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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**

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## 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)***

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## 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)**

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# 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)

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## 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

**Pam MacLeod, MBA, PMP**

Senior Project Director

MA Executive Office of Elder Affairs

**Sandra Martin, MEP, MPH**

Senior Planner and Health Agent

Berkshire Public Health Alliance

Public Health Program at Berkshire Regional Planning Commission

**Ruth Neeman**, **AIA**

Principal, Director of Senior Environments Studio

LWDA

**Ithzel Polanco-Cabadas**

Real Estate Project Manager

2Life Communities

**Philippe Saad, AIA, LEED AP**

Principal

Dimella Shaffer

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## 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**

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## Updates and Accomplishments

1. Distributed our physical infrastructure [**guide**](https://www.mass.gov/doc/af-df-design-considerations-for-physical-infrastructure-0/download) 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**](https://www.americantrails.org/resources/age-and-dementia-friendly-design-considerations-for-physical-infrastructure)

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## Updates and Accomplishments *(Continued)*

1. 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
2. Conducted analysis of state, municipal, and other built environment funding sources to pinpoint opportunities for incorporating age and dementia friendly design standards
3. Identified areas of focus where the team believes it can have the greatest impact

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## Next Steps: Remaining Projects

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.

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## Next Steps: Remaining Projects *(Continued)*

1. **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).
2. **Physical Space at Supportive and Social Day Programs** - Proposed language for upcoming RFR
3. **Layman’s Assessment Tool for Citizen Advocacy of AF/DF Physical Infrastructure** - Boston University’s MetroBridge program

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## 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

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## 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

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## Discussion *(15 mins)*

**(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?

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## 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?

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## **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

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## **Implementation Team Members**

**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

**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

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## **Our Team’s Charge**

**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**

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## **Updates and Accomplishments**

1. Developed a coded analysis of focus group themes and responses[**Focus Groups Coded Analysis**](https://docs.google.com/spreadsheets/d/1XyQuSsZJl7A_9A5IuFOqcj5CHvezQq-Z/edit?usp=sharing&ouid=101202900828004008453&rtpof=true&sd=true)
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)

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## **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**

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## **Next Steps**

1. **Collect Models** - Complete outreach to collect person-driven care planning models

(November 2023 to January 2024)

1. **Recommend Model(s)** - Review and recommend person-driven care planning models to add to resource list

(January 2024 to March 2024)

1. **Recommend Distribution Approach** - Identify an approach for distributing care planning resources to families and providers (March 2024 to June 2024)
   1. Research existing approaches
   2. Explore distribution opportunities
   3. Decide on a recommended distribution approach
2. **Promote Recommended Model(s)** - Identify approaches for promoting use of recommended care planning model(s) among persons living with dementia, caregivers and providers

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## **Challenges**

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

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## **Care Planning Implementation Status**

**Ariadne Labs**

**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

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**Ariadne Labs**

**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

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## **What Users Feel**

**Person Living with Dementia**

Maintain a sense of purpose - a reason to keep living

Accept that my brain is changing and that will bring limitations

Maintain my sense of identity

My environment adapts to meet my needs

Still feel valued and worthy as a person

Grieve the losses

Continue to engage in the world

Continue to do what I can for myself for as long as possible

Feel less alone

Continue to do things that bring me joy

Accept what is out of my control

Feel seen and heard

Feel respected

Feel a sense of peace

Know my family will be ok

**Care Partner**

Feel we’re all in this together

Know what to expect

Know what I will need

Know how to ask for what I need

Feel comfortable talking about this as a family

Grieve the losses

Feel capable of getting the care we need

Feel I have enough help

Enjoy time with PLWD

Take it all a step at a time

Feel confident in the decisions we made

Feel safer - know we’re going to be ok

Rested

Feel seen and heard

We each contribute our strengths to care

Accept what is out of my control

Feel good about the care PLWD receives

Feel good about how I handled what was in my control

Have somewhere to turn in crisis

Can be present in my daily life

Feel better equipped to navigate the system

Maintain my own life

Can easily find and understand information I need

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## **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 & Planning Tool**

**Assessment Areas**

Goals and quality of life

Family strengths and challenges

Community supports

Medical care

**Functional Principles**

Process offers roadmap for families

Family centered goals drive care plan

Focus on quality of life and living with dementia

Strengths-based

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## **BEST BET TOOL: FULL SOLUTION**

Our best bet includes a planning tool + implementation strategies

**WHAT**

**Assessment Areas**

Goals and quality of life

Family strengths and challenges

Community supports

Medical care

**Functional Principles**

Process offers roadmap for families

Family centered goals drive care plan

Focus on quality of life and living with dementia

Strengths-based

**+**

**HOW**

**IMPLEMENTATION STRATEGIES**

**WHO**

Engage and prepare primary user

**WHEN/WHERE**

Embed into current practice

**HOW**

Workflows and training

**WHY**

Messaging to patients and staff

**MEASURE**

Measure process and impact

**IMPROVE**

Improve tool and implementation strategies based on measures

**SUSTAIN**

Develop a system for sustained use and reevaluation

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

Dementia Assessment and Planning Tool

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## **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](mailto:rbroudy@ariadnelabs.org)

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## **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.

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

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

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## **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, 2024
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**