

# Overview of the NAPA Legislation and the Charge to the Council

Laura N. Gitlin, Chair

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## Major Challenges Presented by Dementia

- ▶ Currently there is no way to prevent, treat or cure AD/RD
- ▶ With biomarker identification and early diagnosis, people will live with dementia for longer time periods
- ▶ Dementia is complex with needs for care, services and supports changing over time
- ▶ Care, services and supports may help to reduce disability and address symptoms
- ▶ Better quality of care measures and staff training are imperative
- ▶ Family members and other caregivers need support
- ▶ Stigmas and misconceptions are widespread and impact quality of life.
- ▶ Medical-social/social-medical comprehensive dementia care is needed
- ▶ Public and private progress should be coordinated and tracked.

NAPA WEBSITE:  
<http://aspe.hhs.gov/daltcp/napa/>

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# Key Features of the 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.
- ▶ Create an Advisory Council to review and comment on the national plan and its implementation

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## NAPA Duties of the Secretary of HHS

- ▶ Oversee the creation and updating of the Plan
- ▶ Evaluate all Federal programs including budgets and approvals
- ▶ Carry out annual assessment of the Nation's progress including implementation steps and recommendations for priority actions

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# Terminology

In the introductory language of the National Plan the term “Alzheimer’s Disease” is used but is intended to include AD related dementias:

- ▶ Dementia with Lewy bodies
- ▶ Frontotemporal lobar degeneration
- ▶ Vascular cognitive impairment/dementia
- ▶ Down syndrome

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# Objectives of the National Plan

- ▶ Balance work on biomedical approaches with care, service and support approaches needed by people living with the disease and their care partners/caregivers now
- ▶ National Plan, not just a federal plan: Requires engagement of public and private sector stakeholders
- ▶ It outlines 5 long-term goals, strategies to achieve those goals, and immediate actions
- ▶ Transparent reporting on progress:
  - Implementation timeline is appendix
  - Plan provides an annual reporting on progress to Advisory Council, to Congress and the Secretary

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

- ▶ 24 Federal and Non-federal members
- ▶ 3 Federal work groups: research, clinical care, and long-term services and supports
- ▶ 3 Subcommittees comprised of Federal and Non-federal members: research, clinical care, and long-term services and support

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## Federal Members

- ▶ Assistant Secretary for Planning and Evaluation (ASPE) – oversees the Council and the National Plan
- ▶ Centers for Disease Control and Prevention (CDC)
- ▶ Administration on Community Living (ACL)
- ▶ Centers for Medicare & Medicaid Services (CMS)
- ▶ Indian Health Services (IHS)
- ▶ National Institutes of Health (NIH)
- ▶ Health Resources and Service Administration (HRSA)
- ▶ Food and Drug Administration (FDA)
- ▶ Agency for Healthcare Research and Quality (AHRQ)
- ▶ National Science Foundation (NSF)
- ▶ Veterans Affairs (VA)
- ▶ Department of Defense (DoD)

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## Non-Federal Members

- ▶ Two of each
  - Patient advocates, one of whom is currently living with the disease
  - Caregivers
  - Health care providers
  - State/local health department representatives
  - Researchers
  - Voluntary health association representatives

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## NAPA Advisory Council Role

- ▶ National Plan
  - Revised annually
  - Focuses on new and current activities (new policies, initiatives, programs) and tracks their progress
- ▶ Recommendations
  - Unconstrained
  - Advisory to the Secretary and Congress

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# Research Summits

Alzheimer's disease: 2012, 2015  
AD Related dementias: 2013, 2016  
Down Syndrome: 2014  
Care and Services: 2017

From these summits, recommendations led to milestones, short, middle and long term which led to funding opportunities

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# Questions/Discussion

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## October 27, 2017 -- Advisory Council Meeting #26

The meeting was held on Friday, October 27, 2017, in Washington, DC. The Advisory Council welcomed its new members and invited them to share their experiences and where they see the Council going over the length of their terms. The Advisory Council also spent some time discussing the process of developing recommendations and how those recommendations relate to the National Plan. The Council then spent much of the meeting discussing the National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers, held on October 16-17. Material available from this meeting is listed below and is also available at <https://aspe.hhs.gov/advisory-council-alzheimers-research-care-and-services-meetings#Oct2017>.

Comments and questions, or alerts to broken links, should be sent to [napa@hhs.gov](mailto:napa@hhs.gov).

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### General Information

<b>Agenda</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Meeting Announcement</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Meeting Summary</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Public Comments</b>	<a href="#">[HTML Version]</a>

### Handouts

<b>National Plan to Address Alzheimer's Disease: 2017 Update</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Public Members of the Advisory Council on Alzheimer's Research, Care and Services: 2017 Recommendations</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>

### Presentation Slides

<b>2017 National Plan</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Before NAPA: IADRP</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Clinical Care Subcommittee Update</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Clinical Subcommittee Update</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Developing, Sustaining and Taking Innovations to Scale</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Discussion of Future Meetings</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>

<b>Long-Term Services and Supports Committee Update</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Overview of the NAPA Legislation and the Charge to the Council</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Overview of the National Plan and the Process for Recommendations</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Research Progress for Alzheimer's Disease and Related Dementias</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Research Summit on Dementia Care Overview and Recommendations</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>

## **Videos**

<b>Welcome through Overviews</b>	<a href="#">[Video]</a>
<b>Subcommittees and Fed Workgroups and Future Meeting Discussion</b>	<a href="#">[Video]</a>
<b>Care Summit Overview and Presentation of Recommendations</b>	<a href="#">[Video]</a>
<b>Discussion through lunch</b>	<a href="#">[Video]</a>
<b>Public Comments</b>	<a href="#">[Video]</a>
<b>Marie Schall Presentation and 2017 National Plan Discussion</b>	<a href="#">[Video]</a>
<b>Federal Workgroup Updates through adjourn</b>	<a href="#">[Video]</a>

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