Alzheimer’s is a large and growing epidemic that has a huge impact on states.

- More than 5 million Americans are currently living with Alzheimer’s — a figure expected to reach 13.8 million in 2050.
- Alzheimer’s is the sixth leading cause of death in America, with deaths from the disease having risen 146% between 2000 and 2018.
- In 2019, more than 16 million Americans served as unpaid caregivers for family members and friends with dementia, providing 18.6 billion hours of care at an economic value of nearly $244 billion.
- More than 40% of seniors in assisted living facilities have Alzheimer’s. Additionally, one-third of recipients of home health care and adult day care have Alzheimer’s.
- Average per-person Medicaid spending for seniors with Alzheimer’s and other dementias is 23 times greater than average per-person Medicaid spending across all seniors without dementia.
- In total, caring for people with Alzheimer’s is projected to cost Medicaid $51 billion in 2020 — representing an increase of nearly 25% in the last five years.
- By 2025, 30 states will see Medicaid spending on people with Alzheimer’s increase at least 20%, before inflation. And by 2050, Medicaid spending on those with Alzheimer’s will total an estimated $194 billion (in today’s dollars).

To address the Alzheimer’s epidemic, 49 states, the District of Columbia, and Puerto Rico have published State Alzheimer’s Disease Plans.

- State plans assess a state’s current needs, identify gaps in services, and recommend strategies and policies to better serve individuals living with dementia and their families.
- Once a state plan is developed and published, the next step is translating the vision of the state plan into implemented public policy.

Top 10 Causes of Death Percent Change, 2000-2018

- Alzheimers Disease: 146%
- Accidents: 71%
- Suicide: 65%
- Kidney Disease: 38%
- Respiratory Diseases: 31%
- Diabetes: 23%
- Cancer: 8%
- Heart Disease: 8%
- Stroke: -9%
- Influenza and Pneumonia: -12%
The implementation of state plans is hindered by the multitude of state agencies involved.

- Numerous state agencies administer a variety of programs critical to people with dementia, such as Medicaid, respite care, public health, and Silver Alert.

- Additional critical state efforts include regulatory oversight pertaining to the licensure of care facilities, enforcement of training requirements, and elder abuse protections.

- But, these efforts are often siloed, with multiple state agencies working separately from each other, leading to inaction and inertia.

- The lack of coordination also 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. This in turn makes it more difficult for a state to keep its Alzheimer’s plan updated and relevant to the changing health care landscape.

The key to translating the state plan into action — and to ensure effective programs for people with dementia and their caregivers — is better coordination across state agencies.

- Active coordination between all state agencies, the governor, the legislature, and community stakeholders can improve effective implementation of Alzheimer’s plans.

- Effective implementation can reduce the long-term impact of the disease on state budgets and improve the lives of people with dementia and their caregivers.

What Can States Do?

- Fund a full-time state agency position to coordinate the state’s response to dementia.

- Outline position specifications that focus on consensus recommendations in the State Alzheimer’s Disease Plan and on emerging issues related to dementia in the state.

Establishing a Dementia Services Coordinator position can accelerate a state’s ability to address Alzheimer’s.

- A State Dementia Services Coordinator is an individual (or team of individuals) within the state government whose job is to ensure coordination of Alzheimer’s programs and policies across state agencies.

- Specifically, a State Dementia Services Coordinator would:
  - Oversee the implementation and updating of the State Alzheimer’s Disease Plan
  - Coordinate Alzheimer’s and dementia work groups and task forces
  - Establish and maintain relationships with all relevant state agencies and community organizations in order to meet community needs and prevent duplication of services
  - Evaluate existing Alzheimer’s and dementia programs and services
  - Identify service gaps within the state government
  - Increase awareness of and facilitate access to quality, coordinated care for people with dementia.