

# National Plan to Address Alzheimer's Disease

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# Major Challenges Presented by Alzheimer's Disease and Related Dementias

- ▶ Currently there is no way to prevent, treat or cure Alzheimer's disease and related dementias.
- ▶ Better quality of care measures and staff training are needed.
- ▶ Family members and other caregivers need support.
- ▶ Stigmas and misconceptions are widespread.
- ▶ Public and private progress should be coordinated and tracked.

# Alzheimer's Disease and Related Dementias in the U.S.

- ▶ Estimated 5.4 million people in the U.S. with ADRD
- ▶ Estimated annual costs to health and long-term care systems for caring for people with ADRD: \$109 billion, most of which is long-term services and supports
- ▶ Most care is provided by family and friends for no cost
  - Estimates that this care is worth:
    - Forgone wages: \$50 billion
    - Paying for this care on the private market would cost over \$106 billion

Source: Hurd et al. N Engl J Med 2013;368:1326-34

# National Alzheimer's Project Act (NAPA)

Signed January 4, 2011; Requires the Secretary of the U.S. Department of Health and Human Services (HHS) to establish the National Alzheimer's Project to:

- ▶ Create and maintain an integrated national plan to overcome Alzheimer's;
- ▶ Coordinate research and services across all federal agencies;
- ▶ Accelerate the development of treatments that would prevent, halt, or reverse the disease;
- ▶ Improve early diagnosis and coordination of care and treatment of the disease;
- ▶ Improve outcomes for ethnic and racial minority populations at higher risk;
- ▶ Coordinate with international bodies to fight Alzheimer's globally; and
- ▶ Create an Advisory Council to review and comment on the national plan and its implementation

# NAPA Accomplishments

- ▶ Regular Research Summits to Identify Priorities
  - Alzheimer's Disease Research Summit (2012, 2015, 2018, 2021)
  - Alzheimer's Disease-Related Dementias Summit (2013, 2016, 2019)
  - National Research Summit on Dementia Care & Services (2017, 2020)
- ▶ 55,640 healthcare providers trained on dementia in 2016–2017
- ▶ Creation of unified primary care AD curriculum
- ▶ 34.1% reduction in antipsychotic use among nursing home residents
- ▶ Creation of the ACL National Alzheimer's and Dementia Resource Center (NADRC)
- ▶ Healthy Brain Initiative, 2013–2018 and new 2018–2023 Roadmap
- ▶ Awareness campaigns

# Advisory Council on Alzheimer's Research, Care, and Services

The Advisory Council meets quarterly to discuss the efficacy of government programs to combat Alzheimer's. The members include the following:

- ▶ 12 members representing:
  - 2 Patient Advocates, including a person living with dementia
  - 2 Caregivers
  - 2 Providers
  - 2 State and local government reps
  - 2 Researchers
  - 2 Voluntary health association representatives
- ▶ Department of Health and Human Services  
ASPE, ACL, NIH, AHRQ, CMS, HRSA, IHS, FDA, CDC
- ▶ Department of Defense
- ▶ National Science Foundation
- ▶ Department of Veterans Affairs

# Role of Advisory Council

- ▶ Meet quarterly
- ▶ Make recommendations to Secretary and Congress on priority actions
- ▶ Annual recommendations
- ▶ Work in three subcommittees:
  - Research
  - Clinical Care
  - Long-Term Services and Supports

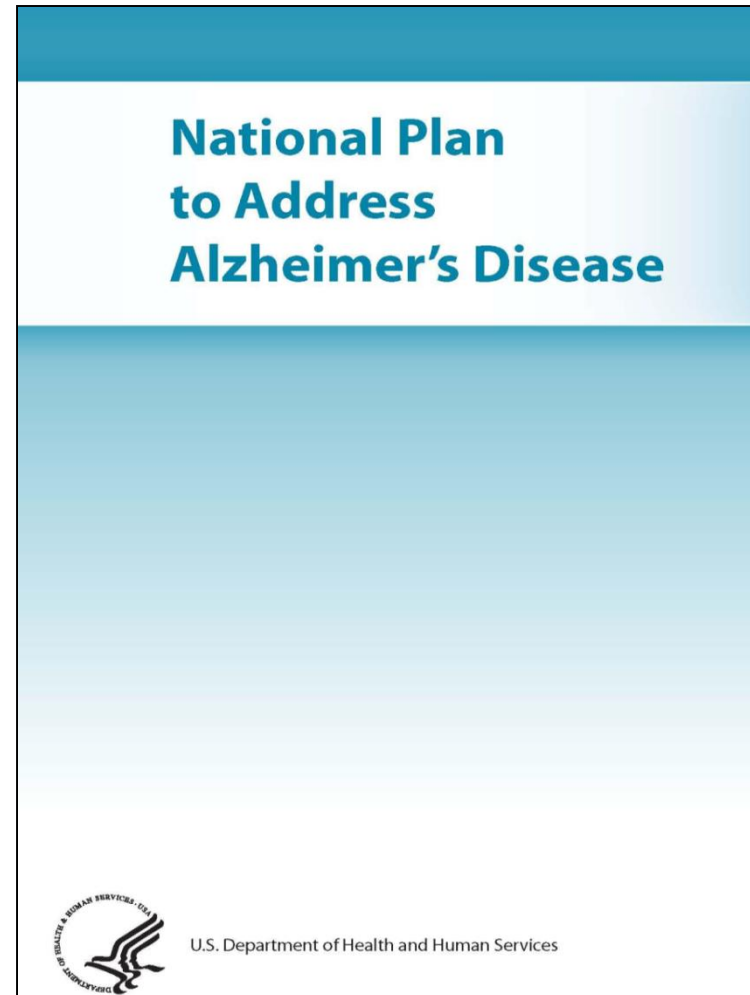
# National Plan Framework

- ▶ National Plan, not just a federal plan: Requires engagement of public and private sector stakeholders
- ▶ Balance work on treatments with care needed by people with the disease and their families now
- ▶ Progress report of completed and ongoing activities of the federal government and non-federal partners
- ▶ Long term goals, strategies to achieve those goals, and immediate actions



# The National Plan

1. Prevent and Effectively Treat Alzheimer's Disease by 2025
2. Optimize Care Quality and Efficiency
3. Expand Supports for People with Alzheimer's Disease and Their Families
4. Enhance Public Awareness and Engagement
5. Track Progress and Drive Improvement



# Implementing the National Plan

- ▶ Set Implementation Milestones Timeline
- ▶ Identify lead agencies and partners
- ▶ Implement many actions immediately
- ▶ Report progress to Advisory Council
- ▶ Update Plan annually

# 2018 Update

- ▶ Released October 19, 2018
- ▶ Available at:  
<https://aspe.hhs.gov/report/national-plan-address-alzheimers-disease-2018-update>
- ▶ Organized into goals, strategies, and actions

# Goal 1: Prevent and Effectively Treat Alzheimer's Disease by 2025

- ▶ NIH Alzheimer's Disease Research Summit
- ▶ National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers
- ▶ International Alzheimer's Disease Research Portfolio (IADRP)
- ▶ 3<sup>rd</sup> ADRD Summit – March 14–15, 2019

## Goal 2: Enhance Care Quality and Efficiency

- ▶ HRSA's Geriatrics Workforce Enhancement Program (GWEP)
- ▶ Dementia Curriculum for Health Care Professionals and Caregivers
- ▶ Research on Awareness of Diagnosis

## Goal 3: Expand Support for People with Alzheimer's Disease and Their Families

- ▶ Care Interventions for Individuals with Dementia and Their Caregivers
- ▶ Public Health Road Map for Tribal Communities
- ▶ National Partnership to Improve Dementia Care in Nursing Homes

# Goal 4: Enhance Public Awareness and Engagement

- ▶ Alzheimer's Disease Programs Initiative (ADPI)
- ▶ Healthy Brain Initiative
- ▶ Key Indicators of Older Adults with Dementia and Their Caregivers

# Goal 5: Improve Data to Track Progress

- ▶ CDC BRFSS Cognitive Decline and Caregiving Optional Modules
- ▶ ICD-9/ICD-10 Coding for Dementia



# 2018 Alzheimer's Legislative Developments

- **January 2018** – Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act signed into law
- **February 2018** – Independence at Home demonstration model extended for an additional two years
- **March 2018** – \$414 million increase in Alzheimer's and dementia research funding signed into law for FY2018
- **March 2018** – Kevin and Avonte's Law of 2017 included in FY2018 funding bill
- **September 2018** - \$425 million increase in Alzheimer's and dementia research funding signed into law for FY2019
- **December 31, 2018** – Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act signed into law

# Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act: P.L. 115-406



Establishes Alzheimer's Centers of Excellence



Provides funding for public health departments across the country



Increases data analysis and timely reporting

\*\*\*Authorizes \$20 million annually for fiscal years 2020-2024 to carry out BOLD related activities

# Current Issues

- ▶ Reduction in inappropriate antipsychotic utilization in nursing homes
  - Increase in schizophrenia?
  - What about the in the community?
- ▶ Care Planning
  - What does a good care plan look like?
  - Why aren't people with dementia getting a care plan?
  - How to engage and incentivize providers to create a care plan?

# 2019–2020 Themes

- ▶ 2019: Where have we been and what have we accomplished so far?
- ▶ 2020: What strategic steps do we need to take to meet our 2025 goals?

# Upcoming Events

- ▶ April 28, 2019: Advisory Council meeting
  - Theme is Clinical Care
  - Please attend in person or watch live at [www.hhs.gov/live](http://www.hhs.gov/live)
- ▶ March 14–15, 2019: Alzheimer's Disease–Related Dementias Summit
- ▶ Summer 2019: Soliciting nominations for five Advisory Council members

# Thank you!



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For more information:

<http://aspe.hhs.gov/national-alzheimers-project-act>