View from the Advisory Council on Research, Care and Services for the National Alzheimer’s Disease Plan

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Research Summit on Dementia Care
NIH
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Disclosures

- Roche, Inc.
- Merck, Inc.
- Genentech, Inc.
- Biogen, Inc.
- Eli Lilly and Co.

- National Institute on Aging:
  - U01 AG006786
  - P50 AG016574
  - U01 AG011378
  - R01 AG011378
  - R01 AG041581
- GHR Foundation
- Mayo Foundation for Education and Research

National Alzheimer’s Project Act

Passed by Congress: 2010
Advisory Council Appointed: 2011
National Plan: 2013
National Plan: 2015
National Plan: 2017

Signed by President: 2011
First National Plan: 2012
National Plan: 2014
National Plan: 2016
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
NAPA
Purpose

- Secretary of HHS shall
  - Create and maintain the National Plan
  - Coordinate Alzheimer’s research and services across Federal agencies
  - Accelerate the development of treatments
  - Improve
    - Early diagnosis
    - Coordination of care and treatment
  - Ensure the inclusion of ethnic and racial populations at higher risk
  - Coordinate with international bodies

NAPA
Advisory Council on Research, Care and Services

- Federal members
  - Centers for Disease Control and Prevention
  - Administration on Aging
  - Centers for Medicare & Medicaid Services
  - Indian Health Services
  - National Institutes of Health
  - Health Resources and Service Administration
  - National Science Foundation
  - Veterans Affairs
  - Food and Drug Administration
  - Agency for Healthcare Research and Quality
NAPA
Advisory Council on Research, Care and Services

- Non-Federal Members – two each
  - Patient advocates, including one person living with the disease
  - Caregivers
  - Health care providers
  - State health departments
  - Researchers
  - Voluntary health associations

US National Alzheimer’s Plan
Goals

1. Prevent and effectively treat AD by 2025
2. Enhance care quality and efficiency
3. Expand supports for people with AD and families.
4. Enhance public awareness/engagement
5. Improve data to track progress
National Plan to Address Alzheimer’s Disease

<table>
<thead>
<tr>
<th>Alzheimer’s Disease Summit(1)</th>
<th>Alzheimer’s Disease Related Disorders Summit(1)</th>
<th>Alzheimer’s Disease in Down Syndrome</th>
<th>Alzheimer’s Disease Summit(2)</th>
<th>Alzheimer’s Disease Related Disorders Summit(2)</th>
<th>Research Summit on Dementia Care</th>
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<td>2012</td>
<td>2013</td>
<td>2013</td>
<td>2015</td>
<td>2016</td>
<td>2017</td>
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The Process

- Summit
- Recommendations
- Milestones
- Concepts
- Approval of concepts
- Funding Opportunity Announcements
National AD Plan Highlights

2012
First National Plan
- AD Summit(1)
- Recommendations
- Concepts
- RFA's

2013
National Plan
- ADRD Summit(1)
- Down Syndrome
- Recommendations
- Milestones from Summits
- Assess progress
- RFA's

2014
National Plan
- Alzheimer's Accountability Act
- Professional Judgment Budget
  (Bypass Budget)
- RFA's

2015
National Plan
- AD Summit(2)
- Milestones
  AD Summits(1, 2)
  ADRD Summits(1)
- Bypass Budget
- $323M FY17
- RFA's

2016
National Plan
- ADRD Summit(2)
- Milestones
  AD Summits(1, 2)
  ADRD Summits(1, 2)
- Bypass Budget
- $400M FY18
- RFA's

2017
National Plan
- Research Care Summit
- Milestones
  AD/ADRD Summits
- Research Care Summits
- Bypass Budget
- $597M FY19
- RFA's

AD/ADRD Research Increases at NIH

<table>
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<tr>
<th>Year</th>
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<tr>
<td>FY2011</td>
<td>$448M</td>
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<td>FY2012</td>
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<td>FY2017**</td>
<td>$941M</td>
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* After FY2014, AD + ADRD
** Estimated
Can We Have an Impact on Care and Services in an Analogous Fashion?

Research Issues Pertaining to Care and Services

- Can we slow progression of disease by care and service interventions?
  - Will behavioral treatments slow decline?
- Environmental impact
- Can we prolong symptomatic benefits?
- Interaction of pharmacological and non-pharmacological approaches
- Role of assistance to families
Challenges in the Care and Services Arena

- Whereas with the AD and ADRD Summits, NIH was the overseeing agency
- Multiple agencies involved in care and services
- Therefore, the Advisory Council on Alzheimer’s Research, Care and Services may need to play a key role in disseminating the recommendations and monitoring and coordinating efforts to move them forward

Future of Care and Services Summits

- This likely will be just the first of Care and Services Summits
- AD and ADRD summits recur approximately every three years
Thank You

- Co-chairs: Laura Gitlin, PhD; Katie Maslow
- Advisory Council members
- HHS ASPE team
  - Rohini Khillan
  - Linda Elam
  - Ruth Katz
  - Richard Frank
  - Don Moulds
  - Helen Lamont
  - Kara Townsend
  - John R. Graham