



OCTOBER 16-17, 2017
NATCHER BUILDING, NIH CAMPUS

Progress to Date

Laura N. Gitlin and Katie Maslow

Presentation to the Advisory Council for the National Alzheimer's Project Act
July 28, 2017

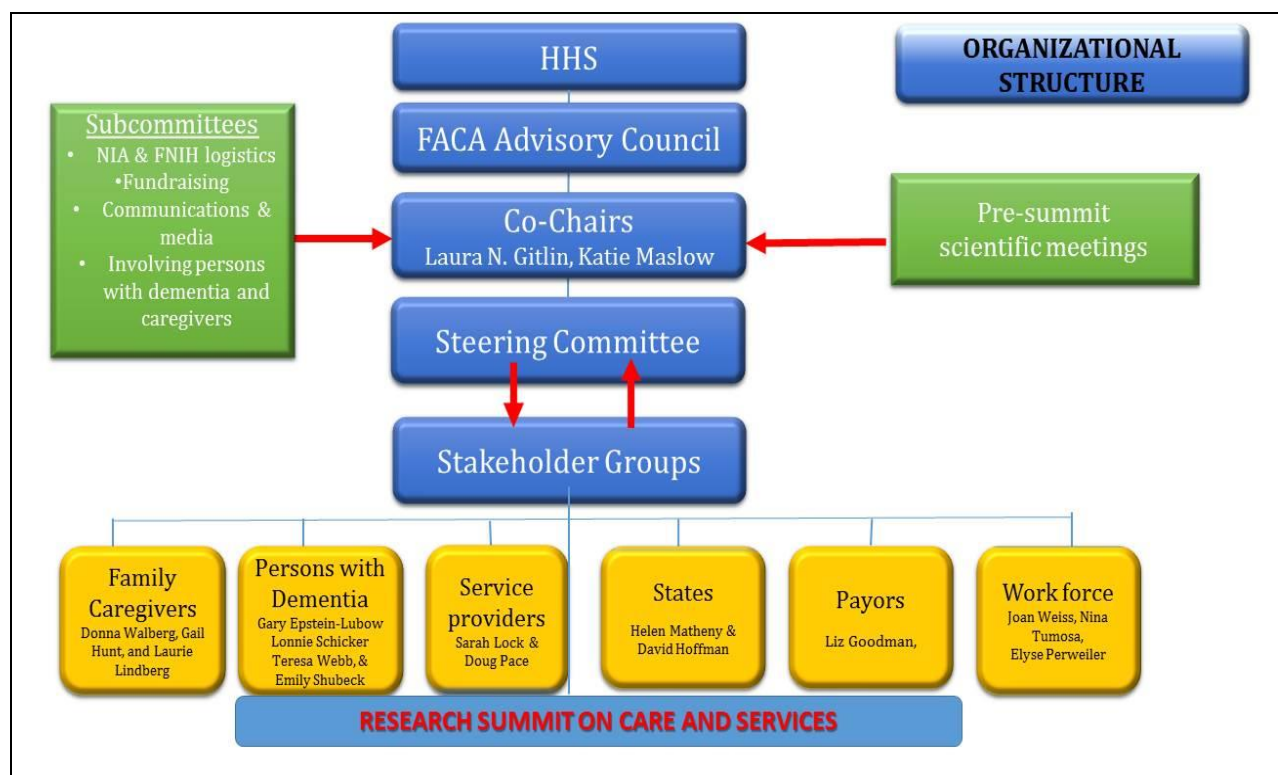
National Research Summit Goals

- Identify what we know and what we need to know to accelerate development, evaluation, translation, implementation, and scaling up of comprehensive care, services, and supports for persons with dementia, families, and other caregivers
- Focus on research needed to improve quality of person- and family centered care and outcomes including quality of life and outcomes across care settings, including quality of life and the lived experience of persons with dementia and their caregivers*

*The term 'caregivers' refers to family members, neighbors, friends, fictive kin, and formal, paid caregivers.

Potential Outcomes of the Summit

- Research recommendations and priorities to inform Federal agencies, foundations, and private sector organizations that fund research on dementia care, services and supports.
- Identification of evidence-based programs, strategies, and approaches that can be used now to improve care, services, and supports
- Identification of methodologies to involve individuals with dementia and families in shaping research and participating in studies
- Research milestones to track and guide acceleration and advancement of evidence-informed care and services
- White papers, briefs, and publications summarizing Summit research recommendations and outcomes; possible post-summit activities to advance policy and practice implications



Steering Committee Members

- Gary Epstein-Lubow, MD (Brown University)
- Lori Frank, PhD (PCORI)
- Richard Hodes MD (NIA)
- Ian N. Kremer JD (LEAD)
- Shari M. Ling, MD (CMS)
- Sarah Lenz Lock JD (AARP)
- Helen Matheny, MS (West Virginia University)
- Lisa McGuire, PhD (CDC)
- Jennifer Mead, MPH (Oregon Dept. of HS)
- Linda O. Nichols, PhD. (VA Medical Center)
- Douglas D. Pace, NHA (Alzheimer's Association)
- Lonni Schicker, EdD, MHSA, RN, Co-chair, Persons Living with Dementia Stakeholder Group
- Jane Tilly, DrPH (ACL)
- Lois A. Tully, PhD. (NINR)
- Teresa Webb, RN, Co-Chair, Persons Living with Dementia Stakeholder Group
- Joan Weiss, PhD, RN (HRSA)

Co-chairs

Laura N. Gitlin, Ph.D.

Katie Maslow, MSW

Executive Committee

Ron Petersen MD, PhD (Mayo Clinic)

Rohini Khillan, MPH (ASPE, HHS)

Summit Funding is Almost Complete

- As of July 18, private sector sponsors had committed more than 90% of the FNIH goal; Sponsor names are shown on the FNIH website
- Very substantial additional funding came from the U.S. Office of Women's Health
- Federal government agencies and private sector organizations have provided additional funding and major in-kind support, including:

ASPE

National Institute on Aging

LEAD Coalition

Gerontological Society of America

Alzheimer's Association

UsAgainst Alzheimer's

Alliance for Aging Research

Others

THANK YOU !!

Summit Agenda is Almost Complete

Day One: Welcome and Introduction: Summit Co-Chairs and Sponsors

- Plenary Speakers –setting the stage
 - Ron Petersen, MD
 - Maria Carillo, Ph.D.
 - Ken Langa, MD, Ph.D.
 - Jennifer Manly, Ph.D.
 - Maria Aranda, Ph.D.
- Session I: Research on Care Needs and Supportive Approaches for Persons with Dementia (Co-chairs: Richard Fortinsky, Ph.D., Ann Kolanowski, Ph.D.)
- Session II: Research on Supportive Approaches for Family and Other Caregivers (Co-chairs: Linda Teri, Ph.D, Lisa Fredman, Ph.D.)
- Session III: Involving Persons with Dementia and Caregivers as Members of the Research Team (Co-Chairs: Mark Snowden, MD, M.P.H, Lee Jennings, MD, M.S.H.S.)

Summit Agenda (cont.)

Day Two

- Plenary Session: Nomenclature: Words Matter: (Co-Chairs: Angela Taylor and Ron Peterson, MD, Ph.D)
- Session IV: Involving Persons with Dementia as Study Participants (Co-chairs: Darby Morhardt, Ph.D., David Bass, Ph.D.)
- Session V: Research on Care Coordination and Care Management for Persons with Dementia and Family Caregivers (Co-chairs: David Reuben, MD., Vincent Mor, Ph.D.)
- Session VI: Thinking Outside the Box (Co-chairs: Chris Callahan, MD., Alan Stevens, Ph.D.)

Cross-Cutting Themes

Crosscutting Themes: Diversity (gender, race, ethnicity, culture, language, literacy, sexual orientation, socio-economic status, geographic location, and living situation [alone or with a caregiver]); Disparities; Etiologies and Disease Stages; Care Settings (home, community, assisted living, nursing home, and medical/health care settings); employment, training, and workforce issues; and technology.

Plenary Lectures will provide information about prevalence and the characteristics of persons with dementia, family caregivers and caregiving situations, emphasizing available data about diversity and other cross-cutting themes

Cross-cutting Chairs will review research recommendations for inclusion of cross-cutting themes

Technology – Dr. Czaja;

Race/ethnicity/culture – Dr. Hinton;

Etiologies/disease stage – Angela Taylor;

Women’s Issues – Mary Worstell, M.P.H. and Jill Lesser

Research Recommendations

Research recommendations will come from many sources, including:

- Session co-chairs and speakers
- Plenary speakers
- Cross-cutting chairs
- Stakeholder groups
- Pre-Summit activities
- Public listening sessions
- Audience members

All proposed recommendations, whether considered during summit presentations or not, will be kept and eventually placed on the summit website.

Roles of Persons Living with Dementia and Family Caregivers

- Persons living with dementia and family caregivers have been participating in stakeholder groups that have been discussing summit-related issues and providing feedback about the summit.
- At least 5 persons living with dementia will be speakers in the summit, and others will participate in other ways.
- At least 4 family caregivers will participate in the summit, and others will participate in other ways.
- By involving persons living with dementia and family caregivers throughout the planning and implementation of the summit, we are hoping to learn about their perspectives and to model valuable roles they can play in the research context

Next Steps

- Registration – free, open to the public
- Support for Session Chairs and Speakers to develop their presentations and recommendations
- Development/Implementation of a Communications Plan for before, during and after the summit
- Logistics and arrangements for summit participants

Questions?

July 28, 2017 -- Advisory Council Meeting #25

The meeting was held on Friday, July 28, 2017, in Washington, DC. The Advisory Council spent the morning discussing information gaps across the three areas of research, clinical care, and long-term services and supports. There was also a presentation on the recently released National Academy of Sciences, Engineering, and Medicine (NASEM) report on preventing cognitive decline. Additional presentations included a presentation on planning and progress towards the October Care and Services Summit and federal workgroup updates. 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#Jul2017>.

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

General Information

Agenda	[HTML Version] [PDF Version]
Meeting Announcement	[HTML Version] [PDF Version]
Meeting Summary	[HTML Version] [PDF Version]
Public Comments	[HTML Version]

Presentation Slides

2017 National Plan Update and Non-Federal Recommendations	[HTML Version] [PDF Version]
Clinical Services Subcommittee Federal Update	[HTML Version] [PDF Version]
CommunityRx for Community-Residing People with Dementia and Their Caregivers	[HTML Version] [PDF Version]
Dementia Caregiving in the U.S.	[HTML Version] [PDF Version]
Development of the FY 19 NIH Bypass Budget for Alzheimer's Disease and Related Dementias	[HTML Version] [PDF Version]
Implications of a Biologically Based Definition of Alzheimer's Disease	[HTML Version] [PDF Version]
Increasing Opportunities for Choice and Control for Persons with Dementia	[HTML Version] [PDF Version]
Interventions to Prevent or Slow Cognitive Decline, MCI and Dementia in Individuals without Dementia	[HTML Version] [PDF Version]
Living Alone With Dementia	[HTML Version] [PDF Version]

Long-Term Services and Supports Committee Update	[HTML Version] [PDF Version]
Managing Chronic Conditions in People Living with Dementia	[HTML Version] [PDF Version]
Preventing Cognitive Decline and Dementia	[HTML Version] [PDF Version]
Research Summit on Dementia Care	[HTML Version] [PDF Version]
The Many Challenges of Alzheimer's Disease	[HTML Version] [PDF Version]

Videos

Welcome thru Clinical Care	[Video]
LTSS Research	[Video]
Public Comments thru Federal Workgroup Updates	[Video]
Recommendations thru Adjourn	[Video]

Last Updated: 06/27/2018