

ON THE ISSUES: MEDICAID AND DEMENTIA

More than 5.5 million people in the United States are living with Alzheimer's disease or another form of dementia. Nearly 25 percent of these individuals receive care through the Medicaid program, the federal-state health insurance program for low-income individuals, as well as certain older adults and people with disabilities. Medicaid covers many services and supports that are essential to the health and well-being of people living with dementia but that are not covered by private insurance and Medicare, such as institutional and community based long-term services and supports, transportation, and respite for caregivers. The broad array of supports and services make the program indispensable for many individuals with significant health care needs.

What is Medicaid?

Medicaid is the health insurance program for low-income adults, children, pregnant women, older adults, and people with intellectual and physical disabilities who have high medical bills and limited resources. The precise eligibility criteria varies from state to state, as each state administers its own Medicaid program, in accordance with broad general requirements established by the federal government. This results in significant differences in eligibility criteria and covered services across the country. In 2016, Medicaid spending nationwide was approximately \$553 billion and the program covered over 70 million people.¹

Medicare, on the other hand, is the federal health insurance program for people over the age of 65 and people with disabilities. In Medicare, states do not determine eligibility or coverage.

Medicaid is a state and federal partnership that provides health insurance for a wide range of individuals, including certain income-eligible adults, parents, children, pregnant women, older adults, and people with disabilities. The precise eligibility criteria varies from state to state.



Medicare is a federal health insurance program for certain individuals. This includes people over the age of 65, people who have received Social Security Disability Insurance for 24 months, and individuals with End Stage Renal Disease or Amyotrophic Lateral Sclerosis.

SERVICES COVERED BY MEDICAID:

- Long-term care in nursing homes
- Assisted living
- Home and community-based services including:
 - Personal Care
 - Homemaker Supports
 - Respite for Family Caregivers
 - Adult Day Services
 - Medication Management
- Dental
- Vision
- Hearing care
- Non-emergency medical and non-medical transportation

Why is Medicaid important for people with Alzheimer’s disease and other forms of dementia?

There are more than 5.5 million Americans living with Alzheimer’s disease or another form of dementia.ⁱⁱ It is estimated that 1.4 million Americans live with Lewy body dementiaⁱⁱⁱ, and at least 50,000 people living with frontotemporal degeneration^{iv}, and many more living with other forms of dementia, like vascular dementia. The Alzheimer’s Association estimates that care costs of dementia will reach an estimated \$259 billion in 2017.^v Of that amount, Medicare and Medicaid will account for \$175 billion, or 67 percent, of the total health care and long-term care payments, while out-of-pocket spending is expected to be \$56 billion.^{vi} Average annual Medicaid spending for an older American with dementia is \$8,182, while the cost for a senior without dementia is only \$349.^{vii}

Nearly all people with dementia in the United States are on Medicare^{viii}, with the exception of approximately 275,000 individuals with young-onset dementia who are not

automatically eligible.^{ix} Nearly 25 percent of individuals with dementia on Medicare also are enrolled in Medicaid. These individuals who are “dually eligible” for both Medicare and Medicaid receive different supports and services from the two programs. Medicare covers primary and acute care, such as inpatient hospital care, as well as some doctor visits and other medical services. Medicare may cover short-term care at a skilled nursing facility on a limited basis or home health care under certain circumstances. Additionally, Medicare Part D covers outpatient prescription drugs. Approximately 9.9 million people, or 25 percent of all Medicare beneficiaries, are known as “dual eligibles” meaning they qualify for both Medicare and Medicaid benefits and receive different services and supports from each program.^x

Medicaid is an important source of coverage, even for individuals who also have Medicare because the service needs of people living with dementia often vastly exceed what Medicare covers. Medicaid provides assistance with Medicare cost-sharing, as well as long-term services. Out-of-pocket costs often are high and most Americans lack long-term care insurance. For those who qualify, Medicaid covers some of the essential services Medicare does not. Medicaid is essential for many people with dementia, particularly when they need to permanently live in assisted living or nursing home settings, which are not covered by Medicare.

SERVICES COVERED BY MEDICARE:

- Physician services
- Inpatient Hospital
- Short-term Skilled Nursing Facility and Inpatient Rehabilitation Care
- Home health
- Prescription Drugs

Medicaid and Family Caregivers

Most people with dementia rely on family or other unpaid caregivers for help with everything from activities of daily living to social interaction. Medicaid covers the primary, acute, and long-term services and supports (LTSS) needs of millions of low-income Americans of all ages. In some cases, Medicaid also assists these caregivers with long-term services and supports like respite services, adult day health programs. It may also provide training and support to caregivers. Some states also administer assessments that determine if the caregiver has any specific needs and identify other programs available to assist them. With limited coverage under Medicare and few affordable options in the private insurance market, Medicaid will continue to be the primary payer for a range of institutional and community-based LTSS for people with dementia and for caregivers needing assistance with daily care tasks.

Nationwide, most LTSS are provided by unpaid caregivers, like relatives and friends, in home and community-based settings that allow many with LTSS needs to age in place. According to a 2015 national survey, “Caregiving in the U.S.”^{xii} most family caregivers are women age 50 and over who care for a parent while maintaining outside employment. This unpaid care ranges from help with getting to medical appointments, or paying bills to more intensive care such as assisting with bathing or wound care. As a person’s daily care needs become more extensive, paid LTSS delivered by direct care workers – medical professionals (such as physicians or nurses) or para-professionals (such as nurse aides or personal attendants) – may be required in addition to or in place of family caregiver services. Given the degenerative nature of dementia and its course often running beyond a decade, LTSS is particularly vital to help individuals remain in their own homes and avoid premature institutionalization. Some of the personal care services may be covered by Medicaid.

Medicaid and Long-Term Care Financing

Long-term services and supports (LTSS) encompasses the broad range of paid and unpaid medical and personal care assistance that people may need when they have difficulty completing self-care tasks because of aging, chronic illness, or disability. LTSS help with activities of daily living like eating, bathing, and dressing, and instrumental activities of daily living like preparing meals, managing medication, and housekeeping. LTSS include, but are not limited to, nursing facility care, adult day health programs, home health aide services, personal care services, and transportation, as well as assistance provided by a family caregiver. Care planning and care coordination services are a required component of Medicaid home and community-based LTSS. These supports help beneficiaries and families navigate the health system and ensure that the proper providers and services are in place to meet beneficiaries’ needs and preferences; these services can be essential for LTSS beneficiaries who often have substantial acute care needs as well. Nationally, Medicaid finances more than half of all paid LTSS.^{xii}

Medicaid Home and Community-Based Services (HCBS)

States have a great deal of flexibility in how they design their state systems of Home and Community-Based Services. States can include services and supports in their state plan. There are many state plan options, including the 1915(c) HCBS Waivers, 1915(i) HCBS State Plan Option and 1915(k) Community First Choice Option.

The most common way states have provided HCBS is through the Medicaid Home and Community-Based Services waiver program authorized under Section 1915(c) of the Social Security Act. The HCBS waivers allow states to set up demonstrations or pilots to provide services that allow those who need care to receive those services in their homes or communities. Under a waiver program, a state can waive certain Medicaid program requirements allowing the state to target services and supports to certain populations and to impose caps on the number of enrollees, often resulting in waiting lists for those services in the state. States frequently have used the 1915(c) HCBS waiver program to tailor services and supports to individuals with Alzheimer's and dementia. Waivers can be used along with federal, state, and local programs, such as Medicaid state plans and Administration on Aging grants.

HCBS waivers usually are targeted to specific populations. Some of the most common target groups include:

- Individuals with intellectual and developmental disabilities, which could include autism;
- Older adults and people with physical disabilities;
- Medically fragile and palliative care; and
- Individuals with traumatic and/or acquired brain injuries.



Self-directed services

Self-directed services like the Cash and Counseling programs allow family members and friends of a Medicaid beneficiary to be paid as caregivers. Cash and Counseling programs are based on Medicaid HCBS waivers. These programs can help people with dementia get the care they need, when they want it, in their home while providing financial support for a caregiver of their choice. The program participant (the individual in need of assistance) hires their family member or friend as their personal care provider. This provides the beneficiary with cash assistance and with the flexibility to "consumer direct" or self-direct the spending of their resources on care providers of their choosing. Most states have their own names for their Cash and Counseling

Programs, typically associated with a specific Medicaid waiver: IndependentChoices in Arkansas, In Home Supportive Services in California, and the Choice Waiver in Michigan.

Presuming the individual in need of care is already Medicaid-eligible, these programs typically work as follows: 1) An assessment to determine the beneficiary's care needs; this includes interviews with caregivers and the beneficiary's physicians; 2) A determination is made regarding how many care hours per month are required; 3) The benefit amount or budget is calculated using the number of care hours and cost of care for that specific geographic area. This budget can be increased or decreased as the beneficiary's needs change. Program participants are considered to be "employers," and they decide how to allocate the budget they are given. They can hire family members as "employees," including their adult children, and in some states, even spouses. Most programs do not exclude the adult children, in-laws or grandchildren. Payment rates to the care providers are determined by the program rules or by the fiscal intermediaries. Typically, care providers are paid an hourly rate several dollars per hour less than the state's hourly average for home care workers.

Research from the Cash and Counseling project provides some important insights into the benefits of participant direction. Evaluation results showed that:^{xiii}

- Participant direction significantly reduced the unmet needs of Medicaid consumers who require personal assistance services;
- Participants experienced positive health outcomes;
- Quality of life for participants and their caregivers improved;
- The program did not result in misuse of Medicaid funds or abuse of consumers; and
- It proved to be a cost-effective option per member.

Demand for participant direction is rising because many people, including those in earlier stages of dementia, want control and independence. This makes participant direction a breakthrough for long-term care.



What would Medicaid cuts, imposition of per capita caps or block grants mean for people with Alzheimer’s disease or other forms of dementia?

The Trump Administration and its allies in Congress aim to radically restructure Medicaid by limiting federal funding to states through per capita caps or block grants. Artificially limiting the amount of spending per Medicaid beneficiary would be devastating for many people living with dementia and their family caregivers. Shifting costs to the states would force states to cut eligibility, reduce benefits, and lower provider reimbursement, particularly for high-cost enrollees who need substantial services under the program.^{xiv} Inevitably, cuts to the Medicaid program will result in enrolling fewer people, cutting services and supports, or both.

Capping federal contributions to Medicaid would put states with larger aging populations at a disadvantage and harm state residents. Per capita cap proposals ignore the real growth rate in health and long-term care costs and the rapidly rising number of Americans living with dementia. If enacted, per capita caps will force states to take actions such as tightening eligibility for Medicaid, removing people who currently have coverage from the program, cutting services or reducing Medicaid payments to service providers. In addition, Medicaid cuts will have a negative impact on the direct care workforce, lowering wages and promoting staff turnover. Required cuts to Medicaid would accelerate over time, with most going into effect beginning in 2020, just as many baby boomers begin to need home and community-based services.^{xv}

According to the 2014 Long-term Services and Supports Expenditure Report, in 2014, for the first time in the Medicaid program’s history, more than half of Medicaid funding for long-term care (53 percent) was spent on home and community-based services aimed at keeping people of all ages out of institutions.^{xvi} However, states need to do more to “rebalance” their systems to provide more access to home and community-based services. There is a great deal of variation across states. The cost of care at home is usually significantly lower than in an institution, and most people want to remain in their own homes as long as possible. Strong HCBS systems help prevent premature institutionalization with its associated higher costs. Genworth Financial reports that, in 2016, the national median cost of

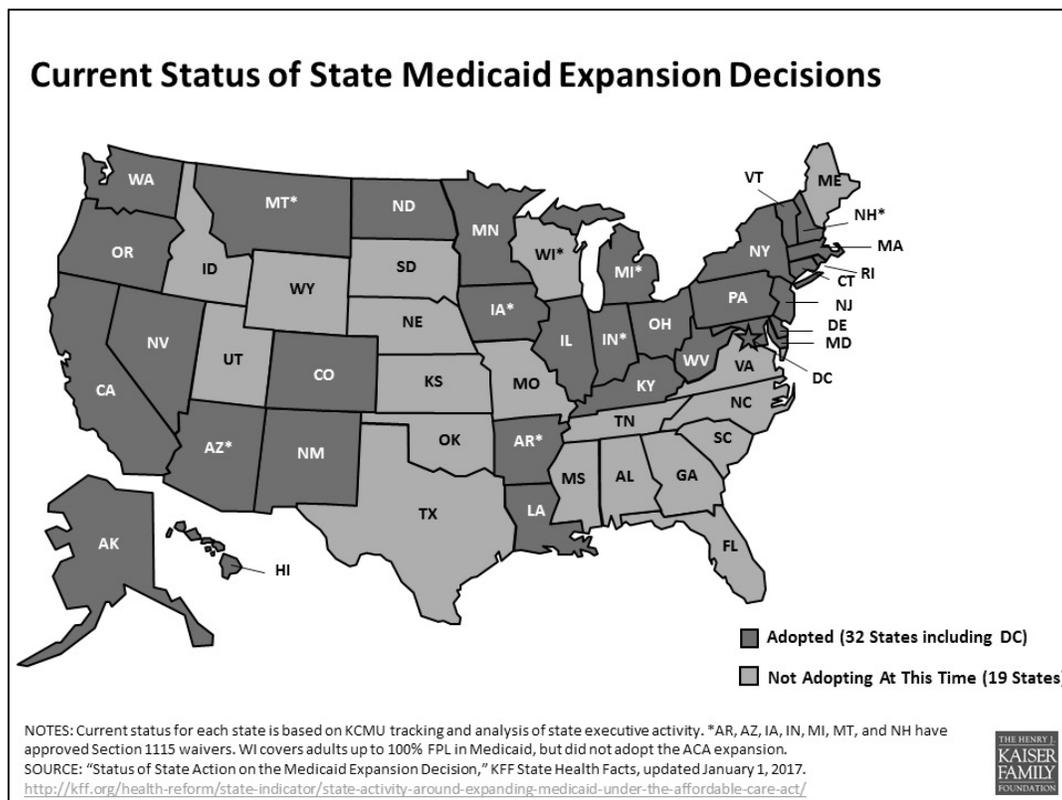
DID YOU KNOW?

- In 2017, there were 74 million people on Medicaid with \$553 billion in payments
- 9.9 million people are eligible for both Medicare and Medicaid
- 24% of people with dementia are on Medicaid
- 17.3 million people on Medicaid received home health services in FY 2016 totaling \$6.3 billion in payments
- 1.2 million people on Medicaid received personal care services in FY 2016 totaling \$11.5 billion in payments^{xviii}
- In 2016, 15.9 million family and friends provided 18.2 billion hours of unpaid assistance to those with Alzheimer’s and other dementias, a contribution to the nation valued at \$230.1 billion^{xiv}
- 5.5 million Americans live with Alzheimer’s disease or other forms of dementia
- 1.4 million people (estimated) have Lewy body dementia
- 50,000 people (estimated) have frontotemporal degeneration
- Approximately 275,000 are younger than age 65, with early-onset Alzheimer’s disease

a shared nursing home room was \$82,125 annually, while the median cost of a home health aide was \$46,332 annually for 44 hours of support each week.^{xvii}

While HCBS are more cost-effective, these services are optional for states. Nursing facility services are mandatory. Under per capita caps, many states would be forced to cut back on HCBS, in turn placing more unsustainable burden on family caregivers trying to support their loved ones at home and resulting in greater reliance on costlier institutional care.

The Impact of Medicaid Expansion



The Affordable Care Act expanded the availability and eligibility of the Medicaid program, which 32 states adopted as of 2017. In these expansion states, Medicaid coverage eligibility includes nearly all adults up to 138 percent of the federal poverty level. In a literature review of more than 100 studies, researchers at the Kaiser Family Foundation found states that expanded Medicaid saw gains in coverage and lower uninsured rates than states that did not expand their Medicaid programs. The review also found that expansion improved access to care, utilization of services and financial stability for Medicaid beneficiaries.^{xviii} Medicaid expansion is particularly important for people who may have been diagnosed with young onset Alzheimer's disease but who are not able to establish Medicaid eligibility through a disability-related group. These participants would not be eligible for Medicare and would likely struggle to receive the supports and services necessary to manage their disease without this Medicaid coverage group.

Issue Brief Recommendations

- Maintain the current Medicaid funding system to ensure that the program is able to meet the needs of an expanding aging population and growing number of people living with Alzheimer’s disease and other forms of dementia.
- Do not impose Medicaid funding limits or per capita caps and do not restructure Medicaid into a block grant program for states.
- Continue to assist states to “rebalance” their Medicaid programs to encourage greater utilization of home and community-based services and reduce premature institutionalization.
- Increase options for individuals and families to self-direct their HCBS to better meet their needs.
- Enhance support for family caregivers within Medicaid, including assessment of caregiver needs and access to evidence-based family support programs.

About the LEAD Coalition

Leaders Engaged on Alzheimer’s Disease (LEAD Coalition) is a diverse and growing national coalition of more than 90 member organizations committed to overcoming Alzheimer’s disease and other forms of dementia. The coalition works collaboratively to focus the nation’s attention on accelerating transformational progress in: (1) care and support to enrich the quality of life of those with dementia and their caregivers; (2) detection and diagnosis; and (3) research leading to prevention, effective treatment, and eventual cures.

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About This Brief

The LEAD Coalition staff, member organizations, and other national experts authored the brief. Please note that this brief does not represent the consensus of the LEAD Coalition or individual alliance member organizations.

Share feedback and questions by emailing info@leadcoalition.org.

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- ⁱ <http://files.kff.org/attachment/Issue-Brief-Medicaid-Enrollment-and-Spending-Growth-FY-2017-and-2018>
- ⁱⁱ <http://www.alz.org/facts/>
- ⁱⁱⁱ <https://www.lbda.org/category/3437/what-is-lbd.htm>
- ^{iv} <https://www.theaftd.org/wp-content/uploads/2009/05/Fast-Facts-Final-11-12.pdf>
- ^v <http://www.alz.org/facts/>
- ^{vi} <http://www.alz.org/facts/>
- ^{vii} http://act.alz.org/site/DocServer/2012_Costs_Fact_Sheet_version_2.pdf?docID=7161
- ^{viii} <https://www.kff.org/about-kaiser-commission-on-medicare-and-the-uninsured/>
- ^{ix} <https://www.usagainstalzheimer.org/crisis>
- ^x <http://www.kff.org/medicaid/state-indicator/dual-eligible-beneficiaries/>
- ^{xi} http://www.caregiving.org/wp-content/uploads/2017/02/DementiaCaregivingFINAL_WEB.pdf
- ^{xii} <https://www.kff.org/medicaid/report/medicaid-and-long-term-services-and-supports-a-primer/>
- ^{xiii} https://www.bc.edu/schools/gssw/nrcpds/template_examples/cash_and_counselingtemplates.html
- ^{xiv} <https://www.kff.org/medicaid/issue-brief/5-key-questions-medicare-block-grants-per-capita-caps/>
- ^{xv} <https://www.agingresearch.org/pressrooms/view/302#.Wi6hMLaZNE4>
- ^{xvi} <https://www.medicare.gov/medicaid/ltss/reports-and-evaluations/index.html>
- ^{xvii} <https://www.genworth.com/about-us/industry-expertise/cost-of-care.html>
- ^{xviii} <http://www.kff.org/medicaid/issue-brief/the-effects-of-medicare-expansion-under-the-aca-updated-findings-from-a-literature-review/>
- ^{xix} <http://www.kff.org/medicaid/issue-brief/medicaids-role-for-people-with-dementia/>
- ^{xx} <https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/CMS-Statistics-Reference-Booklet/2016.html>