Alzheimer's Advisory Council

Executive Office of Elder Affairs
Elizabeth Chen, Secretary

October 27, 2020
3:00-5:00 pm
Video Conference

Agenda

1. **Welcome, Meeting Logistics and Introductions (15 min)**

2. **Brief Updates from Workgroup Leads (10 min)**

3. **Status Update on Chapter 220 of the Acts of 2018 (10 min)**
   - Presentation (5 min)
   - Discussion (5 min)

4. **Physical Infrastructure Workgroup (20 min)**
   - Presentation (10 min)
   - Discussion (10 min)

5. **Caregiver Support and Public Awareness Workgroup (60 min)**
   - Presentation (20 min)
   - Discussion (40 min)

6. **Next Steps (5 min)**

Brief Updates from Workgroup Leads

Two-Minute Updates

1. BOLD[1] Infrastructure (J. Lavery, E. Chen)
2. Quality of Care (L. Pellegrini, M. Brennan)
3. Diagnosis and Services Navigation (T. Farley-Bouvier, J. Wessler)
4. Research (A. Budson)
5. Equitable Access and Care (J. Jackson)

Note: The remaining two workgroups will deliver presentations today.

1. *Building our Largest Dementia Infrastructure*

Alzheimer's Association Update on the Status of Chapter 220 of the Acts of 2018

Susan Antkowiak, VP of Programs & Services

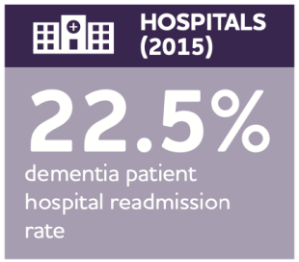
Daniel Zotos, Director of Public Policy & Advocacy

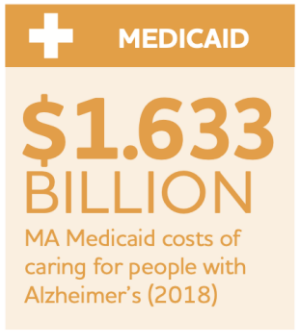
October 27th, 2020

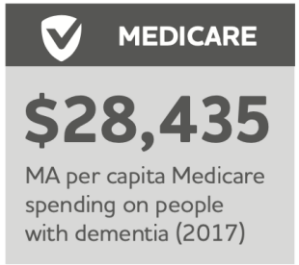
Chapter 220 of the Acts of 2018 Status Update

Top Issues Facing the Commonwealth that Led to Legislative Action

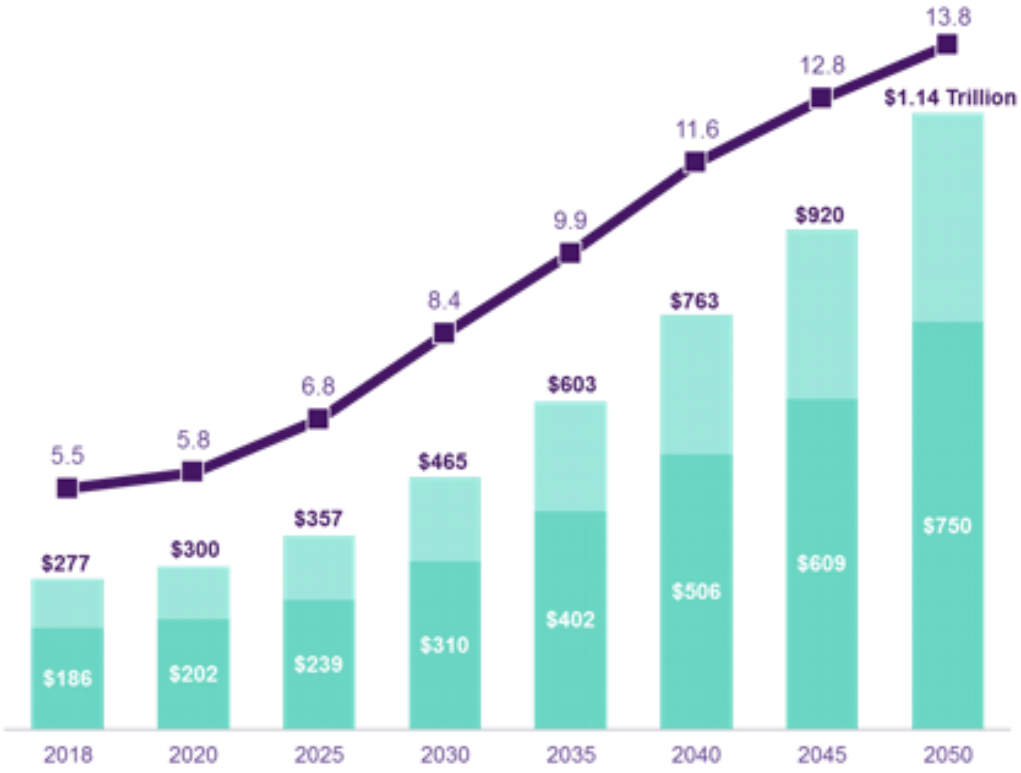
- Alzheimer's and dementia prevalence and cost.
- Diagnosis or lack thereof- less than 50% of people with dementia are diagnosed and of those diagnosed less than 50% are told of their diagnosis.
- MA is ranked 6th highest in the nation for hospital readmission rates for Medicare beneficiaries with Alzheimer's; adds to cost and contributes to poor quality of care.
- Care standards have been established in long-term care (SNFs, ALFs) and home care; acute care setting is the last frontier.







Chapter 220 of the Acts of 2018
Status Update



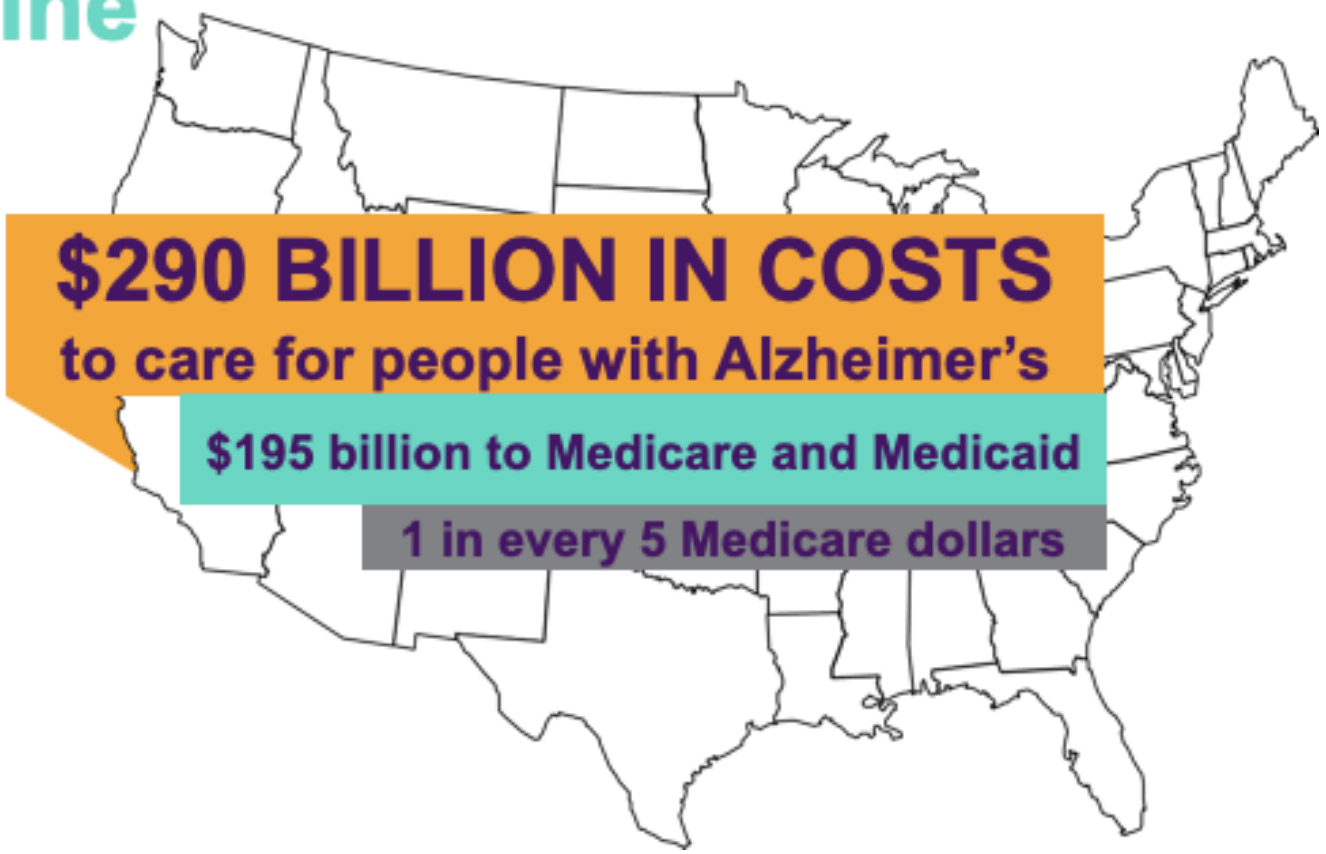
5.8 MILLION Americans are living with Alzheimer's

BY 2050, this number is projected to rise to nearly **14 MILLION**

Chapter 220 of the Acts of 2018
Status Update

The Top Line

The NEW ENGLAND JOURNAL of MEDICINE



Chapter 220 of the Acts of 2018 Status Update

CHALLENGE: INCREASE ACCESS TO DIAGNOSIS AND CARE

Too often, a diagnosis comes late and is not communicated effectively.

- Only half the people affected by AD are diagnosed.
- Of those, only half are told of their diagnosis.

Together, we must scale up our reach and influence.

Chapter 220 of the Acts of 2018 Status Update

August 9, 2018 - H.4116 Signed into Law!

A landmark law hopes to improve Alzheimer's care in Mass.

By Felice J. Freyer Globe Staff, August 12, 2018, 9:05 p.m.

Governor Charlie Baker signed the first-in-the-nation legislation on Alzheimer's into law last week. PAT GREENHOUSE/GLOBE STAFF/FILE 2007

FILED ON: 1/12/2018

HOUSE . . . . . No. 4116

The Commonwealth of Massachusetts

In the One Hundred and Ninety-th General Court
(2017-2018)

An Act relative to Alzheimer's and related dementias in the Commonwealth.

Be it enacted by the Senate and House of Representatives in General Court assembled, and by the authority of the same, as follows:

SECTION 1. Chapter 6A of the General Laws is hereby amended by inserting after section 16Z the following section:-

Section 16AA. (a) The executive office of health and human services, hereinafter the executive office, shall develop and carry out an assessment of all state programs that address Alzheimer's disease and shall create and maintain an integrated state plan to overcome Alzheimer's disease. The state plan shall include implementation steps and recommendations for priority actions based on the assessment. The purposes of the state plan shall be, but shall not be limited to, the following:

(1) accelerate the development of treatments that would prevent, halt or reverse the course of Alzheimer's disease;

(2) help coordinate the health care and treatment of individuals with Alzheimer's disease;

2 of 7

Chapter 220 of the Acts of 2018
Status Update

Chapter 220 of the Acts of 2018 Status Update

Summary

1. Creates permanent statewide advisory council and an integrated state plan to effectively address Alzheimer's disease.

2. Requires content about Alzheimer's and related dementias be incorporated into physicians, physician's assistants, registered nurses and practical nurses continuing education programs that are required for the granting or renewal of licensure.

3. Requires doctors to share an Alzheimer's diagnosis and treatment plan to a family member or legal personal representative within the existing framework of federal and state privacy laws.

4. Requires hospitals that serve an adult population to have an operational plan in place for recognizing and managing individuals with dementia within three years of the laws' enactment.

5. Requires elder protective services caseworkers to be trained on Alzheimer's disease.

https://malegislature.gov/Laws/SessionLaws/Acts/2018/Chapter220#:~:text=Section%2016AA.,the%20treatment%20of%20Alzheimer's%20disease.

Chapter 220 of the Acts of 2018 Status Update

1. Creates permanent statewide advisory council and an integrated state plan to effectively address Alzheimer's disease

- The Advisory Council is up and running and has held five meetings so far.
- Workgroups have recently been formed on the following topics: equitable access & care, quality of care, public awareness, caregiver support, education & respite, initial diagnosis & services navigation, physical infrastructure and research.
- The advisory council shall annually provide to the executive office and the legislature a report which shall include:
  1. Information and recommendations on Alzheimer's disease policy;
  2. Evaluation of all state-funded efforts in Alzheimer's disease research, clinical care, institutional, home-based and community-based programs;
  3. Outcomes of such efforts;
  4. Any proposed updates to the state plan, which the advisory council shall annually review.
- The first report required under section 16AA of chapter 6A of the General Laws shall be provided not later than March 1, 2021.
- Tasked with updating State Alzheimer's Disease Plan (2012).

Chapter 220 of the Acts of 2018 Status Update

2. Requires content about Alzheimer's and related dementias be incorporated into physicians, physician's assistants, registered nurses and practical nurses continuing medical education programs that are required for the granting or renewal of licensure.

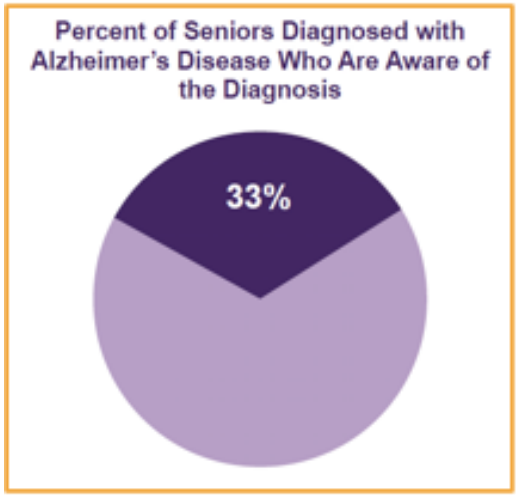
- All licensees will have until November 6, 2022 to complete this one-time requirement.
- Must attest to DPH that you have completed training (similar to domestic violence, opioid)
- Approximately 51,000 licensees have completed training requirement so far (August)
- Current MA CME Offerings
  - Mass Medical Society http://www.massmed.org/ALZ/
    - Launched in February and developed in collaboration with the Alzheimer's Association
    - 417 participants so far
    - 5 modules (3.5 CME total)
  - Mass Health & Hospital Association Online Course
  - Mass Nurses Association
    - Presented to BORIN prior to pandemic
    - Online CE (1.75)
  - Alzheimer's Association, MA/NH Chapter
    - Presented by Dr. Brent Forester
    - 300+ trained
    - No further funding for CME accreditation
  - Alzheimer's Association National Online Course
    - Five 15-minute modules; up to 1.25 CME
    - CME accreditation underwritten by the MetLife Foundation

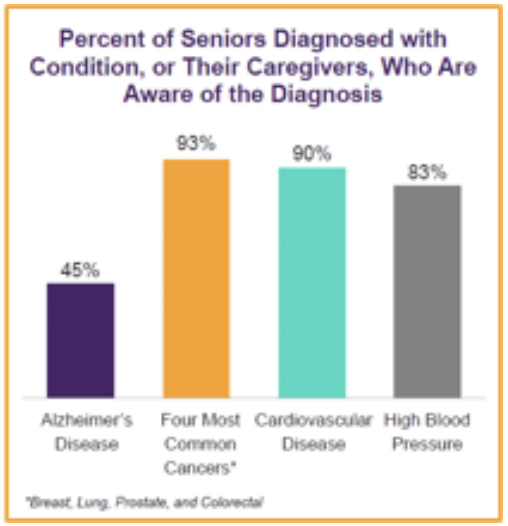
Chapter 220 of the Acts of 2018 Status Update

3. Requires doctors to share an Alzheimer's diagnosis and treatment plan to a family member or legal personal representative within the existing framework of federal and state privacy laws.

- There is no penalty for a physician who does not comply with this requirement, but the spirit of this component is to encourage the physician to use their clinical judgement so that if they determine the patient has dementia, they can alert the family to the necessity to get more involved with supporting and assisting the person.

- **There has been no notification of this requirement to physicians as of yet.**





Chapter 220 of the Acts of 2018 Status Update

4. Requires hospitals that serve an adult population to have an operational plan in place for recognizing and managing individuals with dementia within three years of the laws' enactment

- Develop an operational plan to identify dementia and/or delirium and create a specialized plan if detected
- Ensure designated caregivers are involved in hospital processes including transfers and discharge planning
- Develop QAPI measures including how clinical and relevant non-clinical staff receive routine training
- Mass Health & Hospital Association (MHA) lead a workgroup to develop and action plan document including tools and resources. Report published in 2018.
- Compliance is due October 1, 2021
- **Operational plans would be invaluable during pandemic protocol**
- Between January 1 and August 15, there were 178,563 COVID-19 hospitalizations among Medicare fee-for-service (FFS) beneficiaries. More than a third of them had a diagnosis of Alzheimer's or another dementia.

Chapter 220 of the Acts of 2018 Status Update

5. Requires elder protective services caseworkers to be trained on Alzheimer's disease.

- Executive Office of Elder Affairs has developed and delivered comprehensive dementia training for all elder protective service workers.
  - 240 of the 290 protective service workers in MA have completed training in dementia
  - Of the remaining 50 workers, 40 are currently taking the recently released online training (10 have not yet started it)
  - Turnover among protective service workers has averaged about 5%
  - New workers take the online training within their first month

Alzheimer's Advisory Council

Physical Infrastructure Workgroup
10/27/20

Physical Infrastructure Workgroup

Elizabeth Chen, PhD, MBA, MPH (Workgroup Lead)
Secretary, Executive Office of Elder Affairs
Chair, Alzheimer's Advisory Council

Laura Brelsford
Assistant General Manager
Department of System-Wide Accessibility
MBTA

Elana Brochin
Program Director of Health Equity
MA Assoc. of Community Development Corporations (MACDC)

Angela Cleveland, AICP
President, American Planning Association
Massachusetts Chapter (APA-MA)
Director of Community and Economic Development, City of Amesbury

Jackie DeWolfe
Director of Sustainable Mobility
Office of the Secretary
Massachusetts Department of Transportation

Linda Dunlavy
Executive Director
Franklin Regional Council of Governments

James Fuccione, MPA
Senior Director
Massachusetts Healthy Aging Collaborative

Jeffrey R. Parenti, PE, PTOE, PTP, ENV SP
Deputy Chief Engineer
Division of Design and Engineering
MA Department of Conservation and Recreation (DCR)

Kathryn Quigley
Deputy Director of Strategic Planning
Department of System-Wide Accessibility
MBTA

Patty Sullivan
Program Manager, Dementia Friendly Massachusetts
Massachusetts Councils on Aging

Jeffrey Walker, AICP
Executive Director
Southeastern Regional Planning & Economic Dev. District (SRPEDD)

Amy Walsh, M.Sc., CDP
Dementia Friendly Boston
Age Strong Commission, City of Boston

Sharon M. Yager
Caregiver Specialist
Family Caregiver Support Program
Montachusett Home Care
Leominster, MA

What are Dementia Friendly Communities?

Communities that "foster the ability of people living with dementia to remain in the community and **engage and thrive in day to day living**" *(Dementia Friendly America)*

What is Dementia Friendly Physical Infrastructure?

Dementia Friendly Physical Infrastructure is:

Familiar

Legible

Distinctive

Accessible

Comfortable

Safe

What is Dementia Friendly Physical Infrastructure?

Some examples:

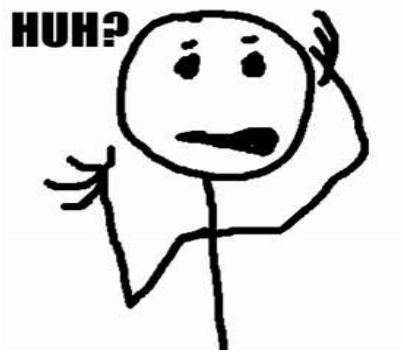
x Familiar
x Legible
✓ Distinctive
x Accessible
x Comfortable
x Safe

✓ Familiar
✓ Legible
✓ Distinctive
✓ Accessible *(Depends on where placed)*
✓ Comfortable
✓ Safe *(Depends on where placed)*

What is Dementia Friendly Physical Infrastructure?

x Familiar
x Legible
x Distinctive
x Accessible

Comfortable
Safe



x Familiar
x Legible
x Distinctive
x Accessible

Comfortable
Safe

Gray shaded items are not applicable

Why is Dementia Friendly Physical Infrastructure Important?

People living with dementia:

- Continue to go out alone, providing sense of self-respect
- Are less aware of dangers and possibility of losing way
- Can't always interpret cues that signal a purpose or entrance
- Can get anxious or confused in complex, crowded or noisy places
- Often use landmarks and visual cues rather than maps or directions

Source: Neighborhoods for Life – A Findings Leaflet by Elizabeth Burton, Lynne Mitchell and Shibu Raman

Challenges

- Age friendly (AF) efforts can sometimes overlook the needs of people living with dementia
- Efforts to make infrastructure accessible are likely to address physical disabilities, but don't always address cognitive disabilities
- Unless a dementia friendly (DF) community is conducting AF efforts as well, they are more likely to focus solely on the social needs of people living with dementia
- MA has over 160 communities working to become DF – few are addressing the physical infrastructure needs of people living with dementia

Opportunities

- ✓ With just a few tweaks and often no additional cost, AF efforts can become dementia friendly and benefit people of all ages and abilities

- ✓ MA has a growing number of communities working to become both AF and DF. MA has developed an *AF/DF Integration Toolkit* to help: https://tinyurl.com/AF-DFtoolkit

- ✓ All MA communities that are aligning AF & DF efforts are addressing the physical infrastructure needs of people living with dementia.

Opportunities

✓AF and DF physical infrastructure plays an essential role in improving social determinants of health, helping to reduce health and wellness disparities not only for people living with dementia, but everyone.

Social Determinants of Health

Economic Stability	Neighborhood and Physical Environment	Education	Food	Community and Social Context	Health Care System
Employment Income Expenses Debt Medical bills Support	Housing Transportation Safety Parks Playgrounds Walkability Zip code/ geography	Literacy Language Early childhood education Vocational traing Higher education	Hunger Access to healthy options	Social integration Support systems Community engagement Discrimination Stress	Health coverage Provider availability Provider linguistic and cultural competency Quality of care

Health Outcomes
Mortality, Morbidity, Life Expectancy, Health Care Expenditures, Health Status. Functional Limitations

Source: Henry J. Kaiser Family Foundation

Physical Infrastructure Workgroup Goal

WORKGROUP GOAL

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

Physical Infrastructure Workgroup Recommendation

Recommendation

Raise awareness of the importance of age and dementia friendly design

Responsible Organization

- **Dementia Friendly Massachusetts (DFM) Leadership Team**
  - Massachusetts Councils on Aging (leader of DFM team)
  - MA Executive Office of Elder Affairs (EOEA)
  - Jewish Family and Children's Service
  - Massachusetts Healthy Aging Collaborative
  - Alzheimer's Association, MA/NH Chapter
  - Latino Health Insurance Program, Inc.

Costs/Resources

- **No incremental cost**
  - Proposed implementation strategies would be included as part of the age and dementia friendly portfolio of activities managed by EOEA and its DFM partners listed above

Raise awareness of the importance of age and dementia friendly design

Implementation Strategies

1. Strengthen relationships between the dementia friendly (DF) community movement and key stakeholders at the municipal, regional and state levels by taking these steps:

   In 2021:

   - Identify regularly scheduled municipal, regional and statewide meetings and conferences for community planners.
   - Develop and deliver at least one presentation to key stakeholders that:
     - clarifies what DF physical structure looks like
     - uses community planning language while discussing DF concepts, e.g., “Smart Growth,” “Housing Choice,” “Transit Oriented Development”
     - allows for a two-way dialogue between the Dementia Friendly Massachusetts (DFM) leadership team and planners

Physical Infrastructure Workgroup Recommendation

Raise awareness of the importance of age and dementia friendly design

Implementation Strategies

2. In 2021 and every year thereafter, continuously improve the presentation, incorporating advice about approaches, tools, or additional knowledge that would increase likelihood of AF & DF planning and design for:
    - Parks, outdoor spaces, transportation, residential and commercial buildings
3. In 2022, determine feasibility of working with community planners to convene webinar. If deemed feasible, convene, record and distribute it to municipal, regional and statewide planners via their websites, newsletters and email blasts.
4. Beginning in November 2020, place “DF physical infrastructure” on monthly agenda of DFM leadership team, who, beginning in 2021, is responsible for:
    - ensuring effective and timely implementation
    - seeking advice from this workgroup as needed
    - reporting back to the Council on progress

Council's comments, questions, approval to adopt?

Recommendation - Raise awareness

Summary of Proposed Implementation Strategies

1. In 2021, strengthen relationships between DF movement and stakeholders by identifying gatherings of community planners; and developing and delivering at least one presentation that allows for a two-way dialogue.

2. In 2021 and every year thereafter, continuously improve the presentation with input from stakeholders.

3. In 2022, determine feasibility of working with community planners to convene a webinar; if deemed feasible, convene, record, and distribute it.

4. Beginning in November 2020, place "DF physical infrastructure" on the monthly agenda of the DFM leadership team, who, beginning in 2021, is responsible for:
   - ensuring effective and timely implementation
   - seeking advice from the Physical Infrastructure Workgroup as needed
   - reporting back to the Council on progress

Alzheimer's Advisory Council

Caregiver Support and Public Awareness Workgroup
10/27/20

Caregiver Support and Public Awareness Workgroup

Workgroup Members
Barb Meehan **Council Member & Co-lead** Alzheimer's Advocate/Former Caregiver
Hector R. Montesino **Council Member & Co-lead** President Embrace Home Care Services
Katie Brandt, MM Director of Caregiver Support Services and Public Relations Massachusetts General Hospital Co-Chair, National Alzheimer's Project Act (NAPA) Council
Jennifer Hoadley, CDP Regional Manager Southeastern MA Alzheimer's Association
Senator Patricia Jehlen Council Member Co-chair, Joint Committee on Elder Affairs
Rhiana Kohl Council Member Caregiver
Kathryn Perrella, LSW, CIRS A/D Options Program Manager Elder Services of the Merrimack Valley and North Shore
Susan Salisbury Community Services and Information Director Tri-Valley, Inc.
Patty Sullivan Program Director Dementia Friendly Massachusetts Massachusetts Councils on Aging (MCOA)

Council's Initial Discussion and Immediate Activities Conducted

Council expressed concern around increased stress among caregivers from:

- Disruption in routine; social isolation; lack of meaningful engagement
- Fewer supports (e.g., in-home support, adult day health, friends, family)
- Restricted visits for PLWD in residential care

Council's initial suggested solutions:

- Provide 4-hour respite opportunities for dementia caregivers
- Develop a telephonic companion visitation program for PLWD

Council's charge:

- Identify strategies to support caregivers of PLWD to implement in the short term

Activities conducted after Council meeting:

- EOEA team examined current services and support landscape; identified challenges
- Due to the challenge around lack of awareness of and subsequent access to services:
  - Role of Public Awareness Workgroup was expanded to include Caregiver Support
  - A "secret shopper" exercise was conducted

Challenges Identified by EOEA Team

- Opportunities for respite and other supports exist, but not everyone knows the path to find them
- Telephonic companion programs exist, but many don't know how to find them. Also, a PLWD's need for visual cues can be a barrier
- Need to ensure that caregiver supports address their specific needs to effectively alleviate the stress associated with the pandemic
- Each person/family has unique needs that when met may be more essential to alleviating stress during the pandemic and beyond, for example:
  - ongoing services in the home
  - opportunities to learn coping strategies or strategies to address specific challenges
  - opportunities for meaningful engagement for the PLWD

Service and Support Landscape for PLWD and their Caregivers

	Services and Supports	Services Targeted Towards…		Eligibility Requirements
		Caregivers	Consumers	
Support for Caregivers	Massachusetts Caregiver Coalition – Caregiving information for workplaces - webinars for working caregivers and resources	x		Employed
	Savvy Caregiver and Powerful Tools for Caregivers (Evidenced Based Programs) – Healthy Living Center	x		None
	Mass Family Caregiver Support Program	x		None
	Support Groups at ASAPs and COAs- coping mechanisms, caregiver relief, grief/loss	x		None
	Employer Resource Guide for supporting caregivers	x		
	Frontotemporal Degeneration (FTD) telephone and in-person support groups for families affected by FTD (the most common form of dementia for people under age 60) - This support is sponsored by the Association for FTD (AFTD)	x	x	None
	Lewy Body Dementia (LBD) Caregiver Line - Telephone support for caregivers of persons living with LBD; links them with experienced LBD caregivers – this support is sponsored by the LBD Association (LBDA)	x		None
Services for Consumers	Adult Day Health (ADH)		x	MH clinical eligibility
	Support Groups at COAs – support programs for early-stage, early onset, and individuals with Mild Cognitive Impairment (MCI)		x	None
	Adult Foster Care Program through MassHealth – program for housing, ADL/IADL support & stipend for caregivers; Caregiver Homes through Seniorlink (MassHealth) - Structured Family Caregiving model is known as Enhanced Adult Foster Care	x	x	MH clinical eligibility
	Personal Care Attendant program through MassHealth – program for ADL/IADL support certain caregivers can receive pay for care they are provided	x	x	MH clinical eligibility
	Memory Cafes – Provides social engagement opportunities for PLWD and caregivers - PLWD must be accompanied by caregiver	x	x	None
	Social Day and other community programs			None*
	In-home ADL/IADL support		x	None*
	Companion support through Home Care programs		x	None*
	Alzheimer's/Dementia Coaching (Habilitation Therapy)		x	EOEA waiver and non-waiver home care enrollees
	Advanced Cellular Personal Emergency Response Service (mobile PERS)		x	EOEA non-waiver home care enrollees
	ABI/MFP Waiver – in-home supports through MassHealth for acquired brain injury members, supports caregiver		x	MH clinical eligibility
Information & Referral	Options Counseling available to caregivers, families and older adults	x	x	None
	Mass.gov webpage/caregiving – multiple resources listed – MFCGS, DDS, DYS, PCA, NF, etc.	x		None
	Resource Connections (Phone & Website) – MassOptions, Alzheimer's Association, ASAP Info & Referral, Brain Injury Association	x	x	None
Alzheimer's Association	Caregiver support groups	x		None
	Support groups and Alz Meet-ups (social events) for people living with early-stage and early onset dementia		x	None
	Community Resource Finder (by zip code)	x	x	None
	Public events to raise awareness and specialized education programs for PLWD, caregivers and the public	x	x	None
	Peer-to-Peer Companion Program – PLWD in the early stages provide telephone companionship for people recently diagnosed with dementia		x	None

WORKGROUP GOALS

Goal 1
Identify, explore and recommend short-term strategies to support caregivers of individuals who are living with a diagnosis of dementia

Goal 2
Identify approaches to improve awareness of the pathways to available supports and services for dementia caregivers and their care partners.

Caregiver Support and Public Awareness Summary of Recommendations

GOAL 1 - Identify, explore and recommend short-term strategies to support caregivers and PLWD

1.1. Using rapid testing, establish opportunities for PLWD living at home and long-term care facilities to safely gather in-person and indoors with caregivers, families and friends

1.2 Establish a volunteer-driven program that provides respite for dementia caregivers focusing on in-person interactions PLWD

1.3. Provide assistive technology to all ASAPs for distribution to PLWD and their caregivers

1.4 Provide tips on how to prepare for post-diagnosis discussions with support service providers

GOAL 2 - Identify approaches to improve awareness of pathways to available supports and services

2.1. Make and distribute three videos in multiple languages of caregivers talking about the help they got and how they got it

2.2. Place on EOEA's mass.gov website, an overview of statewide services, supports and pathways for PLWD and their caregivers

FROM SECRET SHOPPER EXERCIZE

2.3. Implement changes at ASAPs that ensure that stressed dementia caregivers who call an ASAP are consistently and effectively referred to existing service/support options that may be helpful

2.4. Make changes to ensure that referrals helpful to family caregivers flow between ASAP & Alzheimer's Association and vice versa

2.5. Require that ASAP staff include in their referrals the Massachusetts Family Caregiver Support Program when such a referral would likely be helpful to a dementia caregiver

2.6. Make automated phone messages at ASAPs clear and easy for a dementia caregiver to connect to a person for help

Workgroup Recommendations and Implementation Strategies

GOAL 1
Identify, explore and recommend short-term strategies to support caregivers of individuals who are living with a diagnosis of dementia

Recommendations

1.1. Using rapid testing, establish opportunities for PLWD living at home and long-term care facilities to safely gather in-person and indoors with caregivers, families and friends.

Implementation Strategies

1. Examine the Commonwealth's rapid testing capability and rollout strategy.
2. After examining rapid testing rollout plans and evaluating constraints and risks:

   (a) Develop indoor and in-person opportunities in community settings:
   - Identify safe indoor spaces for PLWD to gather with others such as COA's, town spaces, community centers, etc.
   - Develop rapid testing protocols for PLWD to safely gather with others
   - Identify staff needed to acquire and administer rapid tests at gathering places
   - Identify delivery model (i.e., memory cafes or other) and identify staff needed to develop, manage and oversee activities

   (b) Develop indoor opportunities in long-term care settings:
   - Review the rapid testing protocols around visits currently being developed by EOHHS for long-term care facilities; ensure that they will meet the needs of PLWD and their caregivers.

Workgroup Recommendations and Implementation Strategies

GOAL 1
Identify, explore and recommend short-term strategies to support caregivers of individuals who are living with a diagnosis of dementia

Recommendations

1.2. Establish a volunteer-driven program that provides respite for dementia caregivers focusing on in-person interactions PLWD

Implementation Strategies

1. Conduct an inventory of such programs managed by ASAPs COA's, colleges via a survey and learn from their experience, e.g., pitfalls to avoid and success factors.
2. Identify and develop implementation plan for a program deemed feasible to replicate, adjust, and implement in the short term. Estimate costs and seek and acquire funding.
3. For example, Coastline (ASAP) partnership with Bristol Community College's Occupational Therapy Assistant program:
   - Last fall, students worked with clients by engaging them with recreational pursuits.
   - Students developed a plan for their clients to help them perform these activities.
   - Clients socialized with the students and allowed caregivers temporary respite.
   - Students received dementia training resulting in increased understanding of memory loss and its impact on PLWD and their caregivers.
   - This fall, the program will be relying heavily on video conferencing.

Workgroup Recommendations and Implementation Strategies

GOAL 1
Identify, explore and recommend short-term strategies to support caregivers of individuals who are living with a diagnosis of dementia

Recommendations

1.3. Provide assistive technology to all ASAPs for distribution to PLWD and their caregivers

Implementation Strategies

1. Examine associated costs by viewing data from EOEA's prior federal grant for assistive technology where funds were distributed to ASAPs for their clients:
    - Pre-pandemic, assistive technology was well received. For example, robotic pets helped reduce stress and agitation of PLWD caused by isolation and loneliness.
    - During the pandemic, there is an even greater need for the benefits derived from this type of technology.
2. Determine costs, seek and acquire funding, identify responsible parties, and develop an implementation plan for rapid execution.
3. Distribute funds to all ASAPS for purchasing assistive technology for distribution to their clients.

Workgroup Recommendations and Implementation Strategies

GOAL 1
Identify, explore and recommend short-term strategies to support caregivers of individuals who are living with a diagnosis of dementia

Recommendations

1.4 Ensure that caregivers have easy access to tips on how to prepare for post-diagnosis discussions with support service providers

Implementation Strategies

1. Conduct an inventory of guides and tip sheets that are already available on how to prepare for post-diagnosis discussions with support and service providers. Review these existing resources and identify one or more that would be valuable to share with stakeholders.
    - Refer to the Massachusetts Age- and Dementia Friendly Integration Toolkit, which has relevant examples. Review similar resources from the Alzheimer's Association.
2. Determine how to ensure that stakeholders are aware of these resources and encourage them to disseminate them to caregivers
3. Distribute to key stakeholders (e.g., neurologists, primary care physicians, hospitals, senior centers, ASAPs and other organizations in the state's elder services network)

Workgroup Recommendations and Implementation Strategies

GOAL 2

Identify approaches to improve awareness of the pathways to available supports and services for dementia caregivers and their care partners.

Recommendations

2.1. Make and distribute three videos in multiple languages of caregivers talking about the help they got and how they got it.

Implementation Strategies

1. Estimate costs and seek and acquire funding
2. Identify a person who speaks English as well as either Spanish or Portuguese; or one who speaks all 3 languages to provide an overview of dementia and interview the caregivers.
3. Identify 3 dementia caregivers (1 being a person of color, 1 Spanish speaking and 1 Portuguese speaking) to be interviewed for 10 minutes on video. Caregivers would meet criteria such as:
   - Benefited from supports and services that are available statewide with no or limited eligibility requirements
   - An articulate speaker and willing to be on Cable TV
   - Caring for an older adult
4. Work with caregivers on their responses to interview questions
5. Provide phone numbers and website addresses for MassOptions and Alzheimer's Association on screen at end of each video

Workgroup Recommendations and Implementation Strategies

GOAL 2
Identify approaches to improve awareness of the pathways to available supports and services for dementia caregivers and their care partners.

Recommendations

2.1. Make and distribute three videos in multiple languages of caregivers talking about the help they got and how they got it. (Continued…)

Implementation Strategies (Continued…)

6. Disseminate video to:
   - MassAccess to distribute to all local Cable TV stations
   - Senior centers to put in their websites and newsletters
   - Memory Sunday churches to place in their bulletins
   - EOEA's Mass.gov website

Workgroup Recommendations and Implementation Strategies

GOAL 2
Identify approaches to improve awareness of the pathways to available supports and services for dementia caregivers and their care partners.

Recommendations

2.2. Place on EOEA's mass.gov website, an overview of statewide services, supports and pathways for PLWD and their caregivers

Implementation Strategies

1. Determine which of the currently available information would be most useful.
2. Organize that information into user-friendly format and ensure that eligibility criteria are clear.
3. Link to the town-by-town list of ASAPs and the Alzheimer's Association helpline.
4. Post on EOEA's website landing page under *Dementia Information and Resources*, which currently exists, but does not include this information.

Workgroup Recommendations and Implementation Strategies

GOAL 2
Identify approaches to improve awareness of the pathways to available supports and services for dementia caregivers and their care partners.

“SECRET SHOPPER” EXERCISE

To help identify potential gaps in current pathways, a “secret shopper” exercise was conducted.

Goal of Exercise

Evaluate and compare the experiences of 3 dementia caregivers (aka, “secret shoppers”) who were asked to contact the following organizations to seek help to alleviate stress caused by the isolation and loss of routine due to the pandemic”

- MassOptions
- Local ASAPs
- Alzheimer’s Association

GOAL 2
Identify approaches to improve awareness of the pathways to available supports and services for dementia caregivers and their care partners.

"SECRET SHOPPER" EXERCISE (Continued…)

FINDINGS

1. All three caregivers came away without help.

2. Referrals that may be helpful to family caregivers do not always flow between the ASAP and the Alzheimer's Association and vice versa.

3. ASAPs may not be referring caregivers to their local Massachusetts Family Caregiver Support Program (MFCSP) (available to all caregivers) when it may be helpful.

4. Some ASAPs have automated messages that may be so confusing that stressed caregivers hang up and give up.

Workgroup Recommendations and Implementation Strategies

Goal 2
Identify approaches to improve awareness of the pathways to available supports and services for dementia caregivers and their care partners.

"SECRET SHOPPER" EXERCISE (Continued…)

Recommendations

2.3. Implement changes at ASAPs that ensure that stressed dementia caregivers who call an ASAP are consistently and effectively referred to existing service/support options that may be helpful.

Implementation Strategies

1. Identify 3 more caregivers who are not already "in the system."
2. Conduct another secret shopper exercise and:
   - Provide specific guidance prior to their calls
   - Talk to each caregiver after calls; ask each one the same questions
   - Ensure that the caregivers call all 3 organizations
3. Determine if dementia caregivers are effectively referred to existing helpful service/support options; identify areas for improvement; estimate costs; seek and acquire funding; and develop an implementation plan to make improvements.
4. Establish a means for MassOptions, ASAPs and Alzheimer's Association to follow up on satisfaction of caregivers of PLWD after referring to other organizations. This may require establishment of a ticket system and volunteers. Estimate costs; seek and acquire funding.

Workgroup Recommendations and Implementation Strategies

GOAL 2
Identify approaches to improve awareness of the pathways to available supports and services for dementia caregivers and their care partners.

"SECRET SHOPPER" EXERCISE (Continued…)

Recommendations

2.4. Make changes to ensure that referrals helpful to family caregivers flow between the ASAP and Alzheimer's Association and vice versa.

Implementation Strategies

1. Make it a required standard practice that ASAPS include the Alzheimer's Association's 24/7 Helpline in their referrals to dementia caregivers at first contact by:
   - Informing ASAP Executive Directors of this required standard practice.
   - Identifying staff that caregivers first encounter at each ASAP and include this in their training.
   - Implementing this recommendation as well as monitoring and reporting progress (EOEA) to the Council using data from EOEA's statewide referral database.

Workgroup Recommendations and Implementation Strategies

GOAL 2
Identify approaches to improve awareness of the pathways to available supports and services for dementia caregivers and their care partners.

"SECRET SHOPPER" EXERCISE (Continued…)

Recommendations

2.4. Make changes to ensure that referrals helpful to family caregivers flow between the ASAP and Alzheimer's Association and vice versa. (Continued…)

Implementation Strategies

2. Make it a standard practice that the Alzheimer's Association include the appropriate ASAP in their referrals to dementia caregivers at first contact by:

   - Identifying staff that caregivers first encounter at the Alzheimer's Association and include this in their training. Staff would refer to: https://contactus.800ageinfo.com/FindAgency.aspx to identify the ASAP (aka "regional elder care agency") .

   - Implementing this recommendation as well as monitoring and reporting progress (Alzheimer's Association) to the Council.

Workgroup Recommendations and Implementation Strategies

GOAL 2
Identify approaches to improve awareness of the pathways to available supports and services for dementia caregivers and their care partners.

"SECRET SHOPPER" EXERCISE (Continued…)

Recommendations

2.5. Require that ASAP staff include in their referrals the Massachusetts Family Caregiver Support Program (MFCSP) when such a referral would likely be helpful to a dementia caregiver.

Implementation Strategies

1. Identify the situations where ASAP Information and Referral (I&R) staff refer dementia caregivers to the MFCSP.

2. Determine if referrals to the MFCSP are being made where needed and if not, identify areas for improvement and develop an implementation plan to make those improvements.

3. Ensure that this recommendation be implemented (EOEA) and monitor and report progress to the Council using data from EOEA's statewide referral database.

Workgroup Recommendations and Implementation Strategies

GOAL 2
Identify approaches to improve awareness of the pathways to available supports and services for dementia caregivers and their care partners.

"SECRET SHOPPER" EXERCISE (Continued…)

Recommendations

2.6. Make automated phone messages at ASAPs clear and easy for a dementia caregiver to connect to a person for help.

Implementation Strategies

1. Listen to and evaluate automated phone messages from the perspective of a stressed dementia caregiver.

2. Identify and make changes to ASAP automated messages where necessary and ensure that an option to talk to (or leave a message with) a person is always included.

Summary of Recommendations and Discussion with Council

GOAL 1 - Identify, explore and recommend short-term strategies to support caregivers and PLWD

1.1. Using rapid testing, establish opportunities for PLWD living at home and long-term care facilities to safely gather in-person and indoors with caregivers, families and friends

1.2 Establish a volunteer-driven program that provides respite for dementia caregivers focusing on in-person interactions PLWD

1.3. Provide assistive technology to all ASAPs for distribution to PLWD and their caregivers

1.4 Provide tips on how to prepare for post-diagnosis discussions with support service providers

GOAL 2 - Identify approaches to improve awareness of pathways to available supports and services

2.1. Make and distribute three videos in multiple languages of caregivers talking about the help they got and how they got it

2.2. Place on EOEA's mass.gov website, an overview of statewide services, supports and pathways for PLWD and their caregivers

FROM SECRET SHOPPER EXERCIZE

2.3. Implement changes at ASAPs that ensure that stressed dementia caregivers who call an ASAP are consistently and effectively referred to existing service/support options that may be helpful

2.4. Make changes to ensure that referrals helpful to family caregivers flow between ASAP & Alzheimer's Association and vice versa

2.5. Require that ASAP staff include in their referrals the Massachusetts Family Caregiver Support Program when such a referral would likely be helpful to a dementia caregiver

2.6. Make automated phone messages at ASAPs clear and easy for a dementia caregiver to connect to a person for help

Next Steps

Next Council Meetings (to be scheduled)

December 1, 2020
3:00 - 5:00 pm

February 9, 2021
3:00 - 5:00 pm

In the meantime, please direct any questions and materials to:

Pam MacLeod – pam.macleod@mass.gov