Advisory Council on Alzheimer's Disease and All Other Dementias

Executive Office of Elder Affairs
Elizabeth Chen, Secretary

August 8, 2023
3:00-5:00 pm
Video Conference

Agenda

1. Welcome, Logistics, Introductions *(20 min)*
2. Challenges Around Dementia in the Black Community *(35 min)*
3. Equity and Inclusion Team Update *(25 min)*
4. Innovative Dementia Care Models *(35 min)*
5. Next Steps and Vote to Adjourn *(5 min)*

2. Challenges Around Dementia in the Black Community *(35 min)*

1. Panel Members/Speakers (15 minutes)

Dr. Carl V. Hill, Ph.D., MPH, Chief Diversity, Equity and Inclusion Officer, National Office of the Alzheimer's Association

Kevin Reynolds, Diversity, Equity and Inclusion Chair, Alzheimer's Association, MA/NH Chapter

Mr. Leo Foster, Dementia caregiver, Springfield

2. Discussion between Council and Panel Members (20 minutes)

Advisory Council on Alzheimer's Disease and All Other Dementias

3. Equity and Inclusion Team:

Update *(10 min)* and Discussion *(15 min)*

August 8, 2023

Team Leads

Jatin Dave, MBBS, MPH, Council Member - Chief Medical Officer, MassHealth; Director, Office of Clinical Affairs, ForHealth Consulting, UMass Chan Medical School

Hugo Aparicio, MD, MPH, Council Member - Assistant Professor of Neurology, Boston University School of Medicine; Faculty Lead of the Research and Policy Team Program at the BU Center for Antiracist Research; Stroke Specialist in the Department of Neurology, Boston Medical Center

Our Team

Doris Harris, PhD - Doris serves on the Springfield Dementia Friendly Coalition and hosts the radio show, *Health Matters* in Springfield (90.7 FM WTTC). She has an expertise in qualitative and quantitative public health research and is a consultant, health editor, and facilitator. Additionally, she writes a health editorial for Af-Am *Point of View,* a free newsmagazine by and for the African American community in Springfield.

Liana Mendes-Santos - Liana is a Doctor of Psychology. She works as a researcher at the Multicultural Alzheimer's Prevention Program (MAPP) at Massachusetts General Hospital and as a visiting researcher at Boston University's Vision & Cognition Laboratory, which focuses on perception and cognition in aging and neurological conditions.

Kathy Service - Kathy is a nurse practitioner residing in Northampton and a sought-after speaker at the national level on aging issues and dementia, often with a special focus on people with intellectual and developmental disabilities. She has served on advisory boards nationally and internationally, and has written articles, book chapters and educational modules on aging and dementia

Beth Soltzberg - Beth directs the Alzheimer's/Related Dementias Family Support Program at Jewish Family & Children's Service (JF&CS) in Waltham, MA. She manages the state's Dementia Friends movement; serves on the Dementia Friendly Massachusetts Leadership Team; leads the JF&CS Memory Café Percolator; and hosts a biennial symposium entitled, *Let's Talk About Dementia and Culture.*

Judith Thermidor - Judith, an internationally trained physician, is Resident Wellness Director for CSI Support & Development Services. She deploys collaborative efforts to promote clinical trials among underrepresented aging populations and works with Collaboration for Research Equity, Sustainability, and Trust (CREST) at Tufts Medical Center; Alzheimer's Association; Dementia Friends Massachusetts; and the Community Advisory Board at Massachusetts Alzheimer's Disease Research Center (MADRC).

The Team's Charge

Deploy members of the Equity & Inclusion team to:

1. **Review** the Council's work (policies, plans, and deliverables) through a DEI lens
2. **Identify barriers** around DEI that may prevent certain groups from benefiting from the Council's work
3. **Recommend approaches** to eliminate, weaken, or mitigate the impact of those barriers

Progress to Date

1. **Formed Team** - Convened two meetings over last four months
2. **Revised DEI Vision & Pledge** - Fine-tuned this document: **view link here**
3. **Discussed Approach** - Discussed how to effectively view the Council's efforts through a "DEI lens." We asked:
    - How will we know if what we are reviewing is equitable and inclusive?
    - What specific things should we be checking for?
    - How do we prioritize our efforts?
4. **Examined Data** - Looked for state-specific data, and asked researchers:
    - What groups in MA, for which we have evidence, are the most disproportionately affected by barriers to dementia information, care, services, and support? -- *(Will show this data in a minute)*
5. **Discussed Barriers to Accessing Treatments** - Began discussing expected barriers to equitable access to anti-amyloid treatments

Data Overview

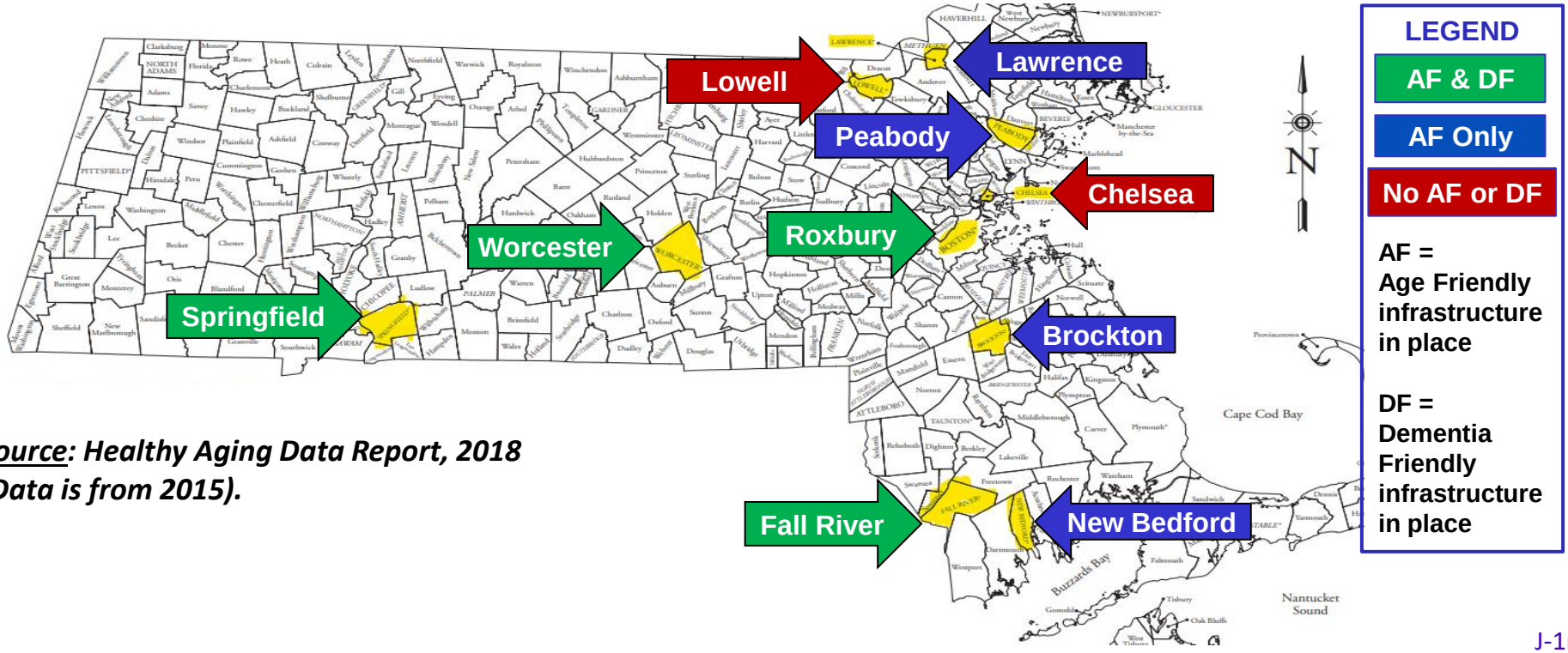
Communities with Older Adults at Significant Risk of Poor Health Outcomes

We received this response from researchers at UMass Boston's Gerontology Institute:

- **"We focus on communities rather than groups, recognizing the influence of where we live, work, play, and pray on health outcomes."**

They recommended the Council focus on 10 specific "priority communities"

- **Communities where older adults face significant risk of poor health outcomes (The analysis was based on multiple health indicators for serious, complex disease (including ADRD), and physical and mental disability)**



***Source*: Healthy Aging Data Report, 2018 (Data is from 2015).**

Data Overview

Communities with the Highest % of Black/African American and Hispanic/ Latino Older Adults

Black/African Americans in Massachusetts - ***At least 2 times more likely to have dementia in U.S.***

- **Highest percentage age 60+ in order (over 20%)** - Randolph, Brockton, Boston, Springfield

- **Highest number age 60+ in order (over 2,000)** - Boston, Springfield, Brockton, Worcester, Randolph, Cambridge

Hispanic/Latinos in Massachusetts - ***About 1.5 times more likely to have dementia in U.S.***

- **Highest percentage age 60+ in order (over 20%)** Lawrence, Chelsea, Holyoke, Springfield, Lynn

- **Highest number age 60+ in order (over 2,000)** - Boston, Lawrence, Springfield, Worcester, Lynn, Holyoke, Lowell, Chelsea

Source: *U.S. Census, 2020*

Link to data (ranked by percentage)

Link to data (ranked by number)

Note: *Blue highlighting indicates intersection with prior slide*

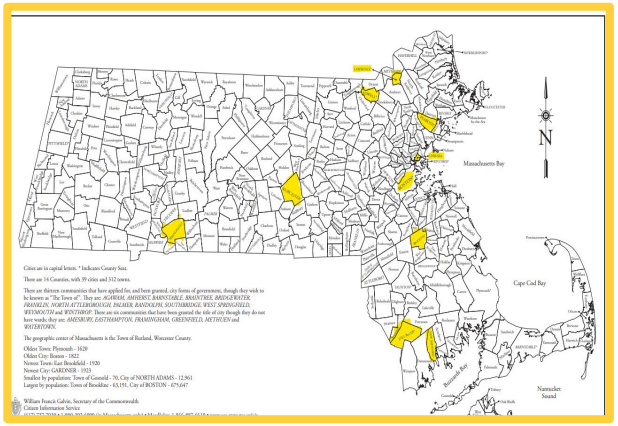
Recommendations

1. **Address Geographic Disparities** - We recommend that the Council and its workgroups consider geographic disparities while developing and implementing its recommendations by:
    - ***Establishing Local Partnerships*** - Form partnerships with local leaders
    - ***Implementing Inclusive Decision-Making*** - Listen to and incorporate feedback from community members
    - ***Practicing Humility*** - Approach all discussions and efforts with humility and a learning mindset
2. **Adopt These Guiding Principles Around Anti-Amyloid Treatment**
    - ***Promote Equitable Access Across the Spectrum*** - Ensure equitable access to screening, imaging, diagnosis, infusions, and monitoring
    - ***Eliminate Barriers by Addressing the Factors that Drive Them*** - Ensure anti-amyloid treatments are free of barriers driven by factors including but not limited to culture, language, poverty, insufficient knowledge, lack of health literacy, insufficient insurance coverage, and lack of transportation; as well as racism, ableism, and other forms of discrimination

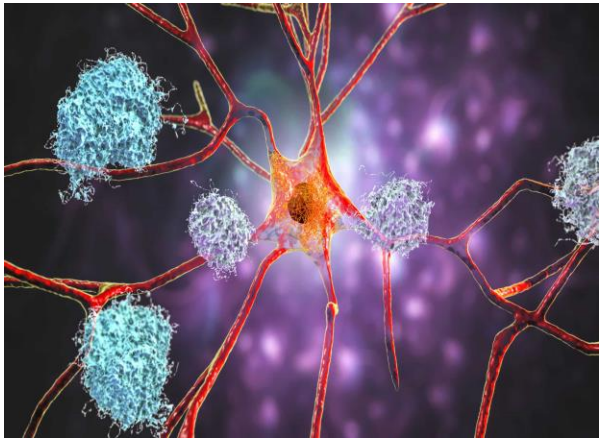
Discussion *(15 minutes)*

What are your thoughts on:

1. Considering geographic disparities while developing and implementing Council recommendations?



2. The Equity & Inclusion Team's initial focus on equitable access to anti-amyloid treatments?



1) J-5m
2) H-5m

4. Innovative Dementia Care Models: New Team on Interprofessional Dementia Care *(5 min)*

Team Co-Leads

Alina Sibley, CNP
Team Lead for Geri-Pal Home Care
Baystate Health, Springfield, MA

Christopher Wight, LICSW
Clinical Social Worker, Dementia Care Collaborative
Division of Palliative Care & Geriatric Medicine,
Massachusetts General Hospital (MGH), Boston, MA

Stephen Bonasera, MD, PhD
Chief, Division of Geriatrics & Palliative Care
Medical Director, Baystate Memory Assessment and Care Clinic
Department of Medicine
Baystate Medical Center, Springfield MA

Joe Costello
Dementia advocate
Retired executive

Brent P. Forester, MD, MSc.
(Council Member)
Dr. Francis S. Arkin Chair of Psychiatry, Tufts University School of Medicine
Chief and Chair, Department of Psychiatry, Tufts Medical Center
Director of Behavioral Health, Tufts Medicine

Lenore Jackson-Pope, RN, BSN, MSM, CCRP
Co-Director of Primary Care Outreach Center for Alzheimer Research and Treatment (CART) and Massachusetts Alzheimer's Disease Research Center (MADRC)
Mass General Brigham
Boston, MA

Jayne Kelleher
Home Care Director, Bethany at Home, Framingham, MA
Board Member of Massachusetts Home Care Aide Council

Liz McCarthy
Health Systems Director
New England Region, Alzheimer's Association

Pam Mirick, RN
Former Family Caregiver, Retired Nurse

Christine Ritchie, MD, MSPH
(Council Member)
Kenneth L. Minaker Endowed Chair in Geriatric Medicine
Research Director, MGH Division of Palliative Care and Geriatric Medicine
Director, Mongan Institute Center for Aging and Serious Illness
Director, MGH Dementia Care Collaborative
Professor of Medicine, Harvard Medical School
Boston, MA

Wayne S. Saltsman, MD, PhD, CMD, AGSF
Chief Medical Officer, All Care VNA, Hospice & Private Home Care Services
Lynn, MA

Amy Walsh
Project Manager
Institute for Health Care Improvement (IHI)
Boston, MA

Innovative Dementia Care Models: Presentation *(15 min)* & Discussion *(15 min)*

Stephen Bonasera, MD, PhD
Chief, Division of Geriatrics & Palliative Care
Medical Director, Baystate Memory Assessment and Care Clinic
Department of Medicine
Baystate Medical Center, Springfield MA

Caregiving…

- Providing care for elders is well documented for *H. sapiens* and *H. neanderthalis*; cetaceans and elephants have also been observed to provide care for elder members of their pod/family
- First recorded mentions in the Epic of Gilgamesh, 2100 BC
- 15.7 million adult family caregivers care for someone who has Alzheimer's disease or other dementia
- The economic value of the care provided by unpaid caregivers of those with Alzheimer's disease or other dementias was $217.7 billion in 2014

Alzheimer's Association. 2015 Alzheimer's Disease Facts and Figures

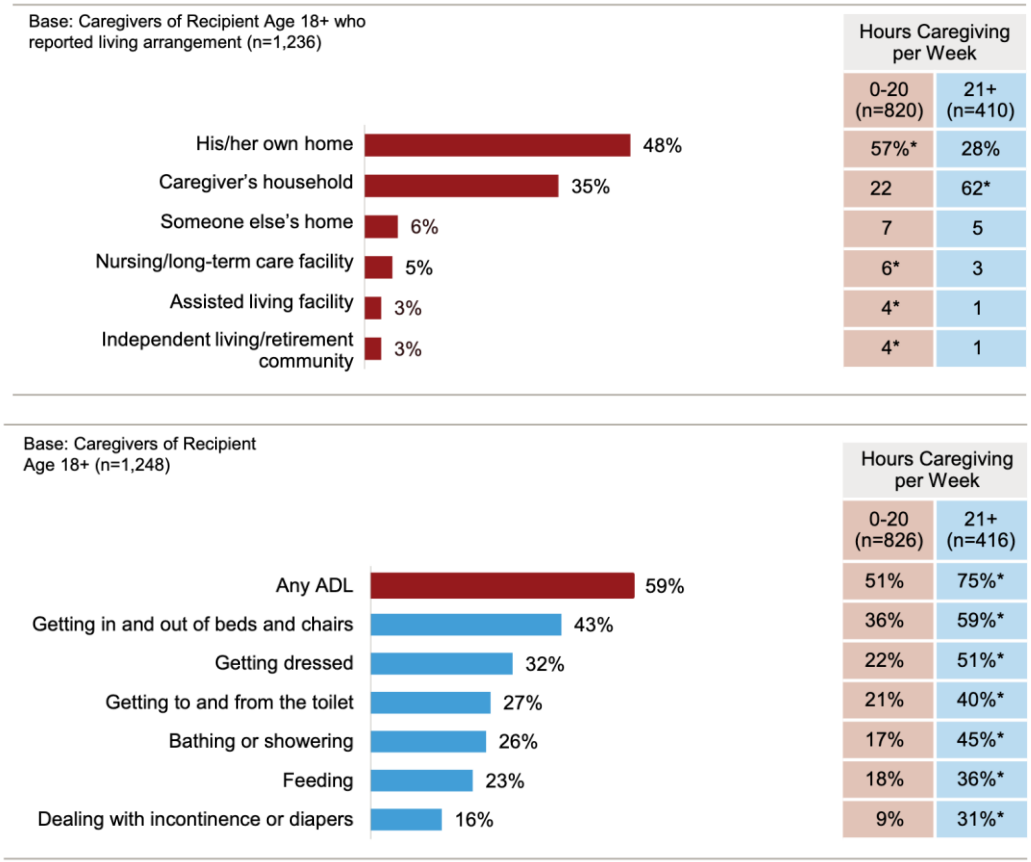
Caregiver Characteristics…

- 65% of care recipients are female, with an average age of 69.4.
- 75% of all caregivers are female, and may spend as much as 50% more time providing care than males
- Higher-hour caregivers (21 hours or more weekly) are nearly 4 times more likely to be caring for a spouse/partner.
- Female caregivers tend to handle the most difficult caregiving tasks (i.e., bathing, toileting, and dressing) compared to male counterparts, who are more likely to help with finances and arrangement of care

National Alliance for Caregiving and AARP. Caregiving in the U.S. 2015
Institute on Aging. Read How IOA Views Aging in America. 2016

More Caregiver Characteristics…

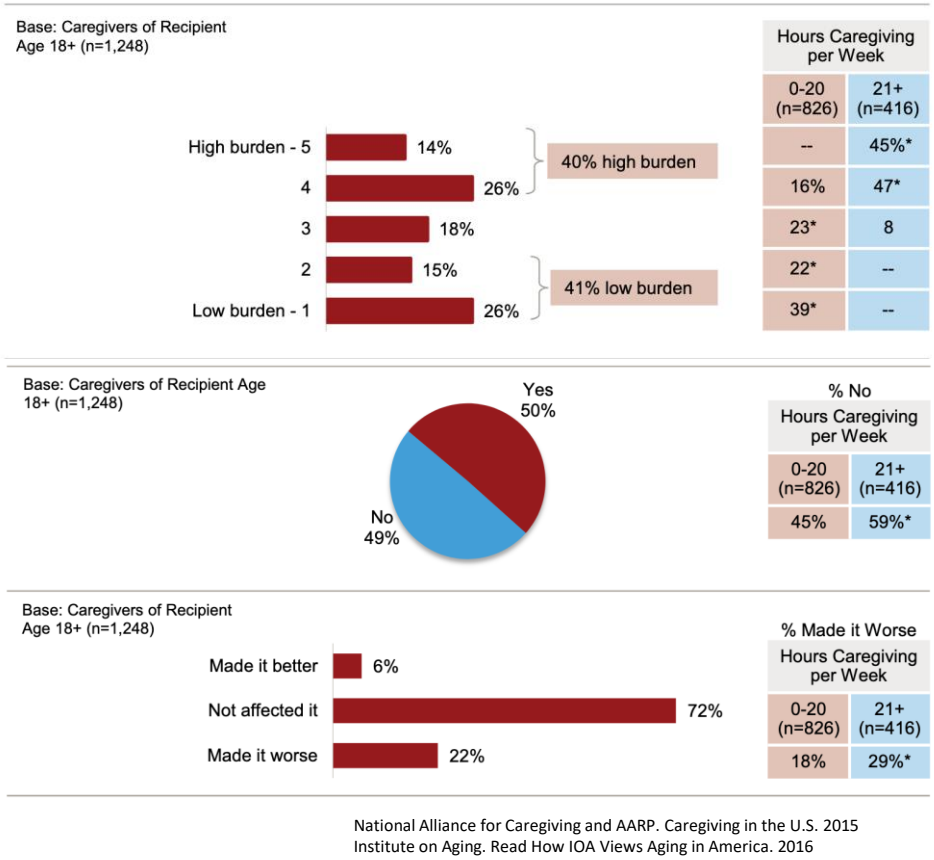
- Persons requiring less care a week tend to reside in their own home, while persons requiring more care a week tend to reside in the caregiver's home
- Persons requiring more care tend to need more help with ADLs, particularly dressing, bathing, toileting, feeding, and continence



National Alliance for Caregiving and AARP. Caregiving in the U.S. 2015
Institute on Aging. Read How IOA Views Aging in America. 2016

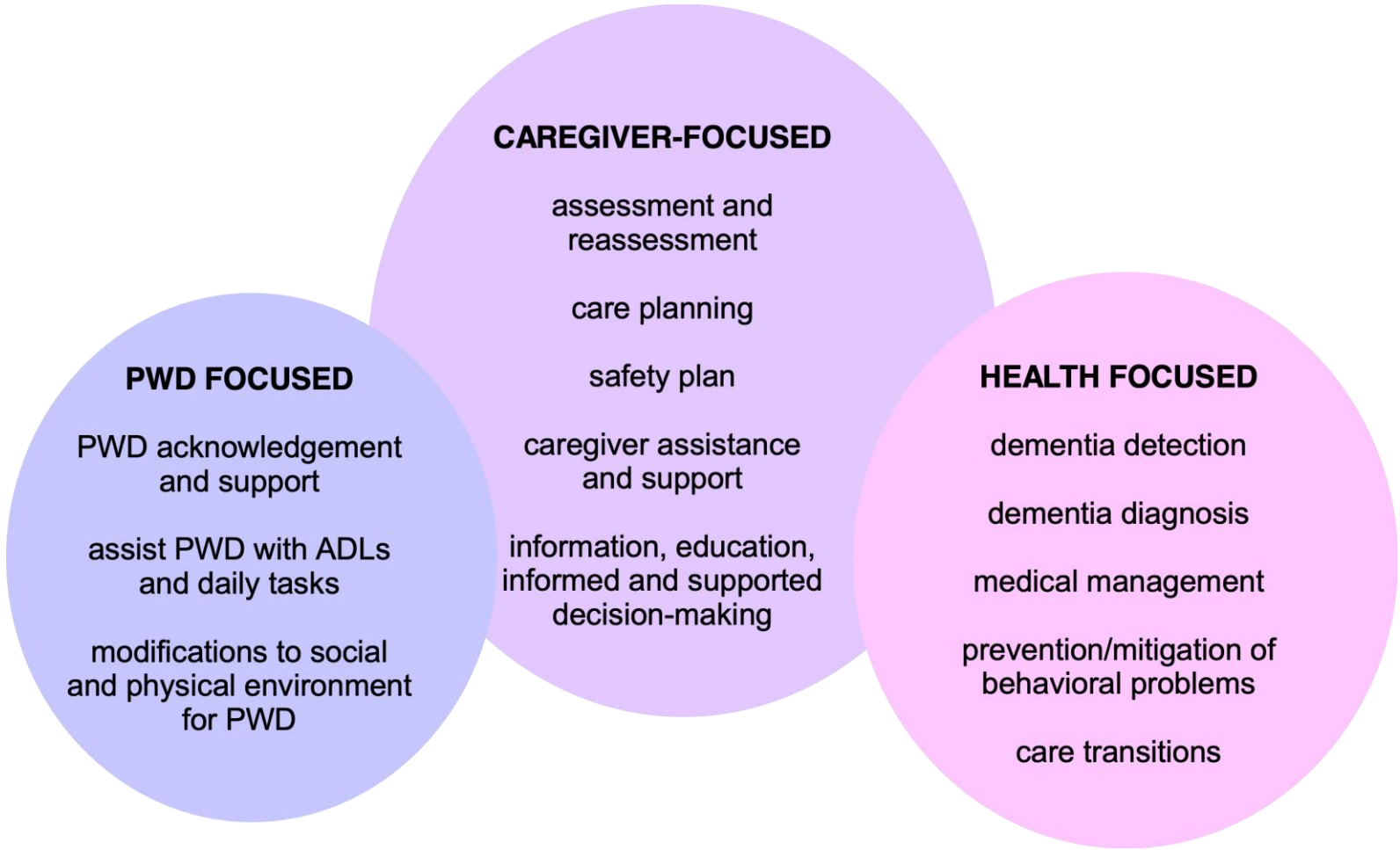
More Caregiver Characteristics…

- Most caregivers who report high levels of burden are providing >20 hrs per week of effort
- Most caregivers working >20 hrs per week feel as if they had no choice regarding their role as caregiver
- 29% of caregivers working >20 hrs per week state that caregiving has had an adverse impact on their health.



National Alliance for Caregiving and AARP. Caregiving in the U.S. 2015
Institute on Aging. Read How IOA Views Aging in America. 2016

What Should Plans that Support Caregivers for PLWD Look Like …



Gitlin LN, Maslow K, Khillan R. Report to the National Advisory Council on Alzheimer's Research, Care, and Services. 2018 Apr 27.

Outcome Measures…

- Involve parties need to identify research priorities and relevant outcomes
- Develop research measures that are important for studying dementia care, services, and supports
- Develop standards for the evidence needed to determine which programs and services are ready for widespread implementation and dissemination

PERSONS WHO RECEIVE CARE

persons with dementia (PWDs)
caregivers

QoL measures (PWD & CG)
CG burden/efficacy

END USERS

health care orgs
residential care orgs
community based services

cost
utilization metrics

CARE PROVIDERS

professionals
paraprofessionals
service providers

assessment tools
(QDRS, NPI, etc.)
encounter metrics

POLICY MAKERS AND PAYERS

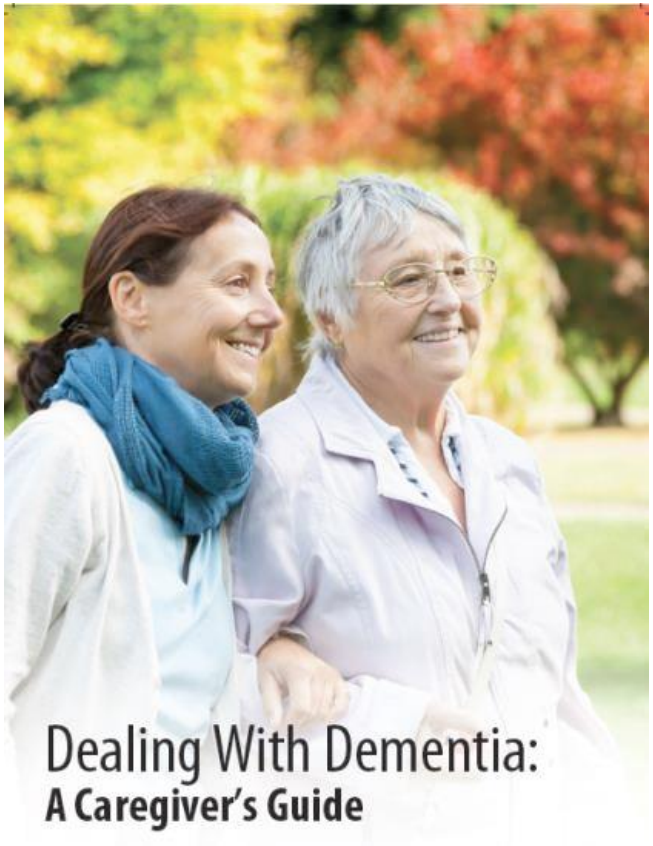
cost
utilization metrics

Gitlin LN, Maslow K, Khillan R. Report to the National Advisory Council on Alzheimer's Research, Care, and Services. 2018 Apr 27.

REACH I and II

Examples of Resources for Enhancing Alzheimer's Caregiver Health Treatment Implementation Strategies

Treatment Implementation Component	Induction Strategy	Assessment Strategy
Treatment Delivery		
Treatment manuals	X	
Structured training	X	
Supervisory monitoring and feedback	X	
Interventionist certification		X
Delivery checklists used by therapist	X	X
Delivery and accuracy checklists used by supervisors	X	X
Treatment Receipt		
Record of contacts and system utilization	X	X
Assessing caregiver knowledge of key treatment concepts and skills	X	X
Interventionist documentation	X	X
Feedback from caregiver		X
Treatment Enactment		
Direct observation of the caregiver	X	X
Caregiver self-report	X	X
Interventionist documentation	X	X

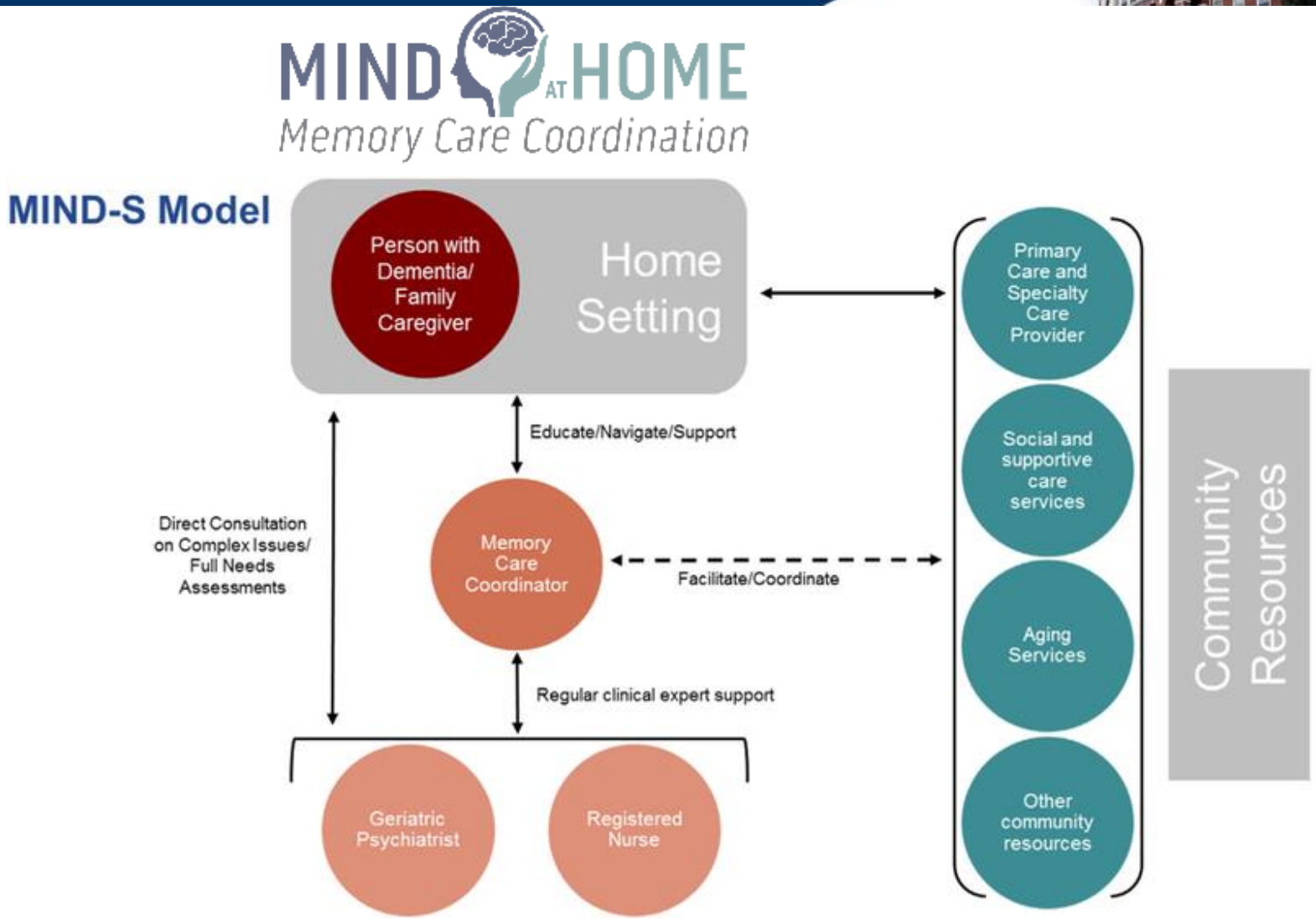


Burgio L *et al*. *The Gerontologist*. 41(4):481-489, 2001.

Rosalynn Carter Institute for Caregiving

- Has undergone clinical trial testing
- "Dealing with Dementia" has proven to be a model educational material of its type
- Structure and organization highly amenable to localization and customization
- Demonstrated cost savings in VA patients, and relatively inexpensive to implement (mostly costs for coach training and FTE)
- Limited nature of services, higher barriers to access community care options
- Does not distribute different tasks to team members with different skill sets
- Ambitious trials tested multiple different interventions, as well as different approaches to implement/assess each intervention
- Individual trials were underpowered, and underestimated efficacy of tested interventions

Mind at Home
Memory Care Coordination



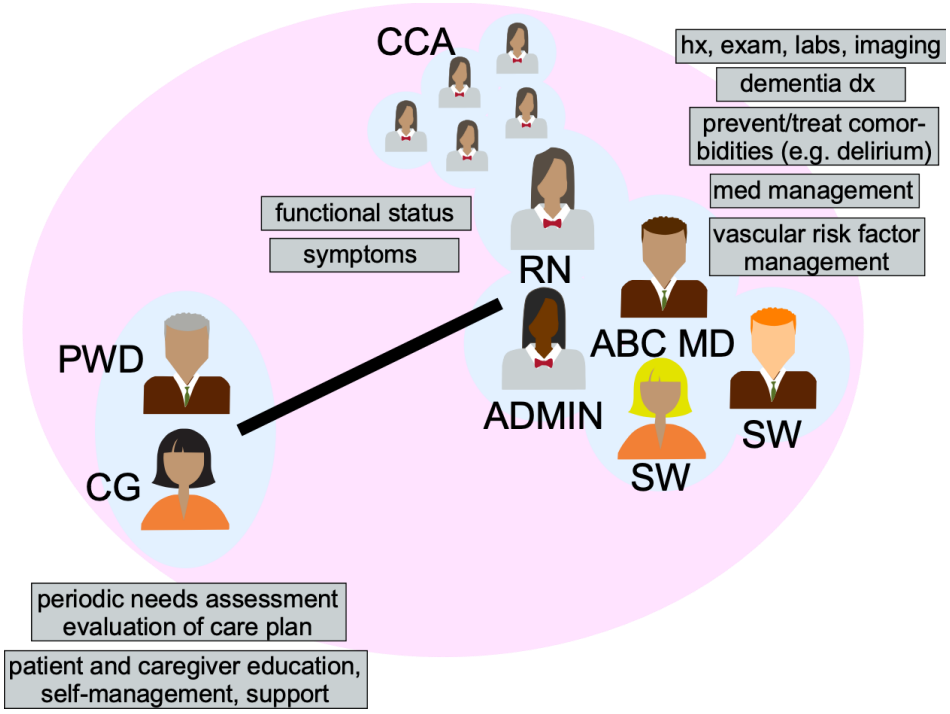
Seamus QM et al., *Contemporary Clinical Trials*. 71:103-112, 2018.

Mind at Home
Memory Care Coordination

MIND AT HOME
Memory Care Coordination

- Only trial at this time to demonstrate successful delay of xitions from home to ALF/SNF
- Prominent trend toward decreasing CG burden and decreasing CG time with PWD
- Currently undergoing 2 year RCT examining Mind@Home intervention in >300 subjects randomized 1:1; major outcomes are to replicate delay in xition from home, and to quantify cost of intervention. Secondary outcomes include CG burden, PWD QoL, PWD NPS, and dyad unmet needs.
- Geropsychiatry has a prominent role in this particular care model, is it part of the 'special sauce?'
- Assessments completed at home, with all the complexities that entails ("getting in the door and establishing rapport," bed bugs, presence of firearms, having no place to sit, the presence of pets, allergies, and suspicions of the motives of researchers")
- Telephone/email f/u assessments

ABC organization

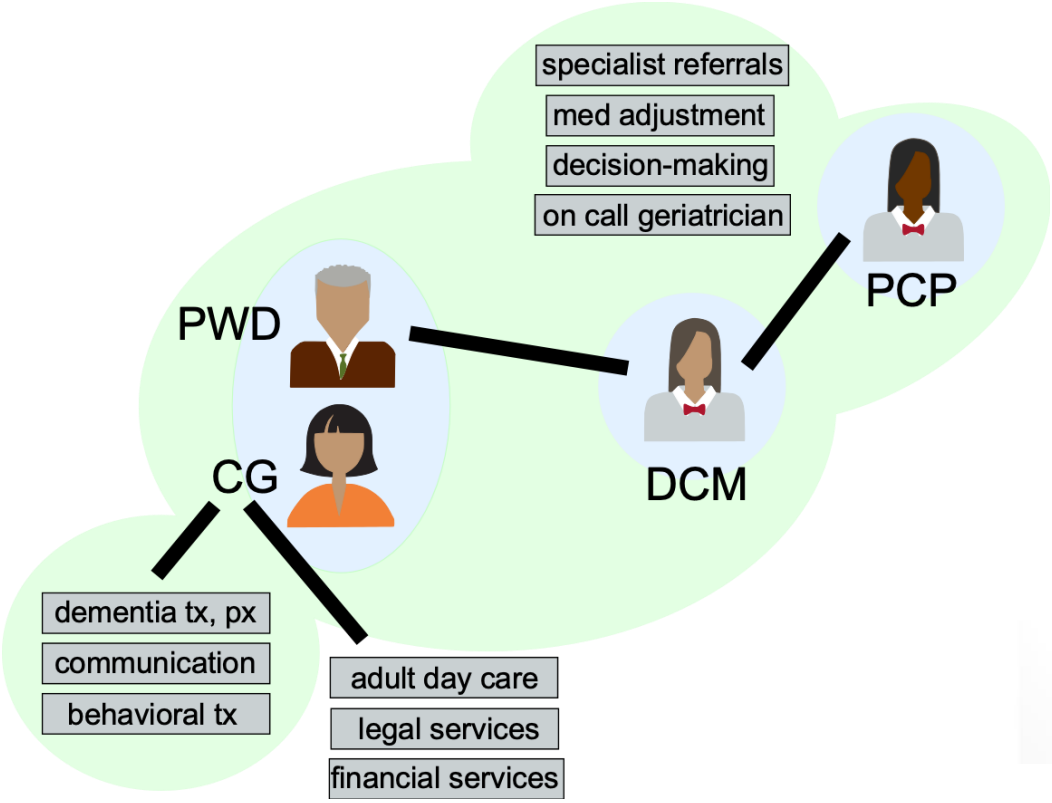


Adapted from:
French et al., *Health Affairs*. 33(4):613-618, 2014
LaMantia et al., *JAGS.* 63:1209–1213, 2015.

Aging Brain Care

- A large QI project, but not a clinical trial.
- Has been implemented across large patient cohort in private-public health care partnership (Eskinazi Health/University of Indiana)
- In its initial implementation, a minority of patients receiving the intervention had dementia; most patients who received intervention had depression
- Assessments at home or in clinic
- Reduced PHQ-9 scores of persons with depression relative to baseline
- Reduced care burden scores of persons with dementia relative to baseline.
- Validated HABC Monitor tool for measuring cognitive, functional, and psychiatric sx of dementia as well as caregiver burden
- Demonstrated cost savings, mostly thru lower ER and hospital spending
- More expensive model to implement given greater FTEs for MD and highly skilled RN team members

UCLA Alzheimer's & Dementia Care (ADC)



Reuben et al., *JAGS*. 61(12):2214-2218, 2013.
Tan et al., *Health Affairs*. 33(4):619-625, 2014.

UCLA Alzheimer's & Dementia Care (ADC)

- A large-scale quality improvement project, but NOT a clinical trial
- Successfully implemented most of their QI goals (had most difficulty with issues surrounding medications)
- Assessments in clinic only
- Program received positive marks from both healthcare providers and caregivers
- Demonstrated cost savings in Medicare patients

- Almost 100% of participants had goals of care conversation, ~70% WRITTEN notes regarding goals of care, low ER and ICU utilization before death, high hospice utilization before death
- Strong emphasis on medical management issues, with availability of 24-hour RTC MD consultation (thru fellowship program), DCM who made medication changes.
- Less emphasis on referrals to community services and organizations

Care Ecosystem organization

Possin et al., PLoS Medicine 2018

Care Ecosystem

- Assessments and interventions by telephone, limited patient portal accessible by internet (Possin et al., *PLoS Medicine* 14(3):e1002260, 2017).
- Intervention provided successfully by care navigators, a new kind of position in the health care system (Bernstein et al., *J Alzheimer Dis*, 71(1):45-55, 2019).
- Created educational infrastructure for robust CTN training (Dulaney S, et al., *Alz Dement*. 16:e041596, 2020).
- Decreased person-with-dementia ER visits (Possin et al, *JAMA Intern Med*. 179(12):1658-1667, 2019).
- Decreased caregiver depression and caregiver burden at both 6- and 12-month time points (Possin et al, *JAMA Intern Med*. 179(12):1658-1667, 2019).
- Increased person-with-dementia QoL (Possin et al, *JAMA Intern Med*. 179(12):1658-1667, 2019).
- Increased caregiver sense of self-efficacy at 6 mo (Merrilees et al., *Dementia*. 19(6):1955-1973, 2020).
- Decreased caregiver depression and ER usage (Guterman et al., *JAMA Neurol*. 76(10):1166-73, 2019).
- Decreased sense of caregiver burden (Bernstein et al., *Alz Dement: Trans Res & Clin Int*. 6(1):e12010, 2020).

Care Ecosystem

- Decreased benzodiazepine, anticholinergic, and atypical antipsychotic use at both 6 and 12 month time points (Liu et al., *Alzheimers Dementia*. 19(5):1865-1875, 2023).
- Increased likelihood that decedents would die in accordance with prior stated preferences (Ma et al., *J Alz Dis*. 83(4):1767-73, 2021).
- Worked with CG and PLWD to successfully address financial abuse and mismanagement (Manivannan et al., J Alzheimer's Dis, 86(1):219-229, 2022)
- Monthly cost to deliver service estimated at $90-110 per person (Rosa et al., *JAGS*. 67(12):2628-33, 2019).
- Estimated PMPM savings of between $500 and $650
- Demonstrated feasibility of using this care model as a clinical service (Rosenbloom et al., *Alz Dement*. 17:e057587, 2021; Possin et al., *Alz Dement*. 18:e063938, 2022.).
- Underlines current thinking that caregivers (properly supported) have positive experiences and develop meaningful connections with the people they are caring for (Bernstein-Sideman et al., in press).
- Demonstrated feasibility of real-time functional monitoring of activity and lifespace in older adults with dementia (Zylstra et al. J Neurosci Meth. 300:59-67, 2018; Manley et al., *Alz Dement Trans Res Clin Int*. 6(1):e12017, 2020).

Discussion *(15 minutes)*

Next Steps and Vote to Adjourn *(5 min)*

Next Steps

Next Meeting

November 7, 2023
3:00 to 5:00 pm

Vote to Adjourn