

# ACCESSING LONG-TERM CARE COVERAGE THROUGH MEDICAID

THE SAFETY NET FOR  
SENIORS FACING  
UNMANAGEABLE COSTS



NATIONAL INSTITUTE ON  
**Retirement Security**

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# EXECUTIVE SUMMARY

Long-term care (LTC) comprises a broad range of paid and unpaid care assistance that people need when experiencing difficulties completing self-care tasks, such as eating, bathing, housework, or taking medication. Aging, chronic illness, or disability are all reasons why individuals, seniors in particular, might need long-term care. The data show that 69 percent of seniors will require some type of long-term services and supports (LTSS).<sup>a</sup> This report emphasizes the importance of planning for long-term care at the individual level and at the state and federal levels.

Five factors highlight the urgent need for a systemic approach for improving the financing of, and access to, long-term care in the United States:

1. Healthcare and long-term care costs can be very high relative to both income and the level of savings that most Americans have managed to accrue.
2. The majority of current workers are not factoring long-term care costs into their retirement plans, despite the high rate of LTSS utilization by current seniors.
3. The country's proportion of seniors continues to rise, which will cause the cost of pay-go financing to continue increasing.
4. Medicaid, a health insurance program originally designed for people of low income, has become the country's primary payer for long-term services and supports.
5. The rising costs associated with Medicaid LTSS coverage have placed enormous pressure on state legislatures to seek ways to contain Medicaid costs through measures such as narrowing eligibility, imposing caps on individual spending, and eliminating optional services.

Even as the country's primary payer of LTSS, Medicaid LTSS coverage has restrictive eligibility rules, is highly variable by state, and is unfamiliar to the general public. A large number of Americans will become acquainted with the system only when they or a loved one find themselves in need of LTSS.

Because of a lack of alternative and feasible ways to finance the cost of their long-term care needs, many middle-class seniors find themselves forced to spend down, i.e., reduce their net worth so they are eligible for Medicaid, or open LTSS-specific trusts in order to qualify for Medicaid LTSS coverage. This frequently requires strategic planning and/or legal help for those with assets in addition to forcing families to deal with bureaucratic confusion while confronting a health crisis that exacts an emotional toll on seniors and their families.

Despite improvements through the Affordable Care Act (ACA), Medicaid LTSS coverage continues to favor institutional nursing facility care over home or community-based care. This occurs even though home or community-based care costs less on an individual basis, may delay the need for institutional-level care, and is largely preferred by beneficiaries and their families.

The National Institute on Retirement Security (NIRS) recommends the following policies to address the unpredictable yet potentially catastrophic costs of long-term care needs:

- Long-term care proposals should provide universal coverage based on need. Washington State is piloting a social insurance program to provide coverage for long-term care costs, and this could serve as an example for other states or even a federal program.
- The programmatic bias toward institutional care over home or community-based care should be eliminated. HCBS costs less than institutional care and is generally preferred by beneficiaries and their caregivers.
- A stronger focus on healthy aging for all should include the integration of healthcare and social services and accountable care systems focused on long-term health.
- The ability of older adults to remain in their communities and live independently should be facilitated by public policy.

<sup>a</sup>In this report, the terms "long-term care" (LTC) and "long-term services and supports" (LTSS) are used interchangeably to describe the types of non-medical care provided to people with chronic conditions.

# INTRODUCTION

This report examines the necessity of planning for long-term care (LTC) costs at the individual level, as well as at the state and federal levels. While concerns about how to pay for long-term care are not new,<sup>1</sup> the situation has been worsening rapidly as the cost of providing services has increased. Although long-term care insurance surged in popularity in the 1990s, insurance companies exited the LTC insurance market in large numbers in the 2000s due to various factors.<sup>b,2</sup> The number of insurers selling long-term care policies shrank from over 100 in the 1990s to less than 15, currently covering about 7 million Americans.<sup>3</sup> Simply put, consumers are now faced with paying higher annual premiums with less choice.

The Employee Benefit Research Institute's (EBRI) most recent *Retirement Confidence Survey* found that only one in five current workers have considered how they would pay for LTC if they were to need it in retirement. While almost three out of four current workers report being confident about their retirement security, only half have tried to calculate how much money they would need to live comfortably in retirement. And among those, about half considered how they would pay for healthcare costs, and only 41 percent how they would pay for long-term care costs if they were to need it.<sup>4</sup> However, 69 percent of seniors will require some type<sup>c</sup> of long-term services and supports (LTSS)<sup>d</sup> for an average length of three years.<sup>5</sup> Together, these data demonstrate a keen misperception of one's own likelihood of needing long-term care and effectively factoring it into one's planning.

EBRI also found that, while 69 percent of current workers are confident or very confident that they will have enough to live comfortably in retirement,<sup>6</sup> confidence rates varied by gender. Women indicated lower levels of retirement

confidence than men. Furthermore, three in every four married women reported feeling confident or very confident about having enough money during retirement, but the rates were significantly lower for divorced women and never-married women.<sup>7</sup> These data are merely one example of how systemic inequalities carry over to retirement.

With healthcare and long-term care costs rising at much higher rates than wages or salaries, it is becoming more difficult for people to afford to cover the costs of long-term care. Medicaid, a program designed to provide health services for low-income families, has become the largest payer of long-term services and supports, covering the cost of half of all LTSS.<sup>8</sup> As this report highlights, this is a fundamental failure of the current system to support seniors in their golden years. Many middle-class seniors find themselves forced to spend down, i.e., reduce their net worth so they are eligible for Medicaid because they are otherwise not able to cover the costs of the LTSS for the length of time that they need it.

Retirement income and savings often are woefully inadequate to cover what can be prohibitively expensive long-term care costs. Half of Medicare beneficiaries in 2019 had savings below \$73,800.<sup>9</sup> According to the Genworth Cost of Care Survey, the national median cost for a year of nursing home care in a private room is \$102,204.<sup>10</sup> Moreover, savings levels are sharply divergent based on race and gender. For example, half of Black Medicare beneficiaries had savings below \$14,500 and half of Latino Medicare beneficiaries had savings below \$9,650.<sup>11</sup>

Medicaid is funded by both federal and state tax dollars, but it is implemented at the state level. As a result, each

**"Together, these data demonstrate a keen misperception of one's own likelihood of needing long-term care and effectively factoring it into one's planning."**

<sup>b</sup> Insurer losses due to erroneous predictions on how many people will cash in, higher premiums, less coverage, drastic drop in market sales (Cohen, M. A., Kaur, R., & Darnell, B., 2013).

<sup>c</sup> This includes services in the home, paid or unpaid, or in nursing, assisted living, or any other facilities.

<sup>d</sup> "Long-term care" (LTC) is the most common term used to refer to non-medical care provided to people with chronic conditions, as opposed to a temporary, acute need. Used interchangeably with LTC in this report and other publications, "long-term services and supports" (LTSS) is the term used by modern U.S. legislation. The term LTC is currently preferred by private industry, while academia and government use LTSS. With the recent trend towards more community and home-based care options, in some contexts, LTSS may imply a more inclusive range of services than LTC.



state must adhere to the minimum federal regulations (the majority of which date back to 1972), but each state also has extensive leeway in expanding eligibility through differing asset and income limits and choosing whether to adopt federally created optional pathways. Furthermore, states also have some flexibility in choosing what type of LTC Medicaid will cover. Therefore, Medicaid coverage differs drastically across the nation, with no two states providing identical coverage under the same eligibility rules. Access to Medicaid coverage can vary even within a state, especially those states that did not expand Medicaid through the ACA, who generally have less robust Medicaid programs. This complicates access to Medicaid coverage due to lack of widespread accurate knowledge about it (compared to Americans' solid understanding of Social Security). This may also make it more difficult for Medicaid recipients to move to another state (compared to Medicare's nationwide coverage). It should be noted that U.S. citizenship or qualified immigration status is a prerequisite for Medicaid coverage.

Another key factor when discussing LTSS costs is the changing demographics of the U.S. Healthcare and LTSS costs are increasing as the U.S. Census Bureau projects that in 2034 the number of seniors will overtake the number of children in the country. This is due in part to the largest generation, Baby Boomers, fully reaching retirement age by 2030.<sup>12</sup> The proportion of people 85 and older is also rapidly growing, has the highest rate of multiple chronic conditions (83%), and is most likely to need long-term

care.<sup>13</sup> Data also show that people who need LTSS are disproportionately low-income, older, live alone or with a relative(s) who is not a spouse, and have high acute care costs.<sup>14</sup> According to current trends, this inevitably will create a higher demand for LTSS, Medicaid LTSS coverage, and associated government spending. Furthermore, the number of Americans living in multigenerational homes has been increasing steadily since the 1980s, currently on par with the 1960s rate of 20 percent.<sup>15</sup> As more Americans find themselves living with people who need LTSS, the affordability and Medicaid coverage of various LTSS options plays an even bigger role, as this report discusses.

The insurance market, individual planning, rising LTC costs and stagnating wages, Medicaid eligibility and spending, changing demographics, and systemic inequality are mutually dependent elements. Taken together, these factors result in some people obtaining LTSS when and for how long they need it, while many other people do not. The complex nature of each of these factors is why accessing and financing long-term care continues to be unresolved. Because demographic trends and systemic inequality are impossible to change in a relatively short period of time, this report explores how Medicaid eligibility interacts with retirement income, savings, and assets for the purpose of receiving LTC coverage. This report also provides a user-friendly summary on the topic.

# I. LONG-TERM SERVICES AND SUPPORTS

Long-term services and supports (LTSS) comprise both medical and non-medical services, which can be provided in nursing homes and other institutions, community settings, and homes. LTSS “encompasses the broad range of paid and unpaid medical and personal care assistance that people may need – for several weeks, months, or years – when they experience difficulty completing self-care tasks as a result of aging, chronic illness, or disability.”<sup>16</sup> These self-care tasks consist of (a) **activities of daily living (ADLs)**, such as eating, bathing, dressing, using the toilet, handling incontinence, transferring to and from beds and chairs, and (b) **instrumental activities of daily living (IADLs)** such as preparing meals, housework, taking medication, managing money, and caring for pets. LTSS needs are assessed based on the level of help needed for ADLs and IADLs. Therefore, LTSS can range from nursing facility care and adult daycare programs to home health aide services and transportation. It is important to note that both private and public insurance plans treat LTSS differently from medical care because the services needed go beyond acute care needs.<sup>17</sup> Although anyone may require LTSS, this report focuses on seniors.

The most traditional form of paid LTSS is institutional care in a nursing home. Since the creation of Medicaid in 1965, the program has covered **long-term care in institutional settings** for eligible populations.<sup>18</sup> Of the people who require LTSS, 18 percent will receive it in a nursing care facility or a residential care facility; this amounts to 3.8 percent of the whole U.S. population who are 65 and over.<sup>19</sup> Residential facilities are not easy to categorize because there is no commonly accepted terminology. However, **nursing homes** are the only category that is licensed to provide skilled around-the-clock nursing care and is most suitable for individuals who require that level of medical supervision. Another type of institutional LTSS care occurs in **residential care facilities**, which provide room, board, and personal care services, as well as supervision 24/7, but are not licensed as nursing homes.<sup>20</sup>

Governmental support for **home and community-based services (HCBS)** as an alternative to institutional care first occurred in 1975. Additional incentives and programs were created in the decades that followed, particularly in response to the 1999 Supreme Court decision *Olmstead v. L.C.*<sup>21</sup> The Affordable Care Act, which passed in 2010,

included provisions for the federal government to provide states with incentives to improve their LTC infrastructure and expand HCBS.<sup>22</sup> Based on their needs, in certain states, individuals may apply for HCBS to be provided in their homes, or they may obtain HCBS by moving to **assisted living facilities or room and care homes** (a.k.a. adult foster care homes), where residents enjoy higher levels of independence (privacy and choice). HCBS is ideal for those who can live independently but need assistance with some daily activities that they are not able to safely perform themselves, e.g., help with bathing or minor nursing/medication assistance. Services covered under HCBS are skilled services, such as home health aides, and nonskilled services, such as personal care, adult day care or day treatment, and homemaking.

Medicaid’s history has resulted in an **entrenched program bias towards institutional care that is more expensive than alternatives which are often preferred by seniors**. The federally mandated pathway for any state participating in Medicaid requires LTSS coverage for nursing homes for mandatory eligibility groups. However, most HCBS coverage is optional at the state level; the only exception is home health services, which accounted for only 13 percent of all HCBS enrollees in 2018<sup>23</sup> (down from 24 percent in 2012<sup>24</sup>, though the decrease in proportion is mainly due to an increase of enrollees in the optional HCBS pathways rather than a decrease in institutional care, whose spending has remained steady since 2010<sup>25</sup>). Yet, even though not all states have opted into the optional HCBS pathways, in 2013, Medicaid HCBS spending exceeded institutional spending for the first time. In 2016, HCBS comprised 57 percent of all Medicaid LTSS spending, while institutional care amounted to 43 percent, though this data includes everyone needing LTSS, not just seniors.<sup>26</sup> In FY 2016, Medicaid LTSS expenditures supporting older adults and people with physical disabilities totaled \$104 billion and 45 percent of that was spent on HCBS.<sup>27</sup> This trend is, in part, explained by beneficiaries’ stronger preference for HCBS, the fact that it is less costly than institutional care for states, and states’ community integration obligations for people with disabilities.<sup>28</sup> Further differences between institutional and HCBS care and its potential implications for families can be found in the Institutional Care vs. Home and Community Based Care section.

**Table 1: Types of Long-Term Services and Supports (LTSS) Settings**

	<b>Facility-Based Care</b>	<b>Home and Community Based Care (HCBS)</b>
<b>LTSS services</b>	Medical and personal services to help with daily living tasks	
<b>Living arrangement</b>	In a facility designed to provide LTSS to patients who live there	In their own home, or with a family member
<b>Location of services</b>	Most services provided onsite	Caregivers visit the home, OR senior visits providers in the community
<b>Level of autonomy</b>	Low	High
<b>Level of isolation from the community</b>	High	Low
	<b>Nursing Facility (Medicaid designation)</b>	<b>HCBS (Medicaid designation)</b>
<b>Live in a facility</b>	Nursing home	Assisted living facility, adult family homes (e.g. adult foster care)
<b>Live in the home community</b>	Nursing home	Integrated LTSS care, usually at home (e.g. PACE program)

## II. PATHWAYS TO MEDICAID ELIGIBILITY

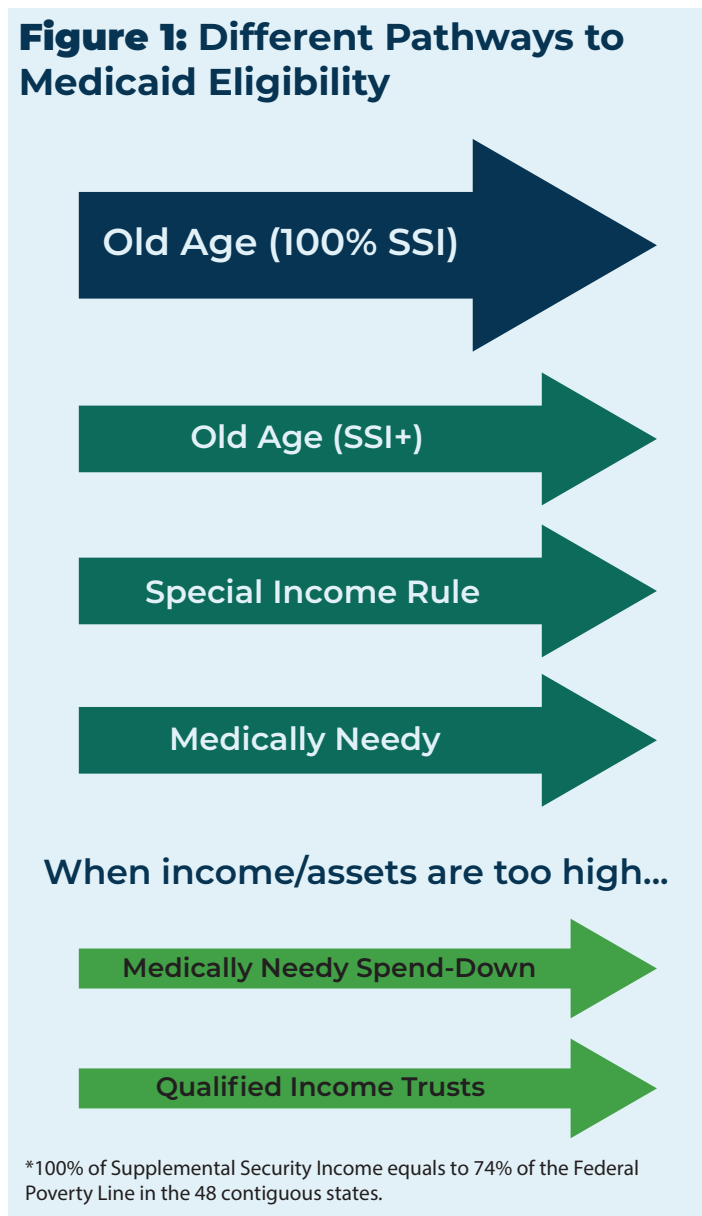
Medicaid eligibility is determined by federal and state law, where the federal government establishes minimum eligibility standards and states can choose whether and to what extent to expand eligibility beyond the minimum standards. Eligibility is determined based on categorical, financial, and functional eligibility criteria. This report largely focuses on the financial criteria and how they differ by pathway. As a result, all pathways are explained with seniors in mind; to simplify how Medicaid works for seniors needing LTSS, other groups eligible through the same pathways are omitted from this report.

### Old Age or Disability Pathway - mandatory

The only category that is federally mandated for Medicaid coverage are Americans receiving Supplemental Security Income (SSI). Individuals receiving SSI meet three basic criteria. First, they have low incomes; the maximum SSI in 2020 is \$783 per month, i.e., 74 percent of the federal poverty line. Second, they have limited assets; usually \$2,000 for an individual and \$3,000 for a couple, in addition to non-countable assets<sup>e</sup> and income disregards<sup>f</sup>. Third, they do not have gainful work; if a person obtains gainful work, they lose their eligibility.

Because this pathway is mandatory, seniors who receive SSI fall into one of the program’s *mandatory eligibility groups* as determined by the federal government.<sup>29</sup> The federal government also mandates that nursing facility services be included in the Medicaid benefit under this pathway, for all categorically needy populations, including seniors. All states implementing Medicaid must provide this pathway. However, eight states have opted for exception *Section 209(b)*; states can use financial and functional criteria different from the SSI rules, as long as they are no more restrictive than what the state had in 1972. As demonstrated in **Table 2** where *Section 209(b)* states are marked with an asterisk, only Connecticut uses more restrictive financial income criteria, but it also applies a significantly more generous general income disregard compared to the federal SSI rules (\$339 vs \$20).<sup>30</sup> However, the other seven states retain that level of leeway and may have different asset limits and/or functional criteria.

**Figure 1: Different Pathways to Medicaid Eligibility**



<sup>e</sup> Each state decides which assets are non-countable for the asset limit test. Many states use federal Social Security Income guidelines, which lists a personal home, one car, and funds for prepaid burial expenses as uncountable assets for the purposes of the asset limit test for Medicaid eligibility.

<sup>f</sup> For the vast majority of states, the income disregard is \$20, the exceptions being New Hampshire at \$13, Maine at \$75, California at \$230, and Connecticut at \$339 (Musumeci, Chidambaram, & Watts, 2019; see endnotes).



**Table 2: Eligibility Criteria for Medicaid LTSS Through the Old Age Pathway Based on the Percentage of the Federal Poverty Line for Individual Income**

State/Territory	% of FPL for Individual	State/Territory	% of FPL for Individual
Arizona	100%	Minnesota*	100%
Arkansas	80%	Missouri*	87%
California	100%	Nebraska	100%
Connecticut*	63%	New Jersey	100%
District of Columbia	100%	New York	83%
Florida	88%	North Carolina	100%
Hawaii*	100% Hawaiian poverty line	Oklahoma	100%
Idaho	80%	Pennsylvania	100%
Illinois*	100%	Rhode Island	100%
Indiana	100%	South Carolina	100%
Maine	100%	Utah	100%
Massachusetts	100%	Virginia*	81%
Michigan	100%	Wisconsin	83%
		<i>All Other States</i>	74%

### Old Age or Disability Pathway – optional (option 1 on Figure 2)

The federal government allows states to provide Medicaid coverage beyond the mandatory 74 percent federal poverty line (FPL) limit up to 100 percent (i.e., SSI+). Effectively, half of the states (25 out of 51) cover seniors above 74 percent, although a handful of states do this through a mechanism different from this optional pathway.<sup>g,31</sup> In summary, one state exercises an income threshold of 63 percent of the FPL, 25 states use the mandatory threshold of 74 percent, seven states fall between 80 percent and 90 percent, and 18 states use the maximum of 100 percent (see Table 2 for list of states).

It should be noted that this optional pathway is distinct

from the Medicaid expansion provided by the Affordable Care Act for working age people, which has been implemented by 38 states, thus far.

### Special Income Rule Pathway – optional (option 2 on Figure 2)

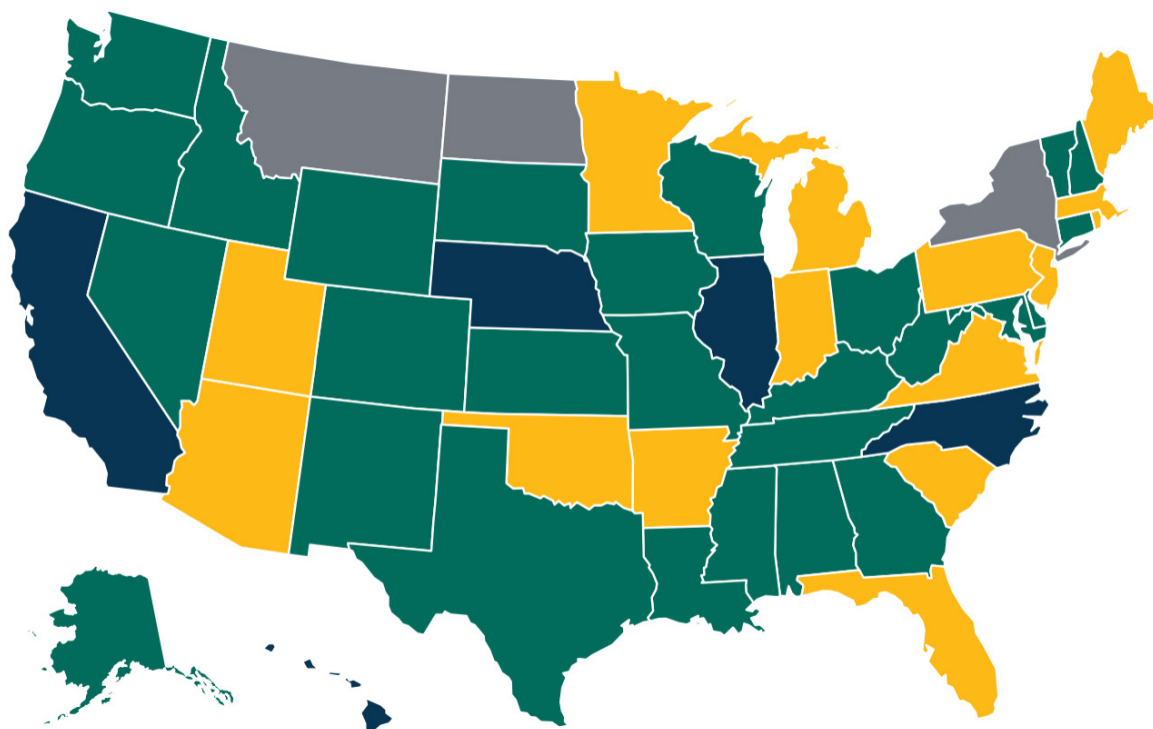
The Special Income Rule expands Medicaid eligibility specifically for the purposes of covering LTSS. This means that states can choose to cover individuals who have a monthly income up to 300 percent of the maximum SSI (\$2,349 in 2020) and who require institutional or home or community-based care. Most states have opted into this pathway: 42 states cover both institutional care and HCBS, while Massachusetts only covers HCBS under this pathway.<sup>h</sup>

<sup>g</sup>For instance, state supplemental payments and/or additional income disregards in ID, MO, NY, and WI raise the effective SSI income limit beyond 74% FPL, rather than through this pathway. The report by Musumeci, Chidambaram, and Watts (2019) count 21 states as having implemented the optional pathway, as ID, MO, NY, and WI use a different mechanism with the same (current) result.

<sup>h</sup>Minnesota's and Missouri's coverage also varies within different types of care and programs.

## Figure 2: Optional Pathways With More Generous Eligibility Criteria Than The Mandatory Pathway, by State

Old Age (SSI+) Special Income Rule Both None



Source: US Census Bureau's cartographic boundary shapefiles, 2016 edition; [Flourish](#)

### Medically Needy Pathway – optional

The Medically Needy pathway expands Medicaid eligibility to seniors with high medical expenses whose income or assets exceed the threshold for the mandatory Old Age pathway. Although the median income limit for this pathway is 48 percent of the Federal Poverty Line, the limits can vary dramatically by state; in 2018 they ranged from 10 percent in Louisiana to 110 percent in Vermont.<sup>i,32</sup> It is relevant to point out that although 33 states cover seniors under this pathway, only 25 provide institutional LTSS coverage since including nursing facility services is not federally mandated under this pathway.<sup>33</sup>

### When income or assets are too high but so are LTSS costs

There are two other ways that seniors may obtain access to Medicaid LTSS coverage if they do not qualify via any of the above criteria. Their options will depend on whether

they live in a spend-down state or an income-cap state. Seven states are currently both spend-down and income-cap states.<sup>j,34</sup>

It is important to note that LTSS Medicaid eligibility also requires that no assets or income be transferred for the sole purpose of meeting the financial eligibility criteria through one of the pathways. When a senior applies for Medicaid, all financial transactions that fall within the “look back” period are reviewed. This entails all assets or income, though the primary focus is on assets that might have been sold under fair market value. Transfers made by the non-applicant spouse are also subject to the same review.<sup>35</sup> The look back period is 60 months (five years) prior to the Medicaid application in all states, except California, where it is 30 months.<sup>36</sup>

Should a transfer be deemed improper, i.e., made for less than the fair market value, the imposed penalty is ineligibility for Medicaid for a specific period of time. The

<sup>i</sup>In the vast majority of states that have opted into this pathway, the medically needy income limit is set below that of the mandatory old, aged, or disability pathway. As a result, in those states, everyone who would qualify for the medically needy pathway, also qualifies for the mandatory pathway. Therefore, if individuals do not qualify via the mandatory pathway, the medically needy pathway is only useful for the spend down process (see section “Spending Down through the Medically Needy Pathway”). However, in a handful of states (NY, ND, VT, WA), the medically needy income limit is higher than the mandatory income limit. For example, in Vermont, the income limit to qualify for the mandatory pathway is 74% of the FPL (or 100% of the maximum SSI), but the income limit to qualify for the medically needy pathway is set at 110% of the FPL (though it varies by region within the state). Therefore, in Vermont, New York, North Dakota, and Washington, it is possible for a senior to qualify for LTSS through the medically needy pathway, but not through the mandatory pathway. In all the other states, this is currently impossible (Musumeci, Chidambaram, & Watts, 2019; see endnotes).

<sup>j</sup>AR, FL, GA, IA, KY, MO, NJ (Missouri's government website indicates that the state has the medically needy pathway and the spend down option; this is different from the information in the Musumeci, Chidambaram, & Watts (2019) report).

number of months of ineligibility corresponds to how many months of LTSS could have been covered by the transferred asset. A state may waive the penalty period if the applicant can prove that they (a) intended to transfer assets at fair market value; (b) transferred the asset(s) for other reasons, not Medicaid eligibility; or (c) recovered the assets that caused the penalty.<sup>37</sup>

### Spending Down through the Medically Needy Pathway

Most states are spend-down states for the senior population (33 of 51).<sup>38</sup> This means that to qualify for Medicaid LTSS coverage, seniors who have countable income over a state's

Medically Needy Income Limit (MNIL) must demonstrate that the excess income is spent on medical and remedial bills for medically necessary services. Thus, all the excess income in a given budget period must be spent on a senior's medical and remedial bills before Medicaid steps in and covers the remaining amount. The budget period varies by state and ranges between one and six months.

If the beneficiary has a spouse still living in the community, a monthly maintenance needs allowance is allocated for the spouse before the excess income is calculated. More details on the impact on spouses is detailed in the Spousal Impoverishment Rules section.

## PRACTICAL IMPLICATIONS<sup>39</sup>

Juan is 80 years old and has been living on his own in Washington, D.C. since his wife, Amanda, died two years prior. He recently was hospitalized for breaking his hip and has been showing early signs of Alzheimer's since his wife's death. After various conversations with his adult children, Maria and Mark, the family decided that it might be time for Juan to get paid help at home, in the community, or to move to a nursing home. However, they must first assess the financial implications of that decision. Thanks to a long career in the Department of Motor Vehicles, Juan's total monthly income amounts to \$2,500. He owns a modest house and a car, and he has no other assets. After subtracting a \$20 disregard, Juan's countable income is \$2,480.

This income is too high to qualify for any of the mandatory or optional pathways available in D.C. since the highest income limit is through the Special Income Rule pathway, at \$2,349 in 2020. However, D.C. allows for a medically needy spend down to attain Medicaid eligibility. The Medically Needy Income Limit for D.C. in 2020 is \$682. To calculate the spend-down amount for each state, the Medically Needy Income Limit is subtracted from a senior's countable income. This monthly difference is then multiplied by the number of months in the budget period set by the state for the Medicaid spend-down. The final amount is the minimum that a senior would need to spend on eligible expenses in order for Medicaid to cover anything over that amount.

Juan, Maria, and Mark are calculating Juan's spend-down amount.

\$2,480 is Juan's countable income  
 \$682 is D.C.'s Medically Needy Income Limit  
 6 months is D.C.'s budget period for nursing home care and HCBS

$\$2,480 - \$682 = \$1,798 \times 6 \text{ months} = \$10,788$

\$10,788 is Juan's spend-down amount for 6 months

Within a six-month period, Juan's medical and remedial costs must amount to at least \$10,788 to qualify for Medicaid LTSS coverage beyond that amount. These bills can include nursing home facility services, assisted living facility services, medical bills such as doctor's visits, prescription costs, urgent care, hospital stays, medical equipment, medically necessary supplies, health insurance premiums, and co-payments. Eligible remedial bills are costs for home modifications, vehicle modifications, and transportation costs to access and receive care.

If Juan and his family opt for care in a **nursing home**, Juan does not have to present any actual bills; D.C.'s Economic Security Administration will compare the cost of institutional care with Juan's monthly excess income. Since Medicaid accepts projected medical bills from nursing facilities, and the average monthly cost of a nursing home in D.C. is around \$9,000, as long as Juan meets the functional eligibility criteria for LTSS (needs that require an LTSS-level of care), D.C.'s Medicaid will find him eligible for LTSS coverage through their program. Juan will pay \$10,788 over the 6-month period (a.k.a. the Spend Down obligation), and Medicaid will cover the rest of the cost of the nursing facility. Due to the automatic nature of application processing for institutional care, Juan is approved immediately, until the end of the budget period. If he applies on April 15th, he will be Medicaid approved from April 1st to September 30th of that year.

## PRACTICAL IMPLICATIONS (CONTINUED)

If Juan and his family opt for **home and/or community-based care**, Juan will need to apply for a Medicaid LTC Home and Community-Based Services (HCBS) waiver. However, Medicaid does not accept projected medical expenses for HCBS. This means that upon applying, Juan will need to provide at least \$10,788 worth of eligible medical and/or remedial bills occurring within the past 90 days of his application, in order to demonstrate that his very recent prior expenses have surpassed the spend-down amount. If Juan does not yet have \$10,788 worth of eligible bills from the past 90 days, Juan will be found ineligible, but he will be able to continue submitting bills to his caseworker until he reaches \$10,788 within his six-month spend-down budget period.

Let's say that Juan applies for the HCBS waiver on April 15th with \$4,788 worth of eligible bills from the past 90 days. At that moment, he is ineligible for Medicaid LTSS coverage because he has not yet reached his spend-down amount. However, after paying out-of-pocket for several very expensive medical tests and daily home health aide services, on June 15th Juan's additional medical bills amount to \$7,500. With the addition of these bills (\$4,788 + \$7,500), Juan has surpassed his spend down amount (\$10,788). He becomes Medicaid eligible from June 1st to September 30th because his budget period started the month that he applied for Medicaid (April), not the month that he was approved (June).<sup>50</sup>

Because Juan has met his Spend Down amount, he automatically will be extended into a second consecutive Spend Down budget period (October to March) without having to apply again. However, a new application is required for the third consecutive Spend Down budget period (April to September of the next year) regardless of the amount of Juan's bills in the second budget period.

It is important to highlight that Juan's total bills amounted to \$12,288 on June 15th, which is \$1,500 more than Juan's Spend Down amount of \$10,788. The \$1,500 is referred to as a carry-over expense. Juan's Medicaid caseworker will apply this carry over expense to his second spend down budget period. The same applies to any additional eligible expenses incurred in this budget period.

The initial shortened eligibility period (June to September) is one example of how Medicaid LTSS coverage is biased in favor of institutional care. Medicaid accepts a projection of institutional care costs, so LTSS financial eligibility is immediate, while to qualify for HCBS through the medically needy spend-down, Juan must first incur expenses in the total amount of his spend-down period before any LTSS coverage begins, even though his total spend-down amount is based on income he will only receive over the course of the following six months. Thus, if Juan and his family do not have \$10,788 of disposable income to cover Juan's bills upfront, institutional care might be the only feasible option for the family.

*NB: The specifics of this example apply only to D.C. While the application process may be largely the same thanks to federal guidelines, each state has significant leeway in creating and implementing its own standards and procedures. This example also does not address the issue of waiting lists that are very common when seeking HCBS waivers. Juan lives in D.C., which at the time of writing does not have a waitlist issue for HCBS waivers.*

Illinois, Minnesota, Missouri, Montana, New York, Ohio, and Utah are Pay-In Spend-Down states. If Juan lived in one of them, on April 15th, the day of his Medicaid application, in addition to \$4,788 worth of bills, Juan could have made a cash lump-sum or installment payment of \$6,000 to reach his Spend Down amount, and thus, become Medicaid eligible before incurring additional expenses. The benefit of this option, when available, is that all of Juan's subsequent medical expenses would be billable at Medicaid payment rates and would be eligible for any discounts and rebates negotiated by Medicaid. Therefore, Juan's expensive medical tests might have reduced his overall spending to \$6,500. While his carry-over expense would be lower (\$500 not \$1,500), Juan's out-of-pocket expense would also only amount to the \$6,000 he paid in (and not the prior \$7,500), since Medicaid would cover anything over his Spend Down amount.<sup>51</sup>

### Qualified Income or Miller Trusts

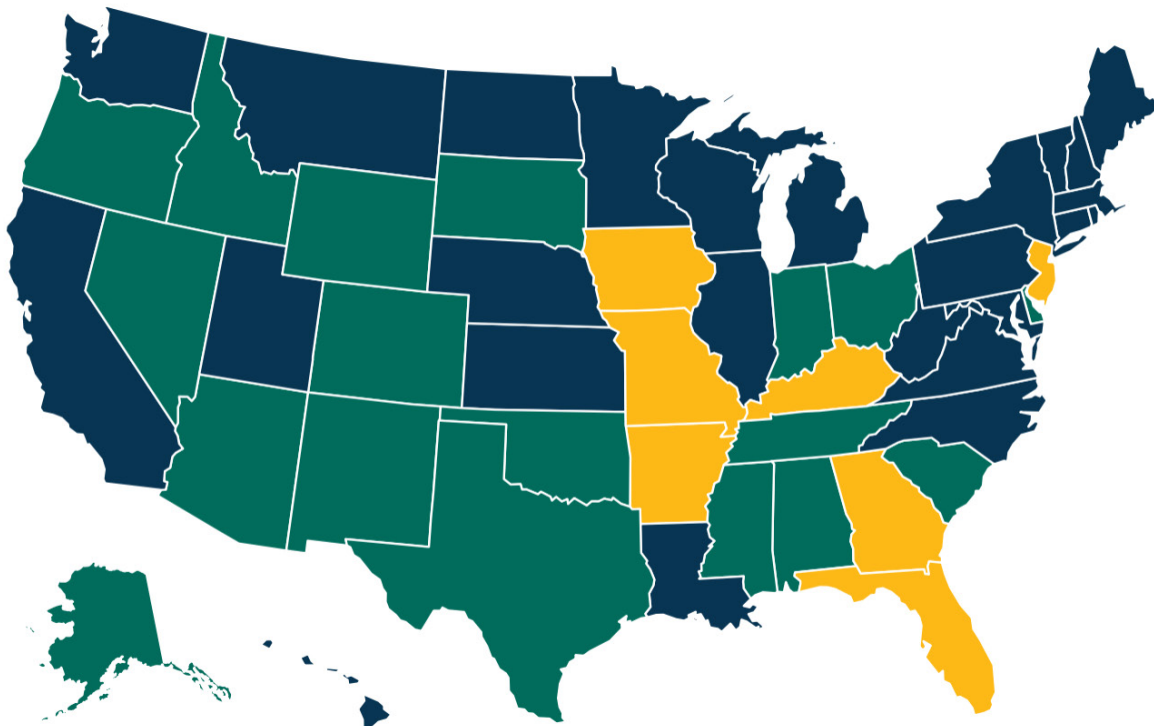
All states that allow trusts for the purpose of accessing Medicaid LTSS coverage also opt-in to the Special Income pathway. Excess income greater than 300 percent of SSI makes seniors ineligible for the Special Income pathway, but in income-cap states, excess income can be placed in a Miller trust to attain eligibility. The trust is used to provide seniors with a personal needs allowance and a spousal allowance (if applicable); the remaining funds are used towards the senior’s cost of care. After the beneficiary’s death, the state is the first remainder beneficiary at death; the state has the right to claim the cost of the beneficiary’s

care up to the total amount that was spent on the beneficiary.

Half of the states (25 of 51) allow Miller trusts to be used by seniors who need institutional care, and 22 of 51 states allow them for HCBS. Some states have income caps for how much can be put in a qualified income trust and depending on the type of care sought, while others do not. It is relevant to note that establishing a Miller trust requires knowledge, strategic planning, and/or access to legal assistance, and thus, may be out of reach for many, particularly those just above the eligibility thresholds.

**Figure 3: Optional Pathways for Seniors Whose Income Limits Are Too High, by State**

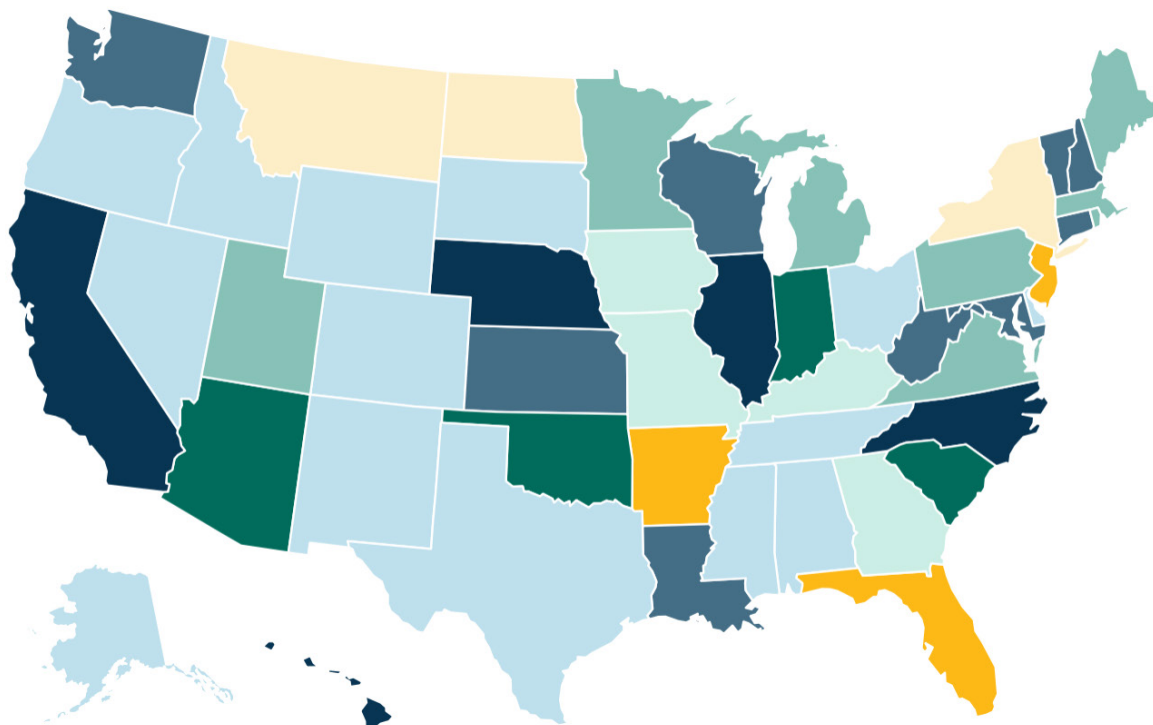
■ Qualified Income Trusts   
 ■ Medically Needy Spend Down   
 ■ Both



Source: US Census Bureau's cartographic boundary shapefiles, 2016 edition; [Flourish](#)



**Figure 4: All Optional Pathways for Seniors to Qualify for Medicaid, by State**



Source: US Census Bureau's cartographic boundary shapefiles, 2016 edition; [Flourish](#)

**Optional Pathways Available**

Old Age (SSI+)	Special Income	QI Trusts	Medically Needy
✓	✓	✓	✓
✓	✓	✓	
✓	✓		✓
	✓	✓	✓
✓			✓
	✓		✓
	✓	✓	
			✓

## III. SPECIAL CONSIDERATIONS

### Dual-eligible Beneficiaries – Medicare and Medicaid

Seniors who are eligible for both Medicare and Medicaid at the same time are called dual-eligible beneficiaries. The vast majority of these beneficiaries receive health insurance coverage under Medicare, a federally run program. Some also have coverage under Medicaid, a program jointly funded by federal and state governments for low-income individuals. While federal standards pertaining to Medicare coverage exist, Medicaid coverage for dual-eligibles is less federally driven and varies. As a result, dual-eligibles may be “full duals” or “partial duals.” Full duals qualify for full benefits from both programs, while partial duals only qualify for some Medicaid benefits. Medicaid covers LTSS only for full eligibles. Therefore, for full eligibles, Medicare covers acute and post-acute care services, while Medicaid covers what Medicare does not, including LTSS.<sup>k,42</sup>

In 2018, there were 5.3 million beneficiaries who were full dual eligibles, compared to 4.2 million in 2006.<sup>43</sup> In 2013, 42 percent of full-benefit dual-eligible beneficiaries accessed some form of LTSS through Medicaid.<sup>44</sup> Twenty percent of these beneficiaries received institutional LTSS coverage through Medicaid, and this 20 percent accounted for more than half (53%) of all Medicaid spending on full-benefit dual-eligibles that year. As the U.S. continues to experience a demographic shift toward an aging population,<sup>1</sup> the number of dual eligibles continues to rise.<sup>45</sup>

Receiving care from two separate systems may impact cost and the quality of care. First, dual-eligible beneficiaries tend to have a higher proportion of chronic illness and, therefore, require costlier care, but conflicting financial incentives may also exist between the two programs, possibly pushing costs even higher. Second, care provided by each program may be uncoordinated, possibly increasing prices and worsening health outcomes. The latter may be particularly salient for populations with multiple chronic conditions and functional limitations; they may end up receiving treatment from various mutually uncoordinated healthcare providers in order to ensure coverage from the assigned programs.<sup>46</sup>

In response to these concerns, the ACA created the Federal Coordinated Health Care Office, also known as the Medicare-Medicaid Coordination Office, to facilitate more effective integration of benefits for dual eligibles that may be implemented through various programs. Although integrated programs have been growing rapidly since 2011, approximately only 10 percent of all full duals, not just seniors, were enrolled in an integrated care program in 2019, indicating that much work remains.

The Program of All-Inclusive Care for the Elderly (PACE) is an example of an integrated care program. PACE was specifically created to provide a comprehensive health and social services program for those older than 55 who require nursing facility care. Its aim is to provide a service package so integrated that it allows most individuals to remain in the community rather than move to a nursing home.<sup>47</sup> The majority of PACE participants are dual eligibles.<sup>48</sup>

### Spousal Impoverishment Rules

The Spousal Impoverishment Rules, enacted by Congress in 1988, protect a portion of a married couple’s income and assets so that the spouse not seeking Medicaid LTSS (frequently referred to as the “community spouse”) may cover their own living expenses after the partner seeks LTSS coverage. These rules were developed in response to the phenomenon of “Medicaid divorce,” when a married couple would divorce in order to preserve assets for the community spouse. Due in large part to these rules and the laws governing the division of property during divorce in various states, Medicaid divorces are much less common than they once were, and would only be relevant for a small percentage of couples today.<sup>m,49</sup>

Federal law made these rules mandatory for all states for nursing home care, but left states the option of covering HCBS. In 2014, a provision in the Affordable Care Act took effect, making spousal impoverishment rules a federal requirement for all HCBS. However, the mandate was not permanent, expiring on December 31st, 2019. It has since been extended five times within a year and a half because each extension was enacted for only three or six months. The current extension was passed through the CARES Act, Section 3812, and it expires on November 30th, 2020.<sup>50</sup> A 2018 survey by the Kaiser Family Foundation found that

<sup>k</sup>As highlighted on Medicare.gov (2020), “Medicare doesn’t cover long-term care (also called custodial care), if that’s the only care you need. Most nursing home care is custodial care.”

<sup>1</sup>The U.S. Census Bureau projects that in 2034 the number of seniors will overtake the number of children in the country, due, in part, to the largest generation, the baby boomers, all reaching retirement age by 2030 (Vespa, 2018).

<sup>m</sup>In 24 of the 51 states a Medicaid divorce still could be relevant if the community spouse has a high level of assets, especially assets in an Individual Retirement Account (IRA), but there are a number of options besides divorce for addressing the issue of high asset amounts.

at least five states intended to scale back or discontinue application of the spousal impoverishment rules applicable to HCBS if the provision was allowed to expire.<sup>51</sup>

The federal maximum for the community spouse's resource allocation is \$123,600, applied by 18 states, while the federal minimum is \$24,720, applied by two states. The remaining states fall in between. The federal income maximum is \$3,090, applied by 19 states, and the minimum \$2,058, applied by 14 states, with the remaining states in between. This is referred to as the monthly maintenance needs allowance. The community spouse also retains any income received solely in their own name. After accounting for these thresholds, the income and assets that remain are used to determine Medicaid eligibility and the Patient Pay Amount.<sup>52</sup>

### Patient Pay Amount

The Patient Pay Amount, also referred to as the Patient Pay Liability or simply Cost-Sharing<sup>53</sup>, is the term used to denote the amount that Medicaid beneficiaries will contribute towards the costs of their LTSS. The Patient Pay Amount will depend on the amount of a senior's countable income as well as the type of LTSS they are seeking. For instance, nursing facilities include room and board in their overall price, while assisted living facilities usually do not. Therefore, a maintenance needs allowance to cover room and board for those applying for assisted living coverage must be taken into account before the final Patient Pay Amount is calculated. The Patient Pay Amount is calculated for all individuals receiving any type of Medicaid LTSS. For some, the Patient Pay Amount will be zero, but this amount must be calculated and input into the state's form. Seniors whose only income is SSI generally have a Payment Pay Amount of zero.<sup>54</sup>

### Medicaid Estate Recovery Program

Federal law requires every state to have a Medicaid Estate Recovery Program. Upon the death of an individual whose LTSS was covered in whole or in part by Medicaid, it is mandatory for the state's Department of Human Services (DHS) to file a claim against the deceased beneficiary's estate up to the amount covered by Medicaid for LTSS. However, DHS may choose to waive estate recovery when it is not cost effective or it would be an undue hardship for other surviving family members. Furthermore, the state will not pursue estate recovery while the spouse lives in the home or a child under age 21, blind or disabled child of any age, or a sibling who has an equity interest in the home.<sup>55</sup>

Medicaid Estate Recovery laws vary by state, and some, such as Wisconsin's, are considered more aggressive than others. It is important to note that applying for LTSS Medicaid coverage may take an emotional toll on seniors who may worry that the Medicaid Estate Recovery Program might claim the few assets they intended to leave to their children. Furthermore, debate exists as to the effectiveness of state recovery efforts thus far. Critics of the current system point to 2014 data that highlight few states doing Medicaid estate recoveries well.<sup>56</sup> Because there is no incentive for individuals to plan for their own LTSS in an efficient and timely manner, this may lead to the overuse and abuse of Medicaid LTSS. As Steve Moses emphasizes, "No further government action has occurred since 2006" to target Medicaid long-term care benefits to the needy or to discourage their overuse by the affluent.<sup>57</sup> This is in contrast to others' equivocal<sup>58,59</sup> or directly oppositional<sup>60</sup> conclusions on the estate recovery program.

### Institutional Care vs. Home and Community Based Care

LTSS coverage through Medicaid maintains a programmatic bias toward institutional care. The federal government only mandates LTSS coverage through nursing care facilities, though states may opt to include HCBS under the old, aged, or disability pathway. Additionally, the optional pathways have different income limit thresholds, which may push people towards institutional care if that threshold is easier to qualify for than the HCBS limit. Furthermore, institutional facility bills can be projected for the spend-down amount and eligibility is retroactive, but the same does not apply for HCBS. This means that to become eligible for Medicaid HCBS coverage, they must first collect bills for Medicaid to find them eligible.

Nevertheless, the majority of HCBS LTSS covered by Medicaid is offered through HCBS waivers; all states have at least one HCBS waiver program in place. The waiver program means that states must prove that HCBS will not be more costly than institutional care for each senior who applies. In practical terms, it also means that Medicaid coverage for institutional care is an entitlement if one meets the eligibility criteria, while in the vast majority of states HCBS is not. Most states report an HCBS waiver waiting list, with an average wait time of 39 months.<sup>61</sup> For seniors hit by a major medical event that need immediate assistance, projecting nursing home costs to obtain immediate eligibility might be the only feasible option for their timeframe.

Despite Medicaid's programmatic bias, recent trends have

<sup>51</sup> After President George W. Bush signed the Deficit Reduction Act of 2005 (DRA '05) placing the first cap ever on Medicaid's home equity exemption, limiting the half-a-loaf loophole, amending the annuity rules, and unencumbering the Long-Term Care Partnership Program, Medicaid planners reassured their colleagues and clients that artificial self-impoverishment to qualify for Medicaid remained feasible and no less ethical than tax planning (Moses, 2020).

demonstrated the benefits of expanding access to HCBS, when appropriate and preferred by the beneficiary. First, as mentioned earlier, beneficiaries generally prefer to stay in their homes and/or their communities rather than being institutionalized, which provides seniors with a higher level of autonomy in decision-making about their daily life. Second, HCBS costs less on an individual basis than institutional care for states<sup>62</sup>; even if some seniors end up in a nursing home after years in HCBS, the state still has lower costs while they are in HCBS. Third, states also have to fulfill community integration obligations for people with disabilities.<sup>63</sup> An emerging perspective on HCBS is that it may also serve to provide preventative services in an attempt to delay the need for future institutional care, which is costlier. For instance, providing HCBS for some **instrumental activities of daily living (IADLs)** such as preparing meals, housework, and transportation may prevent a senior from falling and breaking their hip while doing housework, so the supports allow them to stay on HCBS longer than they would have if they did not receive it as preventative care.<sup>64</sup> However, there are legitimate concerns and supporting data to indicate that facilitating access to HCBS will increase HCBS utilization, rather than merely shifting would-be nursing home beneficiaries to HCBS. In other words, more individuals will apply for Medicaid LTSS coverage if it involves care at home or in the community than if nursing home is the only LTSS option.<sup>65</sup>

It is important to note the impact of the COVID-19 pandemic on seniors. As a high-risk group, seniors already face worse morbidity and mortality outcomes as a result of COVID-19 infection. As a result, nursing homes and assisted living facilities became centers of infection, leading to many deaths. The situation has once again brought to the forefront the benefits of keeping seniors at home and in their communities, when possible to minimize the risk of infection. Therefore, asking for expanded and facilitated access to HCBS is timelier than ever.

## HCBS Supports the Role of the Family in Beneficiaries' Lives

Unmet long-term care needs cause significant burden to families, and public policies can improve the delivery and accessibility of HCBS. Because of the inadequacy of the current long-term care system in the U.S., the implications for families and their roles is examined here.

While LTSS needs affect families of all sizes and structures, those with higher incomes and stronger family and social networks have more resources to cover needed services. Medicaid is often described as serving low-income individuals and families, but the financial impact of LTSS is often significant for families along the income spectrum. Unexpected high expenses can drain assets and reduce family wealth, leading to intergenerational impacts; this is often the case when seniors spend down their assets in order to meet income eligibility requirements for Medicaid.

It is also important to consider how facilitating HCBS may impact families with more limited resources differently. While it is crucially important to ensure that high quality services are fully accessible in underserved communities, certain environments may be particularly challenging to accommodate HCBS, such as small apartments and buildings without elevators. Services should be responsive to individual, family and community needs, and can adjust to changing priorities as health and other conditions change over time. Flexible services that provide family-centered services and supports are an important way to promote equity.

Additionally, because public programs facilitate access to institutional care over HCBS, services provided within an institutional context may not be in line with family preferences, goals, and values. HCBS can have a strong impact on the family's protection function. Families often support older adults in accessing healthcare, housing, food and social support. Facilitating HCBS would particularly support families in maintaining structures

**"As a result, nursing homes and assisted living facilities became centers of infection, leading to many deaths. The situation has once again brought to the forefront the benefits of keeping seniors at home and in their communities, when possible..."**

<sup>65</sup>In a seven-state study, "in most states, the number of additional waiver clients often greatly exceeded reductions in nursing home residents" (Kane et al., 2013)



and relationships. For many families, HCBS entails a financial component; a Social Security check may be a key component of a multigenerational household's budget, and a family can preserve that income only if HCBS is an option. By preventing family impoverishment, long-term care programs can also enhance intergenerational well-being.

LTSS can enable family networks to play mediating roles in the care of family members. HCBS allows families to remain intact and maintain their lifestyles regarding diet, activity, and other priorities. Home care services also can take some responsibility off family members (for example, helping with bathing, use of toilet, and medication compliance) allowing for more choice regarding role definitions within the family. Because studies have shown that expansion of community-based services does not decrease the amount of unpaid care provided by family and friends,<sup>66</sup> greater access to paid services likely would result in better overall care for the chronically ill by helping reduce burnout and caregiver fatigue. Ideally, family members will be more involved in care when an ill relative is able to remain in the home and will have the ability to work in partnership with the providers to support the preferences of the individual and other family members.

Families also have a key role in creating, preserving and

transmitting values, which is often important when caring for an ill or aged family member. Importantly, support services, such as transportation and adult day care, can enable chronically ill individuals to remain involved in their families and communities. Family members are often burdened by the stress of caregiving, yet caregivers can find the role rewarding, and consistent with the value they place on caregiving. The benefits of support services would likely be greatest for women, as women perform the majority of unpaid caregiving.

Caregivers often receive little support, and suffer emotional, physical, financial and work-related difficulties. While many family members willingly take on the caregiving role, they often are not integrated into systems of care, and their needs and abilities are not assessed. Many caregivers are unable to maintain employment due to their caregiving burden. In addition to the financial impact of lost wages on individuals, one study estimated that American companies lose more than \$25 billion each year due to absenteeism of full-time working caregivers.<sup>67</sup> Beyond missed work, caregivers report decreased productivity while at work.<sup>68</sup> While some aspects of family caregiving are difficult to disentangle from routine family interactions, the role is highly variable and can lead to physical, emotional and economic difficulties.

**"The benefits of support services would likely be the greatest for women, as women perform the majority of unpaid caregiving."**

## **IV. THE CASE FOR ACCESSIBLE LONG-TERM SERVICES AND SUPPORTS**

The distribution of long-term care expenses is both wide and unpredictable. The difficulty in anticipating an individual's long-term care needs presents a major challenge to both families and insurers. Many people will have no long-term care expenses, either because they will have no needs, or they will be able to rely exclusively on family caregivers. Both the intensity and duration of long-term care needs determine the lifetime cost. An Urban Institute study projected that an average 65 year old American will incur about \$138,000 in future lifetime expenses for severe long-term care needs; however, 48 percent will likely never experience severe needs, while 15 percent will incur more than \$250,000 in lifetime expenses.<sup>69</sup> Additionally, costs

vary greatly by state, with nursing home costs being more than twice as high in expensive states as in less expensive states.<sup>70</sup>

There have been multiple bipartisan efforts to develop strategies and policy options to address the projected increase in LTSS needs for older adults, demonstrating that the current system leaves many unprotected. For instance, the Commission on Long-Term Care, created by federal law in 2013, made broad recommendations with bipartisan support for a long-term service and support system "built on concepts of (1) person- and family-centered care; (2) a well-trained and adequately supported array of family



caregivers and paid workers; and (3) a comprehensive financing approach that would balance public and private financing to insure the most catastrophic expenses, encourage savings and insurance for more immediate long-term care costs, and provide a strong safety net for those without resources.<sup>71</sup> More recently, two bipartisan reports released in 2016 recommended improving the market for private insurance, revamping Medicaid's long-term care services, and encouraging home and community-based services.<sup>72</sup> Despite these areas of consensus, bipartisan agreement on specific financing strategies has not yet been achieved.

A key challenge remains the philosophical question about the role of government versus individuals and families in providing for the needs of older adults. Yet the uncertainty of future expenses, as well as the extreme costs in some cases, leads to significant financial risks that no one, not individuals nor public entities, are planning for today. Any proposal with voluntary insurance plans will be challenged by adverse selection, regardless of whether the plan is publicly or privately funded. When only individuals likely to need expensive services purchase insurance coverage, the risk to insurers is high, leading to high premiums for coverage, or to insolvent plans. Proposals can aim to reduce costs by minimizing adverse selection. Studies that have modeled different insurance options have found that mandatory options would have the greatest impact on reducing Medicaid costs.<sup>73</sup> Mandatory coverage would have a greater impact on low and middle-income individuals, who have higher expected long-term care costs than high income individuals, and might otherwise be unable to purchase coverage. Yet mandatory coverage is viewed by many as overreach by government.

Another concern is the argument that expanding public coverage would reduce family caregiving. However, studies have shown that unpaid care does not diminish when paid care is also received, suggesting that publicly financed LTSS would supplement but not replace care already provided by unpaid caregivers.<sup>74</sup> Support for public coverage of LTSS reflects the social value of government providing support to older adults to enable independence and wellbeing.

Family caregivers often need support to enable working caregivers to maintain their employment while caring for their family, and such support will have intergenerational benefits in both income and family function. Caregivers are challenged by the healthcare system which focuses on individual autonomy and privacy, at the expense of integrated care and shared decision-making.<sup>75</sup> Providers should appropriately engage family caregivers in care planning, and additional training and incentives might encourage this work.

While consensus regarding financing remains elusive, the need for a robust system of quality services, with appropriate oversight and integration with other health and social services, is less controversial. Additional focus should be placed on building a strong workforce able to support the evolving needs for care. Studies have projected that the United States will need more than 3 million more healthcare workers by 2030 to continue to provide the current level of services to the growing population.<sup>76</sup> The continued shift from institutional care to HCBS will require a change in the staffing structures for LTSS, including particular growth in entry-level roles. An increased focus on worker availability, training and retention will be essential.

It is clear that the cost of inaction will increase in coming years, both in the direct costs within Medicaid and out-of-pocket spending, and in the burden on unpaid family caregivers. A robust system of long-term care services could support older adults and promote healthy aging, rather than covering care only when all other options have run out. Family caregivers remain essential but cannot shoulder the burden of caring for older Americans alone.

**“Family caregivers often need support to enable working caregivers to maintain their employment while caring for their family, and such support will have intergenerational benefits in both income and family function.”**

# POLICY DISCUSSION AND RECOMMENDATIONS

While many previous long-term care proposals have failed to become law for various reasons, the current system will increasingly fall short of meeting the needs of older adults, and it will create pressure on state Medicaid budgets as our country's demographics grow older. Policymakers should prioritize the development of a robust, comprehensive, financially sustainable system that supplements the care already provided by unpaid caregivers.

European countries face similar challenges and some have created long-term care systems that differ in public and private coverage, integration with acute healthcare systems, eligibility, and overall spending on long-term care.<sup>77</sup> For example, the Netherlands has universal long-term care coverage through a public insurance model and no private coverage, and spends a relatively high percent of GDP on long-term care. England, however, is structured more like the U.S., providing public long-term care benefits dependent on income level, with private policies often prohibitively expensive. France has higher rates of private coverage, primarily through a group insurance plan that reduces adverse selection, but because the private insurance provides limited benefits, many older adults still rely on public benefits to supplement coverage. Perhaps the best European country in terms of a role model for the U.S. is Germany, which made a number of changes to expand access and improve LTSS: increasing contributions to fund LTSS, allowing for various caregiver leave options, addressing the special needs of patients with dementia, providing counseling for caregiving relatives, and reforming the nursing professions.<sup>78</sup> Other European countries also have policies to support caregivers, including spending allowances, paid leave, and training, education, respite care, and counseling for caregivers. The long-term care systems in European countries reflect varied social service and healthcare systems, as well as different levels of commitment to addressing the needs of their aging populations.

In the U.S., mandatory coverage for both healthcare and long-term care has been highly controversial. A program created through the ACA that was subsequently repealed is a case in point. The Community Living Assistance Services and Supports (CLASS) program would have been a voluntary public long-term care insurance program that aimed to provide financial support to individuals with serious disabilities, regardless of age. Its structure

(legislatively) was flawed and could not be fixed prior to implementation and demonstrates the financial challenge of a voluntary program. Because of adverse selection, individuals likely to require the most expensive care will sign up while healthy individuals can decline coverage to avoid premiums. The voluntary public coverage was therefore deemed unsustainable and not implemented. However, private insurance markets face similar challenges, and could likely only address the high risk by having prohibitively high premiums. Encouraging private insurance coverage may therefore only benefit the wealthy who are able to afford high premiums.

Trends within the healthcare system may have an impact on the long-term care policy discussion. First is an increased focus on **healthy aging**. The CDC defines healthy aging as “the development and maintenance of optimal physical, mental (cognitive and emotional), spiritual, and social well-being and function in older adults.”<sup>79</sup> Healthy aging can be promoted by physical environments and communities that are safe and support health-promoting attitudes and behaviors, as well as health services and community programs to prevent and minimize the impact of acute and chronic disease. Low-cost prevention programs, such as those that teach senior citizens how to avoid falls or how to manage chronic conditions like diabetes, can reduce hospitalizations and nursing home admissions, which are significant costs for Medicaid programs.

In addition, both clinical and community supports are essential for addressing cognitive decline. The CDC and other federal agencies are focused on medical research to understand and prevent cognitive decline, while developing health promotion strategies to address this challenge within the community context. However, policy action remains essential to reducing the burden of cognitive and physical limitations on family finances and functioning.

Additionally, recognition may be increasing regarding the role of health insurance in promoting lifelong health. The current healthcare system includes payment and incentive systems focused on short-term goals, and an annual enrollment cycle for insurance coverage.<sup>80</sup> Yet Medicare and Medicaid provide increasingly long-term coverage, due to both the increase in life expectancy, and thus, the greater need to manage chronic illness, and Medicaid covering

LTSS. This may increase the focus on health promotion within the healthcare system, incorporating both medical and non-medical approaches. Innovative approaches could include expanded integration of healthcare and social services, and accountable care systems focused on long-term health. While this would be a major shift within the healthcare system, it aligns with the focus on value and outcomes.

Finally, the expansion of healthcare access, through both the Affordable Care Act and Medicaid expansion, may shift public perceptions of the importance of healthcare coverage. While universal coverage is not yet reality, the broader public acceptance of a minimum standard of health coverage for all could potentially affect views regarding long-term care.

Given the failure of both incremental and comprehensive strategies, multiple approaches may be necessary to maximize the likelihood of providing LTSS for all who need it, with a rational financing strategy. While long-term care is often considered within the broader healthcare system, advocacy efforts should proceed both within and beyond this system in order to maximize options for older adults. For example, initiatives for aging-friendly communities, strong transportation infrastructure, affordable and accessible housing, community nutrition programs, and strong public institutions such as libraries, can have significant impact on the ability of older adults to remain in their communities and live independently. While certain aspects of long-term care are more closely linked to medical care and may require trained staff, other services provide social support and enable independence without linkage to health services.

To address the unpredictable yet potentially catastrophic costs of long-term care needs, long-term care programs should provide universal coverage based on need. Some proposals have suggested long-term care services within Medicare, which would expand the entitlement based on the need for care regardless of income, while others have shown positive results from Medicaid managed care.<sup>81,82</sup> The key feature of these proposals is that they do not require an individual to choose coverage in anticipation of their future needs, but rather provide the coverage if necessitated by physical or cognitive decline.

States are leading the way in the absence of federal action to deal with rising long-term care costs. In 2019, Washington became the first state to adopt a social insurance program to address long-term care needs and provide near-universal coverage. The Long Term Care Trust Act was passed by the Washington legislature in April 2019 and signed into law

by the governor in early May.

Washington residents will pay 58 cents of every \$100 in income into the long-term care trust fund beginning in 2022. After paying into the trust fund for ten years, residents can claim up to \$100 a day in benefits, with a lifetime cap of \$36,500. However, residents can access benefits after three years if they experience a catastrophic disabling event, and the lifetime cap on benefits rises with inflation. The earliest the program could begin paying benefits would be 2025.

While a lifetime cap of \$36,500 may seem small, it could go a long way for the many older Americans with more manageable long-term care needs. Relatively few will spend years in a nursing home, the most expensive form of long-term care. Many seniors simply need lower-cost services, such as a home health aide or home modifications, and receiving these services can actually prevent the move to a nursing home. If successful, this program could serve as a model for other states and even a federal program.

In addition to expanding access to LTSS through universal coverage, the bias in favor of institutional care should be eliminated. With data showing that home and community-based care is largely preferred by beneficiaries and that it leads to substantial savings for states, there is no justification for the system to make access to institutional care easier in comparison to HCBS. Furthermore, facilitating HCBS, when appropriate, is in line with human rights obligations to people with disabilities and reduces burnout and caregiver fatigue among family members.

Advocates for older adults should continue to promote public policies to provide insurance against catastrophic expenses, and a more integrated system of high-quality support services for older adults. Optimal programs will have financial costs and, thus, require significant political will. Yet all Americans stand to benefit from programs that serve older adults without frustrating families who are facing emergency health needs.

## CONCLUSION

Healthcare and long-term care costs continue to increase in the U.S. as the proportion of the population 65 and older grows. Simultaneously, Medicaid has become the country's primary payer for expensive long-term services and supports (LTSS). Accessing LTSS coverage through Medicaid occurs through multiple, complex pathways, which are highly variable by state and very confusing for families. Those who cannot qualify for Medicaid coverage pay out of pocket, if they can, or depend on unpaid caregiving by family members.

Multiple approaches are likely to be necessary to maximize the likelihood of providing LTSS for all who need it, with a rational financing strategy. First, all long-term care proposals should provide universal coverage based on need.

Second, a stronger focus on healthy aging for all should entail the integration of healthcare and social services, and accountable care systems focused on long-term, not short-term, health. Third, the ability of older adults to remain in their communities and live independently should be facilitated by the expansion of aging-friendly communities, strong transportation infrastructure, affordable and accessible housing, community nutrition programs, and strong public institutions such as libraries.



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## Our Mission

The National Institute on Retirement Security is a non-profit research and education organization established to contribute to informed policymaking by fostering a deep understanding of the value of retirement security to employees, employers, and the economy as a whole.

## Our Vision

Through our activities, NIRS seeks to encourage the development of public policies that enhance retirement security in America. Our vision is one of a retirement system that simultaneously meets the needs of employers, employees, and the public interest. That is, one where:

- employers can offer affordable, high quality retirement benefits that help them achieve their human resources goals;
- employees can count on a secure source of retirement income that enables them to maintain a decent living standard after a lifetime of work; and
- the public interest is well-served by retirement systems that are managed in ways that promote fiscal responsibility, economic growth, and responsible stewardship of retirement assets.

## Our Approach

- High-quality research that informs the public debate on retirement policy. The research program focuses on the role and value of defined benefit pension plans for employers, employees, and the public at large. We also conduct research on policy approaches and other innovative strategies to expand broad based retirement security.
- Education programs that disseminate our research findings broadly. NIRS disseminates its research findings to the public, policy makers, and the media by distributing reports, conducting briefings, and participating in conferences and other public forums.
- Outreach to partners and key stakeholders. By building partnerships with other experts in the field of retirement research and with stakeholders that support retirement security, we leverage the impact of our research and education efforts. Our outreach activities also improve the capacity of government agencies, non-profits, the private sector, and others working to promote and expand retirement security.

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The National Institute on Retirement Security is a non-profit research institute established to contribute to informed policy making by fostering a deep understanding of the value of retirement security to employees, employers, and the economy as a whole. NIRS works to fulfill this mission through research, education, and outreach programs that are national in scope.



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