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# Expanding Opportunities for Older Americans:

SELF-DIRECTED HOME & COMMUNITY BASED SERVICES

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UNITED STATES SENATE SPECIAL COMMITTEE ON AGING

# TABLE OF CONTENTS

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<b>Executive Summary</b> .....	2
<b>Introduction</b> .....	3
<b>Medicaid HCBS Challenges</b> .....	4
Shift to HCBS.....	4
Medicaid Expenses.....	5
Perverse Incentives.....	5
Fraud and Abuse.....	6
Care Quality.....	7
<b>New Models and State Examples</b> .....	9
South Carolina.....	9
Florida.....	11
Utah.....	12
<b>Conclusion</b> .....	13



# EXECUTIVE SUMMARY

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The harrowing effects of the COVID-19 pandemic have highlighted caregiving challenges in America. Most tragically, one out of every five COVID-19 deaths occurred in nursing homes. Caregivers on the front lines have continued to serve older Americans, admirably braving the increased health risks. As a result, both caregivers and patients have borne the brunt of the pandemic. Aging care needs will only grow in COVID's wake: 7.2 million older Americans required care in 2020; 14.3 million will need it in 2065. Policymakers and stakeholders recognize these changes and are seeking to respond. Unfortunately, the Biden Administration's \$400 billion caregiving proposal overlooks the core needs of older Americans, doubling down on expensive and inadequate policies.

The Administration's proposal relies almost exclusively on Medicaid's Home & Community Based Services (HCBS) program. It would pump funding into labor costs and expand enrollment. Government financed 71% of spending on Long-Term Services & Supports (LTSS) in 2018, up from 63% 20 years earlier. This plan would continue the alarming cost trend. Radical expansion of the caregiving sector poses four major problems:

- To qualify, families would have to spend down almost the entirety of their assets, making care conditional on drained savings and disproportionately impacting Black families, whose wealth is eight times lower than that of white families;
- Exorbitant price hikes for existing caregiving consumers, who would have to pay at least 15% more to afford higher labor costs;
- The near total absence of support for family caregiving, a popular, flexible, and widely used resource;
- A substantial increase in funding for a program rife with fraud and devoid of quality measures.

A better path forward would invest sustainable funding in a significant push for a self-directed care model, which would allow caregivers and recipients to make informed decisions about the services they need while providing resources to do so. This path would:

- Allow older Americans and caregivers to manage personal budgets;
- Build on the success of self-directed care in the Veterans Health Administration, which operates 71 programs across the country, and increased enrollment by 22% last year;
- Encourage state Medicaid programs to establish self-directed care options, which served over 1.2 million in 2019, an increase of two thirds since 2011;
- Empower the nation's volunteer army of 53 million family caregivers through sustainable funding that will improve conditions for caregivers while enhancing service quality.

Some states are taking these steps on behalf of older Americans and their caregivers.



## INTRODUCTION

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The federal government has a critical role to play in supporting the care needs of older Americans. This role should be primarily defined by the preferences and interests of our seniors, who typically value aging at home and in the community, with the assistance of caregivers they know and trust. It should also prioritize affordable care to prevent bankrupting families and taxpayers.

Older Americans usually prefer to age at home. According to AARP, 86% of Americans aged 65 and older would like to stay in their current home or community. In fact, 66% expect to stay in their current home and never move, while 12% expect to move but stay within their community.<sup>1</sup>

Self-directed care programs help older Americans continue to live in their homes. The Administration's plan neglects self-direction, funneling almost half a trillion in funding to an inflexible program. Medicaid is a safety-net initiative, designed to aid people with low incomes or disabilities; it is not designed to be the nation's default caregiving program.

Medicaid's dramatic growth also displaces self-directed care options while overshadowing one of America's most valuable but little-recognized resources - our family caregivers. Over 50 million people, or one in five Americans, serves as a family caregiver as of 2020. They play a substantial role in the care sector, without imposing unmanageable cost burdens, and can benefit from additional flexibility in training and support systems.



This blueprint describes challenges in Medicaid's caregiving model and outlines opportunities for self-directed care models that support older Americans and the backbone of caregiving - family caregivers.



# MEDICAID HOME & COMMUNITY BASED SERVICES CHALLENGES

Long-Term Services & Supports (LTSS) refers to a broad range of health and health-related services that an individual needs over an extended period of time, including nursing home and home care.

## SHIFT TO HOME & COMMUNITY BASED CARE

The federal government has steadily grown its share of the caregiving sector for decades. In 1981, Medicaid spending on HCBS accounted for only 1% of Medicaid spending on LTSS. By 2016, it reached 57%.

On March 11, 2021, President Biden signed the \$1.9 trillion American Rescue Plan providing record-setting funding officially defined as relief but substantially directed to separate policy priorities, niche interests, and prior political commitments. The American Rescue Plan strongly incentivized states to increase Medicaid spending overall and to spend more of that money on HCBS.

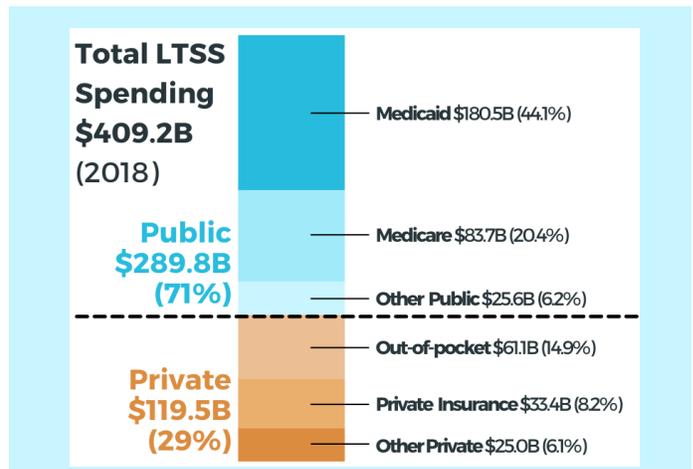


Figure 1: Long Term Services and Supports by Payer, FY 2018 (Colello, 2020)

In 2018, public financing of nursing home and home care totaled \$409 billion, over one eighth of the \$3.1 trillion spent on health care. Government finances 71% of LTSS spending, with Medicaid and Medicare accounting for 64% of all LTSS spending nationwide. Medicaid contributes the most to this total and LTSS accounts for a third of all Medicaid spending.<sup>2</sup>

## **AN EXPENSIVE GOVERNMENT PROGRAM**

The nonpartisan Congressional Budget Office observes that the American Rescue Plan will increase Medicaid HCBS spending by \$12.6 billion in 2021 and 2022.<sup>4</sup> The Administration's caregiving plan would only add to this growth over the next ten years, justifying the surge in taxpayer expense with speculation that additional funding would lower overall health care costs.

Yet sharp rises in HCBS spending have not reduced care costs over time. Medicaid still spends slightly more on care in specialized settings than on HCBS for older Americans and people with physical disabilities. Overall spending on LTSS continues to grow.<sup>5</sup>

## **PERVERSE INCENTIVES DESTROYING HOUSEHOLD WEALTH AND HARMING THE MOST VULNERABLE**

When the federal government crowds out private care by shifting more taxpayer dollars to Medicaid, individuals and families not previously dependent on the program are heavily incentivized to use it. To qualify, these older Americans must run down their savings, minimizing their wealth to demonstrate acceptable poverty.<sup>6</sup> To shelter whatever remains, they must undergo complex financial planning.

This financial planning is expensive – too expensive for many families, pushing them to abolish their wealth entirely to qualify. Middle and lower-income households, disproportionately made up of minorities, then struggle to leave any assets to their children, widening the racial wealth gap. The wealth of Black families is 8 times lower than that of white families.<sup>7</sup> This gap also reflects other economic disparities: 18% of Black families and 12% of Hispanic families are in debt, compared to 8% of white families.<sup>8</sup> Over the past 3 decades, this wealth gap has held steady.<sup>9</sup>

Growth in enrollment by people who would not normally qualify for Medicaid also crowds out access for people with disabilities – the very group for whom the program was designed. In 2018, 589,940 Americans with intellectual or developmental disabilities were on waiting lists for Medicaid services.<sup>10</sup>

The Administration's proposal would also harm older Americans who remain independent of Medicaid. Because the proposal would increase wages for care

workers whether or not they contract with Medicaid, older Americans who pay directly for these services will face higher costs themselves. One analysis estimates a price increase of at least 15%.<sup>11</sup>

## FRAUD AND ABUSE IN MEDICAID HOME & COMMUNITY BASED SERVICES

Older Americans who depend on Medicaid for HCBS also lose to fraud and abuse.

Non-medical Personal Care Services are especially vulnerable to fraud. Between 2014 and 2020, the Inspector General opened more than 200 investigations involving fraud and patient harm and neglect in Personal Care Services.<sup>13</sup>



The simplest fraud is billing Medicaid for home visits by Personal Care attendants that never happened. The OIG published its last report on Medicaid Personal Care Services in 2012 when it summarized the results of audits in 7 states. Four had substantial error rates, ranging from 16% in North Carolina to 40% in New Jersey.<sup>14</sup>

In a recent report, the Office of the Inspector General (OIG) of the U.S. Department of Health and Human Services notes its work as a watchdog “consistently demonstrates that patients and programs may be vulnerable to fraud and abuse in home and community-based settings. Moreover, home-based services may not meet quality of care requirements.”<sup>12</sup>

A recent federal law, the 21st Century Cures Act, imposed requirements on states to establish Electronic Visit Verification (EVV). Some states began to implement EVV in 2018. It is still too early to tell whether EVV has detected or prevented fraud.

Early estimates that Texas and South Carolina reduced fraud between 3% and 7% by implementing EVV have not been independently verified. A recent report by Medicaid and CHIP Payment and Access Commission (MACPAC), an independent advisory body that examines how to improve Medicaid, suggested fraudsters were able to circumvent protective technology used in Ohio.<sup>15</sup>

Some states require attendants who provide Personal Care services to register or enroll with the state. The state may impose minimum age, education, and health status requirements for registration. None of these measures have been shown to prevent fraud or abuse.

Dramatically increasing spending on these services would increase their attractiveness to fraudsters. Older Americans, taxpayers, and honest Personal Care attendants and their employers would pay the price.

Beyond outright fraud, providers of care in specialized settings can claim the increased spending on HCBS by reclassifying the care they provide. A nursing home operator, for example, could relabel part of a nursing home as a “community setting.” In 2014, the federal Centers for Medicare and Medicaid Services (CMS) finalized a rule to prevent this kind of financial gamesmanship.

The rule requires states to develop plans ensuring that caregiving is delivered in appropriate settings. For example, if a provider bills for services delivered in an HCBS setting located right beside a nursing home, that provider would likely violate the rule.<sup>16</sup> Seven years later, this rule is still not enforced. Originally, CMS gave states until 2022 to comply, but the deadline was extended to 2023 because of the pandemic. This delay suggests federal and state governments are not prepared to manage the Administration’s proposed spending hikes and accompanying program expansion.

## **QUALITY IN MEDICAID HOME & COMMUNITY BASED SERVICES**

Older Americans deserve high quality care at home irrespective of its funding source. Yet, there are no commonly accepted quality measures for these services. In 2018, CMS introduced a scorecard for states’ Medicaid programs. HCBS are not yet included in the scorecard.

CMS invited the public to contribute information on a set of recommended quality measures for HCBS by last November.<sup>17</sup> CMS has not yet indicated when it will take the next step.

An organization that represents 56 state and territorial agencies on aging and long-term services and supports directors, ADvancing States, launched National Core

Indicators – Aging and Disabilities (NCI-AD™) in 2015.<sup>18</sup> Among other questions, this patient survey determines:

- Percentage of people who like where they live,
- Percentage of people who know whom to contact if they have a complaint about their services,
- Percentage of people whose paid support staff do things the way they want them done.

This survey is a positive development, but just 19 states participated in the last full survey. The 2019-2020 survey was cut short because of the pandemic and only 7 states reported their results.<sup>19</sup>

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



## PATHS FORWARD – NEW MODELS AND STATE EXAMPLES

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The demand for effective care services has grown over time. It is also increasingly difficult to ignore the dedication, compassion, and commitment of America’s caregiving workforce – and its needs. Caregiving is a deeply personal issue and policymakers have an obligation to get it right. Bold reform can boost seniors’ quality of life, support caregivers, and tackle new challenges. Pushing \$400 billion into an inflated, rigid, and unaccountable program rewarding union loyalty over outcomes, however, misses the mark for productive reform. The Administration and its partners in Congress should instead adopt a sustainable funding mechanism that supports alternative models, including the National Family Caregiver Support Program. Federal resources should empower patients and families as informed consumers making their own choices, and financial assistance should improve conditions for caregivers while enhancing service quality.

We have seen evidence from some states that flexibility works. In these cases, government does not dictate wages or fees for providers. Instead, family caregivers are supported by community-based organizations through robust sustainable funding that allows patients to choose what works best for them.

### SOUTH CAROLINA

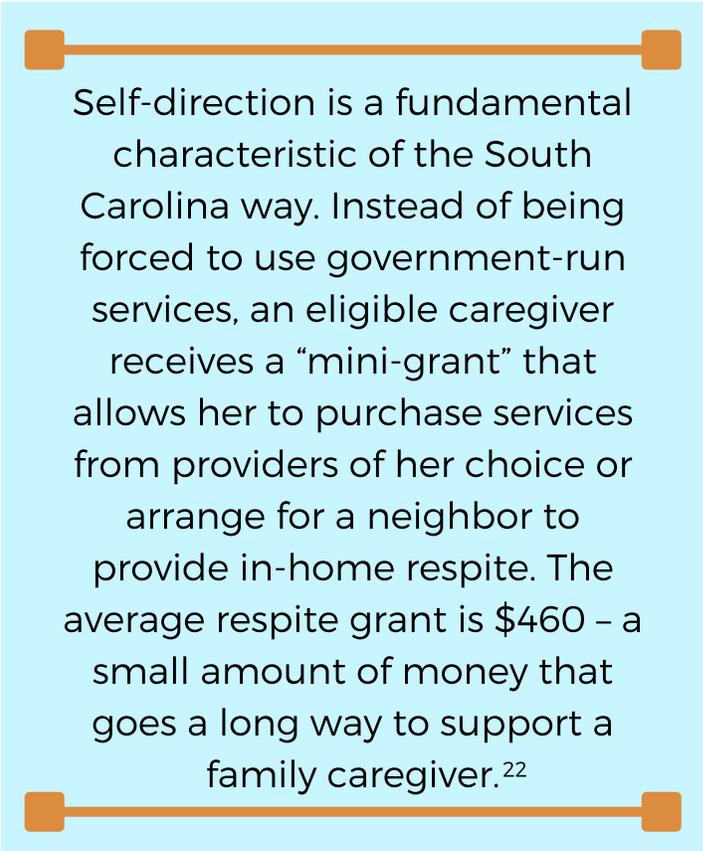


More than 770,000 family caregivers in South Carolina provide 737 million hours of free services to chronically ill, disabled, or frail elderly loved ones each year.<sup>20</sup> If their services were replaced by workers paid \$15 per hour, it would cost over \$11 billion annually.

The South Carolina Department on Aging has also instituted a robust system of caregiver assessment, which looks at a family caregiver's needs, strengths, resources, and ability to care for a loved one.<sup>21</sup>

Regional Family Caregiver Advocates work one-on-one with caregivers, providing counseling, support, and help in gaining access to available community services. This approach has sparked the growth of care providers with deep roots in our communities.

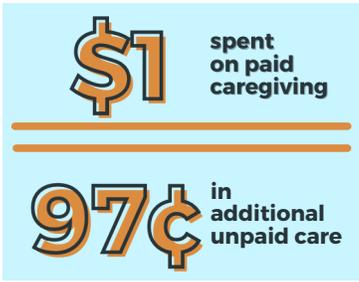
The ARK of SC started in 1996 at St. Luke's Lutheran Church in Summerville, South Carolina, providing respite care for 13 families with Alzheimer's disease and other dementias. With the support of local leaders and philanthropists, the ARK later bought its own building, and now provides an array of services from caregiver support and respite to transportation and first responder training. The ARK reaches seniors in five counties, and is training other providers across the state to deliver these same high-quality services. The Lieutenant Governor's Office on Aging has recognized the ARK as a model respite program and recommended it for replication across the state.<sup>23</sup>



Self-direction is a fundamental characteristic of the South Carolina way. Instead of being forced to use government-run services, an eligible caregiver receives a “mini-grant” that allows her to purchase services from providers of her choice or arrange for a neighbor to provide in-home respite. The average respite grant is \$460 – a small amount of money that goes a long way to support a family caregiver.<sup>22</sup>

South Carolina's approach has resulted in a successful environment for care services. The state ranks 7th in the country in an AARP scorecard for the fewest number of people in nursing homes whose needs could be met with HCBS. It is 8th in the country for successfully discharging Medicare beneficiaries into the community from post-acute care.<sup>24</sup> These results are especially important in light of the pandemic, during which one in five of America's COVID fatalities occurred in nursing homes.

South Carolina illustrates the benefit of supporting family caregivers. The United States has a vast volunteer army of family caregivers who provide HCBS. The role of



family caregivers is growing. In 2020, 53 million unpaid family caregivers – one in five Americans – provided care to an adult with health or functional needs.<sup>25</sup> For people turning 65 in the years 2020-2024, every dollar spent on paid caregiving over their lifetimes will be matched by 97 cents of unpaid care.<sup>26</sup>

Compared to Medicaid programs, the nation’s 53 million caregivers benefit from a small fraction of federal spending. The National Family Caregiver Support program received \$189 million in Fiscal Year 2021. Yet, this modest appropriation - amounting to less than \$4 per caregiver - is still a boon for millions of family caregivers. Grants managed by state aging offices fund community-based organizations like The ARK of SC all over the country.

## FLORIDA



Florida provides an example of how an agency can work with a successful federal program. In 2010, the Senior Connection Center of Tampa was one of the first Area Agencies on Aging to participate in the Veteran Directed Care (VDC) Program (then called Veteran-Directed Home and Community Based Services).

The VDC Program is jointly managed by the Veterans Health Administration (VHA) and the Agency for Community Living of the U.S. Department of Health & Human Services.

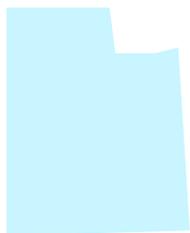
The Senior Connection Center, which serves five counties in central Florida, first partnered with the James A. Haley Veterans’ Hospital in Tampa. Over the past decade, the Senior Connection Center has expanded to collaborate with three VHA hospitals in its area and reports high satisfaction among veterans who live in both urban and rural communities.<sup>27</sup>

By controlling their own care budgets, veterans can hire providers they prefer. They do not have to accept whomever the VHA decides to send into their homes. This

The Veteran Directed Care program lets veterans self-direct their Home & Community Based Services and continue living independently at home. Eligible veterans manage their own flexible budgets, decide which mix of goods and services best meet their needs, and hire and supervise their own workers. The Area Agency on Aging provides a counselor who facilitates assessment, plans care and services, arranges financial management, and provides ongoing counseling and support to veterans, their families, and caregivers.

results in better continuity of services. Because of trendsetters like the Senior Connection Center, the VDC Program has succeeded nationally. In 2019, 71 VDC programs operated across the country, and enrollment increased 22% last year.<sup>28</sup>

## UTAH



Utah introduced more flexibility into caregiving when the pandemic created service challenges.<sup>29</sup> For home-delivered meal services, the state let Medicaid participants use delivery services such as DoorDash and UberEats. Utah also reimburses providers not enrolled in Medicaid, such as Lyft or Uber drivers.

The state allows participants to receive services at churches, hotels, and shelters, and in their own homes or the homes of direct-care providers. It also makes it easier to adapt home care. Participants receive purchase cards to buy specialized medical equipment and assistive technology from vendors outside of Medicaid's government-run supply chain.

Utah also expanded participants' ability to make adaptations to their homes. Participants receive purchase cards to buy specialized medical equipment and assistive technology from vendors outside of Medicaid's traditional government-run supply chain.

**Over 1.2 Million**

**Older Americans and Americans with disabilities were enrolled in self-directed home care in 2019**

All states can offer older Americans similar choices via waivers from CMS. States are increasingly doing so. In 2019, there were 152 publicly funded self-directed home care programs for older Americans, up from 58 just three years earlier. Over 1.2 million older Americans and Americans with disabilities were enrolled in self-directed home care in 2019, an increase of two-thirds since 2011.<sup>30</sup>



## CONCLUSION

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The COVID-19 pandemic underscores the value of home care for older Americans, most of whom prefer it to nursing homes or other settings. The federal government supports this preference, but primarily does so through Medicaid's heavy-handed and increasingly costly services. The program's perverse incentives limit choice, raise costs, bankrupt families while deepening racial disparities, and fail to provide quality care. Requiring taxpayers to increase spending for questionably beneficial and possibly fraudulent care – already the trend in recent decades – is fiscally reckless and creates more hurdles for the most vulnerable patients and families.

Patients and families want flexibility for patient-centered, self-directed care, not government-directed bureaucracy. The National Family Caregiver Support program is a prime example of how federal spending can be highly effective when invested in local organizations that know the needs of their communities. An effective alternative to the Administration's proposal would bolster this initiative and similar programs, empowering older Americans and their caregivers to manage their budgets while building on the success of self-direction in innovative state responses to caregiving challenges. Policies focused on self-directed care would keep costs low and help consumers, patients, and families make choices that work for them. Such policies would also respect and cultivate the critical role played by millions of family caregivers. Choice, flexibility, and enterprising and common-sense improvements to existing arrangements will improve caregiving quality and access more than any aggressive government transformation.

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