

**Family Caregiving Advisory
Council Meeting
August 12, 2020**



Call to Order

Lance Robertson
Administrator/Assistant Secretary for Aging
Administration for Community Living



A Message from the HHS Secretary

Secretary Alex Azar

U.S. Department of Health and Human Services



Council Chair Opening Remarks

Lance Robertson

Administrator/Assistant Secretary for Aging
Administration for Community Living



Roll Call

Agenda Overview and Updates

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



Agenda

12:50–1:00 **Agenda Overview and Updates**

1:00–1:45 **Synching with National Alzheimer’s Project Act Activities**

1:45–2:45 **Council Discussion and Vote: Refining the National Strategy Goals**

2:45 **Adjourn to Subcommittee Meetings**



Synching with National Alzheimer's Project Act (NAPA) Activities

Helen Lamont, Ph.D.

Senior Long-Term Care Analyst

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

U.S. DHHS, Assistant Secretary for Planning and Evaluation

Katie Brandt

Co-Chair

National Alzheimer's Project Act (NAPA) Council



Coordinating NAPA and RAISE Recommendations

HELEN LAMONT, PH.D.

KATIE BRANDT, M.M.

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

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.

What is NAPA?

National Alzheimer's Project Act (NAPA)

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

- Includes both non-federal and federal members
- Convened quarterly since September 2011 (with the exception of April 2020)
- Annual recommendations in July

National Plan to Address Alzheimer's Disease

- First released on May 15, 2012
- Updated annually
- Next update expected October 2020

Recommendations inform:

- HHS Secretary
 - Informs the development of the National Plan Update
- Congress
 - Federal funding and policy priorities
- States
- Public
- International

What topics does NAPA cover?

Three broad (and somewhat overlapping) subcommittees: Research, Clinical Care, Long-Term Services and Supports

Five goals of 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

Family Caregivers: Part of the LTSS subcommittee and Goal 3, but essential to successful biomedical research, high-quality care, and public awareness

NAPA and RAISE

SIMILARITIES

- Population
- Recognize the important role of caregivers
- Importance of integrating caregivers in healthcare system
- Affordable, accessible, culturally competent LTSS essential
- Caregiver support
- Advance research on care models and interventions

DIFFERENCES

- Focus on preventing or effectively treating
- RAISE more diversity in conditions, diagnoses, ages of care recipients and different caregiving roles
- Biomedical research, diagnosis, and clinical care for people with dementia are major areas
- Some initiatives driven by PLWD

2020 Recommendations

- July 20 meeting: Recommendations presented by subcommittee chairs
- Approved by non-federal members of the Advisory Council
- Inform future work in the [National Plan to Address Alzheimer's Disease: Update](#) (scheduled to be released in October 2020)
- NAPA Recommendations: <https://aspe.hhs.gov/advisory-council-recommendations>
- Recommendations go to HHS Secretary Azar and are transmitted to Congress

2020 LTSS Recommendations

- Decrease disparities and expand access to LTSS, including home and community-based services (HCBS).
- Improve integration of clinical care with HCBS including systematic identification, assessment, support, referral and engagement of persons living with ADRD and their caregivers by health care systems.
- Provide high quality, person- and family-centered LTSS.
- Address behavioral and psychological symptoms of ADRD across care settings.
- Prepare the nation to reduce risk factors thought to lead to ADRD.

Recommendation I.

Decrease Disparities and Expand Access to Affordable LTSS, including home and community-based services (HCBS)

- By 2025, programs beyond Medicaid that provide LTSS should be expanded to support individuals and their caregivers with unmet needs, including diverse, under-served, and high-risk populations living with ADRD.
 - State models for expanding the availability of LTSS and/or supporting unpaid caregivers through 1115 waivers and other strategies should be evaluated by ASPE and, if warranted, disseminated broadly to encourage adoption by other states. See the LTSS toolkit for examples: https://www.chcs.org/media/Strengthening-LTSS-Toolkit_032019.pdf
 - Congress should expand the Family Medical Leave Act (FMLA) and States should expand supports for paid leave for caregivers.
 - States should expand voluntary long-term care savings accounts
 - Congress and States should expand tax credits for caregivers
- Expand access to HCBS through health care providers and systems
 - Congress should sustain Section 2404 protections against spousal impoverishment in the Affordable Care Act (ACA), and the section 1915(i) HCBS state plan option, Community First Choice (CFC) attendant care services and supports, and individuals eligible through a medically needy spend down to HCBS waivers.

Recommendation II.

Improve integration of clinical care with HCBS

- By 2025, hospitals and healthcare provider practices serving people living with ADRD will have in place procedures to:
 - Identify and document a caregiver or authorized health care proxy, where appropriate, to participate in care planning and better assure goal implementation.
 - Co-design person- and family-centered care plans with the individual and caregiver or authorized health care proxy (where appropriate), so that plans are concordant with the individual's goals of care and can be supported in the community or other long-term care setting.
 - When undertaking discharge planning from a facility, the individual living with ADRD and a caregiver or authorized health care proxy, should be involved so as to lessen risk of re-hospitalization or other adverse events.
 - Assess the person living with ADRD and the caregiver's LTSS needs, provide them with disease education, caregiver training and HCBS, and/or refer them to community-based services. This should include information about costs and coverages for these services.
- By 2025, CMS will have quality measures in place that will encourage health care systems to implement these recommendations.

Recommendation III.

Provide high quality, person- and family- centered LTSS

- Research should be funded through federal agencies and other public and private funders to study the implementation of evidence-supported dementia and caregiving interventions.
- Federal agencies and other public and private organizations should disseminate evidence-supported interventions and person- and family-centered care planning models.
- Federal agencies and other organizations should convene representatives from professional societies in an effort to develop and harmonize practice guidelines as pertains to care planning, caregiver support and HCBS recommendations across the evidence.
- To expand the applicability of evidence-supported interventions for people living with ADRD and for caregivers from diverse, underserved, and high-risk populations living with dementia, NIH should:
 - Establish a repository of assessment and outcome tools and instruments that have been validated for use with culturally and linguistically disparate populations.

Recommendation III.

Provide high quality, person- and family- centered LTSS (continued)

- Federal agencies, states and other organizations should build workforce capacity to provide dementia capable LTSS including training on person- and family-centered care planning and evidence-supported interventions for people living with ADRD and caregivers.
- CMS and other federal payors should create care and payment models for use of effective evidence-supported interventions for people living with ADRD and caregivers, as well as for person-and family-centered care planning.

Cross-Cutting Recommendations

1. The Department of Health and Human Services (HHS) and federal partners should improve and expand emergency preparedness, response, and recovery with specific consideration of the needs of individuals living with Alzheimer's Disease and Related Dementias and their caregivers.
2. The Advisory Council and federal partners should develop a national goal to reduce the burden of risk factors to prevent or delay onset of Alzheimer's Disease and related dementias.
3. Advance Health Equity by Addressing Racial and Ethnic Disparities in Alzheimer's Disease and Related Dementias

Key Opportunities

Improve LTSS- Federal support is a significant ask, but opportunities to assist caregivers through improvements to Medicare and Medicaid.

Educate states about models of excellence in:

- LTSS delivery and financing
- Caregiver assessment and support,
- Evidence-supported caregiver interventions
- HCBS provision

Areas for joint aligned recommendations:

- Disparities in service access that we should both address
- Protection of caregiver financial security (tax credits, LTC insurance financing, etc.)
- Improvements to Medicare and Medicaid

Opportunities to Collaborate

- Reference and amplify recommendations
- Cross-presentations– October 2020 NAPA meeting?
- Build off the research accomplishments, particularly in caregiver interventions and assessments
- Shared membership and commitment by federal staff
- Reduction in the burden of disease alleviates suffering for all– shared success!

*“I need information.
He needs hope.”*

-FTD Caregiver



Thank You

For more information, see:

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



National Alzheimer's Project Act

The National Alzheimer's Project Act (NAPA) 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/ADRD). The law calls for a National Plan for AD/ADRD 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/ADRD and reduce the financial burden of these conditions on those with the diseases, their families, and society.

In order to inform the National Plan for AD/ADRD, 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 Institute 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 NAPA's charges to coordinate research and services across agencies, accelerate the development of AD/ADRD treatments, improve early diagnosis and coordination of care, reduce ethnic and racial disparities in rates of AD/ADRD, and coordinate with international efforts to fight these conditions. The Plan this 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 Listserv is also available that will automatically email you a monthly message. To join, send an email to LISTSERV@LIST.NIH.GOV. Whatever email address this message is sent from will be what is used in the Listserv. The only thing that needs to be in the body of the message is:

subscribe NAPA-L 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 (added October 2019)
- National Plan to Address Alzheimer's Disease: 2019 Update (added October 2019)
- New Advisory Council Members (added October 2019)
- October 2019 Advisory Council Meeting Material (added September 2019)

RESEARCH SUMMIT ON DEMENTIA CARE
Building Evidence for Services and Supports

ALTHOUGH THE 2017 SUMMIT IS OVER, THE WORK HAS JUST BEGUN. CONTINUE TO SEND YOUR STORIES, THOUGHTS AND RECOMMENDATIONS TO NAPA@HHS.GOV, WITH THE SUBJECT LINE "SUMMIT COMMENT".

THE NEXT SUMMIT IS BEING PLANNED NOW FOR MARCH 2020. SO KEEP CHECKING NIH'S 2020 DEMENTIA CARE & CAREGIVING SUMMIT PAGE OR THE 2017 SUMMIT HOME PAGE FOR UPDATING INFORMATION.

FIND INFORMATION ON:

NAPA WHAT IS ALZHEIMER'S DISEASE & RELATED DEMENTIAS

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

- National Plans -- updated Oct 24

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

NAPA OTHER INFORMATION ON AD/ADRD

- Agency Reports -- updated Jan 28

Council Discussion and Vote: Refining the National Strategy Goals

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



Wendy Fox-Grage Project Director
RAISE Family Caregiving Resource and Dissemination Center
National Academy for State Health Policy (NASHP)



Wrap Up & Next Steps

Adjourn to Subcommittee Meetings

Thank you

