

Family Caregiving Advisory Council Meeting

February 11 – 12, 2020

Day 1



The Agenda

February 11, 2020

1:00 – 1:10 Welcome and Roll Call

1:10 – 1:20 Open and Convening Remarks

1:20 – 1:30 Agenda Overview and Updates

1:30 – 2:00 Decision Making Processes

2:00 – 2:30 Fine-Tuning Our Guiding Principles

2:30 – 3:40 Revise and Expand Goals

3:40 – 4:00 Wrap Up & Overview of Day 2

Welcome and Roll Call

Greg Link, Director
Officer of Supportive and Caregiver Services
Administration for Community Living

Open and Convening Remarks

Lance Robertson

Administrator/Assistant Secretary for Aging
Administration for Community Living

Agenda Overview and Updates

Greg Link

Director, Office of Supportive and Caregiver Services
Administration for Community Living

Kitty Purrington, JD

Senior Program Director, Chronic and Vulnerable Populations
National Academy for State Health Policy (NASHP)

Rani Snyder, MPA

Vice President, Program
The John A. Hartford Foundation

Decision Making Process – The NAPA Model

Helen Lamont, Ph.D.

Senior Long-Term Care Analyst

Office of Disability, Aging, and Long-Term
Care Policy

Office of the Assistant Secretary for Planning and
Evaluation



Recommendation-Making Process: The NAPA Model

HELEN LAMONT, PH.D.

OFFICE OF DISABILITY, AGING, & LONG-TERM CARE
POLICY

The principal advisor to the Secretary of the U.S. Department of Health and Human Services on policy development, and is responsible for major activities in policy coordination, legislation development, strategic planning, policy research, evaluation, and economic analysis.

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

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

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

Public

- Meets quarterly
- **Annual recommendations to Secretary and Congress on priority actions**
- Work in three subcommittees: Research, Clinical Care, Long-Term Services and Supports

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

Federal Government

Subcommittee Structure

- Research, clinical care, long-term services and supports
- Consist of federal and non-federal Advisory Council members
- Each subcommittee has a chair (non-federal)
- Monthly teleconference meetings
- Primary responsibilities are to craft annual recommendations, share information, and plan one meeting per year

Recommendations

- Approved annually in July to inform fall release of [National Plan to Address Alzheimer's Disease: Update](#)
- Range in level of ambition and areas of focus
- Range in specificity
- Number of recommendations varies greatly
- Sometimes continue previously recommendations that were not implemented
- NAPA Recommendations: <https://aspe.hhs.gov/advisory-council-recommendations>

2012

2019

30. Fully fund caregiver support under AOA.

- o AOA currently has the National Family Caregiver Support Program, a component of which can be expanded to better meet the needs of caregivers of individuals with AD.
- o These improvements can result in mitigation of other system costs.
- o This program is currently dramatically underfunded and therefore unable to meet the needs of this growing population.
- o Fully funding this program can enhance other related efforts to improve quality of life for people with AD and their caregivers.
- o We recommend that program funding be doubled to move toward full funding.

31. HHS and state lead entities should assure that caregiver physical health/behavioral health risk is assessed and addressed regularly. Caregiver illness and mortality contribute to the enormous personal and financial cost of AD.

- a. The health and well-being of a caregiver has a direct impact on the health and quality of life of a person with AD.
- b. Whenever a caregiver accompanies a person with AD to a health care appointment; emergency department visit; or hospitalization, the attending health care provider should ask if the caregiver is well for the purpose of information and referral to care if needed.
- c. HHS should explore adding a Health Effectiveness Data and Information Set question to assess that this is occurring.
- d. Appropriate federal agencies and state lead entities should assure that the importance of this action is incorporated into training of health care providers and incorporated into education messages for the public.
- e. Caregiver needs assessments should be made an explicit permitted use of federal funds by states under the National Family Caregiver Support Program.]

32. The Office of the National Coordinator, in partnership with the private sector, should assure that development of health information technology includes tools for caregivers to assist in the care of the person with AD to address dementia and multiple chronic conditions as well as maintain their own mental and physical health.

- a. Caregivers should have access to reminder tools; communication methods among caregivers; home monitoring tools; and enhanced decision supports that help instill confidence and reduce isolation.

LTSS RECOMMENDATION 1. Improve Access to Affordable LTSS

Background: Impoverishment can be an issue for individuals and caregiving families who may be forced stop working or to spend down their personal savings trying to purchase or furnish care for a relative with AD/ADRD. Unpaid caregivers providing substantial HCBS may be less able to be productive members of the workforce. For the most part, LTSS are not covered by Medicare. And, while Medicaid covers some LTSS costs for low-income beneficiaries who qualify, for many individuals and families, out-of-pocket LTSS costs drain their personal savings. According to AARP's Family Caregiving Cost Study (2015), the average out-of-pocket cost caring for a person with dementia is \$10,697 annually and full-time in-home care or assisted living residential care can cost \$4,000 a month or more. This is prohibitive for most middle to lower income individuals and families. The recommendations below focus on non-means-tested programs that can expand the availability of LTSS, especially in home and community-based settings

To help assure that people living with AD/ADRD and their families can access the LTSS they need, including HCBS, it is recommended that:

- a. By 2025, programs beyond Medicaid that provide LTSS (e.g., OAA, state and non-profit programs) should be expanded to support individuals and families with unmet needs, including under-served, diverse populations.
 - o Congress should expand covered populations to include people under the age of 60 with a diagnosis of young onset AD/ADRD in the reauthorization of the Older Americans Act.
 - o Congress should increase funding for the ACL Alzheimer's Disease Program Initiative from \$23.5M to \$50M to increase the number of individuals benefitting from tailored education and supports; target the program to under-served and high-risk populations; and evaluate the program's reach and impact.
 - o Congress should increase funding for the ACL National Family Caregiver Support Program (NFCSP) from \$180M to \$360M, target the program to families of people with AD/ADRD, and evaluate the reach and dementia capability of the program.
 - o Congress should establish new funding for ACL respite programs, target the funding to under-served and high-risk populations and evaluate the programs' reach and impact.
 - o Operating divisions within the US Department of Health and Human Services such as CMS, ACL, CDC and HRSA, as well as the VA, should tailor programs to address the HCBS needs of a heterogeneous population living with AD/ADRD and their families and caregivers.
 - o Disbursement of resources should consider communities and populations with the greatest need, using objective data sources (like U.S. Census data) for determinations.
 - o State models for expanding the availability of LTSS and/or supporting unpaid caregivers through 1115 waivers and other strategies should be evaluated and, if warranted, disseminated broadly to encourage adoption by other states See the Medicaid LTSS toolkit for examples: <https://www.chcs.org/media/Strengthening-LTSS-Toolkit>

Adoption of Recommendations

- July meeting:
 - Each subcommittee chair presents the recommendations from their subcommittee
 - Edits to language or suggestions for expansion
 - Non-federal members of Advisory Council vote on recommendations (Feds abstain)
 - (Generally give subcommittee chairs authority to make changes discussed during meeting)
- Subcommittee chairs finalize recommendations, send to DFO and Advisory Council co-chairs
- Recommendations go to HHS Secretary Azar and are transmitted to Congress

Observations

- Leadership on recommendations is important for consistency, but groups will differ
- Opportunity for all members to serve on as many subcommittees as they want
- Recommendations close to final prior to full Advisory Council presentation and voting
- Recommendations that are specific and have a target agency/implementer are more likely to be implemented
 - Federal members assist in this
- Some recommendations are purposely ambitious, but perhaps not feasible



Thank You

For more information, see:

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



National Alzheimer's Project Act

The National Alzheimer's Project Act (NAPPA) creates an important opportunity to build upon and leverage HHS programs and other federal efforts to help change the trajectory of Alzheimer's disease and related dementias (AD/DRD). The law calls for a National Plan for AD/DRD with input from a public-private Advisory Council on Alzheimer's Research, Care and Services. The Advisory Council makes recommendations to HHS for priority actions to expand, coordinate, and condense programs in order to improve the health outcomes of people with AD/DRD and reduce the financial burden of these conditions on those with the disease, their families, and society.

In order to inform the National Plan for AD/DRD, HHS has partnered with the U.S. Department of Veterans Affairs (VA), the National Science Foundation (NSF), and the U.S. Department of Defense (DOD) to convene an Interagency Group on Alzheimer's Disease and Related Dementias. The group includes HHS representatives from the Office of the Assistant Secretary for Planning and Evaluation (ASPE), Office of the Assistant Secretary for Health (OASH), National Institutes on Aging (NIA), Centers for Medicare & Medicaid Services (CMS), Centers for Disease Control and Prevention (CDC), Administration on Aging (AOA), Health Resources and Services Administration (HRSA), Agency for Healthcare Research and Quality (AHRQ), Substance Abuse and Mental Health Services Administration (SAMHSA), Food and Drug Administration (FDA), Indian Health Service (IHS), and Administration for Children and Families (ACF). The Interagency Group is working to carry out NAPPA's charges to coordinate research and services across agencies, accelerate the development of AD/DRD treatments, improve early diagnosis and coordination of care, reduce ethnic and racial disparities in rates of AD/DRD, and coordinate with international efforts to fight these conditions. The Plan the group developed was presented to the Advisory Council for review, and updated annually.

WOULD YOU LIKE TO BE ALERTED WHEN NEW INFORMATION IS AVAILABLE? A Listserve is also available that will automatically email you a monthly message. To join, send an email to LISTSERV@2017NAPPA.GOV. Whatever email address the message is sent from will be what is used in the Listserve. The only thing that needs to be in the body of the message is:

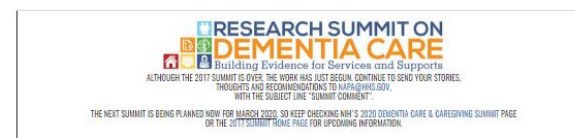
subscribe NAPPA, your name
(your name, of course, being the name of the person joining)

Comments and questions, or alerts to broken links, should be sent to napa@hhs.gov.

WHAT'S NEW:

NAPA Information

- Public Members of the Advisory Council on Alzheimer's Research, Care and Services: 2019 Recommendations **(posted October 2019)**
- National Plan to Address Alzheimer's Disease: 2019 Update **(posted October 2019)**
- New Advisory Council Members **(posted October 2019)**
- October 2019 Advisory Council Meeting Material **(posted September 2019)**



FIND INFORMATION ON:

NAPA WHAT IS ALZHEIMER'S DISEASE & RELATED DEMENTIAS

NAPA ADVISORY COUNCIL ON ALZHEIMER'S RESEARCH, CARE, & SERVICES

- Advisory Council Members – **updated Oct 11**
- Meeting Material – **updated Sep 20**
- Public Comments – **updated Sep 16**
- Meeting & Event Videos – **updated Oct 19**

NAPA NATIONAL PLAN & OTHER NAPA DOCUMENTS

NAPA OTHER INFORMATION ON AD/DRD

- National Plans – **updated Oct 24**

- Agency Reports – **updated Jun 28**

Fine-Tuning Our Guiding Principles

Casey R. Shillam, Ph.D., RN

Dean, Professor

School of Nursing

University of Portland

Guiding Principles

1. “Family caregiver” is an inclusive and holistic term that includes all who are caring for individuals across the life span with chronic or other health conditions, disabilities, or functional limitations.
2. Promoting greater adoption of **person- and family-centered care** puts the person and family (as appropriate) at the center of care teams.
3. Efforts to support family caregivers should further individuals’ **autonomy, choice, and ability** to engage meaningfully in their communities.
4. Recommendations should **recognize and support family caregivers** for health equity, in a manner that respects and appreciates their complexity, diversity, and dignity.
5. The national strategy will be **a living document with ongoing actions** to be taken by federal, state and local governments, communities, providers, and others while fostering cross-discipline and cross-sector collaboration.

Revise and Expand Goals

Alan B. Stevens, Ph.D.

Director, Center for Applied Health Research,
Baylor Scott & White Health

Professor, Texas A&M University Health Sciences
Center

August 2019 FCAC Advisory Council Meeting – Adopted Goals

- *Goal/Subcommittee 1: Assist Caregivers in Optimizing Care and Support for their Loved Ones*
- *Goal/Subcommittee 2: Enable Caregivers to Provide Care While Maintaining their Health and Well-Being*
- *Goal/Subcommittee 3: Enhance Public Awareness, Education, and Engage Non-governmental Entities to Support Caregivers*
- *Goal 4 (not adopted): Improve Data and Track Progress*

August 2019 FCAC Advisory Council Meeting – Adopted Goals

Goal/Subcommittee 1: Assist Caregivers in Optimizing Care and Support for their Loved Ones

- Priority #1: Empowerment through resource identification and access
- Priority #2: Incentivize and support workforce development

August 2019 FCAC Advisory Council Meeting – Adopted Goals

Goal/Subcommittee 2: Enable Caregivers to Provide Care While Maintaining their Health and Well-Being

- Priority #1: Assessment to build a plan of care and support for family caregivers
- Priority #2: Increase and improve capacity to meet family caregiver needs:
 - Across the continuum of care/life
 - Short term and long term workforce development and financial consideration
 - Increase availability of resources and services
 - Uptake of evidence-based practices

August 2019 FCAC Advisory Council Meeting – Adopted Goals

Goal/Subcommittee 3: Enhance Public Awareness, Education, and Engage Non-governmental Entities to Support Caregivers

Priority #1: Create the Value Proposition for family caregivers for multiple audiences, work to identify gaps

Priority #2: Identify and engage traditional and non-traditional partners

August 2019 FCAC Advisory Council Meeting – Adopted Goals

Goal 4 (not adopted): Improve Data and Track Progress

In addition, the RAISE Act articulates six areas for which recommended actions are to be considered in the National Strategy, including:

1. Greater adoption of person/family-centered care;
2. Assessment, service planning, care transitions and coordination;
3. Information, education, training, referral, care coordination in hospice, palliative care and advance planning;
4. Respite options;
5. Financial security and workplace issues; and
6. Improved service delivery.

Goals – Other Examples (National Alliance for Caregiving)

- Expand Caregiver Access to Supports and Services
- Invest in Research and Evidence-Based Practices
- Protect Financial Security of Caregivers
- Include Caregivers as a Vital Member of the Health and Human Services System
- Enhance the Health and Wellness of Caregivers

Wrap Up & Overview of Day 2

Greg Link, Director

Office of Supportive and Caregiver Services

Administration for Community Living

Wendy Fox-Grage, Project Director

National Academy for State Health Policy (NASHP)