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# Alzheimer’s Advisory Council

**Executive Office of Elder Affairs**

**Elizabeth Chen, Secretary**

**May 5, 2021**

**3:00-5:00 pm**

**Video Conference**

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## Agenda

1. **Welcome, Logistics, Introductions (10 min)**
2. **Quality of Care Workstream (50 min)**

* Care Planning Presentation (10 min) and Discussion (15 min)
* Staffing & Training Presentation (10 min) and Discussion (15 min)

1. **Caregiver Support and Public Awareness Workstream (50 min)**
2. Four 5-minute presentations:

* Video production
* Website development
* Cross-referrals
* Caregiver experience

1. Discussion (30 min)
2. **Closing Remarks and Final Roll Call (10 min)**

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Alzheimer’s Advisory Council

Moving from Planning to Action, 2021

Workstream: Quality of Care

Implementation of Recommendations

Status and Discussion

May 5, 2021

Workstream Leads

Maura Brennan, MD

Linda Pellegrini, MS, GNP-BC

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## Quality of Care Workstream Recommendations

As described by the Council in the Alzheimer’s State Plan:

Recommendation #1

Develop a person-directed

care plan framework and template

Recommendation #2

Develop a plan that ensures staff receive training and support needed to build and retain interprofessional teams with expertise in dementia

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## Recommendation #1: Care Planning

**Recommendation #1**

Develop a person-directed care plan framework and template

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## Care Planning Implementation Team

Linda Pellegrini, MS, GNP-BC

Council Member & Workstream Co-lead

Care Planning Implementation Team Co-lead

Geriatric Nurse Practitioner

UMass Memorial Medical Center

Susan Antkowiak

Council Member

Care Planning Implementation Team Co-lead

Vice President of Programs & Services

Alzheimer’s Association

Mike Belleville

Council Member

Dementia Advocate

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

Mass. Alzheimer’s Disease Research Center, MGH

Gad A. Marshall, MD

Medical Director of Clinical Trials at Center for Alzheimer Research and Treatment,

Brigham and Women’s Hospital (BWH); Associate Neurologist at BWH; Assistant in Neurology at Massachusetts General Hospital; Associate Professor of Neurology at Harvard Medical School

Victoria Martischnig

Graduate Student (MPH candidate)

Southern New Hampshire University

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## Care Planning Implementation Team

**Updates and Accomplishments**

* Gathering resources (e.g., Workbook: What Matters to Me; My Health Matters, Stanford Letter Project, etc. )
* Convening preliminary meetings with potential collaborators
* Intern acquired - Victoria Martischnig, Public Health Graduate Student, Southern New Hampshire University
* Collaboration with Diagnosis & Services Navigation Workstream Leads

**Next Steps**

* Convene two focus groups, one comprised of people living with dementia, the other comprised of caregivers
* Make decision if using an existing tool or create a new template

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## Care Planning Challenges and Solutions

**Challenges**

* Avoid redundancy, template should be value-added
* Due to underdiagnosis, it will be challenging to engage people living with dementia early enough for them to fully participate
  + when will it be appropriate to engage caregivers
  + how do we engage caregivers and maintain the voice of the person living with dementia
* Engaging unsupported individuals
* Funding a third-party convener of stakeholders to develop the template

**Solutions**

* Convene focus group of people living with dementia and caregivers to explore usefulness of template, ensuring voice of person living with dementia is incorporated

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## Care Planning Discussion (15 min)

**Discussion**

1. Is the person-driven care plan template an effective tool for developing care plans based on the values and priorities of the person living with dementia?
   * Can the tool effectively engage the voice of the person living with dementia regardless of stage of disease?
   * Do we have the opportunity to market this to healthcare professionals and the public?
   * Will we have the necessary resources and funding?
2. How do we promote the partnership between practitioners and their patients to utilize the person-driven model of care planning?

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## Recommendation #2: Staffing & Training

**Recommendation #2: Staffing & Training**

Develop a plan that ensures staff receive training and support needed to build and retain interprofessional teams with expertise in dementia

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## Staffing & Training Implementation Teams

**Interprofessional Training**

**Implementation Team**

***Maura J. Brennan, MD***

**Council Member & Training Implementation Team Co-lead**

Program Director

Baystate Health Geriatrics Workforce Enhancement Program

***Robert Schreiber, MD***

**Training Implementation Team Co-lead**

Vice President and Medical Director

Program of All-inclusive Care for the Elderly (PACE)

Fallon Health

***Pam Mirick, RN***

Former Caregiver and nurse

***Nina M. Silverstein, PhD***

Professor of Gerontology

University of Massachusetts Boston

**Direct Care Worker Recruitment & Retention Implementation Team**

***Tara Gregorio***

**Recruitment & Retention Implementation Team Co-lead**

President, Massachusetts Senior Care Association

***Lisa Gurgone, MS***

**Recruitment & Retention Implementation Team Co-lead**

Executive Director

Mass Home Care

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Interprofessional Training   
Implementation Status

**Updates and Accomplishments**

* Two ECHO programs up/forthcoming: Baystate Geriatrics Workforce Enhancement Program (GWEP) (an age-friendly/QI focus), UCLA/Alzheimer's Assoc. ECHO focused exclusively on dementia care
* Completing list of existing resources to identify gaps and opportunities for rapid initial spread of current tools and resources including those available at Centers of Excellence, GWEPs, CBOs/ Alzheimer's Assoc., Health Resources and Services Administration (HRSA), etc.

**Next Steps**

* Broaden group to wider range of professional caregivers: APs, social workers, community health workers, direct care workers, etc.
* Compile and post an annotated online list of resources/tools for interprofessional teams with URL links
* Connect to other workgroups so training can be designed/adapted as necessary to achieve all Advisory Council goals
* Meet with Institute for Healthcare Improvement (IHI) leadership and Alzheimer’s Assoc. to leverage collaboration with Age-Friendly Health System (AFHS) movement and ongoing Alzheimer's Assoc. initiatives

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Interprofessional Training   
Challenges and Solutions

**Challenges**

* Multiple stressors and competing demands of frontline clinicians and concomitant difficulty in securing time/team support for training
* Gaps in perceived value of geriatrics & dementia care by clinicians, systems, patients and families

**Solutions/Potential Strategies**

* Make trainings/ongoing coaching as practical and valuable as feasible—synchronous and asynchronous times, professional development (CME, project support, etc.), support for individual patient care, linked to AFHS recognition, incorporate into training/planning for Annual Wellness Visits, adapt to individual circumstances and resources
* Consider a phased-in mandate for an interprofessional team (> 4 professions) with expertise in dementia and ongoing training/support for care of older adults?
* Leverage AFHS movement for public relations campaign as feasible

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Direct Care Worker Recruitment & Retention

Implementation Status

**Updates and Accomplishments**

* Launched the Direct Care Worker Recruitment & Retention Implementation Team in April as part of the Council’s Quality of Care Workstream
* Began to develop a list of existing Direct Care Workforce initiatives and trainings

|  |  |
| --- | --- |
| **Retention and Recruitment Initiatives** | **Research and Analysis** |
| Extended Care Career Ladder Initiative (ECCLI), Personal and Home Care Aide Training Initiative, Commonwealth’s Long term Care Staffing Portal | State Auditor Reports on Home Care, Research by Home Care Aide Foundation, “Who Will Care for Us?” by Dr. Paul Osterman, MIT, Cliff Effect Research, UMASS Boston |
| **Wage and Benefit Initiatives** | **Policy and Strategy Groups** |
| Nursing Home Quality Initiatives, Salary Reserve/Enough Pay to Stay Initiatives, COVID19 Temporary Rate Increases | MA Healthcare Workforce Development Collaborative, Reinventing Work Initiative (Federal Reserve Bank), MA Legislative Commission for Nursing Homes Quality |
| **Career Ladders and Curriculum Development** |  |
| Extended Career Ladder Initiative (ECCLI), Alzheimer’s Supportive Home Care Aides, PHCAST Training, Community Colleges/Vocational Schools, Training Providers |  |

**Next Steps**

* Gather Feedback from stakeholders on additional resources
* Review existing Direct Care Worker initiatives and trainings for best practice recommendations, with a focus on ADRD Training and Support

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Direct Care Worker Recruitment & Retention   
Challenges and Solutions

**Challenges**

* Interprofessional Staff – Recognizing and valuing the Direct Care Worker (DCW)
* Financial
* Education/Training
* Availability of Workers

**Solutions**

* Quality Jobs Initiatives/Career Ladders/Upskilling Existing Staff
* Align Work with Existing Initiatives Working to Re-Envision the DCW System
  + Massachusetts Health Care Collaborative Direct Care Initiatives Recommendations - Harvard Project on Workforce research to update our understanding of direct care training and career pathway models
  + American Rescue Plan Act Investments
  + Federal and State Efforts to Support DCWs and Caregivers

- President Biden’s American Jobs Plan

- Senator Spilka’s Caregiver Initiative

* Gather a list of core competencies for ADRD training for DCWs

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Discussion (15 min)

**Interprofessional Training and Direct Care Worker Recruitment & Retention**

1. How can we motivate universal training and track consistent participation?
2. Are we more likely to achieve our goals by focusing exclusively on the problem of dementia care or can we secure more traction by linking to broader movements, notably AFHS or perhaps Patient Priorities Care, which include a focus on care for those with dementia or can be readily adapted/expanded to do so?
3. How can we improve the lives of direct care workers through training, professional development, better wages? What is the role for state legislation?

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Alzheimer’s Advisory Council

Moving from Planning to Action, 2021

**Workstream: Caregiver Support & Public Awareness**

**Implementation of Recommendations**

**Status and Discussion**

**May 5, 2021**

**Workstream Leads**

**Barbara Meehan**

**Hector R. Montesino**

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Caregiver Support & Public Awareness

**As described by the Council in the Alzheimer’s State Plan:**

**Recommendation #1**

Make and distribute three videos (English, Portuguese, Spanish) of caregivers talking about the help they got, and how they got it

**Recommendation #2**

Place on the Massachusetts Executive Office of Elder Affairs (EOEA) website, an overview of statewide pathways, services, and supports for people living with dementia and their caregivers

**Recommendation #3**

Implement changes at the Aging Services Access Points (ASAPs) to ensure that stressed caregivers get what they need in an effective and consistent manner

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Implementation Team Presentations

**Caregiver Support & Public Awareness Workstream**

* Today, each of this workstream’s four implementation teams will provide a brief presentation:
* Video Production (5 min)
* Website Development (5 min)
* Cross-Referrals (5 min)
* Caregiver Experience (5 min)
* To make the most of our time, **please make note of your questions during the presentations and we will convene a 30-min Q/A session after all four have been presented**

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Recommendation #1: Video Production

**Recommendation #1**

Make and distribute three videos (English, Portuguese, Spanish) of caregivers talking about the help they got, and how they got it

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Video Production Implementation Team

***Barbara Meehan***

**Council Member & Workstream Co-lead**

**Implementation Team Co-lead**

Alzheimer's Advocate/Former Caregiver

***Hector R. Montesino***

**Council Member & Workstream Co-lead**

**Implementation Team Co-lead**

President

Embrace Home Care Services

***Milagros Abreu, MD, MPH***

President/ CEO and Founder

The Latino Health Insurance Program, Inc.

***Jennifer Hoadley, CDP***

Regional Manager Southeastern MA

Alzheimer's Association, MA and NH Chapter

***Patty Sullivan***

Program Director

Dementia Friendly Massachusetts

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Video Production Status

**Updates & Accomplishments**

* Established contact with MassAccess who will work with us to film and format videos and provide them to all MassAccess cable channel members.  The videos will be available to download and available for viewing on YouTube
* Identified interviewers
* Solidified material to cover in videos
* Determined that the video needs to be 30 minutes

**Next Steps**

* Identify caregivers for videos by end of May 2021
* Work with caregivers to establish comfort
* Contact non-MassAccess cable TV stations; distribute videos widely

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Video Production Challenges and Solutions

**Challenges**

* Providing video access in multiple venues
* Finding caregivers comfortable with being in video

**Solutions**

* Dr. Abreu will help identify appropriate caregivers who speak Spanish and Portuguese
* Other team members will identify appropriate English-speaking caregiver

*We will have time for your questions soon. In the meantime, Barb Meehan will present the work of the Website Development Team.*

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Recommendation #2: Website Development

**Recommendation #2**

Place on the Massachusetts Executive Office of Elder Affairs (EOEA) website, an overview of statewide pathways, services, and supports for people living with dementia and their caregivers

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Website Development Implementation Team

***Pam MacLeod, MBA, PMP***

**Implementation Team Lead**

Senior Project Director

MA Executive Office of Elder Affairs and UMass Medical School

***Molly Evans***

Senior Policy Manager

MA Executive Office of Elder Affairs

***Anagha Kumar***

Student Intern, Harvard College

MA Executive Office of Elder Affairs

***Annette Peele, MSW***

Director of Community Programs

MA Executive Office of Elder Affairs

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Website Development Status

**Updates & Accomplishments**

* Developed a “website mock-up”
* Described available services, supports and resources
* Presented information in a topic-by-topic format
* Began recruiting caregivers to test a draft version of the website
* Developed a guide with questions to help facilitate a discussion with the website’s evaluators (caregivers)

**Next Steps**

* Will build and have caregivers use and test the website in May and June 2021

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Website Development Challenges & Solutions

**Challenges**

* Including enough information to be helpful, but not so much that it becomes overwhelming
* Avoiding government jargon when describing programs/services

**Solutions**

* Categorize information and include Tables of Contents for easy navigation
* Ensure that each webpage contains a short list of information with headings for easy scanning
* Have caregivers test a draft version of the site and incorporate their feedback before going live

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Website Development Question for Council

The website’s resources are organized by the following topics. **Did we miss any important topics?**

Table of Contents in the “About” webpage

1. Services *(When users select this topic, they will be directed to the service categories on the next slide)*
2. Caregiver Support
3. Social Engagement
4. Resources on Alzheimer’s Disease and Related Dementia
5. Clinical Trial Participation
6. Advocacy and Volunteering

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Website Development Question for Council

**Did we miss any important service categories?**

Table of Contents in the **“Services”** webpage

1. Service Navigation and Referral
2. Support Groups and Peer-to-Peer Companion Programs
3. Elder Abuse Prevention
4. Insurance Navigation and Support
5. In-Home Programs, Services, and Meals
6. Community-Based Supports for MassHealth Members
7. Locating a Nursing Home or Assisted Living Residence

*Next up: Pam MacLeod will introduce work designed to address the third recommendation of the caregiver support & public awareness workstream*

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Recommendation #3: Caregiver Experience

**Recommendation #3**

Implement changes at the Aging Services Access Points (ASAPs) to ensure that stressed caregivers get what they need in an effective and consistent manner *(all caregivers including dementia caregivers)*

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Caregiver Experience Implementation Teams

**Cross Referrals Implementation Team**

***Pam MacLeod, MBA, PMP***

**Implementation Team Lead**

Senior Project Director, MA Executive Office of Elder Affairs (EOEA) and UMass Medical School

***Referrals from ASAPs***

***Kathy Devine***

Director, Prescription Advantage Operations, EOEA

***Carole Malone***

Assistant Secretary, EOEA

***Annette Peele, MSW***

Director of Community Program Services, EOEA

**Referrals from Alzheimer’s Association**

***Nicole McGurin***

Programs & Services Director

Alzheimer's Association, MA/NH Chapter

***Julia Perriello***

Manager, Helpline and Community Referrals

Alzheimer's Association, MA/NH Chapter

**Caregiver Experience Implementation Team**

***Amanda Bernardo***

**Implementation Team Lead**

Director of Communications and Strategic Initiatives

MA Executive Office of Elder Affairs (EOEA)

***Kathy Devine***

Director, Prescription Advantage Operations, EOEA

***Molly Evans***

Senior Policy Manager, EOEA

***Pam MacLeod, MBA, PMP***

Senior Project Director, MA Executive Office of Elder Affairs (EOEA) and UMass Medical School

***Annette Peele, MSW***

Director of Community Program Services, EOEA

***Lynn C. Vidler, BSW, MBA***

Director of Home and Community Programs

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(1) Cross-Referrals Team

**Make cross-referrals a standard practice between the ASAPs and Alzheimer’s Association**

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(1) Cross-Referrals Team Status

**Updates and Accomplishments**

* Reviewed current practices around cross-referrals between MA elder service agencies (ASAPs) and the Alzheimer’s Association Helpline (aka “24/7 Helpline”)
* Checked the resource database on the 24/7 Helpline website used by the public to ensure accuracy of its ASAP information
* Made improvements to the internal resource database used by 24/7 Helpline staff to highlight the role of ASAPs
* Determined that referrals from the ASAPs’ Information & Referral staff to the 24/7 Helpline and vice versa are already considered a standard practice (when practical and appropriate) and part of staff training

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(1) Cross-Referrals Team Next Steps

**Next Steps**

***Will reinforce cross-referrals as a best practice:***

* Alzheimer’s Assoc. will place this topic on the agenda of an upcoming meeting of its MA/NH Chapter staff
  + Will showcase ASAP offerings and provide example of how a referral made a positive difference for an individual or family
* EOEA will distribute brief talking points about the 24/7 Helpline (provided by Alzheimer's Assoc.) to all supervisors of ASAP call-takers
* EOEA has placed this topic on the agenda of all three regional Aging & Disability Resource Consortia (ADRC) meetings to be convened in May 2021
  + Attendees will include I&R staff, options councilors, and family caregiver support specialists

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(1) Cross-Referrals Team Challenges & Solutions

**Challenges**

* As its primary focus, the 24/7 Helpline provides brief counseling to address an “in-the-moment” crisis or emergency, often making an ASAP referral impractical
* ASAP call-takers, however, are more likely to receive comprehensive information from callers, so it almost always makes sense to refer callers affected by dementia to the 24/7 Helpline along with referrals to local programs and services
* Although cross-referrals are considered standard practice (when practical), caregivers that participated in the caregiver support workgroup’s quick and very limited test were not referred in either direction although doing so would have benefited their situations

**Solutions**

* EOEA and the Alzheimer's Assoc. will reinforce cross-referrals as a standard practice (applying the approach described in the previous slide)
* The Caregiver Experience Team will conduct a robust review and evaluation of caregiver experience and cross-referrals will be part of that review

*Next up: Amanda Bernardo will present progress made on our Caregiver Experience Project*

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(2) Caregiver Experience

1. Conduct a robust evaluation of the caregiver experience when contacting ASAPs, identify areas for improvement at ASAPs, and implement improvements where needed
2. Require that ASAP staff refer caregivers to the Massachusetts Family Caregiver Support Program when appropriate
3. Assess all ASAPs' automated phone messages and make changes to ensure these are clear and make it easy for caregivers to connect to individuals for help

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(2) Caregiver Experience Team Status

**Updates & Accomplishments**

* + The Caregiver Experience Team had a successful kick-off meeting to design project scope, which included an exercise to discuss the ideal caregiver experience
  + The team defined project scope and agreed to recruit a diverse set of caregivers to assist with caregiver experience project
  + The team discussed the general concepts of the project with select members of aging network and will bring in stakeholders, as applicable

**Next Steps**

* + Due to the COVID-19 vaccine distribution, the team has had to briefly pause the caregiver experience project; it will resume work and begin recruiting caregivers this spring
  + The team expects to the complete the project in fall 2021

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(2) Caregiver Experience Team Challenges and Solutions

**Challenges**

* + There may be challenges in recruiting caregivers that are not already directly connected with the aging services network
  + There are challenges designing a project that balances both understanding what the caregiver experience is when they contact the aging network, while also acknowledging that finding the aging network may present its own set of difficulties for a caregiver

**Solutions**

* + The team has identified a variety of partners that may be able to assist in the recruitment of caregivers
  + The team agreed to define the project scope as reviewing the experience once a caregiver has connected with the aging services network

*Next up: Hector Montesino and Barb Meehan will facilitate a Q/A session*

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(2) Caregiver Support & Public Awareness Discussion (30 min)

1. **Your Questions and Comments?**

* Video Production
* Website Development
* Cross-Referrals
* Caregiver Experience

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Next Steps

**Next Council Meeting - September 1, 2021, 3:00 to 5:00 pm**

Presentations/Discussions on:

* 1. Equitable Access & Care
  2. Diagnosis & Services Navigation