

National Research Summit on

Care, Services, and Supports for Persons with Dementia and Their Caregivers

Summit Virtual Meeting Series

July 10, July 21, and August 13, 2020

<https://www.nia.nih.gov/2020-dementia-care-summit>



National Institute
on Aging



2020 Summit Co-Chairs



David B. Reuben, MD

Director, Multicampus Program in Geriatric
Medicine and Gerontology
Chief, Division of Geriatrics
Archstone Professor of Medicine
David Geffen School of Medicine at UCLA



Jennifer L. Wolff, PhD

Eugene & Mildred Lipitz Professor, Dept. of
Health Policy and Management
Director, Roger C. Lipitz Center for Integrated
Health Care, Johns Hopkins Bloomberg
School of Public Health

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The Association for Frontotemporal Degeneration

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Welcome

- Purpose and Structure of Summit
- Organization of Gaps and Opportunities by Themes and Cross-Cutting Themes
- Process for Incorporating Input and Your Participation
- Summit Logistics

2020 Care, Caregiving, & Services Summit

- The primary anticipated outcome of the 2020 summit is the identification of gaps and opportunities for research priorities to inform federal agencies, foundations, and private sector organizations.
- The Summit will also summarize the state of the science, identify gaps in knowledge, and highlight progress that has been made since, and as a result of, the 2017 Summit.

Restructuring to Accomplish Original Objectives

- Planned 2-day, in-person meeting March 24 & 25, 2020
- Due to COVID-19, switched to 3 virtual sessions in July & August 2020
 - Short research presentations
 - Introduction of draft research Gaps and Opportunities
 - Reactor panelists' perspectives
 - Moderated questions and answers and discussion
- Summit Program with speaker bios: <https://go.usa.gov/xfCss>

Organization: Six Summit Themes

<https://www.nia.nih.gov/2020-dementia-care-summit>

- **Theme 1:** Impact of Dementia
- **Theme 2:** Long-Term Services and Supports in Home, Community, and Residential Care Settings for Persons with Dementia and their Caregivers
- **Theme 3:** Services and Supports in Medical Care Settings for Persons with Dementia

Integration: The Present and Future of Integrated Long-Term and Medical Care

- **Theme 4:** Participation of Persons with Dementia and their Caregivers in Research
- **Theme 5:** Intervention Research, Dissemination, and Implementation
- **Theme 6:** Research Resources, Methods, and Data Infrastructure

Organization: Cross-Cutting Themes

1. Perspectives from persons with dementia and their caregivers
2. Health disparities
3. Ethics
4. Technology
5. Etiologies

Process: Input from Various Sources Leads to Diverse Perspectives

- Request for Information (RFI) published in the NIH Guide in April 2019
- Summit Steering Committee

Summit Steering Committee

- **Jennifer Wolff, Johns Hopkins University, Steering Committee Co-chair**
- **David Reuben, UCLA, Steering Committee Co-chair**
- María Aranda, University of Southern California
- Susan Beane, Healthfirst
- Malaz Boustani, Indiana University School of Medicine
- Katie Brandt, Massachusetts General Hospital
- Chris Callahan, Indiana University School of Medicine
- Elena Fazio, National Institute on Aging
- Lori Frank, RAND
- Jason Karlawish, University of Pennsylvania
- Ian Kremer, LEAD Coalition
- Helen Lamont, Office of the Assistant Secretary for Planning and Evaluation, HHS
- Katie Maslow, Gerontological Society of America
- Michael Monson, Centene Corporation
- Vincent Mor, Brown University
- Joanne Pike, Alzheimer's Association
- Melanie Schicker, Minnesota State University (Retired)
- Robyn Stone, LeadingAge
- Sheryl Zimmerman, University of North Carolina

Process: Input from Various Sources Leads to Diverse Perspectives

- Request for Information (RFI) published in the NIH Guide in April 2019
- Summit Steering Committee
- HHS Office of the Assistant Secretary of Planning and Evaluation (ASPE) gathered input from 5 Stakeholder Groups

Stakeholder Groups

- Persons Living with Dementia
 - *Co-Chairs.* Gary Epstein-Lubow, Monica Moreno
- Family Caregivers of Persons Living with Dementia
 - *Co-Chairs.* Lisa Gwyther, Ann Cheslaw
- Service Providers, including in-home and community-based services, nursing home, rehabilitation, assisted living and hospice care, public health services, and health care professional groups
 - *Co-Chairs.* Doug Pace, Sarah Lock
- Workforce Development
 - *Co-Chairs.* Joan Weiss, Nina Tumosa, Robert Espinoza
- Payers
 - *Co-Chairs.* Elizabeth Goodman, Alice Bonner

Process: Input from Various Sources Leads to Diverse Perspectives

- Request for Information (RFI) published in the NIH Guide in April 2019
- Summit Steering Committee
- HHS Office of the Assistant Secretary of Planning and Evaluation (ASPE) gathered input from 5 Stakeholder Groups
- Input from federal partners
- Input from the NAPA Advisory Council
- Providing opportunities before, during, and after the Summit meetings for audience participation and engagement

Process: Producing Research Gaps and Opportunities

- Research Gaps and Opportunities are organized by Summit theme
- Stakeholder groups shared draft recommendations from their perspective with the Steering Committee during the planning process, for consideration
- Preliminary recommendations will be unveiled by theme/session

Your participation:

During the session: Zoom Q&A

- Submit a comment during the session using the Zoom Q&A. All will be read though time will not permit all to be discussed.

During or after the session: Respond to RFI

- Navigate to <https://www.nia.nih.gov/2020-dementia-care-summit#RFI> to suggest a modification to a draft gap and opportunity OR suggest a new gap/opportunity.
- All suggestions will be reviewed after the session and before the finalized list is generated.

After the Summit's final Gaps and Opportunities are released:

- Stay engaged and work towards implementing research that improves the lives of persons living with dementia and their caregivers.
- Visit <https://www.nia.nih.gov/2020-dementia-care-summit> for more information.

Summit Virtual Meeting Series

Today's Event: Virtual Meeting 1

- Welcome
- Setting the Stage
- Theme 1: Impact of Dementia
- Theme 4: Participation of Persons with Dementia and their Caregivers in Research

Setting the Stage



Richard Hodes,
M.D., Director of
the National
Institute on Aging



Lonni Schicker, EdD,
RN, Summit Steering
Committee member,
person living with
dementia



Katie Brandt, MM,
Summit Steering Committee
member, Director of Caregiver
Support Services and Public
Relations for the
Frontotemporal Disorders Unit
at Massachusetts General
Hospital, Co-Chair of the
National Alzheimer's Project
Act Advisory Council on
Alzheimer's Research, Care, and
Services



Arne Owens,
Deputy Assistant
Secretary, Office of
Disability, Aging, and
Long-Term Care
Policy, ASPE



Laura Gitlin, PhD,
FGSA, FAAN, 2017
Summit Co-Chair,
Distinguished
Professor and Dean
of College of Nursing
and Health
Professions, Drexel
University

2020 National Research Summit on Care, Services, and Supports for People Living with Dementia and their Caregivers

Richard J. Hodes, M.D.

Director

National Institute on Aging

NIA's Commitment



- Promote health equity
- Eliminate health disparities
- Enhance the diversity of the scientific workforce

NIA AD/ADRD Appropriations

2011	2012	2013	2014	2015	2016	2017	2018	2019	2020
National Alzheimer's Project Act (NAPA)	\$50 M* redirected within NIH budget	\$40 M* redirected within NIH budget	\$100 M additional approp.	\$25 M additional approp.	\$350 M additional approp.	\$400 M additional approp.	\$414 M additional approp.	\$425 M additional approp.	



\$350M in additional appropriations as of 12/20/19

*One-year money
Years displayed are fiscal years

Growth of AD/ADRD Research Spending at NIH

NIH Funding for AD/ADRD Research – *in millions*

From NIH's Research, Condition, and Disease Categories (RCDC) System

Research/Disease Areas (Dollars in millions and rounded)	FY 2015	FY 2016	FY 2017	FY 2018	FY 2019	Difference – FY15 to FY19
AD/ADRD	\$631	\$986	\$1,423	\$1,911	\$2,398	3.8-fold increase
Alzheimer's Disease	\$589	\$929	\$1,361	\$1,789	\$2,240	3.8-fold increase
Alzheimer's Disease Related Dementias¹	\$120	\$175	\$249	\$387	\$515	4.3-fold increase
Lewy Body Dementia	\$15	\$22	\$31	\$38	\$66	4.4-fold increase
Frontotemporal Dementia	\$36	\$65	\$91	\$94	\$158	4.4-fold increase
Vascular Cognitive Impairment/Dementia	\$72	\$89	\$130	\$259	\$299	4.2-fold increase

¹The ADRD row reflects the sum of the three existing RCDC categories: Frontotemporal Dementia, Lewy Body Dementia, and Vascular Cognitive Impairment/Dementia—where duplicates are removed.

https://report.nih.gov/categorical_spending.aspx

AHRQ-National Academies Study on Dementia Care & Caregiving

- **Status:**

- Agency for Healthcare Research & Quality (AHRQ)**

AHRQ's Minnesota Evidence Based Practice Center released a **draft evidence review** on March 24, 2020 and will release a final version soon

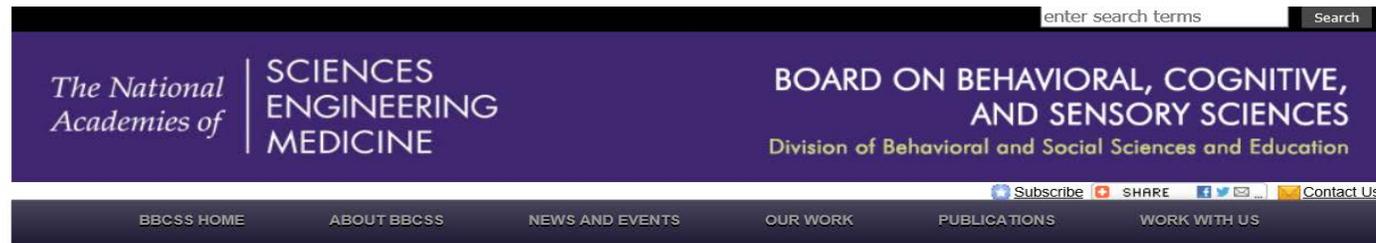
- National Academies of Sciences, Engineering, and Medicine (NASEM)**

NASEM Committee held a public workshop on April 15, 2020 and will reconvene to draft their report, expected to be released in early 2021



NASEM Decadal Survey of Behavioral and Social Science Research on AD/ADRD

www.nas.edu/AlzheimersDecadal



The screenshot shows the top navigation bar of the NASEM website. On the left, it features the logo for 'The National Academies of SCIENCES ENGINEERING MEDICINE'. On the right, it identifies the 'BOARD ON BEHAVIORAL, COGNITIVE, AND SENSORY SCIENCES' and its 'Division of Behavioral and Social Sciences and Education'. A search bar is located at the top right. Below the header, there is a row of social media icons for 'Subscribe', 'SHARE', and 'Contact Us'. A dark navigation bar at the bottom contains links for 'BBCSS HOME', 'ABOUT BBCSS', 'NEWS AND EVENTS', 'OUR WORK', 'PUBLICATIONS', and 'WORK WITH US'.



Project Overview

The National Academies' Division of Behavioral and Social Sciences and Education will appoint a committee to conduct a decadal survey focusing on developing a research agenda for the next decade in the behavioral and social sciences as it relates to Alzheimer's disease (AD) and Alzheimer's disease-related dementias (ADRD). For this Decadal Survey, drawing on extensive input from the scientific



CALL #1 FOR WHITE PAPERS

We are seeking input from researchers and stakeholder communities for the first phase of this project.

[SUBMIT WHITE PAPERS](#)

NIA Launches a Data Sharing Landing Page

Data Sharing Resources for Researchers

There are a variety of data sharing policies, considerations, resources, and guidance available to support researchers in safely and efficiently sharing data from their studies. NIA also provides data resources to the Alzheimer's and aging research community.

To learn more about data sharing at NIH, see the [NIH Sharing Policies and Related Guidance on NIH-Funded Research Resources](#) and the [NIH Data Sharing FAQs](#),

<https://www.nia.nih.gov/research/data-sharing-resources-researchers>

<https://www.nia.nih.gov/research/grants-funding/nia-specific-funding-policies#datasharing>



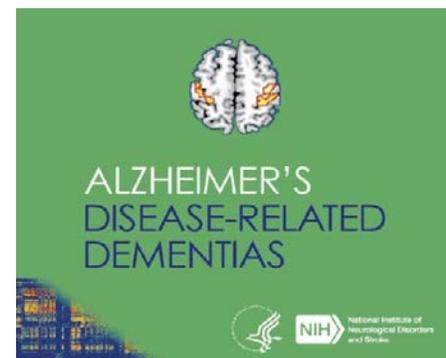
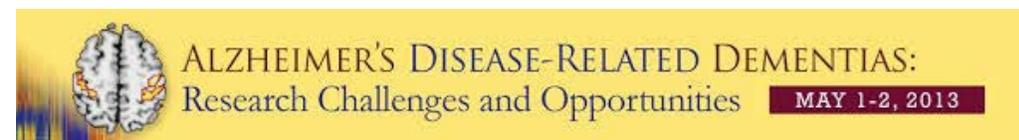
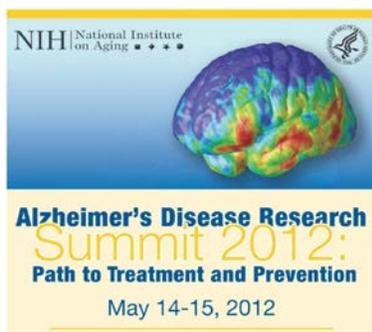
Alzheimer

Alzheimer's Semipostal Stamp

Total Raised to Date:
\$1,061,777

AD/ADRD Summits

- **Alzheimer's Disease Summits:** 2012, 2015, 2018, 2021 (*virtually*)
- **ADRD Summits:** 2013, 2016, 2019, 2022
- **Dementia Care, Caregiving, & Services:** 2017, 2020 (*virtually*)



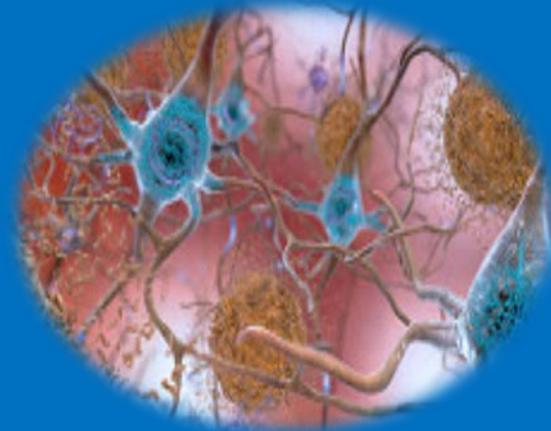
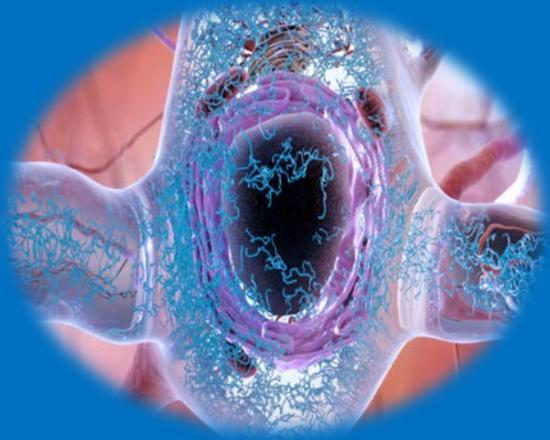
2020 Dementia Care, Caregiving, & Services Summit Virtual Meeting Series

Ways to Share Your Perspective:

- Participate in live discussions during today's event and two future virtual meetings
- Respond to NIA's Request for Information



[https://www.nia.nih.gov/
2020-dementia-care-
summit](https://www.nia.nih.gov/2020-dementia-care-summit)



NIA

The Leader in Aging Research



Why aren't we all on the same page?

My Journey

1. Diagnosis
2. Communication
3. Planning for the future



Lonni Schicker, EdD, RN, 2020 Summit Steering Committee member, person living with dementia, and retired registered nurse and professor of health administration

Caregiver Perspective

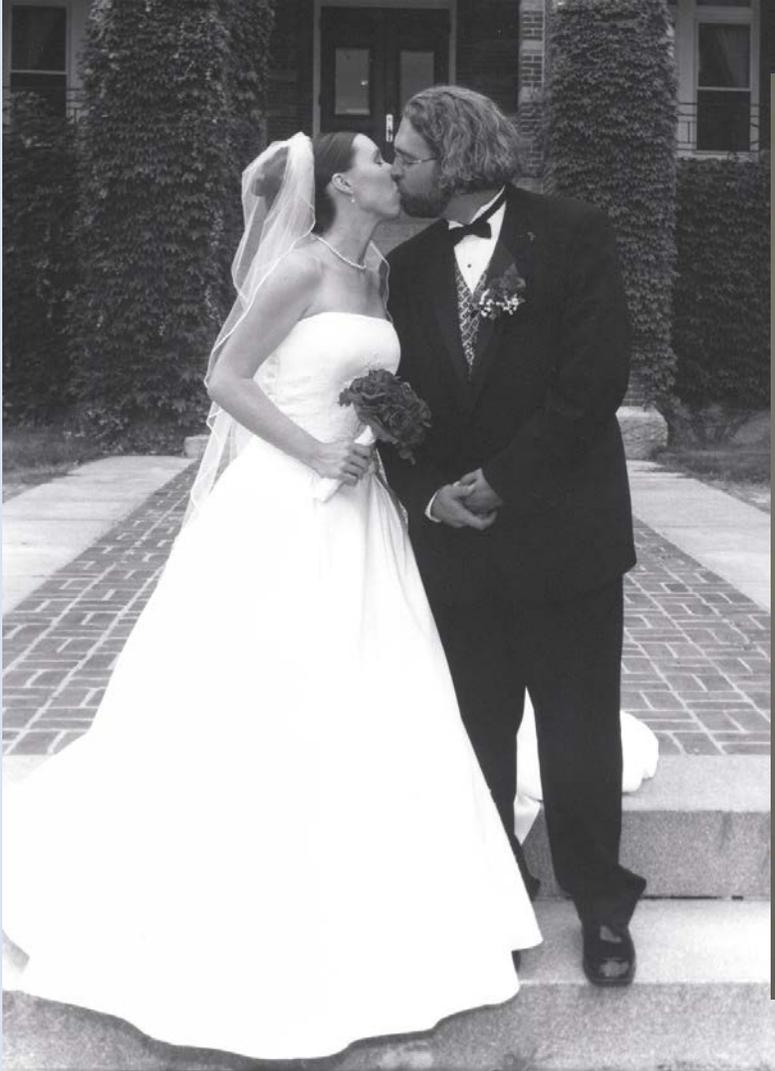
Katie Brandt, Caregiver

July 10, 2020

National Institute on Aging

[National Research Summit on Care, Services, and Supports for
Persons with Dementia and Their Caregivers](#)

Love started the story...



Multi-Generational Impact

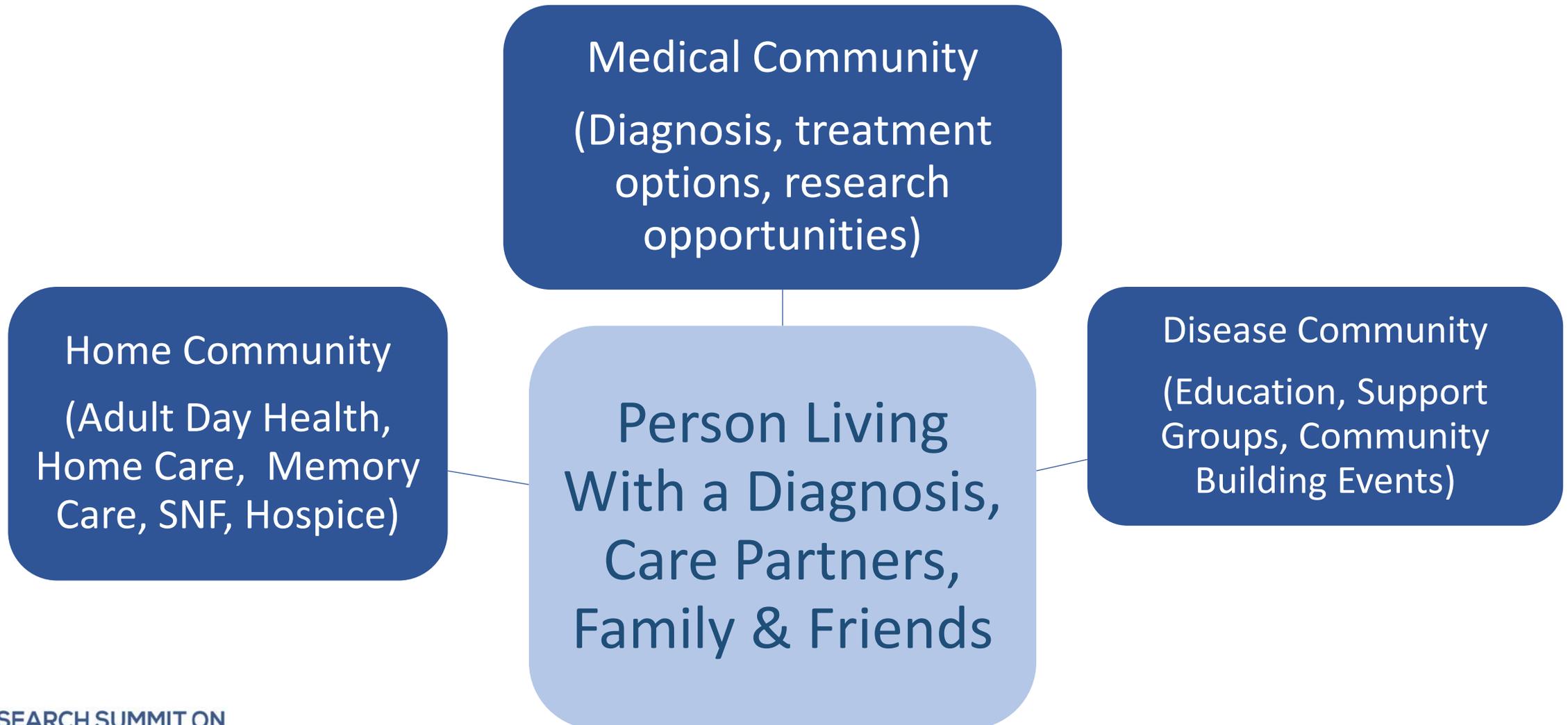
- Financial Vulnerability
- Employment Disruption
- Barriers to Accessing Services and Supports
- Loss of Community

Unique With Common Needs

- Respite
- Training and Education
- Community Connections
- Specialized Care Providers



Trifecta for Care Planning





Evolving Goals of Care

- Person and Family-Centered
- Incorporating Values and Culture
- Empowerment Through Education



Moving forward with love...



National Alzheimer's Project Act (NAPA) Advisory Council on Alzheimer's Research, Care and Services



Co-Chair, Katie Brandt, MM, Massachusetts General Hospital, Frontotemporal Disorders Unit
Co-Chair, Allan Levey, MD, PhD, Emory University, Alzheimer's Disease Research Center

Acknowledgement & Gratitude

Amy Almeida, PhD
Loren Blanchard
Noah Brandt
Alicia Calef, MS
Brad Dickerson, MD
Albert Galaburda, MD
Diane Lucente, MS, CGC
Tom McMullen
Megan Quimby, MS, CCC-SLP
Bonnie Wong, PhD/ABPP-CN
Alzheimer's Association
Association for Frontotemporal Degeneration
Boston-area FTD Support Group
Massachusetts Biotech Council
National Alzheimer's Project Act (NAPA) Advisory Council
Patients, Caregivers & Family Members in our Dementia Community



Given in Loving Memory of Michael Brandt & Diane McMullen



National Alzheimer's Project Act

ARNE OWENS

**DEPUTY ASSISTANT SECRETARY FOR
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.

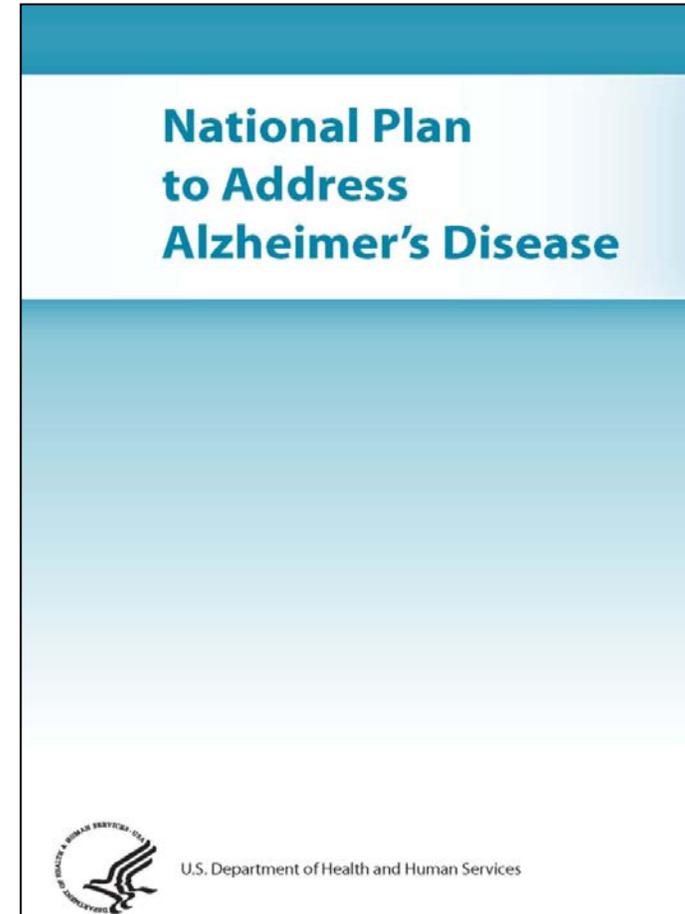
National Alzheimer's Project Act (NAPA)

Enacted 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

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



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 Members

- Meets quarterly
- **Annual recommendations to Secretary and Congress on priority actions**

Department of Health and Human Services

- ASPE, ACL, NIH, AHRQ, CMS, HRSA, IHS, FDA, CDC
- Department of Veterans Affairs
- Department of Defense
- National Science Foundation

Federal Members

National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers

- First Summit in 2017- result of a recommendation of the Alzheimer's Advisory Council
- Gaps and opportunities identified through Summit will inform:
 - NIA research plans
 - Recommendations of the Advisory Council
- Opportunity to take advantage of great minds in the field



Thank You!

For more information, see:

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

U.S. Department of Health & Human Services

ASPE
OFFICE OF THE ASSISTANT SECRETARY FOR PLANNING AND EVALUATION

Search Site...

ABOUT - TOPICS - PUBLICATIONS - DATA AND TOOLS -

NATIONAL ALZHEIMER'S PROJECT ACT HOME - ABOUT - COORDINATION - NATIONAL ALZHEIMER'S PROJECT ACT

10/31/2019

Facebook, Email, Twitter, Plus

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/AR/D). The law calls for a National Plan for AD/AR/D 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/AR/D 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/AR/D, 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/AR/D treatments, improve early diagnosis and coordination of care, reduce ethnic and racial disparities in rates of AD/AR/D, 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@LISTNH.GOV. Whatever email address the 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 UPCOMING INFORMATION.

FIND INFORMATION ON:

<p>NAPA WHAT IS ALZHEIMER'S DISEASE & RELATED DEMENTIAS</p>	<p>NAPA ADVISORY COUNCIL ON ALZHEIMER'S RESEARCH, CARE, & SERVICES</p> <ul style="list-style-type: none"> Advisory Council Members - updated Oct 11 Meeting Material - updated Sep 20 Public Comments - updated Sep 16 Meeting & Event Videos - updated Oct 19
<p>NAPA NATIONAL PLAN & OTHER NAPA DOCUMENTS</p> <ul style="list-style-type: none"> National Plans - updated Oct 24 	<p>NAPA OTHER INFORMATION ON AD/AR/D</p> <ul style="list-style-type: none"> Agency Reports - updated Jan 28

2020 National Research Summit on Care,
Services, and Supports for People Living
with Dementia and their Caregivers

Progress to Date

Laura N. Gitlin, Ph.D. FGSA, FAAN

Distinguished Professor, Dean, College of Nursing and Health Professions

Drexel University

Adjunct Professor, Johns Hopkins School of Nursing

#DeanDrexelCNHP

Funding Sources and Disclosures

Funded by:

- National Institute on Aging
- National Institute on Mental Health
- Veterans Administration
- PA Department of Tobacco
- Alzheimer's Association
- Administration on Community Living



Disclosures:

Consultant to various community-based agencies concerning dementia care;
Inventor of an online program for an intervention (Tailored Activity Program) for which
Johns Hopkins University, Drexel University, and Dr. Gitlin are entitled to fees.



Where We
Began:
October 2017

Goals of First Historic Summit

- Identify existing evidence & what we need to know to provide comprehensive dementia care that improves quality of care & outcomes across all care settings and for individuals/families from diverse backgrounds & living situations
- Embrace complexity:
 - Recognize, examine and understand diversity defined broadly as:
 - race, ethnicity, gender, age, etiologies, disease stages, living arrangements, geography, financial status, **social and structural determinants of access to care, quality of care received & role of discrimination and racism**



2017 Summit Lessons Learned

Paradigm switch:

- Care is important & matters
- Care can address clinical symptoms, may slow disease progression
- Involving people living with dementia & care partners aligns research questions and measures with what matters
- Need to involve stakeholders throughout research process
- We have evidence we can move to the real world

464
recommendations

12 “Buckets” of
recommendations

<https://aspe.hhs.gov/system/files/pdf/259156/FinalReport.pdf>

- Heterogeneity
- Lived experience
- Caregiver relationships, roles networks
- Person/family-centered care models spanning disease continuum and etiologies
- Engaging people living with dementia as research team members
- Financial burdens and cost of care
- Living environments & arrangements
- Nomenclature
- Workforce development
- **Research methods (Measurement)**
- **Scale up/disseminate evidence**
- **Technology**

Since October 2017 Summit NIA Funding Opportunities

26 funding opportunities and 4 Notices of Special Interest on dementia care and caregiving topics such as:

- *home and community-based services*
- *lucidity in dementia*
- *pragmatic dementia care clinical trials*
- *care and caregiver support interventions*
- *assistive technology*
- *dementia care workforce*
- *interpersonal processes with care partners and health care providers*

Since October 2017 Summit: NIA Awards

- Approximately **129 new NIA awards** came out of care-related funding opportunities (does **not include** awards from other NIH Institutes or continuing awards)
- Number of awards ***will likely increase as*** some opportunities are still accepting applications
- Many **more** awards have been granted to **investigator-initiated research** on dementia care and caregiving topics (i.e., not submitted to a targeted funding opportunity)
- **RFA-AG-18-030 Dementia Care and Caregiver Support Interventions**
- **RFA-AG-19-007 Roybal Centers for Translational Research on Dementia Care Provider Support**

Measuring What Matters

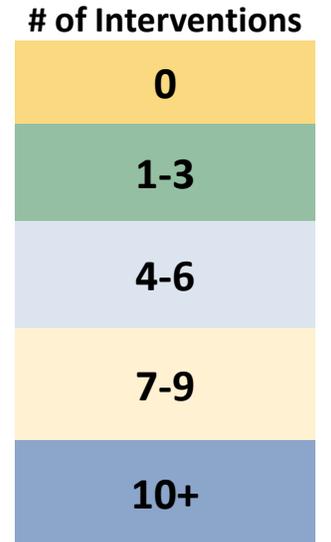
LINC-AD: Leveraging an Interdisciplinary Consortium to Improve Care and Outcomes for Persons Living with Alzheimer's and Dementia (R24AG065185)

- Led by Dr. Fazio (Alzheimer's Association), Dr. Zimmerman (University of North Carolina), and members of Alzheimer's Association with guidance from 38 Research Steering Committee Members and a Care and Support Advisory Group
 - Critique existing outcome measures and care tools and identify gaps
 - Promote development of new outcome measures and care tools
 - Facilitate dissemination, adoption, implementation, and sustained use of existing and new outcome measures and care tools

Heat Map of Caregiver Outcomes

(54 Published Efficacy Studies)

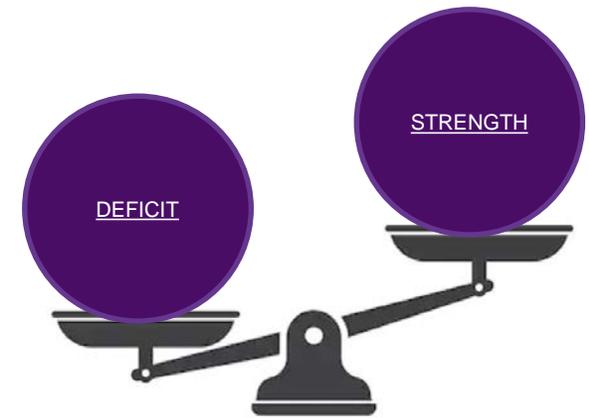
Intervention Setting	Caregiver Outcome Domain Categories								
	Mental Health	Stress/Strain/Burden	Physical Health	Psychosocial Resources	Quality of Life/Well-being	Social Support	Dyad Relationship	Knowledge	Community Resource Utilization
Home	7	6	5	6	5	2	2	0	1
Hospital/ Medical Center	2	3	1	1	1	2	0	1	2
Telephone/ Web-based	11	13	7	7	3	4	1	1	2
Community Space (Library, School, Adult Day Service etc.)	7	7	3	5	1	1	3	1	1
Totals	27	29	16	19	10	9	6	3	6



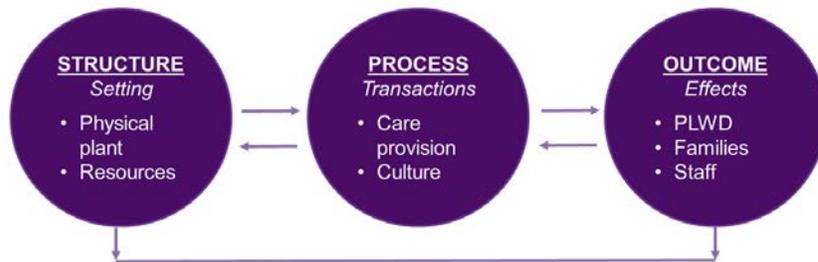
LINC-AD

Promote measures that ...

- Foster a constructive balance between strength and deficit assessments
- Consider measures from different stakeholder perspectives and a health equity lens
- Provide a practice-based conceptual framework to inform measurement
- Emphasize evidence-based tools to guide structures and processes of care

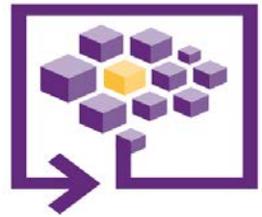


2018 Dementia Care Practice Recommendations



Slide provided by Drs. Zimmerman and Fazio

Implementing Evidence in HealthCare Settings



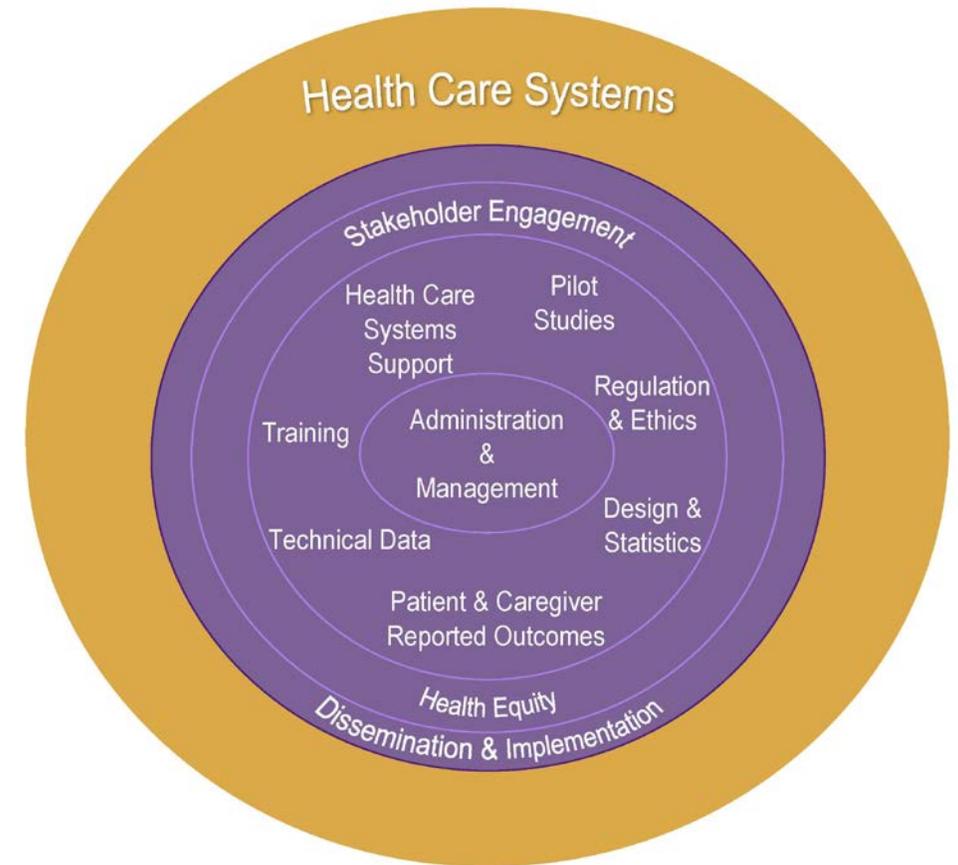
NIA IMPACT
COLLABORATORY
TRANSFORMING DEMENTIA CARE

NIA IMbedded Pragmatic Alzheimer's Disease (AD) and AD-Related Dementias (AD/ADRD) Clinical Trials (IMPACT) Collaboratory (PIs: Mor and Mitchell)

The Collaboratory aims to:

- Spur innovation to improve dementia care
- Develop and disseminate technical, policy, and best practices for moving evidence to health systems
- Enhance research development and investigator capacity
- Engage a variety of stakeholders
- Provide technical assistance in pragmatic trial design

**Journal of the American Geriatrics Society,
Vol. 68, No. S2, July 2020**



Slide adapted from NIA.



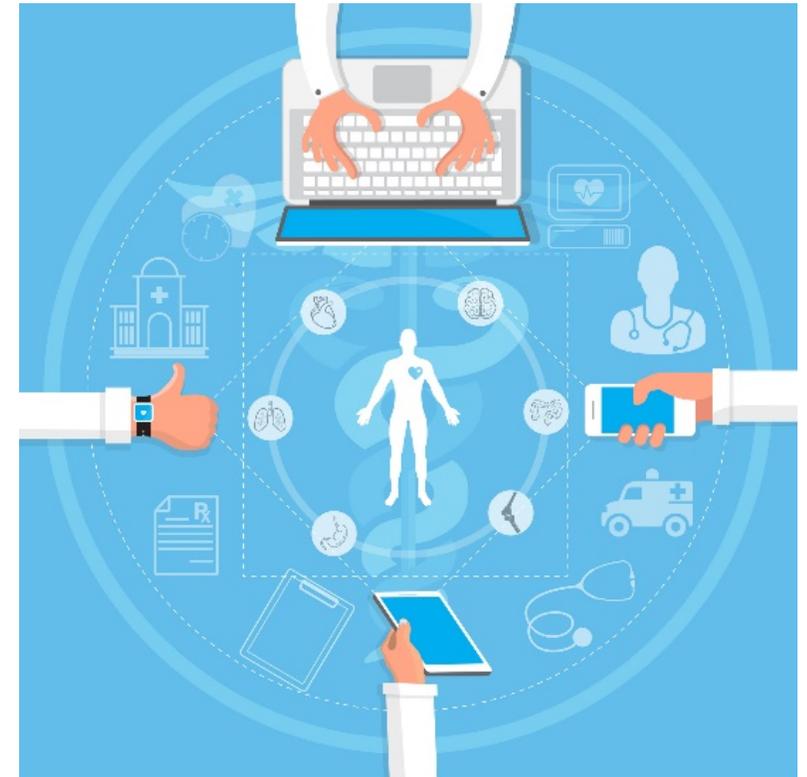
#DementiaCareSummit

Technology

iCare- AD/ADRD Challenge

- 33 submissions for mobile device applications or web-based methods
- 1st place: MapHabit- mobile app (Dr. Zola)
- 2nd place: Dementia Care Software System (UCLA; Dr. Reuben)
- 3rd place: Caregiver411 (N.C. A&T State)- mobile app (Dr. Naney)

<https://nia.nih.gov/challenge-prize>





- Peer navigator

- DICE approach

- WeCareAdvisor Prescription

- Caregiver Survival Guide

- Daily messaging (emails)

Funded by NIA (R01AG061116)
Gitlin, Kales, Lyketsos

Introduction

Welcome to WeCareAdvisor



Hi Julie. I'm Martha, I have been working as a care associate for 2 years.

As you know, caring for someone with dementia is hard work. The good news is that WeCareAdvisor is here to help.

People with dementia often have challenging behaviors, and these behaviors can change over time. WeCareAdvisor uses a process called **DICE** to help you understand and manage these behaviors.

Here's what it's like to use the DICE process...



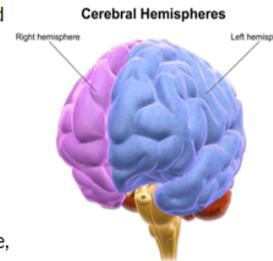
1. **Describe** - First choose a behavior that's challenging for you or Jacob. Then answer a few questions to describe the behavior. These questions help WeCareAdvisor choose the best tips for your situation.
2. **Investigate** - Next, you get to "play detective" and think about what might be contributing to Jacob's behavior. You'll answer questions to identify and rule out possible triggers for the behavior.
3. **Create** - Then, WeCareAdvisor will give you a behavior prescription with tips to help prevent and manage the behavior. The tips are based on your answers and are specific to your situation.
4. **Evaluate** - After a week, WeCareAdvisor will ask you how things are going and whether the tips were helpful. If things haven't improved, you can get new tips to try.

1. What is Dementia?

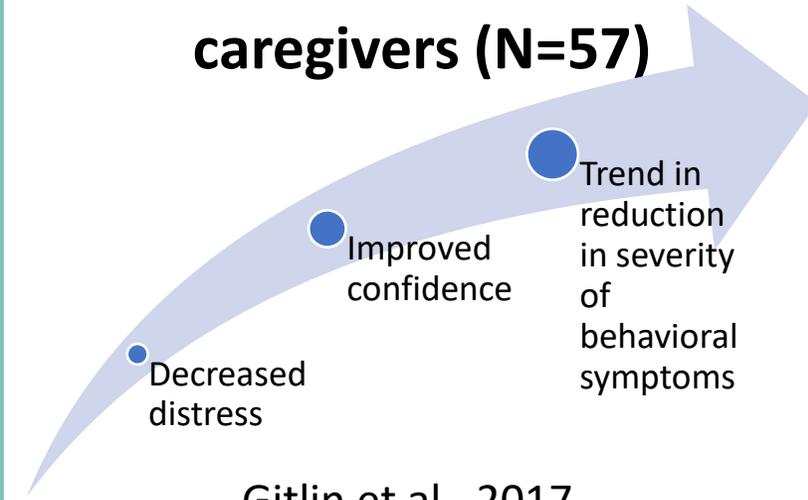
A. The brain and how it changes with dementia

i. Brain structure

- The brain is divided into two hemispheres, the left and the right
- For most right-handed people, the left hemisphere controls:
 - Senses and movement for the right (opposite) side of the body
 - Linear (step by step) thinking
 - Language
 - When the left hemisphere is damaged (for example, by a stroke), the right side of the body may be affected (weaker or less able to feel, notice or recognize things). The person may also have trouble with slurred speech or finding the right words to use.
- For most right-handed people, the right hemisphere controls:
 - Senses and movement for the left (opposite) side of the body
 - Recognizing spatial information (physical location, size and movement of things around you)
 - When the right hemisphere is damaged, the left side of the body may be affected (weaker or less able to feel, notice or recognize things). The person may also have trouble with finding objects in space or judging distances.
- Both hemispheres have four lobes: frontal, parietal, temporal and occipital. The first three lobes are discussed here because they



Outcomes for caregivers (N=57)



Gitlin et al., 2017
Kales et al., 2018

Summary

- Within 33 months, NIA produced an impressive array of initiatives and awards (with more forthcoming).
- Science of care and services at a critical inflection point:
 - Next three years promises to yield important new understandings of lived experiences, testing of novel care approaches for diverse populations & settings, integration of evidence in different healthcare systems
- While intervention development is slow, new iterative models, technology, implementation science and pragmatic trial designs hold promise of accelerating use of evidence in care settings to address different care needs to improve everyday life.
- We have a lot of work ahead but with recognition of the importance of involving stakeholders and evidence how to do so effectively, the future is promising.