residents and their families. Based on Genworth’s Cost of Care survey, the nationwide median annual cost for a private room at a nursing home facility is \$105,850 in 2020.¹⁵

In Florida, there are approximately 690 licenses nursing homes with approximately 84,450 beds at a given time.¹⁶ By occupancy, there are an estimated 70,149 residents in nursing homes across the state (roughly an 83 percent occupancy

¹² National Institute on Aging (NIH), “Residential Facilities, Assisted Living, and Nursing Homes,” May 1, 2017. Accessed on Oct. 12, 2021.

¹³ U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality, “Long-Term Care for Older Adults: A Comparative Effectiveness Review of Institutional versus Home and Community-Based Care,” Dec. 20, 2011.

¹⁴ National Academy of Medicine, “Reimagining Nursing Homes in the Wake of COVID-19,” Sept. 21, 2021.

¹⁵ Genworth, Cost of Care Survey: 2020, Dec. 2, 2020.

¹⁶ Florida Health Care Association (FHCA), “Facts About Long Term Care in Florida,” Accessed on Oct. 12, 2021.

rate).¹⁷ It should be noted that current figures may not reflect the impact of COVID-19 on occupancy. The average length of stay for Medicare patients with short rehabilitative stays is around 33 days, and the average length of stay for longer term Medicaid and private pay patients is around 386 days, on average.¹⁸ Compared to the national median, nursing home costs within Florida are higher on average, reaching a median annual cost of \$117,804 in 2020 for a private room.¹⁹ Given the intensive use of healthcare resources, nursing homes typically represent the most expensive option of continuum of care for prospective long-term care patients.

Assisted Living Facilities (ALFs)

Assisted living facilities (ALFs) provide care and supervision to older individuals who can no longer live independently; however, the level of personal or medical assistance is not as intensive as in a nursing home setting.²⁰ These ALFs are typically set up in such a way to encourage social interaction and intellectual stimulation among individuals. For example, residents at ALFs often live in their own apartments while sharing common space and have access to a variety of amenities that encourage overall wellness. The reduced need for intensive medical intervention means there are fewer specialized medical staff present and fewer medical technologies available on site. Assisted living facilities generally provide some of the following services to their residents:

- Social and recreational activities;
- Prescription medication management;
- Housekeeping and laundry services;
- Exercise, health, and wellness programs;
- Meals and dining services; and
- Assistance with ADLs.²¹

According to the National Center for Health Statistics, there are roughly 29,000 ALFs in the U.S. with nearly one million beds available to residents.²² As of the latest national statistics, there are more than 811,000 residents who take part in these residential care communities, maintaining an occupancy rate around 82 percent.²³ Since many ALFs do not provide the same level of personal or medical care found in nursing homes, the respective costs for residents and their families are lower as a result. According to Genworth's survey, the median annual cost for a private room at ALFs is around \$51,600 in 2020.²⁴ This amount is about 51 percent less expensive than the annual median cost for nursing home residents, as detailed previously.²⁵ The median length of stay for residents is around 22 months, and roughly 60 percent of residents will eventually move out to transition into nursing homes due to worsening conditions.²⁶

In the state of Florida, there are 3,080 licensed ALFs, representing approximately 106,100 beds.²⁷ Assisted living residents in Florida often do not possess as severe comorbidities as residents in nursing homes; however, more than 46 percent still struggle with Alzheimer's disease or other forms of dementia.²⁸ Activities of daily living are another area where residents often

17 Kaiser Family Foundation (KFF), "Total Number of Residents in Certified Nursing Facilities," Accessed Oct. 12, 2021.

18 Florida Health Care Association (FHCA), "Facts About Long Term Care in Florida," Accessed on Oct. 12, 2021.

19 Genworth, Cost of Care Survey: 2020, Accessed on Oct. 12, 2021.

20 AARP, "Finding the Right Long-Term Care for Your Loved One," Jan. 13, 2020.

21 National Institute on Aging (NIH), "Residential Facilities, Assisted Living, and Nursing Homes," May 1, 2017. Accessed on Oct. 12, 2021.

22 National Center for Health Statistics, "Residential Care Communities," Accessed on Oct. 12, 2021.

23 Ibid.

24 Genworth, Cost of Care Survey: 2020, Dec. 2, 2020.

25 To find this cost difference, Florida TaxWatch compared the difference in price between nursing homes (\$105,850) and assisted living facilities (\$51,600). The two cost estimates represent the national annual median for 2020 according to Genworth's Cost of Care survey.

26 American Health Care Association (AHCA) and National Center for Assisted Living (NCAL), "Assisted Living: Facts and Figures," 2018. Accessed on Oct. 12, 2021.

27 Florida Health Care Association (FHCA), "Facts About Long Term Care in Florida," Accessed on Oct. 12, 2021.

28 American Health Care Association (AHCA) and National Center for Assisted Living (NCAL), "Fast Facts: State Profile for Assisted Living - Florida," 2018. Accessed on Oct. 12, 2021.

require some additional assistance with more than half of residents needing help with bathing, walking, and dressing.²⁹ Based on cost estimates, the median annual cost for a private room at an ALF is around \$44,400 in 2020.³⁰ This amount is approximately 62.3 percent lower than the median annual price for a nursing home room in Florida.³¹ When comparing median prices, ALFs present a less expensive continuum of care option relative to nursing homes, but they can still be rather expensive options for many families.

Home and Community-Based Services (HCBS)

Home and community-based services (HCBS) provide elderly individuals with the opportunity to receive health and personal care services in their own home or community setting.³² For those residents who cannot, or do not desire receiving care in a facility setting, HCBS offer a preferable alternative to allow aging in place.³³ Different HCBS programs can address the diverse needs of people with varying levels of functional limitations and medical requirements. Formal caregivers include “personal care aides,” who provide a range of assistive services around the household, and “home health aides,” who may perform medical duties like checking vital signs or monitoring mental condition.³⁴

Some home health agencies might provide nursing and rehabilitative services to individuals who desire to be at home but are not well enough to stay home alone.³⁵ In general, the services that HCBS can provide include, but are not limited to:

- Assistance with ADLs like eating, bathing, toileting;
- Home meal deliveries;
- Transportation;
- Home safety assessments;
- Homemaker and chore services; and
- Physical and occupational therapy.³⁶

According to the Kaiser Family Foundation, there are more than 2.5 million HCBS enrollees around the nation who are covered through optional Medicaid state waivers,³⁷ and nearly 1.2 million who receive optional personal care services through their state.³⁸ Throughout the U.S., the median annual cost for in-home care through home health aides is \$46,176 in 2020 according to the Genworth Cost of Care Survey.³⁹ In Florida, the median annual price for HCBS—as proxied by the average price for a home health aide—is around \$43,290 in 2020.⁴⁰ This amount is roughly 6.3 percent less expensive than the national average and is also a less expensive option than nursing home and ALF options described previously. Although HCBS do not preclude the possibility of participants moving on to a nursing home facility at a later point, HCBS provide an ideal, cost-effective alternative for aging in place.

29 American Health Care Association (AHCA) and National Center for Assisted Living (NCAL), “Fast Facts: State Profile for Assisted Living - Florida,” 2018. Accessed on Oct. 12, 2021.

30 Genworth, Cost of Care Survey: 2020, Dec. 2, 2020.

31 To find the cost difference, Florida TaxWatch compared the difference in price between nursing homes in Florida (\$117,804) and assisted living facilities in Florida (\$44,400).

32 Centers for Medicare & Medicaid Services (CMS), Home & Community Based Services, Accessed on Oct. 13, 2021.

33 Ibid.

34 AARP, “Finding the Right Long-Term Care for Your Loved One,” Jan. 13, 2020.

35 Ibid.

36 Centers for Medicare & Medicaid Services (CMS), Home & Community Based Services, Accessed on Oct. 13, 2021.

37 A Medicaid waiver allows the federal government to waive rules that usually apply to a state’s Medicaid program. The intention is to allow states to accomplish certain goals, such as reducing costs, expanding coverage, or offering additional services to target populations. Under traditional Medicaid, states are not required to provide HCBS, but state waivers allow them to expand these services within the state.

38 Kaiser Family Foundation (KFF), “Medicaid Home and Community-Based Services Enrollment and Spending,” Feb. 4, 2020.

39 Genworth, Cost of Care Survey: 2020, Dec. 2, 2020. Note: The calculation assumes home health aides work an average of 37 hours per week. The assumption is based on the average number of hours worked by home health aides according to the U.S. Census Bureau, Current Population Survey (CPS), 2021 Annual Social and Economic (ASEC) Supplement.

40 Genworth, Cost of Care Survey: 2020, Dec. 2, 2020. Note: The calculation assumes home health aides work an average of 37 hours per week. See footnote above for assumption basis.

The state of Florida maintains several programs that provide HCBS to elderly individuals, including the Community Care for the Elderly (CCE), Home Care for the Elderly (HCE), and the Alzheimer Disease Initiative (ADI).⁴¹ Administered by the Florida Department of Elder Affairs, these state-funded programs provide an array of home and community services, including adult day care, home-delivered meals, chore assistance, home health aide, personal care, and more to functionally impaired elderly individuals.⁴² The HCE program also provides a basic subsidy of \$160 for all program participants to be used for medical supplies, home nursing, and some other services to maintain an individual at home.⁴³ These programs seek to enable individuals to live in the least restrictive environment that aligns with their preferences and needs. Compared to Medicaid funded HCBS, these programs are primarily funded by state general revenue and provide services to some 72,000 elderly individuals.⁴⁴ Due to a mixture of high demand and budgetary constraints, there is currently a waitlist for state-funded HCBS exceeding 85,500 people as of September 2021.⁴⁵

The state of Florida also provides HCBS to Medicaid recipients who qualify and enroll in the state's long-term managed care plan.⁴⁶ Managed care plans offer residents services ranging from adult companion care and homemaker services to personal care and medication administration. Many individuals who first enter the state's long-term care system through the state-funded CCE program are eventually deemed eligible to receive HCBS through Medicaid. In the Fiscal Year (FY) 2019-2020, individuals spent an average of 3.8 months in the CCE program before becoming eligible and transitioning to the state's Medicaid long-term care program.⁴⁷ As of September 2021, there were around 76,650 elderly individuals receiving HCBS through the state's Medicaid long-term managed care plan.⁴⁸

Informal Family Caregiving

Even though there are a variety of care options available for elderly residents, restricting factors such as waitlists, excessive costs, and budget constraints can limit families in their ability to secure formal care for loved ones. Some families, for example, may be unable to afford a home health aide or place someone in a nursing home. Oftentimes the onus for caregiving then gets placed on family members who do not receive formal pay for their services.⁴⁹ Family caregivers spend an average of 23.7 hours per week providing care for their family members and help with activities such as bathing, dressing, transporting, and managing medication.⁵⁰ In many situations, these family members must also take time off from work to care for their relatives and endure many physical, emotional, and financial hardships as a result. Based on prior research, around one-fifth of family caregivers have left their jobs to care for family, while another one-fifth have had to cut back to part-time work.⁵¹

The combination of high out-of-pocket caregiving expenses and foregone earnings has a sizeable economic impact. In 2019, estimates suggested that across the nation, family caregivers provided 34 billion hours of care for adults with health limitations—a figure that equates to an economic value of more than \$470 billion.⁵² The same study found that Florida's 2.9

41 The Florida Department of Elder Affairs provides additional state-funded programs, such as the Local Services Programs (LSP), Respite Care for Elders Living in Everyday Families (RELIEF), Professional Guardians (OPPG); however, for this report, only three programs are highlighted.

42 Department of Elder Affairs, "2020 Summary of Programs & Services," May 5, 2021. https://elderaffairs.org/wp-content/uploads/2020_SOPS_web.pdf

43 Department of Elder Affairs, "Home Care for the Elderly (HCE) Program," May 4, 2021.

44 Office of Program Policy Analysis and Government Accountability (OPPAGA), "Department of Elder Affairs: State-Funded Home and Community Services," 2021.

45 Department of Elder Affairs, "Statewide Analysis Accessed Prioritized Consumer List – Total by Assessed Rank Level and Program As of 9/27/2021," Accessed on Oct. 20, 2021. https://fcoa.starchapter.com/images/other/waitlistreport_092021.pdf

46 Note: The state's long-term managed care plan is administered through a joint 1915(b)/1915(c) waiver, which allows the state of Florida to provide HCBS through a managed care model. This particular waiver is explained in greater detail later in the report. Source: Department of Elder Affairs, 2020 Summary of Programs and Services, Jan. 2020.

47 Office of Program Policy Analysis and Government Accountability (OPPAGA), "Department of Elder Affairs: State-Funded Home and Community Services," 2021.

48 Agency for Health Care Administration (AHCA), SMMC LTC Enrollment by County/Plan Report (as of Sept. 30, 2021), available at http://ahca.myflorida.com/Medicaid/Finance/data_analytics/enrollment_report/index.shtml (last visited Oct. 19, 2021).

49 AARP Policy Institute, "Valuing the Invaluable: 2019 Update – Charting a Path Forward," Nov. 2019.

50 AARP and National Alliance for Caregiving, 2020 Report: Caregiving in the U.S., May 2020.

51 Ibid.

52 AARP Policy Institute, "Valuing the Invaluable: 2019 Update – Charting a Path Forward," Nov. 2019.

million family caregivers provided care to around 2 million family members without receiving compensation. The amount of services provided amounted to 2.4 billion hours of unpaid care, totaling around \$31 billion in economic costs.⁵³ Since many of these services were not formally reimbursed through government programs or offset by income gains, these family services are subsequently classified as uncompensated care. Access to HCBS, or the lack thereof, has important secondary effects on the economy beyond what may be readily apparent. For this reason, addressing the contributing factors that reduce access to formal care is of economic and fiscal importance as well.

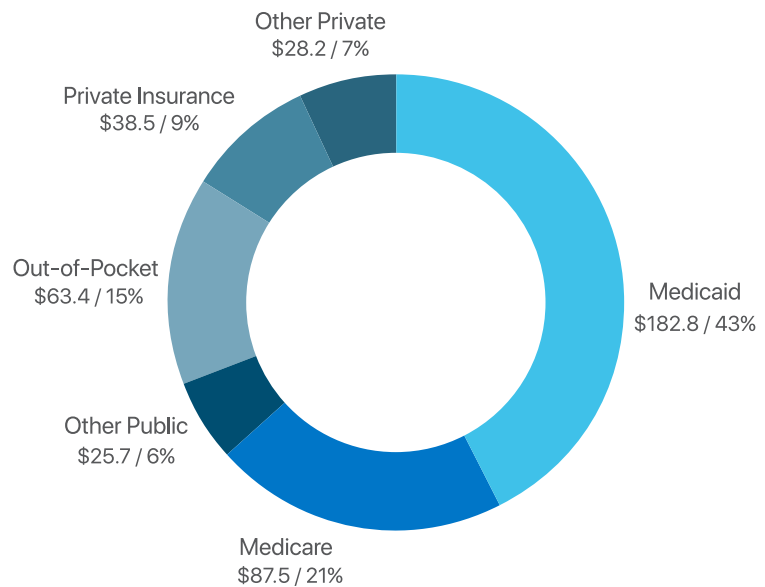
Funding for Long-Term Care

As demonstrated by the continuum of care options outlined in the previous section, LTSS encompass a broad array of settings and services that assist individuals over an extended period of time. Given the long-term nature of services, paying for these programs can quickly become expensive, exceeding what many families may be able to afford on their own. As such, LTSS spending is financed by a variety of public and private sources; however, public sources pay for a majority of LTSS spending in the U.S.⁵⁴

Based on data compiled from the Congressional Research Service (CRS), total U.S. spending on LTSS reached \$426.1 billion in 2019, equaling about 13.3 percent of the total \$3.2 trillion spent on personal health care during the year.⁵⁵ These payments went to services provided in skilled nursing facilities, other congregate settings, and home and community-based locations. It is important to note that since the estimates only incorporate formal figures on LTSS and do not consider uncompensated care provided by family caregivers, the aggregate amount likely underestimates the true magnitude of spending.⁵⁶

Public sources paid for a majority of LTSS in the U.S. (69.5 percent) with Medicaid comprising the largest source of funding at around \$182.8 billion in 2019, equating to about 43 percent of the national total (See Figure 1). Medicare formed the second-largest public payer, accounting for \$87.5 billion in spending, or 20 percent of the national total. Although a relatively small portion, other public sources, including the Veterans Health Administration (VHA), contributed \$28.2 billion in spending.⁵⁷

FIGURE 1. U.S. LONG-TERM SERVICES AND SUPPORTS SPENDING
BY PAYER / 2019



Source: Congressional Research Service (2021)

53 AARP Policy Institute, "Valuing the Invaluable: 2019 Update – Charting a Path Forward," Nov. 2019.

54 Congressional Research Service (CRS), "Who Pays for Long-Term Services and Supports?" Aug. 5, 2021.

55 Ibid.

56 Ibid.

57 Ibid. Note: The CRS analysis uses compiled data from the National Health Expenditure Account (NHEA) within the Centers for Medicare & Medicaid Services, Office of the Actuary.

In the absence of public funding sources for LTSS, individuals and their families resort to private sources for funding. According to the 2019 data, private sources accounted for 30.5 percent of total LTSS expenditures in the nation, with out-of-pocket spending representing the largest category at \$63.4 billion in total spending—about 15 percent of the total. Private insurance was second, providing \$38.5 billion or around 9 percent of total LTSS expenditures. Philanthropic and other private grants formed the bulk of the remaining private sources, contributing \$28.2 billion in spending.⁵⁸

Contrary to what is commonly believed, Medicare coverage of LTSS for seniors is extremely limited. According to the Centers for Medicare & Medicaid Services (CMS), Medicare does not cover non-skilled personal care, such as help with activities of daily living, if that is the only form of care needed for individuals.⁵⁹ Instead, Medicare policies primarily cover acute and post-acute medical care, including rehabilitative services rendered in skilled nursing or home health settings following major surgery.⁶⁰ Even then, Medicare benefits are capped in duration and require individuals to pay for the entirety of the costs beyond 100 days.⁶¹ With limited coverage under Medicare and few affordable private insurance options for families, Medicaid serves as the primary source of funding for LTSS across the nation.

Medicaid is a joint federal-state health insurance program and the largest source of funding for LTSS in states. Federal law stipulates that states must provide skilled nursing services to individuals who require nursing facility care, and states are prohibited from limiting access to these facilities. Although not required, states have the option to expand access to LTSS through HCBS. Medicaid waivers are the primary way that states can expand eligibility and offer HCBS to seniors and people with disabilities.⁶² By maintaining HCBS waivers, states can cap enrollment, often resulting in waiting lists when the number of people seeking services is larger than the number of available slots.

In Florida, the Statewide Medicaid Managed Care (SMMC) program is the state's integrated managed care program for providing Medicaid enrollees with mandatory and optional services. Within the SMMC program is the Long-Term Care Managed Care (SMMC – LTC) that provides services to frail elderly individuals in nursing facilities or home and community-based settings.⁶³ The state of Florida maintains a joint Section 1915(b)/1915(c) federal Medicaid waiver that authorizes the use of HCBS in a managed care delivery model.⁶⁴ As of September 2021, there were 121,908 residents in Florida enrolled in the state's SMMC – LTC program, including 76,650 individuals (62.9 percent) enrolled in HCBS and 45,258 individuals (37.1 percent) enrolled in non-HCBS settings, such as nursing homes.⁶⁵

When analyzing the breakdown of Florida's Medicaid LTSS expenditures by setting, it becomes apparent that most spending in Florida is directed toward institutional care settings. Between 2013 and 2018, Medicaid expenditures for institutional LTSS rose from about \$3.3 billion to \$4.3 billion—about a 29.7 percent increase (See Figure 2). At the same time, Medicaid expenditures for LTSS in home and community-based settings rose from about \$1.8 billion to \$2.5 billion—approximately a 37.6 percent increase. Even though HCBS spending rose by a higher percentage, its total spending still comprises a smaller proportion of total state LTSS spending when compared to institutional settings. Based on the latest available data from CMS, the state of Florida allocates around 37.1 percent of total LTSS spending to HCBS.⁶⁶

58 Congressional Research Service (CRS), "Who Pays for Long-Term Services and Supports?" Aug. 5, 2021.

59 Centers for Medicare and Medicaid Services, "Your Medicare Coverage: Long-Term Care," Accessed Oct. 18, 2021.

60 U.S. Department of Health and Human Services, "Long-Term Care Services and Supports for Older Americans: Risks and Financing, 2020 ASPE Research Brief," Jan. 2021.

61 U.S. Department of Health and Human Services, "Long-Term Care Services and Supports for Older Americans: Risks and Financing, 2020 ASPE Research Brief," Jan. 2021.

62 Kaiser Family Foundation (KFF), "Medicaid and Long-Term Services and Supports: A Primer," Dec. 2015.

63 Department of Elder Affairs, "Statewide Medicaid Managed Care Long-Term Care Program," Accessed on Oct. 18, 2021.

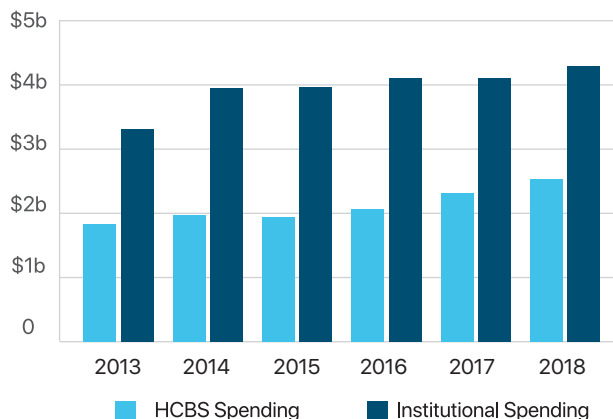
64 The Section 1915(c) waiver authorizes the state to provide HCBS as an alternative to institutional care for specific populations, and the Section 1915(b) waiver allows the state to do so under a managed care approach. For more information, see Centers for Medicare & Medicaid Services (CMS), "State Medicaid Plans and Waivers."

65 Agency for Health Care Administration (AHCA), SMMC LTC Enrollment by County/Plan Report (as of Sept. 30, 2021), available at http://ahca.myflorida.com/Medicaid/Finance/data_analytics/enrollment_report/index.shtml (last visited Oct. 19, 2021).

66 Centers for Medicare & Medicaid Services (CMS), "Medicaid Long Term Services and Supports Annual Expenditures Report: Federal Fiscal Years 2017 and 2018," Jan. 7, 2021.

Unlike a fee-for-service (FFS) service arrangement whereby Florida's Agency for Health Care Administration (AHCA) pays providers directly for each service rendered to an enrollee, AHCA contracts with privately managed care plans for coordination and payment of LTSS for Medicaid enrollees. These privately managed care plans receive a set payment per enrollee per month—known as a capitated rate—based on the number of recipients enrolled in the managed care plan.⁶⁷ For nursing homes, assisted living facilities, and HCBS, Medicaid reimburses for services that are rendered by licensed, Medicaid-participating providers within the managed care plan. For example, a Medicaid-participating home health agency would provide services to beneficiaries and receive a capitated payment each month for the services.⁶⁸

FIGURE 2. MEDICAID LTSS EXPENDITURES IN FLORIDA, HCBS AND INSTITUTIONAL SETTINGS
IN \$ BILLIONS / 2013–2018



Source: Centers for Medicare & Medicaid (CMS), Medicaid LTSS Expenditures Reports

In addition to LTSS funding that flows from Medicaid dollars, public funding for LTSS can also derive from state general revenue and enter the system through Florida's aging network. The Department of Elder Affairs oversees and manages 11 Area Agencies on Aging (AAA) that in turn coordinate with one or more Community Care for the Elderly Lead Agencies across the state. These lead agencies contract with direct service providers to serve elders and provide various personal care services.⁶⁹ Based on state appropriations for FY 2021-2022, Florida spends around \$174.5 million in general revenue to fund the various programs and activities throughout the aging network, providing public resources for home and community-focused activities, such as the CCE and HCE programs.⁷⁰

Defining and Measuring Quality for Long-Term Care

Given the significant public investment in the delivery of LTSS across the nation, and the impending growth in elderly populations over the coming years, ensuring the delivery of high-quality services becomes a core goal for beneficiaries, families, providers, and policymakers. Arriving at a standardized, consensus view of what exactly constitutes quality for long-term care proves a difficult task given the variation in LTSS programs across states and the range of settings where services may be provided. Nevertheless, understanding what factors contribute to quality health outcomes among recipients has an important bearing on directing the future use of public funding to maximize positive health benefits and minimize cost inefficiencies.

Due to the nation's extensive history with nursing home usage, federal quality standards exist for skilled nursing facilities across the U.S. with oversight from the CMS. Nursing homes in Florida receive an overall quality rating using the CMS Five-Star Rating System, which is based on three domains: health inspection data; staffing ratios; and quality measures of resident care.⁷¹ The last category—quality measures of resident care—is itself comprised of fifteen additional subcategories

67 Agency for Health Care Administration, "Florida Medicaid's Covered Services and HCBS Waivers," Accessed Oct. 19, 2021.

68 Ibid.

69 Department of Elder Affairs, "2020 Summary of Programs & Services," May 5, 2021

70 Office of Program Policy Analysis and Government Accountability (OPPAGA), "Department of Elder Affairs: State-Funded Home and Community Services," 2021.

71 Centers for Medicare & Medicaid Services (CMS), "Five-Star Quality Rating System," Oct. 8, 2021.

that analyze the physical and medical needs of short-term and long-term stay residents in nursing homes. Quality measures of resident care include metrics such as the percentage of residents who were given antipsychotic medication and the percentage of residents whose need for assistance with activities of daily living has increased (for more information and a full list of measures see Appendix A).⁷² After weighting scores in each domain, nursing homes are assigned four individualized star ratings from one to five stars for the following categories, viewable on the CMS Nursing Home Compare website:⁷³

1. Overall Rating;
2. Health Inspection Results;
3. Staffing Levels; and
4. Quality Measure Data (of Resident Care).

Even though defined quality measures exist for nursing homes, several shortcomings limit their effectiveness in conveying patient quality. Although measurable, many of the metrics (e.g., percentage of patients receiving vaccines, given antipsychotic medication, having pressure ulcers, etc.) speak more to patient quality of care and safety. Notably absent, however, are metrics on the quality of life, including but not limited to measures on patient satisfaction and preferences. These quality of life measures are crucial given the documented relationship between higher quality of life experiences and fewer depressive symptoms and comorbidities.⁷⁴ Based on academic studies, the CMS Nursing Home Compare website—designed to provide families with a basic overlook of quality—is also inconsistent at times, not adequately reflecting patient safety and being limited by a lack of general awareness among families.⁷⁵

For home and community-based settings, a principal challenge for defining quality is that state-centric HCBS waiver programs result in substantial cross-state variation, as well as conceptual and practical challenges for measurement.⁷⁶ Most of the current measures to gauge the quality of HCBS revolve around compliance with Section 1915(c) waiver reporting requirements. There are fewer quality measures for service delivery and caregiver support, however.⁷⁷ In the past few years, efforts have been underway to standardize and enhance HCBS quality measures across the U.S. Two examples of these efforts include:

- HCBS Consumer Assessment of Healthcare Providers and Systems (CAHPS) Survey: Measures the experience of care for beneficiaries who use HCBS. There are 19 quality measures that include topics such as patient ratings for staff reliability and helpfulness, personal safety and respect, any unmet needs, recommending services to others, and global ratings for the personal assistance staff.⁷⁸
- National Core Indicators for Aging and Disabilities (NCI – AD): Focus on beneficiaries' reports of their quality of life and health outcomes. Among many other questions, the patient survey determines the percentage of people who enjoy where they live, feel they have control of their life, or whose paid support staff do things the way they want them to be done.⁷⁹

Despite the number of steps that have been taken to improve quality reporting among HCBS in recent years, outstanding gaps and challenges remain. For example, the NCI – AD is a collaborative effort between state Medicaid agencies to gather standardized performance and outcome measures; however, not all states participate.

72 Centers for Medicare & Medicaid Services (CMS), "Design for Care Compare – Nursing Home Five-Star Quality Rating System: Technical Users' Guide," Jan. 2021. <https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandCompliance/downloads/usersguide.pdf>

73 To visit the nursing home compare website, visit <https://www.medicare.gov/care-compare/?providerType=NursingHome&redirect=true>

74 Raes et. al., "The relationship of nursing home price and quality of life," *BMC Health Services Research*. 20, 987 (2020).

75 See, e.g., Brauner et. al., "Does Nursing Home Compare Reflect Patient Safety In Nursing Homes?" *Health Affairs* (2018). Konetzka and Perrillon, "Use of Nursing Home Compare Website Appears Limited by Lack of Awareness and Initial Mistrust of the Data," *Health Affairs* (2016).

76 National Quality Forum, "Quality in Home and Community-Based Services to Support Community Living: Addressing Gaps in Performance Measurement," Sept. 2016.

77 Medicaid and CHIP Payment and Access Commission (MACPAC), "Quality of Home and Community-Based Services," 2021. Accessed Oct. 21, 2021.

78 Centers for Medicare & Medicaid Services (CMS), "Technical Assistance Guide for Analyzing Data from the Consumer Assessment of Healthcare Providers and Systems Home and Community-Based Services (HCBS) CAHPS Survey," Jul. 2021.

79 National Core Indicators – Aging and Disabilities (NCI-AD), "2021-2022 NCI-AD Indicator Crosswalk," Sept. 8, 2021.

Currently, there are only 23 states that participate, not including Florida.⁸⁰ As a result, the ability to effectively define and measure quality for HCBS in the state of Florida remains lacking.

“Until all states report these [quality] indicators, and the CMS has established evidence-based guidance, we cannot be confident there is adequate quality control in Medicaid caregiving services.”

—SENATOR TIM SCOTT, RANKING MEMBER, U.S. SENATE SPECIAL COMMITTEE ON AGING⁸¹

The question, “What is quality?” remains a perennial question for LTSS, especially in light of the impending demographic changes over the coming years. A few takeaways can be gleaned from the existing quality measures for nursing homes and HCBS discussed in this section.

- Quality of care cannot be viewed in isolation from quality of life—both are invaluable for accurately gauging overall outcomes for LTSS, yet too often quality measures focus solely on quality of care or the prevention of abuse.
- Quality measures exist so that families can make informed decisions on what services to receive; however, many families are not aware of such resources, such as the CMS compare website. Therefore, simply measuring quality does not immediately translate into elderly residents and their families understanding the evaluations.
- Once a standardized, comprehensive, and measurable set of quality metrics is incorporated—especially for HCBS—it becomes easier to recognize and reward value rather than simply paying for capitation. In other words, there is a financial incentive to improve quality outcomes for providers when agreed upon quality measures exist to guide public resources. This in turn yields downstream benefits to elderly residents who receive higher quality services.

The Value of Expanding Home and Community-Based Services (HCBS)

As the nation contends with the unrelenting challenges created by the COVID-19 pandemic and confronts the looming challenges associated with a rapidly aging population, it has become imperative to identify and expand effective, cost-efficient methods that meet the long-term healthcare needs of the most vulnerable. Institutional settings for receiving LTSS remain the default for many states given the required coverage under state Medicaid plans; however, over the past two decades, HCBS have emerged as a favorable alternative to better serve individuals’ preferences and save taxpayer dollars.⁸² Nearly 90 percent of elderly adults indicate their desire to remain at home to age in place, and the COVID-19 pandemic has only accelerated this preference among families seeking to minimize infections risks.⁸³

Understanding why expanding HCBS is a worthwhile policy priority for Florida requires deeper analysis into the potential health, economic, and fiscal benefits that HCBS can produce for families, taxpayers, and the state of Florida.

Physical Safety

Quite poignantly, the COVID-19 pandemic exposed and amplified the physical risks of infection in many residential long-term facilities. Published findings in the *Journal of Post-Acute and Long-Term Care Medicine* (JAMDA) found that between March and July 2020, some 37 percent of nursing home residents and 14 percent of assisted living facility residents nationwide

80 National Core Indicators – Aging and Disabilities (NCI-AD), “NCI – AD States,” 2021. Accessed Oct. 21, 2021.

81 U.S. Senate Special Committee on Aging, “Expanding Opportunities for Older Americans: Self-Directed Home & Community-Based Services,” Jun. 2021.

82 Gorges et. al., “A National Examination of Long-Term Care Setting, Outcomes and Disparities among Elderly Dual-Eligibles,” *Health Affairs* 38(7): 1110-1118 (2020). Retrieved from U.S. National Library of Medicine.

83 Capital Caring Health (Reported in GlobeNewswire), “Nearly 90% of Americans Age 50 And Older Want To ‘Age in Place,’” May 10, 2021.

contracted COVID, compared to two percent of HCBS residents.⁸⁴ When it came to actual mortality, death rates among HCBS residents was less than one percent—in contrast to death rates at nursing homes (11 percent) and assisted living facilities (five percent).⁸⁵ In response to heightened health risks, many nursing home facilities barred families from visiting loved ones in an attempt to stem the rapid rise in infections. Even months after vaccines became widely available and safety precautions were put in place, Florida’s nursing home population remains at heightened risk. As of the end of summer 2021, there were between 4.3 and 5.3 positive COVID-19 cases per 100 nursing home residents—about three times the national average.⁸⁶

Based on the available data over the past year, HCBS appear a safer alternative to minimize the physical risk of contracting, and potentially dying from COVID-19. This is not to suggest that all physical risks are eliminated by providing LTSS in home-based settings—certainly many beneficiaries receiving HCBS may still be particularly vulnerable to disease due to existing comorbidities. The risk, however, is substantially lower than in residential settings based on existing medical studies.⁸⁷ The pandemic has also shown the intricate connection between physical safety and social isolation. For many residential facilities, measures were put in place to reduce the spread of contagion, often producing social isolation and loneliness in residents as a byproduct.⁸⁸ In contrast, providing physically safer care in a home setting has the added benefit of potentially minimizing social isolation and loneliness.

Fiscal Savings and Economic Benefits

The choice of where to receive long-term care is a deeply personal one, driven in large part by a mix of medical needs, preferences, and costs. Receiving care in a home or community-based setting rather than in an institutional one is markedly less expensive for many individuals and their families. In Florida, the average monthly payment for a private room in a nursing home was \$9,817 in 2020.⁸⁹ Notably cheaper, the average monthly price for hiring a home health aide (a proxy price for HCBS) was \$3,608 during the same year. The difference in prices yields an individual-level cost savings of around \$74,500 per year for those seeking LTSS.⁹⁰

In addition to saving money for individuals and their families, increased use of HCBS also translates into realized fiscal savings for the state of Florida and taxpayers. If simply considering the cost of providing LTSS to 10,000 Florida residents (See Table 1), the cost of providing care in a home setting rather than in a residential nursing home setting would lead to fiscal savings amounting to \$745 million annually, before adjusting for inflation.⁹¹ It should be noted that this estimate assumes Medicaid covers all the LTSS expenses incurred by the eligible residents.⁹²

TABLE 1. ESTIMATED COSTS FOR LTSS OPTIONS IN FLORIDA

| Setting | Annual Cost Per Person | Cost Per 10,000 People |
|--------------------------|------------------------|------------------------|
| Nursing Home | \$117,804 | \$1,178,040,000 |
| Assisted Living Facility | \$44,400 | \$444,000,000 |
| Home Health Aide (HCBS) | \$43,290 | \$432,900,000 |

Source: Genworth Annual Cost of Care Survey (2020); U.S. Census Bureau, Current Population Survey, 2021 Annual Social and Economic (ASEC) Supplement; Florida TaxWatch Calculations

84 Robison et. al., “Community-Based Long-Term Care Has Lower COVID-19 Rates and Improved Outcomes Compared to Residential Settings,” *Journal of Post-Acute and Long-Term Care Medicine* 22(2): 259-260 (Feb. 2021).

85 Ibid.

86 AARP Public Policy Institute, “AARP Nursing Home COVID-19 Dashboard,” Updated Oct. 14, 2021. Accessed Oct. 21, 2021.

87 Robison et. al., “Community-Based Long-Term Care Has Lower COVID-19 Rates and Improved Outcomes Compared to Residential Settings,” *Journal of Post-Acute and Long-Term Care Medicine* 22(2): 259-260 (Feb. 2021).

88 Abbasi, “Social Isolation—The Other COVID-19 Threat in Nursing Homes,” *JAMA* 324(7): 619-620 (2020).

89 Genworth, *Cost of Care Survey: 2020*, Accessed on Oct. 12, 2021.

90 Ibid.

91 Cost Savings Per 10,000 Floridians = \$1,178,040,000 - \$432,900,000 = \$745,140,000.

92 In reality, Medicaid may cover a portion of provided services with other public programs or out-of-pocket expenses covering the remainder of costs. For illustrative purposes, this calculation assumes Medicaid covers the entirety of costs.

The estimated fiscal savings presented above provide a brief back-of-the-envelope calculation per a set number of Floridians. A much more plausible figure, however, would be the expected cost savings from marginally reducing the HCBS waitlist in Florida and allowing residents to receive LTSS at home rather than in a residential care setting. Assuming the current waitlist of 85,500 individuals for Florida’s state-funded HCBS programs (e.g., Community Care for Elderly program), a one percentage point decrease in the waitlist would be associated with a \$63.7 million cost savings for Florida’s taxpayers.⁹³ Once again, it should be cautioned that actual cost savings may vary widely depending on additional factors, such as individual healthcare needs, length of stay, and availability of caregivers. In the absence of a current, comprehensive Florida HCBS cost savings study, these fiscal savings should be viewed as conservative estimates and a benchmark for future analysis.

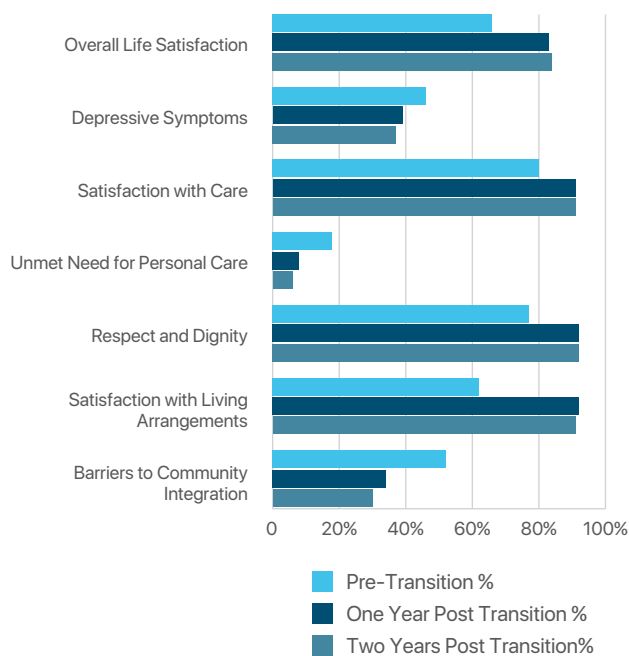
Finally, HCBS provide policymakers and the economy with certain economic benefits. Often overlooked, informal family giving—as discussed before—typically results in uncompensated care for elderly individuals. Family members often take time off work to care for loved ones, which results in foregone earnings and increased expenses. Family caregivers age 50 and older, who leave the workforce and provide care to a family member, lose an average of \$304,000 in lifetime wages and benefits that would have been earned otherwise.⁹⁴ Furthermore, family caregivers reported an average of \$7,242 in out-of-pocket medical expenses every year.⁹⁵ Considering these two factors together—foregone earnings and extra expenses—providing HCBS conceivably allows family caregivers to juggle less between care and work, foregoing less in earnings and allowing more money to be spent in the local economy for non-LTSS related items. Based on the aggregate value of uncompensated care provided in Florida, expanding HCBS can potentially yield economic benefits exceeding \$30 billion annually.⁹⁶

Improved Quality of Life and Care

Granting individuals greater choice on where to receive LTSS shows a discernible impact on quality of life. According to one federal government report analyzing transitions from institutional locations to home and community settings, patients who transitioned reported significant improvements in life satisfaction, better quality of care, and community integration.⁹⁷

Survey responses from the empirical study found that overall life satisfaction rose 16.9 percentage points in the first year (See Figure 3). Satisfaction with care and living arrangements both increased, rising by 11.7 and 30.5 percentage points, respectively, within the first year of transitioning to HCBS. Finally, the percentage of individuals reporting depressive symptoms and barriers to community integration subsequently decreased over the two successive years.

FIGURE 3. QUALITY OF LIFE AFTER TRANSITIONING TO HCBS
IN \$ BILLIONS / 2013–2018



Source: U.S. Department of Health and Human Services (2017)

93 1% of Current Waitlist = 0.01 * 85,000 = 855 individuals. The difference in annual cost per year between a nursing home and a HCBS is around \$74,514. Cost Savings = 855 * \$74,514 = \$63,709,470.

94 AARP Policy Institute, “Understanding the Impact of Family Caregiving on Work,” Accessed Sept. 2021.

95 AARP, “Family Caregivers Spend More Than \$7,200 A Year On Out-of-Pocket Costs,” Jun. 29, 2021.

96 AARP Policy Institute, “Valuing the Invaluable: 2019 Update – Charting a Path Forward,” Nov. 2019.

97 U.S. Department of Health and Human Services, “Report to the President and Congress: The Money Follows the Person (MFP) Rebalancing Demonstration,” Jun. 2017.

Beyond just quality of life indicators, the study also found that participants who opted to move to HCBS settings experienced higher quality of care. Based on the findings, the individuals who went on to receive HCBS had statistically significant reductions in re-institutionalization within 180 days, and there was a lower chance of hospitalization; however, specific quality measures relating to hospitalization and other health care metrics did not exhibit statistical significance.⁹⁸ Given the paucity of empirical studies measuring the direct relationship between HCBS usage and quality of care outcomes, more national and sub-national research is needed to understand the relationship between the two. It is clear, nevertheless, that providing HCBS yields tremendous returns to quality of life by bolstering satisfaction, choice, and dignity for individuals.

Looking Ahead: Federal Opportunity to Expand HCBS

In March 2021, the federal government passed the American Rescue Plan Act (ARPA), which among other things provided an additional ten percentage point increase in federal matching funds to “enhance, expand, and strengthen” HCBS around the country—an estimated \$11.4 billion in value.⁹⁹ Under the ARPA, states can claim the additional ten percentage point increase in the federal medical assistance percentage (FMAP) between the eligible period of April 1, 2021, and March 31, 2022. Although states are afforded wide discretion on what to do with the additional nonrecurring funds, options include expanding HCBS eligibility and access by raising existing income limits, increasing waiver enrollment caps, and reducing waiting lists. States can also potentially increase the scope of covered services or offer supports to caregivers. Regardless of the expenditure category, all HCBS-related funds must be expended by March 31, 2024.¹⁰⁰

According to Florida’s spending plan—submitted to the federal government pursuant to the ARPA requirements—the state anticipates receiving \$1.1 billion in enhanced federal funds to develop and/or expand HCBS programs.¹⁰¹ Initial estimates suggest Florida will save approximately \$453 million in state funds from the ten percentage point increase in the FMAP for HCBS expenditures, between April 1, 2021 and March 31, 2022.¹⁰² Among the provisions within the spending proposal, some proposed activities include providing one-time stipends to providers of HCBS for retention, one-time subsidy payment to the Department of Elder Affairs’ HCE program, and reducing the waitlist for the iBudget waiver—a state Medicaid waiver for individuals with developmental disabilities.¹⁰³ For a more comprehensive breakdown of the proposed spending activities, visit Appendix B. Notably absent from the spending plan, there is no indication that the additional funds will be used to reduce waitlists for HCBS programs serving primarily elderly populations or address uncompensated care from family caregivers.

Although the federal government has granted Florida conditional approval on their HCBS \$1.1 billion spending proposal, the spending must still receive approval from the Florida Legislature before being expended.¹⁰⁴ Since the enhanced funding is nonrecurring, a principal challenge moving forward will be providing direct support to HCBS expansion in Florida while confronting recurring issues that will extend beyond the pandemic. For example, even as the demand for health and personal care services will inevitably rise, there will continue to be a shortage of direct care workers and a lack of formal supports for family caregivers that complicate providing LTSS in the decades ahead.

The practical issues that accompany a rapidly aging population have only been exacerbated by the COVID-19 pandemic and the heightened awareness of the physical risk of infection. With a growing elderly population in Florida, policymakers and stakeholders will increasingly be pressed to expand cost-effective and quality solutions to meet the state’s LTSS needs. An opportunity arises to enable greater aging in place that will require fewer taxpayer dollars and deliver more value and better outcomes to individuals seeking care.

98 U.S. Department of Health and Human Services, “Report to the President and Congress: The Money Follows the Person (MFP) Rebalancing Demonstration,” Jun. 2017.

99 Kaiser Family Foundation (KFF), “How Could \$400 Billion New Federal Dollars Change Medicaid Home and Community-Based Services?” Jul. 16, 2021.

100 Kaiser Family Foundation (KFF), “Potential Impacts of Additional Federal Funds for Medicaid HCBS for Seniors and People with Disabilities,” May 28, 2021.

101 Agency for Healthcare Administration (AHCA), “Home and Community Based Services Spending Plan and Narrative: American Rescue Plan Act of 2021 Section 9817,” Sept. 2021.

102 Ibid.

103 Ibid.

104 Florida Politics, “Florida to get \$1.1 billion boost in Medicaid money,” Oct. 13, 2021.

Conclusions

Similar to demographic trends across the U.S., Florida will encounter a rapid increase in the number of elderly residents requiring long-term care and services. Florida's 65 and older population is anticipated to grow by 52.1 percent over the next two decades from 4.4 to 6.7 million elderly residents. A variety of continuum of care options exists to accommodate the impending rise in long-term healthcare utilization, ranging from nursing homes to home and community-based settings. Not only do these options differ in their public costs and quality outcomes, but the COVID-19 pandemic has spotlighted the importance of physical risk and exposure to infection when considering what long-term settings exist. Due to the projected growth in Florida's elderly population over the coming decades, it will be critical to expand resources across the state's entire continuum of care.

For policymakers in Florida, HCBS have emerged as a cost-effective way to deal with the physical risk associated with COVID-19 and prepare for the demographic changes that will occur. These home and community settings enable aging in place, yielding documented benefits to individual satisfaction, happiness, and dignity. Due to cost differentials between facility-based and home-based settings, there is also a fiscal benefit accruing to taxpayers from expanding HCBS. Based on this report, a one percentage point decrease in the HCBS waitlist in Florida would be associated with a \$63.7 million cost savings for Florida's taxpayers. Furthermore, providing care to 10,000 elderly Floridians through HCBS rather than in institutional settings can potentially save approximately \$745 million annually in public funds. For family caregivers who often provide uncompensated care, expanding HCBS produces economic benefits by reducing the amount of out-of-pocket expenses and foregone earnings that caregivers must endure.

Enhanced federal funding for HCBS in response to the pandemic signifies a continued federal push to meet the nation's LTSS needs increasingly through home and community services. These efforts and additional funds present the state of Florida with an acute opportunity to position the state for a demographic wave of aging. Ultimately, how the state decides to spend the funds on promoting, expanding, and enhancing HCBS will have tremendous implications for the next few decades as aging is intertwined with the dignity of many older Floridians and the fiscal and economic well-being of the state.

Recommendations

1. [Expand the use of HCBS in Florida by reducing waitlists to state-funded HCBS program \(e.g., Community Care for the Elderly or Home Care for the Elderly\) and by improving access through the Medicaid 1915\(b\)/1915\(c\) waiver.](#)

Florida currently spends around 37.1 percent of total LTSS on HCBS throughout the state, even though the U.S. spends more than 56.1 percent of total LTSS expenditures on HCBS.¹⁰⁵ As analyzed throughout this report, expanding the use of HCBS in Florida yields significant economic and fiscal benefits to taxpayers and the state while also improving quality of life outcomes among individuals and their families. Often cited as a potential pitfall of expanding access to HCBS, the “out of the woodwork effect” contends that if access or benefits are too attractive, consumers will come out of the woodwork to take advantage of the opportunity, thereby raising long-run costs. A recent empirical study, however, analyzed two decades worth of aggregate LTSS data and found that states can make significant advances in HCBS expansion without increasing overall long-term services utilization or costs.¹⁰⁶ Making use of additional federal funds made available through the federal ARPA provides an ideal opportunity to expand HCBS.

2. [Identify and standardize quality measures for HCBS in Florida that incorporate metrics involving both quality of life and quality of care. Ensure such quality metrics are readily available to families and potential long-term care recipients.](#)

The tremendous growth in HCBS over the past several decades has prompted continued calls for a standardized set of quality measures for HCBS across the U.S. Since state Medicaid coverage for HCBS is optional and varies considerably between states, deriving a common set of quality measures proves difficult. Nonetheless, several options do exist that expressly measure quality for HCBS. The National Core Indicators for Aging and Disabilities (NCI – AD) is one example that currently provides insights on HCBS quality, but Florida is one state that does not participate in the program. Quality metrics should include both quality of life (e.g., satisfaction and preferences) and quality of care (e.g., hospitalization rates and safety standards). By closing gaps in HCBS quality measures, there can be improved oversight as well as an incentive to improve value among HCBS providers.

3. [Conduct empirical studies to measure the direct relationship between HCBS usage and quality outcomes.](#)

On a national level, there is a dearth of empirical studies that quantitatively measure the direct, causal relationship between HCBS usage and quality outcomes. The variation between state HCBS programs makes it difficult to make these empirical conclusions on an aggregate level. For Florida, however, analyzing how HCBS can potentially influence quality of care and quality of life outcomes will be crucial for understanding the actual health benefit of expanding HCBS.

4. [Recognize and support the role that family caregivers serve in providing long-term care to family members. Integrate informal caregiving into any comprehensive plan to improve HCBS usage in Florida.](#)

In many situations, family caregivers often assume the mantle of responsibility when it comes to providing much-needed medical and personal care to loved ones. In doing so, these family caregivers incur a cost from taking care of others and providing uncompensated care. For Florida, some 2.9 million family caregivers provided 2.4 billion hours of informal care, totaling \$31 billion in economic value.¹⁰⁷ Yet despite the strenuous work and billions in saved taxpayer dollars, many family caregivers do not receive formal support or compensation for their efforts. As the state of Florida considers ways to bolster access to HCBS, improve retention among the direct service workforce, and provide additional supports, the role of family caregivers should also be taken into account.

105 Centers for Medicare & Medicaid Services (CMS), “Medicaid Long Term Services and Supports Annual Expenditures Report: Federal Fiscal Years 2017 and 2018,” Jan. 7, 2021.

106 Berish et. al., “Is There a Woodwork Effect? Addressing a 200-Year Debate on the Impacts of Expanding Community-Based Services,” *Journal of Aging & Social Policy* 31(1):85-98 (2019). Accessed from the National Library of Medicine.

107 AARP Policy Institute, “Valuing the Invaluable: 2019 Update – Charting a Path Forward,” Nov. 2019.

Appendix A

All nursing homes that participate in either the Medicare or Medicaid program must submit periodic resident-level data on various variables, including the health and functioning of residents, services provided, and changes in the resident's status. The data goes into a national database known as the Minimum Data Set (MDS), which the Centers for Medicare & Medicaid Services (CMS) maintains.

For the nursing home Five-Star Rating System, quality measures are based on the performance on 15 metrics. These metrics include nine long-stay measures and six short-stay measures. It should be noted that not all quality metrics measured in the national MDS are used for computing in the Five-Star Rating System. The 15 quality metrics include:

- **Short-Stay Residents**

1. Hospitalization – The percentage of residents who were previously hospitalized prior to nursing home placement and were re-hospitalized (unplanned) within 30 days.
2. Emergency Room – The percentage of residents who within 30 days of nursing home placement had to go to the emergency room for outpatient care.
3. Antipsychotics – The percentage of residents who were given an antipsychotic medication and hadn't previously been given such a medication.
4. Bed Sores – The percentage of residents who have new pressure ulcers (also called bed sores) or who already had them, but they got worse.
5. Independence – The percentage of nursing home residents who showed improvement in their ability to move around independently.
6. Transitions – The rate in which residents were successfully transitioned back to living at home or in the community.

- **Long-Stay Residents**

1. Activities of Daily Living – The percentage of residents whose need for assistance with activities of daily living (i.e., bathing, dressing, eating, using the toilet) has increased.
2. Hospitalization – The number of unplanned hospitalizations that occurred per 1,000 long-stay resident days.
3. Emergency Room – The number of outpatient emergency room visits per 1,000 long-stay resident days.
4. Movement – Percentage of residents whose ability to move about without assistance has become more difficult.
5. Bed Sores – Percentage of high-risk residents who have pressure ulcers (bed sores).
6. Catheters – Percentage of residents who either have or had a catheter inserted and left in within the last seven days.
7. Urinary Tract Infections – Percentage of residents, within the last 30 days, who had a urinary tract infection.
8. Falls – Percentage of residents, within one full calendar year, that had a major injury due to a fall.
9. Antipsychotics – Percentage of residents who were given an antipsychotic medication.

Appendix B

HCBS Capacity Building – Expanding Provider Capacity: Stipends (\$356.4 million)

- Offers one-time stipend to HCBS waiver providers to support program activities.

HCBS Capacity Building – Expanding Provider Capacity: Recruitment/Retention (\$266.6 million)

- Creates financial incentives to both recruit new workers and increase the retention rates of the direct care workforce. Offers one-time direct payments to all HCBS waiver providers for capacity building and workforce retention/development.

HCBS Capacity Building – Quality Improvement Activities (\$12.0 million)

- Implements improvements to quality oversight activities by purchasing delayed egress systems for group homes and adult day training centers.

HCBS Capacity Building – Expanded Use of Technology (\$63.6 million)

- Not limited to the purchase of smartphones, computers, and/or internet activation fees for people receiving HCBS to address functional needs, promote independence, and/or support community integration.

HCBS Capacity Building – Providing Access to Additional Equipment or Devices (\$63.6 million)

- Not limited to the purchase of eyeglasses, wheelchair transfer boards, adaptive cooking equipment, and other additional environmental modifications that address functional needs.

HCBS Capacity Building – Addressing Social Determinants of Health (\$127.9 million)

- Supports care for Floridians aged 60 and older in family-type living arrangements within private homes, as an alternative to institutional or nursing home care.

COVID Related HCBS Needs – Mental Health and Substance Use Disorders Services (\$50.0 million)

- Assists eligible individuals in receiving mental health services, substance abuse treatment, and recovery services, and necessary rehabilitative services to regain skills lost during the pandemic.

HCBS Capacity Building – Implementation (\$4.0 million)

- Uses contracted services funding to assist with implementation activities and required reporting.

HCBS Capacity Building – Expand iBudget Waiver (\$191.3 million)

- Expands the Home and Community-Based Services Waiver by removing the greatest number of individuals permissible under the additional funding from the waiting list.

HCBS Capacity Building – PPEC Rate Increase (\$10.8 million)

- Increases provider rates to assist eligible children with medically complex conditions to receive continual medical care.

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As an independent, nonpartisan, nonprofit taxpayer research institute and government watchdog, it is the mission of Florida TaxWatch to provide the citizens of Florida and public officials with high quality, independent research and analysis of issues related to state and local government taxation, expenditures, policies, and programs. Florida TaxWatch works to improve the productivity and accountability of Florida government. Its research recommends productivity enhancements and explains the statewide impact of fiscal and economic policies and practices on citizens and businesses.

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