

# Alzheimer's Disease Action Plans: Overview

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March 27, 2015



**North Carolina Institute of Medicine**  
*shaping policy for a healthier state*

# Federal Action on Alzheimer's

- National Alzheimer's Project Act (NAPA) signed into law January 2011. Required creation of a national action plan to address Alzheimer's and coordinate nationwide efforts
- This law requires:
  - A national plan (updated annually and submitted to Congress) on addressing Alzheimer's.
  - Annual recommendations for priority actions for improving health outcomes and lowering costs
  - Annual evaluation of all federally funded efforts in Alzheimer's research, care and services
  - The creation of an Advisory Council on Alzheimer's Research, Care, and Services.

# Federal Action on Alzheimer's

- First National Plan to Address Alzheimer's Disease released in 2012, with the first annual update released in June 2013.
- National goals
  - Effectively treat and prevent Alzheimer's by 2025
  - Improve quality and efficiency of care for individuals with Alzheimer's
  - Expand supports for individuals with Alzheimer's and their families
  - Increase public awareness and engagement
  - Improve data collection in order to better gauge need and progress
- Fiscal year 2014 budget proposal included \$100 billion in additional funding for research, awareness, outreach, and caregiver support

# Why do states need their own plans?

Alzheimer's Association recommends that state plans:

- Involve essential stakeholders
- Define issues of most relevance to their state
- Strategize for short and long-term actions and goals
- Improve services and supports

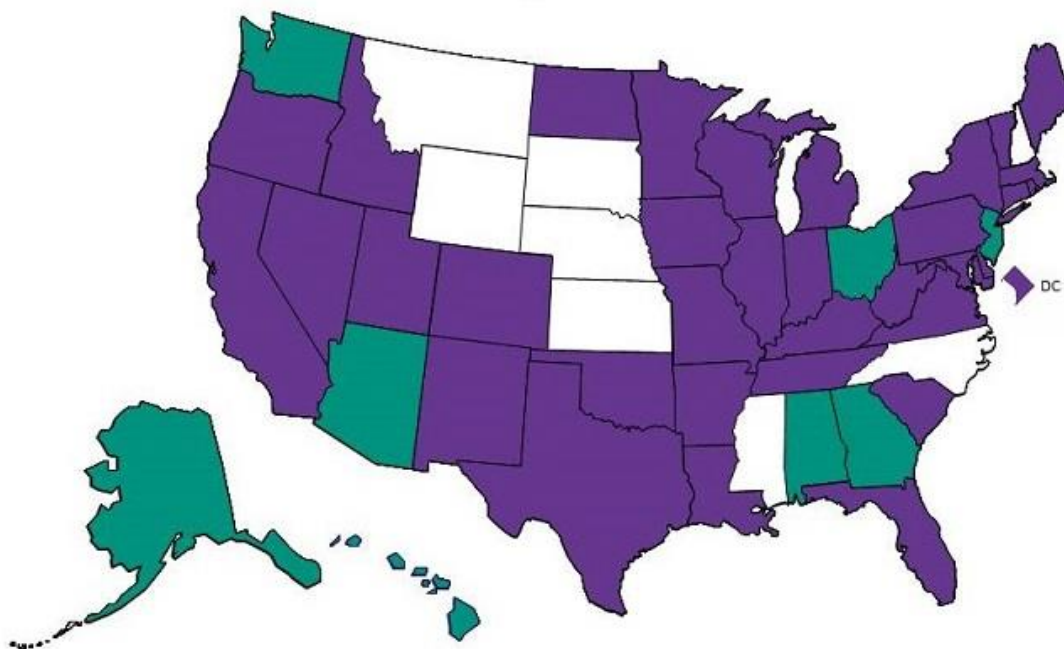
With final goal of creating a dementia-capable system for the state

# Why do states need their own plans?

- Written specifically to address state's needs
- Can more efficiently target state and local funds
- States may provide services and benefits that the federal government does not and/or address gaps
- State stakeholders can be held accountable
- States have authority over licensing and jurisdiction over law enforcement and other legal issues

# The state of the state (plans) - 2014

36 states have finalized state plans, with an additional 7 states in the development phase. Seven states (incl. NC) have no state plan.



Source: M. Baumgart, Senior Policy Director, Alzheimer's Association. April 29, 2014  
<http://aspe.hhs.gov/daltcp/napa/042914/Mtg12-Slides7.shtml>

# Topics and Key Recommendations

Public Awareness - 27

Early Detection and Diagnosis - 18

Care and Case Management - 32

Quality of Care - 27

Health Care System Capacity - 20

Training - 33

Workforce Development - 20

Home- and Community-Based Services -  
28

Long-Term Care - 18

Caregivers - 30

Research - 25

Brain Health - 14

Data Collection - 27

Safety - 27

Legal Issues - 16

State Government Structure - 19

Source: M. Baumgart, Senior Policy Director, Alzheimer's  
Association. April 29, 2014

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# Topics and Key Recommendations

## Increase public awareness

- Early symptoms and detection, including differences between normal aging and symptoms of dementia
- Prevalence among minority populations
- Pursuit of funding for outreach (public, private, corporate, philanthropic)
- Working with non-traditional partners



# Topics and Key Recommendations

## Early detection and diagnosis

- Improved detection tools for primary care and other health care providers
- Universal reimbursement for dementia screening

Source: [http://act.alz.org/site/PageNavigator/state\\_plans.html](http://act.alz.org/site/PageNavigator/state_plans.html)

# Topics and Key Recommendations

## Supporting unpaid Alzheimer's caregivers

- Increase professional guidance and awareness of support services for caregivers
- Identify caregiving as risk factor and address health (physical/behavioral/mental) issues of caregivers
- Financial assistance: tax credits, cash benefits, paid time off, additional reimbursement for care provided

# Topics and Key Recommendations

## Legal Issues

- Education and assistance for persons living with Alzheimer's and caregivers
- Increase awareness of and access to services for advance planning issues, power of attorney, etc.
- Work with state regulators on expanding training for legal professionals on issues around dementia

# Implementation

- Propose a timeline and establish a Task Force or other body of stakeholders
- Assign responsibility for action items, building in methods of assessing accountability and measures to track progress
- Build in methods of reporting progress to state legislative oversight group
- Keep stakeholders engaged, and build in methods of modifying action plan, as needed
- Establish plan for reconvening - to assess progress, challenges, and next steps
- Learn from other states' successes and challenges

Sources: "From Plan to Practice: Implementing the National Alzheimer's Plan in Your State." National Alliance for Caregiving. July 2014.

[http://act.alz.org/site/PageNavigator/state\\_plans.html](http://act.alz.org/site/PageNavigator/state_plans.html)

# Implementation

## Indiana

- Plan first released in 2013, following Task Force, public input meetings, and electronic surveys
- Began as a community effort, then legislators and policymakers were brought on board
- 13-member voluntary council, appointed by Commission on Aging, oversee implementation – has met 5 times through 2014 to track implementation
- Success so far:
  - Getting new administration and legislators on board to continue the plan. Engaging a broad variety of stakeholders – using both statewide in-person meetings and Internet survey



# Implementation

## Rhode Island

- Developed by Long Term Care Coordinating Council, with broad stakeholder engagement. Lt. Governor and director of Division of Elderly Affairs were co-chairs
- Created 6 subgroups:
  - Caregivers
  - Access
  - Legal services
  - Workforce (incl. direct care workforce and impact of Alzheimer's disease on workforce)
  - Long-term care
  - Research and clinical care

## State listening sessions



Sources: "From Plan to Practice: Implementing the National Alzheimer's Plan in Your State." National Alliance for Caregiving. July 2014.

# Implementation

## Rhode Island (continued)

- Immediate steps for implementation included:
  - Nursing Home Greenhouse Regulations
  - State procurement for non-emergency Medicaid transportation (NEMT) broker
  - Dementia-capability training for first responders
  - Approval from CMS under Rhode Island's §1115 waiver renewal application to expand cost-not-otherwise-matched (CNOM) services to low and middle income individuals under age 60 with a dementia diagnosis
  - Appointment of Director of Elderly Affairs to the Legislative Commission to Study the Feasibility of Modernizing Probate Law

# What's Next for North Carolina?

- Starting the NCIOM Task Force, by legislative mandate, in March 2015
- Engagement of a broad stakeholder group
- Prioritizing categories of action
- Establishing common agenda for 2015 and beyond