# Massachusetts Advisory Council on Alzheimer's Disease and All Other Dementias

**Executive Office of Elder Affairs**
**Robin Lipson, Secretary**

**January 9, 2025**
**3:30-5:00 pm**
**Video Conference**

# Agenda

I. **Welcome, Logistics, Introductions** ***(10 minutes)***

II. **Team Accomplishments, Deliverables, and Proposals**

   A. Dementia Care Planning Team ***(25 minutes)***

   B. Team on Interdisciplinary Dementia Care ***(30 minutes)***

   C. Equity and Inclusion Team ***(20 minutes)***

III. **Next Steps and Vote to Adjourn** ***(5 minutes)***

Massachusetts Council on Alzheimer's
Disease and All Other Dementias

# Dementia Care Planning Team
# Updates, Accomplishments, and Discussion

## January 9, 2025


**Team Co-Leads**

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

**Linda Pellegrini,** Geriatric Nurse Practitioner
UMass Memorial Medical Center

# The Council's Team on Dementia Care Planning

## Team Co-Leads

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

**Linda Pellegrini,** Geriatric Nurse Practitioner
UMass Memorial Medical Center

**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)

**Pam MacLeod, PMP, MBA**
Senior Project Director
Massachusetts Executive Office of Elder Affairs

**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 Goal

## Goal

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

Source: Massachusetts State Plan on Alzheimer's Disease and Related Dementias

# Updates and Accomplishments

- ✓ **Continued to collect and review person-centered care planning resources and tools**
- ✓ **Researched, discussed, and agreed upon the benefits of person-centered dementia care planning, its unique characteristics, and key elements**
- ✓ **Reviewed and provided advice to Ariadne Labs on prototypes of its care planning tool**
- ✓ **Designed a dementia care planning toolkit (nearly complete)**

  ***Preliminary Title:*** **"Care Planning For Living Well With Dementia"**

  ***Purpose:*** Facilitate the creation of person-centered care plans that support living well with dementia

  ***Intended Audiences:***

  - People living with dementia
  - Dementia care partners and families
  - Community-based service providers
  - Residential care providers
  - Healthcare providers

- ✓ **Developed a detailed communication plan**

# Findings

## 1. Insights

- **Effective Dementia Care Planning is Inconsistent -** While exceptions exist, anecdotal evidence suggests that dementia care plans may lack availability, omit key elements like patient values and care partner roles, and may fail to adapt to disease progression
- **Collaboration is Essential -** Effective dementia care planning involves discussions among the person with dementia, healthcare providers, community service providers, residential care providers, care partners, and family members
- **Dementia Care Planning Fosters Stability** - Dementia care plans can provide clarity, avoid emergencies, and alleviate stress for care partners
- **Dementia Care Plans are Flexible and Evolving -** Dementia care plans can take any form, start simple, and grow over time, supporting communication through all stages of the disease

# Findings

## 2. Benefits of a Person-Centered Dementia Care Plan

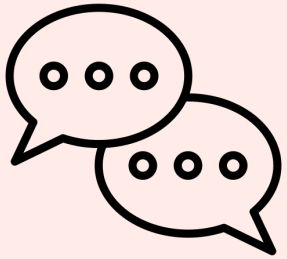
- **Personalized Approach -** Looks beyond diagnosis, respecting life experiences, preferences, goals, and values while addressing medical, emotional, social, spiritual, and physical needs
- **Empowerment -** Empowers individuals, families, and care partners to address the complexities of dementia
- **Care Alignment -** Aligns care with how the person responds to dementia, improving health and wellbeing
- **Navigation Assistance -** Helps care recipients and care teams manage care and navigate support
- **Crisis Prevention -** Reduces uncertainty, minimizes crises, reduces care partner stress
- **Meaningful Living -** Fosters meaningful and joyful lives for people affected by dementia
- **Better Outcomes -** Leads to better care, health outcomes, and improved quality of life for care recipient and care partner; and fewer hospitalizations, ER visits, and long-term care placements

# Findings

## 3. Unique Aspects of Dementia Care Planning

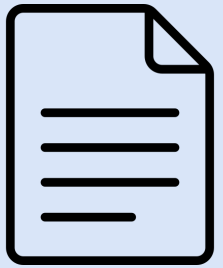
- **Cognition and Communication Support -** Supports cognition, communication, and behavior
- **Quality of Life Focus -** Prioritizes maintaining quality of life, not just treating the disease
- ***Personhood* Preservation -** Acknowledges the need to maintain a sense of personhood and self-determination
- **Flexible Approach -** Adapts as needs change with each stage of the disease; and acknowledges care partner's essential and evolving role as the dementia progresses
- **Safety Considerations -** Addresses contributing factors for agitation, aggression, or safety risks

# Steps to Developing a Person-Centered Dementia Care Plan



**(1)**

***Discuss*** **and gather relevant person-centered information, and agree on plan of action**



**(2)**

***Document*** **and update goals, strategies, and other pertinent information**

# Summary of Key Elements of Person-Centered Dementia Care Planning

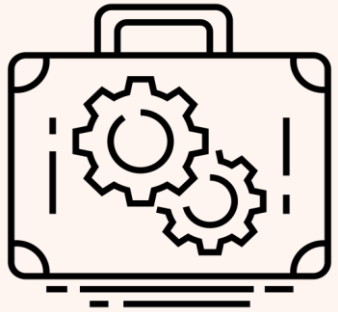
**Discuss**

- Involve all key stakeholders
- Collect information on concerns, values, interests, abilities, preferences
- Identify care gaps and assess risks/benefits of potential interventions
- Agree on care and support to be provided and approaches for delivering it
- Maintain ongoing discussions to monitor and adjust plan as needs evolve

**Document**

- Goals of care centered on the person's priorities and what matters most to them
- Assessment of cognitive, functional, and safety status
- A plan and referrals for addressing medical, emotional, social, and spiritual needs
- Strategies to address risks to health, safety, and quality of life
- Support for care partners and identification of circle of support
- Approaches for medication management
- Proactive strategies to handle crises, health changes, and end-of-life care
- Regular updates to the care plan

# Toolkit Overview



**Reflecting on our findings, our team developed a toolkit on dementia care planning**

- Outlines the benefits of dementia care planning
- Describes what person centeredness means for people with dementia
- Includes key elements of dementia care plans and provides samples
- Provides a reference sheet to community-based services and supports
- Includes a discussion worksheet for individuals and their care teams
- Provides online links to helpful dementia care planning resources
- Includes guidance on equitable and inclusive care planning

# Next Steps

## January 2025

- **Finalize the toolkit** and develop webinar slides to accompany its release
- Coordinate with key contacts to plan and implement **outreach activities**

## February 2025

- Develop and distribute **flyers** with link to the toolkit and webinar registration

## March 2025

- Convene both **webinars**, record them, and distribute the recording **(final milestone)**
- Recognize this team's achievements and **bring its work to a close**.

### *Outreach to People Living with Dementia and Dementia Care Partners*

*(Email Distribution Lists, Newsletters, and Social Media)*

1. *Caring for the Caregiver webinar (distribution list)*
2. *Massachusetts Councils on Aging*
3. *Dementia Friendly Massachusetts*
4. *Alzheimer's Association*

### *Outreach to Individuals Providing Care and Support for Clients or Patients Diagnosed with Dementia*

#### Community-Based and Residential Care Providers

*(Email Distribution Lists, Newsletters, and Social Media)*

1. *Dementia Friendly Massachusetts*
2. *Dementia Friends Massachusetts*
3. *Massachusetts Family Caregiver Support Program*
4. *Massachusetts Aging Services Network*
5. *Massachusetts Councils on Aging*
6. *Massachusetts Healthy Aging Collaborative*
7. *Massachusetts Assisted Living Association*
8. *Massachusetts Senior Care Association*
9. *Hospice & Palliative Care Federation of Massachusetts*

#### Healthcare Providers

*(Email Distribution Lists, Newsletters, and Social Media)*

1. *Massachusetts Medical Society*
2. *Gerontological Advance Practice Nurses Association, New England Chapter*
3. *Massachusetts Neurologic Association*
4. *Massachusetts Health and Hospital Association*
5. *Massachusetts Academy of Family Physicians*
6. *Massachusetts League of Community Health Centers*
7. *Massachusetts Association of Physician Assistants*

# Discussion *(10 minutes)*

1. **In general, what are your thoughts about our team's deliverables?**
2. **Do you have any advice for our team?**
3. **Could you recommend a communications contact to assist with our outreach at:**
    a) *Massachusetts Medical Society*
    b) *Massachusetts Neurologic Association*
    c) *Massachusetts Health and Hospital Association*
    d) *Massachusetts Academy of Family Physicians*
    e) *Massachusetts League of Community Health Centers*
    f) *Massachusetts Association of Physician Assistants*

Massachusetts Council on Alzheimer's Disease and All Other Dementias

# The Council's Team on Interdisciplinary Dementia Care (IDC) Status, Proposal, and Discussion

## January 9, 2025

**Christopher Wight, MSW, LICSW**
Clinical Social Worker
Department of Neurology, Memory Disorders Unit
Massachusetts General Hospital, Boston, MA

# The Council's Team on Interdisciplinary Dementia Care

## Team Co-Leads

**Alina Sibley, CNP (through August 2024)**
Team Lead for Geri-Pal Home Care, Baystate Health, Springfield, MA

**Christopher Wight, LICSW**
Clinical Social Worker, Memory Disorders Unit
Department of Neurology, Massachusetts General Hospital, 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

**Kathryn M. Corelli, MD**
Internal Medicine Physician, Chestnut Hill, MA

**Joe Costello**
Organizational Consultant and Dementia Advocate

**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

**Pam MacLeod, MBA, PMP**
Senior Project Director
MA Executive Office of Elder Affairs

**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

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

# Our Team's Original Goal

## Original Goal

**Develop a plan that ensures that staff in primary care across the state receive the training and support needed to build and retain interprofessional dementia care teams**

Source: Massachusetts State Plan on Alzheimer's Disease and Related Dementias

# Updates and Accomplishments

## ✓ Reviewed Gaps Within Current Dementia Care System

### *Gaps in Dementia Care*

- ***Caregiver support and education***
- *Clinical and nonclinical* ***care navigation/care planning***
- ***Coordination*** *with care for other chronic conditions*
- ***Home safety and behavior management***
- ***Medical and community care integration***
- ***General understanding of dementia risk factors***
- *Availability of* ***interdisciplinary dementia care*** *workforce*
- ***Primary care workforce availability and education***
- ***Polypharmacy risk management***
- ***Equitable access to high quality care***
- ***Awareness of available services*** *among healthcare professionals and the public*
- ***Timely communication*** *of diagnosis*

# Updates and Accomplishments

## Conducted Analysis of Effective Dementia Care Within Primary Care

- ✓ Identified 40 key service elements, benefits, requirements, and responsible professionals
- ✓ Studied evidence-based interdisciplinary dementia care models
- ✓ Evaluated five models with Care Ecosystem chosen as a fit for Massachusetts
- ✓ Aligned the services with Care Ecosystem's capabilities, GUIDE, and Age-Friendly Health Systems
- ✓ Studied comparable initiatives here and in other states

# Perspective Informed by Analysis

## Current Perspective Informed by the Team's Analysis

**Although effective dementia care relies on interdisciplinary collaboration, achieving this requires augmentation of existing, geographically-based infrastructure that:**

- Exhibits a strong focus on **dementia care navigation** and **caregiver support with clinical expertise;**
- supports existing provider capabilities;
- strengthens collaboration; and
- interconnects services for seamless coordination.

# Recommended Revised Team Goal

## Team Vision, Mission, and Revised Goal *(For Council Review)*

### Vision

**A sustainable, centralized model of integrated dementia care in Massachusetts**

### Mission

**Address gaps in dementia care**

### Revised Goal (Proposed State Plan Amendment)

**Develop a plan that ensures that individuals with dementia and their care partners have access to an evidence-based dementia care navigation program**

# Preliminary Proposal for Further Development

*Pilot a Care Ecosystem Program in Massachusetts*

# Why Pilot a Care Ecosystem Program in Massachusetts?

## Challenges

- Overburdened primary care practices
- Confused patients and consumers
- Fragmented or suboptimal care, caregiver stress, high costs

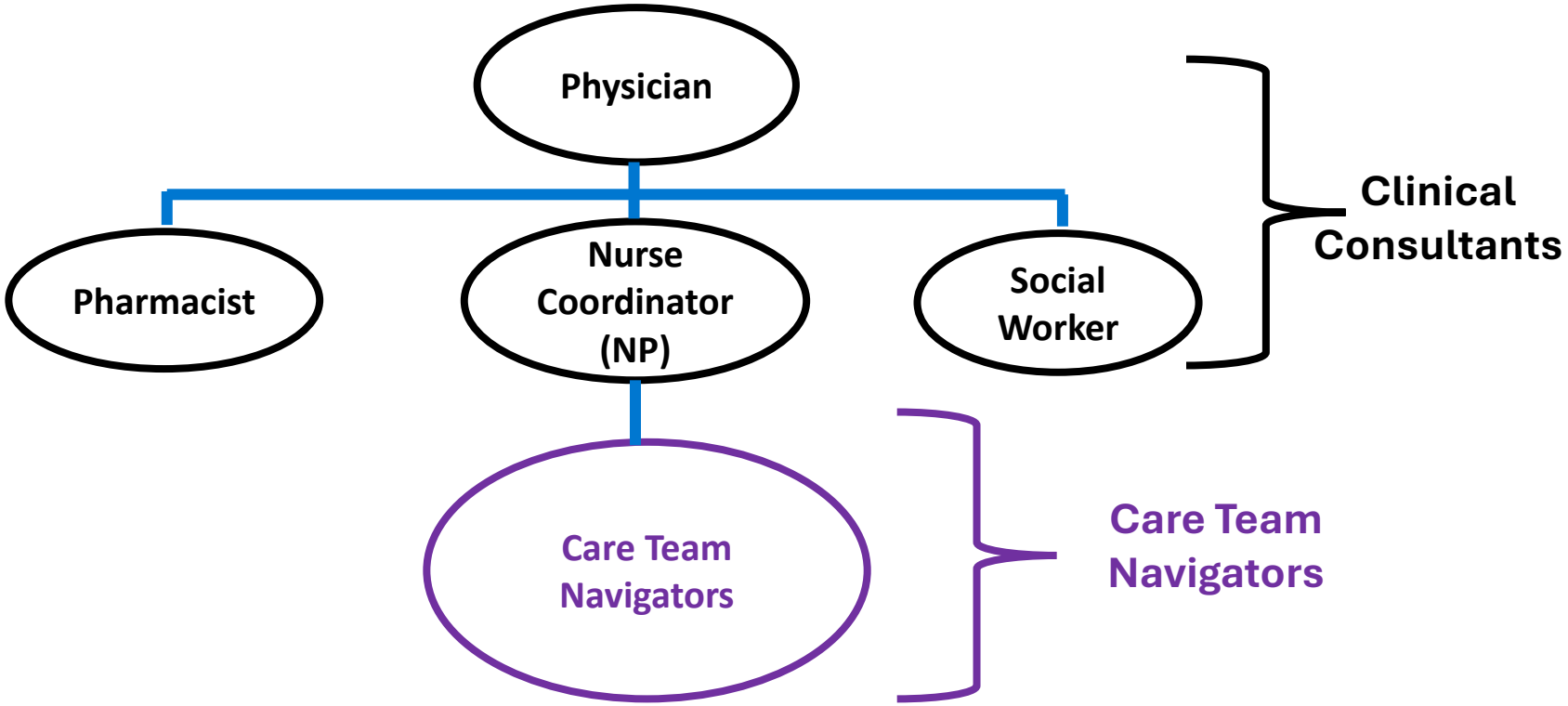
## Solution: Care Ecosystem

- ★ Provides primary care practices with clinical consultation
- ★ Provides ongoing person-centered care planning and care navigation
- ★ Streamlines care management; improves patient outcomes; reduces caregiver stress; lowers health care costs

**Care Ecosystem utilizes a proven, evidence-based approach to dementia care**

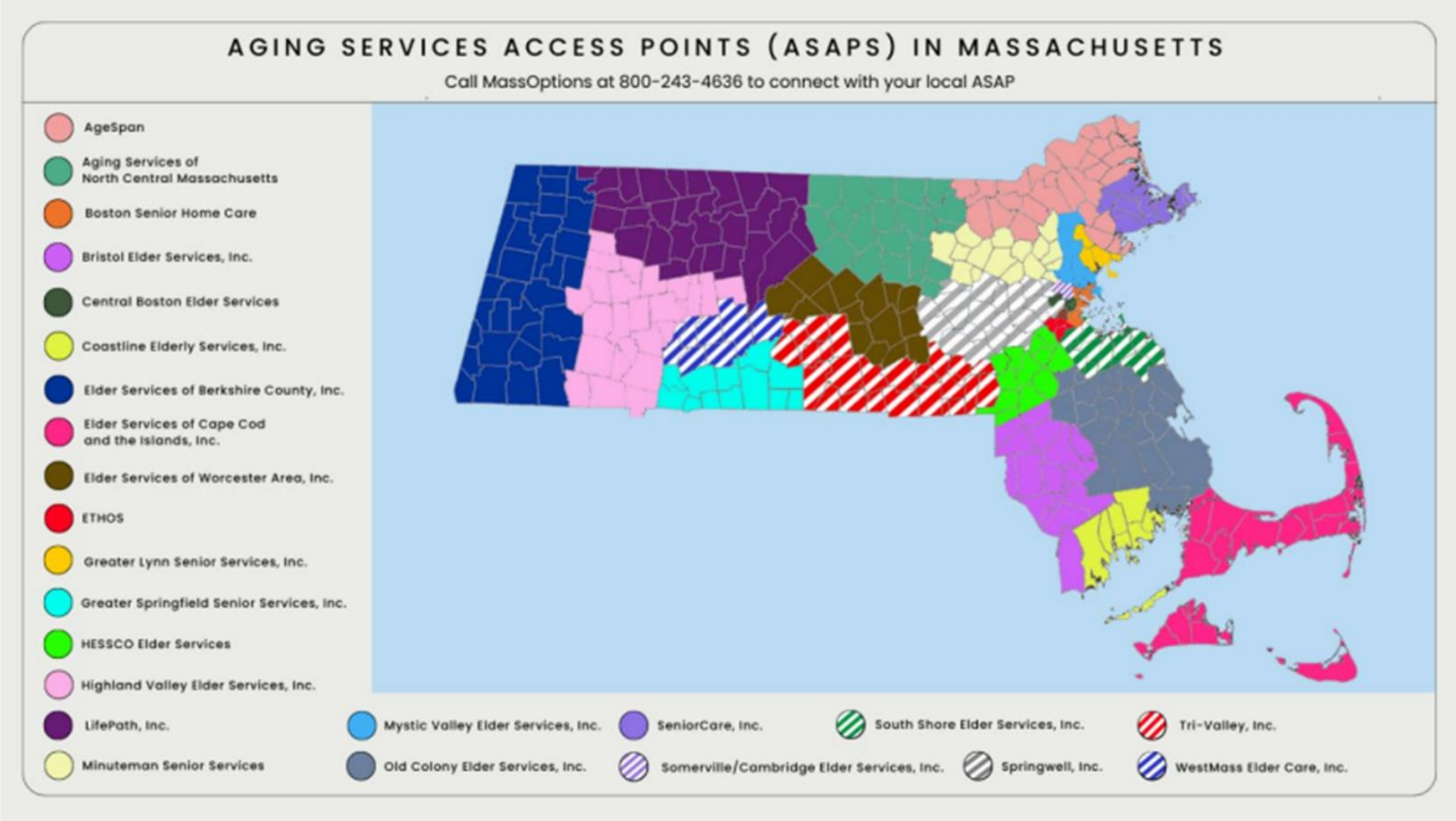
# Care Ecosystem Team:
# Clinical Consultants and Care Team Navigators

## Care Ecosystem Team




**We envision a centralized, grant-funded, state-contracted Team**

# Care Ecosystem Team:
# ASAP Infrastructure – Dementia Care Equity



# Transforming Dementia Care with Support from Care Ecosystem Team

## Key Participants in the Care Ecosystem Program

### Dementia Patient/Caregiver Dyads

**Maintain trusted ongoing relationship with the program's Care Team Navigators**

### Primary Care Practices

- **Refer patients** to program's care team navigators
- **Receive consultation** from the program's clinical consultants
- **Continue to make all medical decisions and provide all medical care**

### Clinical Consultants

***(Physician, Pharmacist, Nurse Coordinator, Social Worker***

**Provide PCP with clinical consultation on medical components of care**

### Care Team Navigators

- **Receive referrals to program; conduct intake interviews**
- **Maintain ongoing trusting relationships** with dyads
- **Identify available services**; develop and maintain person-centered care plans
- **Ensure delivery of planned care and support**
- **Collaborate with clinical consultants on medical issues**

### ASAP & Other Community Service Providers

**Receive support from Care Team Navigators**

### Program Manager

**Oversees all activities**

**Care Ecosystem Team = Care Team Navigators and Clinical Consultants**

# Key Considerations and Issues to Resolve

1. Assess stakeholder interest
2. Identify how this program may align with existing MassHealth programs and initiatives
3. Continue gathering information about similar programs
4. Explore options around program coordination and leadership (e.g. state vs. health system/practice level)
5. Evaluate options for operationalizing the program
6. Identify sources of grant funding and determine costs
7. Explore sustainable revenue streams beyond grant funding (e.g., billing/service codes)
8. Determine financial benefits and return on investment
9. Develop sustainability and scalability plan

# Discussion *(20 minutes)*

1. In general, what are your thoughts about piloting a centralized model of comprehensive dementia care in Massachusetts with a strong focus on dementia care navigation and ongoing caregiver support?

2. What do you like the most about this concept and what are your biggest concerns?

3. What advice do you have for our team?

Massachusetts Advisory Council on

Alzheimer's Disease and All Other Dementias

# Equity & Inclusion Team
# Updates, Accomplishments, and Discussion

## January 9, 2025

**Hugo Aparicio, MD, MPH (Council Member) -** Associate Professor of Neurology, Boston University School of Medicine; Stroke Specialist in the Department of Neurology, Boston Medical Center

# The Council's Team on Equity & Inclusion

## Team Co-Leads

### Hugo Aparicio, MD, MPH

**(Council Member)**

Associate Professor of Neurology, Boston University School of Medicine; Stroke Specialist in the Department of Neurology, Boston Medical Center

### Jatin Dave, MD, MBBS, MPH

**(Council Member until mid-December 2024)**

Chief Medical Officer, MassHealth; Director, Office of Clinical Affairs, ForHealth Consulting, UMass Chan Medical School

(Until mid-December 2024)

**Doris Harris, PhD,** Consultant, Springfield Dementia Friendly Coalition member, host of *Health Matters* radio show in Springfield (90.7 FM WTTC)

**Pam MacLeod, MBA, PMP,** Senior Project Director, Massachusetts Executive Office of Elder Affairs

**Kevin Reynolds,** Diversity, Equity and Inclusion Chair, Alzheimer's Association, Massachusetts/New Hampshire Chapter

**Kathy Service, NP,** Consultant on aging issues and dementia, often with a special focus on people living with intellectual and developmental disabilities

**Beth Soltzberg, LICSW, MBA,** Director, Alzheimer's/Related Dementias Family Support Program, Jewish Family & Children's Service, Waltham

**Judith Thermidor,** Resident Wellness Director, CSI Support & Development Services, Community Health Educator in Haitian Creole and Spanish

# Our Team's Goal


**Our Team's Goal**
***(Calendar Year 2024)***

Recommend approaches to eliminate, weaken, or mitigate the impact of barriers that may prevent certain groups from benefiting from the Council's work.

Source: Massachusetts Advisory Council on Alzheimer's Disease and All Other Dementias Annual Report (Calendar Year 2023)

# Updates and Accomplishments

✓ **Defined Equity Priorities –** Identified Equity and Inclusion Areas of Focus Specific to Dementia Care

- ☑ Stigma and Cultural Sensitivity
- ☑ Cultural Humility
- ☑ Communication and Language
- ☑ Health Literacy
- ☑ Beliefs about Medication
- ☑ Family Involvement

- ☑ Traditional Healers and Religious Spiritual, and Cultural Practices
- ☑ Referrals to Community Services and Supports
- ☑ Assessing Cognitive Function
- ☑ Dietary Considerations

- ☑ Assessing Behavioral Health
- ☑ Cultural Competence in Advanced Care Planning and Palliative Care
- ☑ Community Engagement

✓ **Developed Diversity, Equity, and Inclusion (DEI) Tool -** Identified key considerations within each area of focus to guide the Council and its teams in reviewing their work through a "DEI lens"

- Shared it with the Council's Dementia Care Planning team to include in their toolkit
- Piloted the use of the DEI tool with Harvard School of Public Health's Ariadne Lab to refine its care planning tool currently undergoing testing
- Will share the DEI tool with the Council's team on Interdisciplinary Dementia Care

# Updates and Accomplishments

✓ **Discussed Approach for Refining DEI Tool -** Identified benefits and logistics around hosting an annual listening session with people living with dementia within communities exhibiting significant health disparities and high dementia risk

✓ **Organized and Hosted Listening Session with Secured Funding and Venue**

- Secured funding from Point32Health Foundation for one listening session in 2024
- Identified a health center and attained its agreement to host a session with its patients
- Developed questions for participants using our DEI tool as a guide
- Convened session in September 2024 in a health center within a predominantly African American/Black community in Springfield

✓ **Refined the DEI Tool -** Updated our DEI tool based on feedback from this listening session with the potential opportunity for further enhancements through ongoing community engagement initiatives

# Updates and Accomplishments

✓ **Explored the Following Topics with Listening Session Participants**

- Understanding dementia and its impact on families
- Cultural and family beliefs about health and traditions
- Communication with healthcare providers
- Influence of family and others on decisions affecting health or wellbeing
- Accessing and benefiting from community services
- Engaging the community
- Discussing and addressing stressful behaviors

# Key Findings from Listening Session

## 1. Lack of Effective Communication with Healthcare Providers

*"I asked what the medication is for, and he told me not to worry about that"*

*"He seldom looked at me."*

*"The PCP or care providers are sometimes not listening. I want the best care; we are very important"*

**Much of what we heard is reflected in these summary phrases:**

- Recognize me as a person and as an important person
- Look at me, not the computer; look me in the eye while speaking
- Be attentive and present; don't rush; listen to me and my questions
- Respect my desire and need to understand my health and medication
- Get to know me as a human being; know my needs and preferences
- Do not make assumptions based on my culture, race, or ethnicity

# Key Findings from Listening Session

## 2. Lack of Knowledge of Available Services

- Most participants were somewhat silent when asked about available community services, except for one who referred to the Alzheimer's Association, Greater Springfield Senior Services, and hospice care
- One participant said: "I'm afraid of some services because I heard they can take away all my money"
- Another participant recommended that a phone number for help be posted at senior centers, grocery stores, and church bulletins

# Key Findings from Listening Session

## 3. Insights

- **Importance -** Although it takes significant effort, sessions like this are essential
- **Engagement -** Participants valued the opportunity to be heard, felt respected, and said they would be happy to do it again
- **Facilitation -** A key success factor was the skilled facilitator, Dr. Doris Harris who is well-known, respected, and trusted in the community and health center

# Next Steps

## Wrapping Up Our Team's Work in January 2025

- Include a link to our DEI tool in the Dementia Care Planning team's toolkit
- Provide the team on Interdisciplinary Dementia Care with the DEI tool for reference while designing its deliverables
- Having achieved our goal, convene a final team meeting on Friday, January 10, 2025, to:
    - identify approaches for operationalizing annual listening sessions within existing statewide programs such as Dementia Friendly Massachusetts; and
    - develop a process for ensuring ongoing refinements to the Council's DEI tool.

# Discussion *(10 minutes)*

## Your comments or questions?

(For example, how do we continue to develop and implement the use of the DEI tool?)

# Next Steps & Vote to Adjourn

## Next Council Meeting, April 29, 2025

1. Present and vote on annual report
2. Discuss the Council's priorities going forward

## Remaining Council Meetings in 2025 *(3:30 to 5:00 pm)*

- ***Tuesday, April 29, 2025***
- ***Thursday, September 18, 2025***
- ***Tuesday, December 16, 2025***

## Vote to Adjourn