

State Policy Priorities



Alzheimer's disease, the most common form of dementia, is a critical public health issue in America with more than 6 million Americans living with Alzheimer's disease today. By 2050, the number of people age 65 and older living with Alzheimer's is projected to reach 12.7 million, barring the development of medical breakthroughs to prevent or cure the disease. State governments are essential to reducing the long-term impact of dementia on state budgets and improve the lives of individuals living with dementia and their families.

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Increase access to care, support and treatment

Dementia is one of the costliest conditions to society with the impact on state Medicaid budgets forecasted to top \$60 billion in 2022, while 70% of the total lifetime cost of caring for individuals living with dementia is still borne by families. The demand for direct care workers is projected to grow by more than 40% between 2016 and 2026, while their availability is expected to decline. This is particularly alarming as states across the nation are experiencing an unprecedented health care workforce shortage. Ensuring adequate access to home and community-based services (HCBS), improving care coordination, and streamlining the delivery of care for individuals living with dementia will mitigate the long-term impact on state budgets and improve the lives of those impacted by this devastating disease.

State actions :

- » Reduce health care barriers and increase access to residential and home and community-based services.
- » Ensure Medicaid programs provide appropriate coverage for FDA-approved treatments for Alzheimer's.
- » Create a statewide crisis response system that is sensitive to the changing behaviors of a person living with dementia.
- » Strengthen the health care workforce and address staffing shortages.
- » Establish or strengthen programs that support informal caregivers.

2

Improve quality of care

One in three seniors in America dies with Alzheimer's or another dementia. Between 2020 and 2025, every state across the country will have experienced an increase in the number of people with Alzheimer's. Yet 55% of primary care physicians caring for people living with Alzheimer's report there are not enough dementia care specialists in their communities to meet patient demand. Too often direct care providers and clinicians do not have sufficient dementia-specific knowledge to effectively support those living with dementia. Quality care delivered by trained providers leads to better health outcomes for individuals and caregivers, puts less strain on state health systems, and reduces care costs through decreased readmissions rates to hospitals.

State actions :

- » Increase dementia competency among health care providers so they can deliver person-centered care.
- » Improve residential and HCBS provider licensure requirements for dementia care.
- » Establish and implement quality measures that protect and enhance the lives of individuals living with dementia regardless of care setting.
- » Ensure that individuals living with dementia who are under court-ordered guardianship receive services

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Advance risk reduction, early detection and diagnosis

Alzheimer's disproportionately affects underserved and underrepresented populations, yet most states have not yet launched a coordinated effort to address health inequity and the impact of dementia on these communities. The need for greater awareness of the warning signs for a cognitive impairment which can lead to an Alzheimer's diagnosis is critical, particularly among underserved communities with a higher risk of developing dementia. Today, only half of those living with Alzheimer's have received an official diagnosis, with more than one-half of primary care providers indicating that they are not fully comfortable diagnosing a mild cognitive impairment due to Alzheimer's disease. An early and accurate diagnosis of Alzheimer's can improve access to care and support services, enhance quality of life and significantly reduce the financial impact of the disease.

State actions :

- » Expand access to resources in underserved communities to reduce stigma and increase early detection and diagnosis of dementia.
- » Incentivize care planning for individuals and families living with dementia.
- » Incentivize and advance dementia risk reduction strategies across provider and community settings.

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Ensure a coordinated statewide response to Alzheimer's disease

As the number of Americans living with Alzheimer's continues to grow, so will the impact on state health systems, budgets and workforce. Numerous state agencies administer a variety of programs critical to people with dementia and their families. Efforts are often siloed with state agencies working separately from each other, leading to inaction and inertia. The lack of coordination hinders the ability of a state to evaluate the effectiveness of policy efforts across the spectrum of programs serving those with dementia and their families. Addressing this public health crisis requires a coordinated response.

State actions :

- » Improve the collection, availability and utilization of dementia-related data by relevant state agencies.
- » Establish a statewide Alzheimer's/Dementia task force that is administered by the state.
- » Develop, implement and regularly update a State Alzheimer's/Dementia Plan in collaboration with community stakeholders.
- » Establish a permanent, full-time Dementia Coordinator position and/or Dementia Unit within the relevant state agency to work across agencies in implementation of the State Alzheimer's/Dementia Plan.
- » Ensure all relevant statewide plans and assessments include the needs of individuals living with dementia and their families.