

Advisory Council on Alzheimer's Disease and All Other Dementias



**Executive Office of Elder Affairs
Elizabeth Chen, Secretary**

**November 7, 2023
3:00-5:00 pm
Video Conference**



Agenda



1. Welcome, Logistics, Introductions *(10 min)*
2. Challenges Around Dementia in Asian Communities *(30 min)*
3. Physical Infrastructure Team Update and Discussion *(25 min)*
4. Care Planning Team Update and Discussion *(25 min)*
5. Discussion of Council's Role Around Early Dementia Detection and Diagnosis *(25 min)*
6. Next Steps and Vote to Adjourn *(5 min)*



2. Challenges Around Dementia in Asian Communities (30 min)



1. Panel Members/Speakers (15 minutes)

Dale Chin, caregiver

Jun Yang, caregiver

David Ho, caregiver

2. Discussion Between Council and Panel Members (15 minutes)

3. Age and Dementia Friendly Physical Infrastructure



Implementation of Recommendations

Status and Discussion

November 7, 2023

Implementation Team Co-leads

Patty Sullivan, Program Director
Dementia Friendly MA
MA Councils on Aging (MCOA)

James Fuccione, Executive Director
MA Healthy Aging Collaborative
(MHAC)



Implementation Team Members



Implementation Team Co-Leads

Patty Sullivan, MS

Program Director
Dementia Friendly MA
MA Councils on Aging

James Fuccione, MPA

Executive Director
MA Healthy Aging Collaborative

Team Members

Beth Giannini, AICP

Transportation Program Manager
Franklin Regional Council of Govts

Ruth Neeman, AIA

Principal, Director of Senior
Environments Studio
LWDA

Pam MacLeod, MBA, PMP

Senior Project Director
MA Executive Office of Elder Affairs

Ithzel Polanco-Cabadas

Real Estate Project Manager
2Life Communities

Sandra Martin, MEP, MPH

Senior Planner and Health Agent
Berkshire Public Health Alliance
Public Health Program at Berkshire
Regional Planning Commission

Philippe Saad, AIA, LEED AP

Principal
Dimella Shaffer



Age and Dementia Friendly Physical Infrastructure



Our charge as described in the Alzheimer's State Plan:

Goal

Identify and incorporate dementia-friendly physical infrastructure into age-friendly physical infrastructure work



Recommendation #1 (Raise Awareness for Community Planning)

Raise awareness of the importance of age- and dementia-friendly design

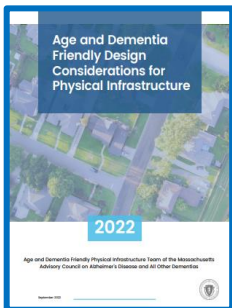


Recommendation #2 (Incorporate Scoring into Public Projects)

Incorporate age and dementia friendly scoring into all state-funded physical infrastructure projects



Updates and Accomplishments



1. Distributed our physical infrastructure [guide](#) to numerous organizations who in turn shared the link with their networks
2. Worked with the American Planning Association-MA who included an article about our guide in their spring 2023 newsletter
3. Delivered presentations about the guide to numerous organizations, for example:
 - MA Assisted Living Association, MA Councils on Aging, Leading Age MA, MA Library Association, Dementia Friendly Maine, MA Health and Hospital Association, and regional transportation providers
4. Continued to promote the guide's usage among age and dementia friendly communities and local and regional planning agencies
5. Shared the guide while promoting the FY 2024 round of grant opportunities from the state's Shared Streets and Spaces Program
6. American Trails, a national organization, included the guide in their [resource library](#)



Updates and Accomplishments (*Continued*)



7. Fostered collaborative relationships with design, planning, and public infrastructure procurement sectors to promote a shared vocabulary and comprehension of age and dementia friendly design principles
8. Conducted analysis of state, municipal, and other built environment funding sources to pinpoint opportunities for incorporating age and dementia friendly design standards
9. Identified areas of focus where the team believes it can have the greatest impact



1. **Senior Housing** - Discuss suggested edits with the MA Executive Office of Housing and Livable Communities to their design requirements for senior housing (known as “Appendix L”).
2. **Design Guidelines** - Discuss potential edits with the MA Division of Capital Asset Management and Maintenance (DCAMM) around their *Designer Guidelines and Procedures* for designers working on state and municipal funded physical infrastructure projects.
3. **Emergency Shelters** - Discuss potential enhancements with the MA Emergency Management Agency (MEMA) around their *Mass Care and Shelter Coordination Plan*.
4. **Library Construction and Renovation** - Discuss potential language around including age and dementia friendly requirements in calls for proposals from the MA Public Library Construction Program (MPLCP) of the MA Board of Library Commissioners.



5. **Senior Center Construction and Renovation** - Explore options around legislative language to ensure that senior centers are age and dementia friendly (to discuss further with you later today).
6. **Physical Space at Supportive and Social Day Programs** - Proposed language for upcoming RFR
7. **Layman's Assessment Tool for Citizen Advocacy of AF/DF Physical Infrastructure** - Boston University's MetroBridge program



Challenges



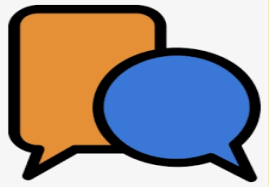
1. Bringing our ambitious projects to a close and fully incorporated into the work of procurement officials, planners, architects, dementia experts, and everyone else who works with older adults
2. Reaching the long-term goal of having *many* of the state's procurement processes reflect the needs of older adults and all people living with dementia



Solutions



1. Identified seven specific initiatives that we can realistically accomplish within the next twelve months (listed on Slides 6 and 7)
2. At Dementia Friendly Massachusetts (DFM) and the MA Healthy Aging Collaborative (MHAC), with the help of this team, we've successfully operationalized much of this team's work:
 - As part of our day-to-day jobs at DFM and MHAC, we will continue to build partnerships with the design, planning, and procurement communities to share the PI guide and raise awareness of the importance of age and dementia friendly design



DISCUSSION (15 mins)



Our Questions

(1) We plan to continue to seize opportunities that align with a broad interpretation of our team's charge. Part of our charge, as indicated in the state plan, is to:

- “Incorporate age and dementia friendly scoring into all state-funded physical infrastructure projects”

We interpret “scoring” as:

- Any approach that results in explicit preference for (or specific requirements around) the inclusion of age and dementia friendly characteristics in proposed infrastructure projects that receive funding from the state or a municipality.

Question: Do you agree that we continue our work with this broad interpretation of our charge?



DISCUSSION (*Continued*)



Our Questions (*Continued*)

(2) **Current State Budget Earmarks:** Recent annual state budgets have included earmarked funding for the construction and modernization of specific senior centers and other specific projects that serve older adults.

- **Question:** If this practice continues, how likely would it be for the legislature to consider James and my recommendation that in future budgets, language be included that requires that this Council's PI guide be considered in the implementation of these state-funded projects?

4. Person-Directed Care Planning



Care Planning Implementation Team

Status and Discussion

November 7, 2023

Implementation Team Co-leads

Susan Antkowiak, VP of Programs & Services
Alzheimer's Association, MA/NH Chapter

Linda Pellegrini, Geriatric Nurse Practitioner
UMass Memorial Medical Center



Implementation Team Members



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Susan Antkowiak, VP of Programs & Services
Alzheimer's Association, MA/NH Chapter

Linda Pellegrini, Geriatric Nurse Practitioner
UMass Memorial Medical Center

Team Members

Rachel Broudy, MD

Faculty Lead on Elder Care Work at Ariadne Labs
Medical Director, Pioneer Valley Hospice and
Palliative Care
Board Member, Life Path Aging Services Access Point
(ASAP), Franklin County

Deb Dowd-Foley

Caregiver Specialist
Elder Services of Worcester Area, Inc.

Laurie Herndon, MSN, GNP, BC

Project Director, Hinda and Arthur Marcus Institute for
Aging Research, Hebrew SeniorLife

Judy Johanson

Dementia Advocate
Massachusetts Alzheimer's Disease Research Center,
Massachusetts General Hospital (MGH)

Aaron Madow

Graduate Student (MPH Candidate)
University of Massachusetts

Gad A. Marshall, MD

Medical Director of Clinical Trials, Center for
Alzheimer Research and Treatment, Brigham and
Women's Hospital (BWH)
Associate Neurologist, BWH
Assistant in Neurology, (MGH)
Associate Professor of Neurology, Harvard
Medical School

Pam Mirick, RN

Former Family Caregiver, Retired Nurse

Our team's charge as described by the Council in the State Plan:

Develop a person-directed care plan framework and template





Updates and Accomplishments



1. Developed a coded analysis of focus group themes and responses [Focus Groups Coded Analysis](#)
2. Reviewed transcripts of focus group discussions to further develop themes
3. Welcomed new workgroup member: Rachel Broudy, MD, Ariadne Labs
4. In September 2023, explored collaboration with Ariadne Labs and reviewed person-driven care planning models
5. Re-assessed original vision of person-centered/person-directed care plan and discovered no readily accessible plan for people living with dementia that meets our workgroup's recommendations (see next slide)



Original Vision of Essential Characteristics of Every Person-Directed Care Plan



Includes voice of person living with dementia and care partners in its development and implementation

Established early upon diagnosis

Updated frequently

Reflects ongoing changes

Shared across care providers and settings

Helps the person living with dementia and care partners navigate care through all stages

Reflects ongoing quality of care advocacy from care partners (including medication review)

Available in multiple languages

Reflects best practices in care planning based on goals of care and what matters most to patient

Integrates personally meaningful goals with clinical goals and ensures quality of life and a positive approach to care

Reflects discussion of values, beliefs, interests, abilities, concerns, likes and dislikes

Allows for choice/success, dignity and respect

Reflects wishes for future and how to live the best life possible

Includes discussion of natural history and prognosis to help patients and families understand prognosis and progression of disease as they work with providers in setting goals

Includes goals around diet and exercise

Includes advance care plan and plan for when/if person living with dementia or their caregiver becomes ill or hospitalized



1. **Collect Models** - Complete outreach to collect person-driven care planning models
(November 2023 to January 2024)
2. **Recommend Model(s)** - Review and recommend person-driven care planning models to add to resource list
(January 2024 to March 2024)
3. **Recommend Distribution Approach** - Identify an approach for distributing care planning resources to families and providers
(March 2024 to June 2024)
 - a) Research existing approaches
 - b) Explore distribution opportunities
 - c) Decide on a recommended distribution approach
4. **Promote Recommended Model(s)** - Identify approaches for promoting use of recommended care planning model(s) among persons living with dementia, caregivers and providers

Challenges



**Identify accessible and reliable
resources for person-driven care
planning models**

Care Planning Implementation Status



BRIGHAM HEALTH



**BRIGHAM AND
WOMEN'S HOSPITAL**



HARVARD T.H. CHAN
SCHOOL OF PUBLIC HEALTH

Rachel Broudy, MD

Faculty Lead on Elder Care Work, Ariadne Labs

Medical Director, Pioneer Valley Hospice and Palliative Care

Board Member, Life Path Aging Services Access Point (ASAP), Franklin County



BRIGHAM HEALTH



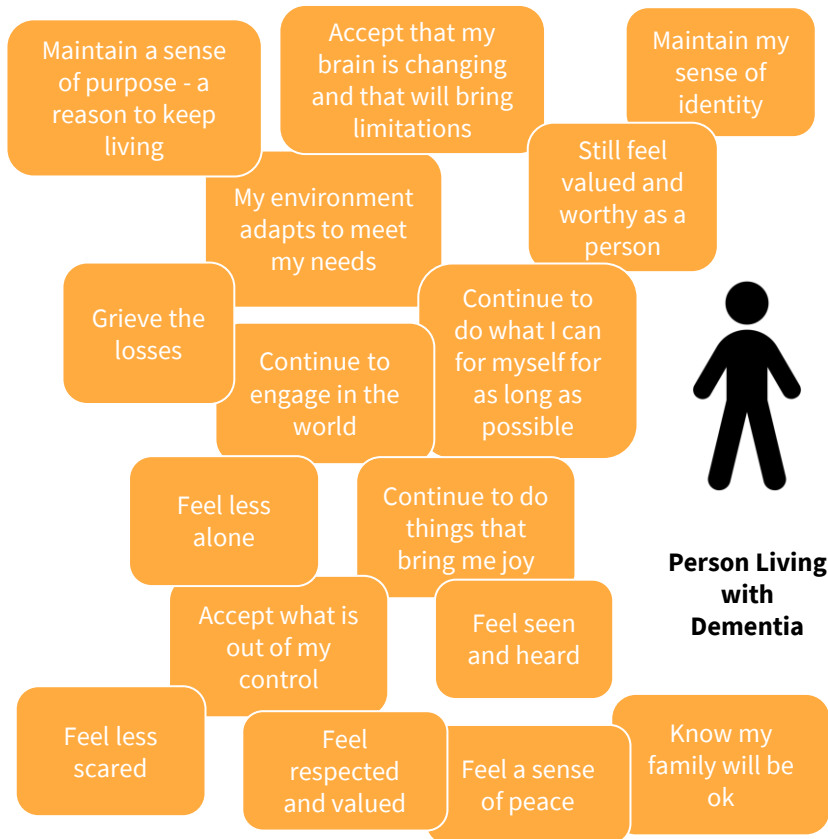
BRIGHAM AND
WOMEN'S HOSPITAL



HARVARD T.H. CHAN
SCHOOL OF PUBLIC HEALTH

We are a joint center for
health systems innovation at
Brigham & Women's Hospital
and the Harvard T.H. Chan
School of Public Health

WHAT USERS FEEL



BEST BET TOOL: ASSESSMENT & PLANNING TOOL

Our best bet is a holistic strengths-based assessment and care planning tool that supports families in living well with dementia

ASSESSMENT AREAS

FUNCTIONAL PRINCIPLES

Goals and quality of life

Family strengths and challenges

Community Supports

Medical Care



Process offers roadmap for families

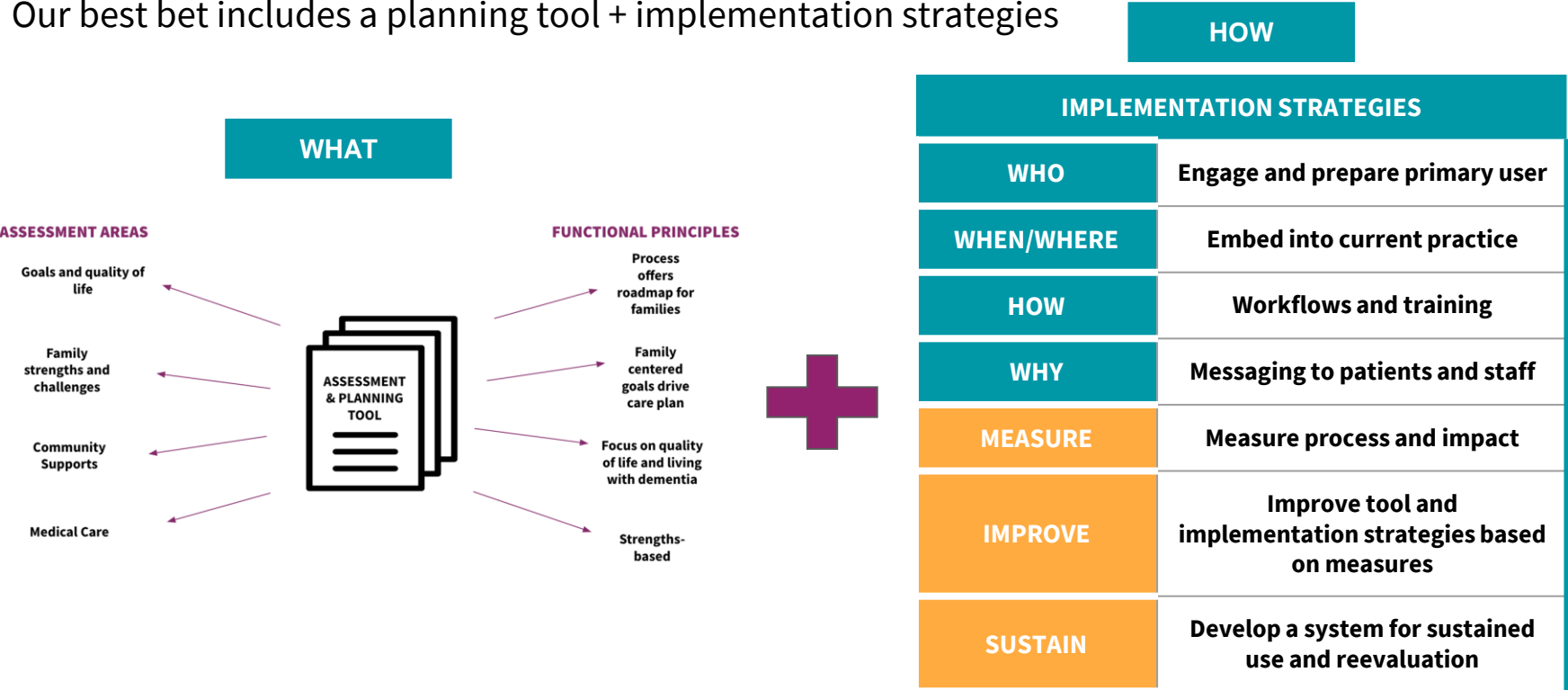
Family centered goals drive care plan

Focus on quality of life and living with dementia

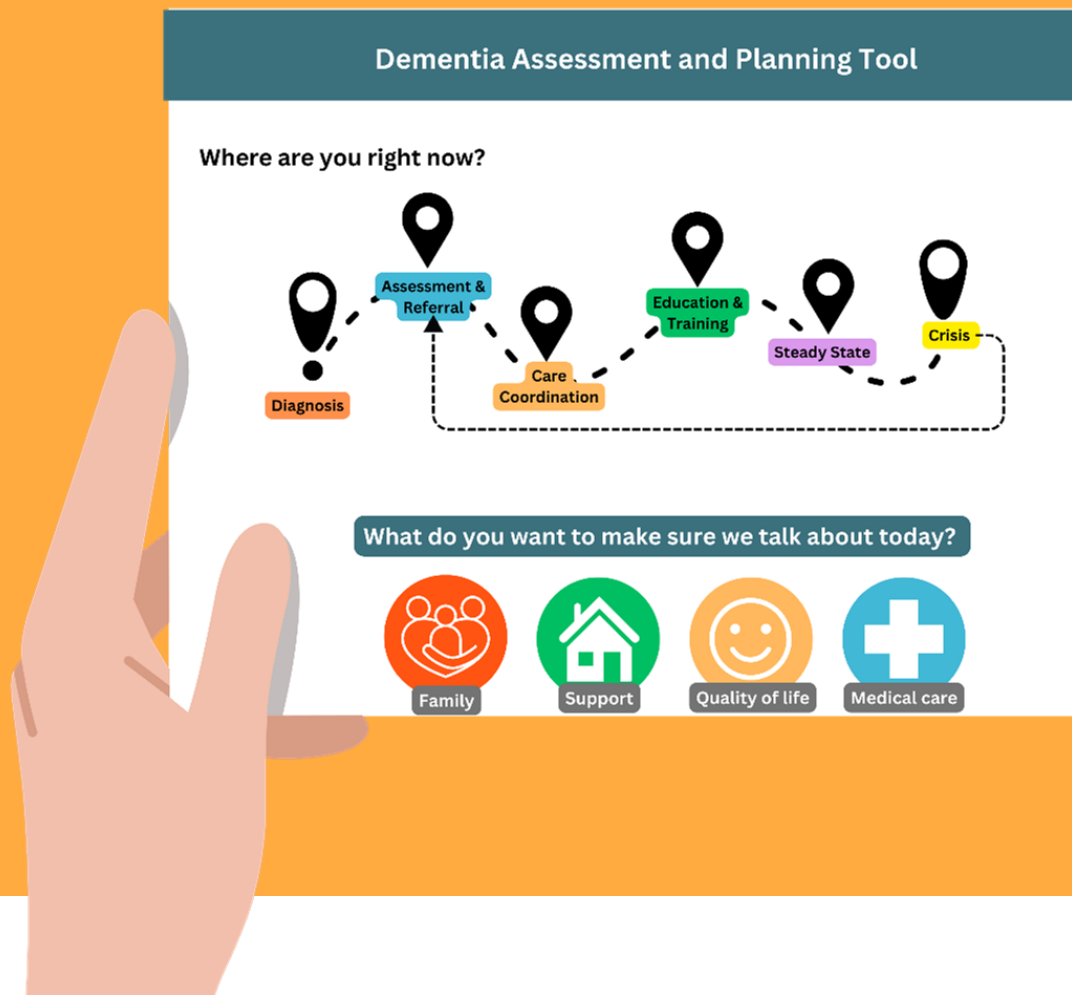
Strengths-based

BEST BET TOOL: FULL SOLUTION

Our best bet includes a planning tool + implementation strategies

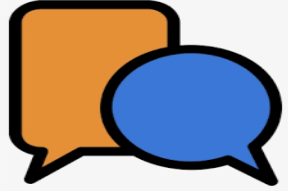


BEST BET TOOL: WHAT COULD THIS LOOK LIKE IN PRACTICE?



Interviews and Focus Groups

- Learning from you:
 - What do you want and need in an assessment and care planning tool?
 - How would you use it?
- Providers, people living with dementia and their friends, supporters and families, and community organizations
- Please reach out to learn more
- rbroudy@ariadnelabs.org



DISCUSSION (15 min)



1. Do you agree with or have comments and questions about our refined goal?

Original Goal - Develop a person-directed care plan framework and template

Refined Goal - Recommend, distribute, and promote person-centered and person-directed care planning resources; and collaborate with Ariadne Labs in their development of a person-centered assessment and care plan for people living with dementia and their caregivers.

2. Are there person-driven care planning models, or accessible and reliable resources for such models that you can recommend to us?



5. Discussion of Council's Role Around Early Detection and Diagnosis (25 min)



1. Which two do Council Members believe are the areas of greatest need?
 - 1) Equitable access to screening, assessment, and diagnosis
 - 2) Culturally sensitive provider/patient communication that respects culturally diverse beliefs, which may include stigmatizing perceptions of dementia
 - 3) MCI and early dementia detection and screening by health care workers
 - 4) Access to culturally sensitive cognitive assessments, including family observations, clinician interviews, and diagnostic testing (biomarkers)
 - 5) Public awareness of early warning signs (individuals and health care providers)
 - 6) Role of emerging technologies on access to screening and diagnosis
 - 7) Effective communication of diagnosis
 - 8) Other?
2. What strategy and practical activities can this Council (or a new Council workgroup) implement to significantly enhance detection and/or diagnosis?



6, Next Steps & Vote to Adjourn (5 min)



Next Steps

1. Draft the Council's next annual report
2. Review and vote on the report at next Council meeting on February 6, 2023
3. Submit the annual report (due on March 1, 2024)

**Council Meetings, 2024
(3:00 pm to 5:00 pm)**

2/6/24

5/7/24

8/6/24

11/5/24

Vote to Adjourn