

# Dementia in the United States and the National Alzheimer's Project Act

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

- ▶ Estimated 5 million people in the U.S. with Alzheimer's disease and related dementias
  - The U.S. population over age 85 is growing; thus, experts expect there will be a large increase in this number.
- ▶ Estimated annual costs to health and long-term care systems for people with Alzheimer's disease and related dementias: \$109 billion, most of which is long-term care
- ▶ Estimated costs of care by family and friends
  - Foregone wages: \$50 billion
  - In the private market, this care would cost over \$106 billion

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

# 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.

# Investments and Resources prior to National Alzheimer's Project Act

- ▶ Research
  - \$502 million on research in 2010
  - Vast majority (\$457 million) funded by the National Institutes of Health (NIH)
- ▶ Clinical care
  - Detection and diagnosis
  - Treatment and care coordination
  - Training
- ▶ Long-Term Care
  - Nursing home entitlement from the government for people who meet need criteria
  - Smaller programs to support national network of aging services providers

# President Obama's Investment

- ▶ Designed to take immediate action on Alzheimer's disease.
- ▶ Increased Alzheimer's disease research funding.
  - The National Institutes of Health (NIH) immediately dedicated an additional \$50 million in 2012.
- ▶ In 2013 NIH Director, Dr. Francis Collins, provided \$40 million from the Director's Fund to support new Alzheimer's research.
- ▶ Support for people with Alzheimer's disease and their families and educating the public and providers.

# Key Features of the National Alzheimer's Project Act (NAPA)

Signed January 4, 2011, required 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 and related dementias
- ▶ 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.
- ▶ Create an Advisory Council to review and comment on the national plan and its implementation

# Early Activities

- ▶ Formation of Federal Interagency Workgroup & Advisory Council
- ▶ Formation of Research, Clinical Care and Long-term Services and Supports subcommittees
- ▶ Quarterly formal meetings of the Advisory Council and ad hoc meetings of federal workgroups and subcommittees
- ▶ Work to date addresses current programs serving those with Alzheimer's and related dementias and their caregivers, possible improvements to programs, and new initiatives.

# National Plan

- ▶ Balance work on treatments with care needed by people with the disease and their families now
  - ▶ National Plan, not just a federal plan: requires engagement of public and private sector stakeholders
  - ▶ Long-term goals, strategies to achieve those goals, and immediate actions, which are reviewed annually
  - ▶ Transparent reporting on progress:
    - Implementation timeline is appendix
    - Bi-annual reporting on progress to Advisory Council
  - ▶ Final Plan released May 2012:  
<http://aspe.hhs.gov/daltcp/napa/NatPlan.shtml>
- Most recently, the 2014 Update was released April 2014  
<http://aspe.hhs.gov/daltcp/napa/NatPlan2014.shtml>



# Goals

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

## National Plan to Address Alzheimer's Disease



U.S. Department of Health and Human Services

# Progress to Date

- ▶ Developed recommendations on how best to advance research: [Alzheimer's Disease Research Summit 2012: Path to Treatment and Prevention](#)
- ▶ Created an appendix to the National Plan with a list of milestones to reach 2025 goals: <http://aspe.hhs.gov/daltcp/napa/NatlPlan2014.shtml#append2>
- ▶ Provided resources to train more than 10,000 health care providers on topics from dementia diagnosis to effective behavior management
- ▶ Brain Health Resource made available online, which presents information about risk factors associated with brain health for the public: [http://www.acl.gov/Get\\_Help/BrainHealth/Index.aspx](http://www.acl.gov/Get_Help/BrainHealth/Index.aspx)
- ▶ NIH research summit on other related dementias (May 2013)
- ▶ Began work on a National Cognitive Health Awareness Campaign (September 2014)

# Resources: Additional Information

- ▶ NAPA website:  
<http://aspe.hhs.gov/daltcp/napa/>
- ▶ <http://www.alzheimers.gov>
- ▶ National Institute on Aging:  
<http://www.nia.nih.gov/alzheimers>
- ▶ National Family Caregiver Support Program:  
[http://www.aoa.gov/AoA\\_programs/HCLTC/Caregiver/index.aspx](http://www.aoa.gov/AoA_programs/HCLTC/Caregiver/index.aspx)