### **Alzheimer's Advisory Council**



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

August 25, 2020 3:00-5:00 pm Video Conference





- 1. Welcome, Meeting Logistics and Introductions (15 min)
- 2. How the Pandemic Affects the Council's Work (60 min)
- 3. MA BOLD Infrastructure Initiative (25 min)
  - Presentation (10 min)
  - Discussion (15 min)
- 4. Status Update on Chapter 220 of the Acts of 2018 (10 min)
  - Presentation (5 min)
  - Discussion (5 min)
- 5. Revised Timeline for Council and Workgroups (5 min)
- 6. Next Steps (5 min)



#### **How the Pandemic Affects the Council's Work**



#### **Assumption**

#### Continued social distancing for another 12-24 months

Isolation

➤ How has this period of isolation affected individuals and families living with early, mid, and late-stage ADRD?

# Shifting Perspectives

➤ How has your perspective shifted around the issues this Council had planned to address?

## Additional Supports

➤ What additional supports are needed during the pandemic?

#### Workgroups

- 1. Equitable Access & Care
- 2. Quality of Care
- 3. Public Awareness
- 4. Caregiver Support
- 5. Diagnosis & Services Navigation
- 6. Physical Infrastructure
- 7. Research



#### Massachusetts Department of Public Health

# MA BOLD INFRASTRUCTURE INITIATIVE PROPOSAL

Alzheimer's Advisory Council Meeting August 25th, 2020

Ben Wood, MPH
Director, Division of Community Health Planning and Engagement

### **BOLD Infrastructure for Alzheimer's Act**

- Passed into law on December 31, 2018 the Act directs the CDC to:
  - Establish Alzheimer's and Related Dementias Public Health Centers of Excellence
  - Increase Data Analysis and Timely Reporting
  - Provide Funds to Support Public Health Departments
    - CDC-RFA-DP20-2004
      - MA Core BOLD Initiative (application submitted 5/21/20)
      - Promote use of the Healthy Brain Initiative's State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map

### **MA Core BOLD Initiative Overview**

Thank you EOEA and Alzheimer's Association MA/NH Chapter

- Core Funding Track (Enhanced Funding Track required having a completed State ADRD Plan)
  - Planning grant
  - Focused on integrating actions from the Road Map (RM) in the development and then implementation of a State ADRD Plan: ensuring a public health approach is embedded
  - Given progress in the development of State ADRD Plan, significant work will be required in first year then moving to capacity building efforts to implement the RM actions

### **MA Core BOLD Initiative Strategies**

#### Three Strategies

- 1. Support increased communication across the state related to the primary, secondary and tertiary prevention of dementia
- 2. Create the Massachusetts Integrated ADRD State Plan using the RM Series actions, public health approaches, and a leading with race framework (grant requires inclusion of 4 RM actions)
- 3. Analyze and use available data, including BRFSS, and the RM series to set jurisdiction-wide priorities

### MA Core BOLD Initiative Approach & Priorities

#### **Approach**

- Develop/Convene a Public Health Working Group attached to the Alzheimer's Advisory Council
- Review/Discuss RM actions, engage stakeholders, review data and information
- Feed recommendations to Alzheimer's Advisory Council to inform State ADRD Plan, evaluate process
- Staffing (new hires): 1FTE Healthy Aging Specialist, .5FTE Epidemiologist

#### **Priorities**

- Focus on Equity and Leading with Race and Racism approach
- Focus on community engagement
- Focus on prevention (MDPH/BCHAP expertise in primary prevention)

Massachusetts Department of Public Health mass.gov/dph 8

### MA Core BOLD Initiative BRFSS Objectives

- Alzheimer's Advisory Council priorities to better address ADRD Caregiver needs and experiences and issues around dementia diagnoses led to:
- Agreement to include the Caregiver module in CY21 BRFSS and then include the Cognitive Decline module later (with plans to include each of these modules every four years)
  - Caregiver Module will be included in CY21 regardless of MA Core BOLD Initiative Grant
  - Caregiver module FAQs: <u>https://www.cdc.gov/aging/healthybrain/brfss-faq-caregiver.htm</u>
  - Cognitive Decline module FAQs: <u>https://www.cdc.gov/aging/healthybrain/brfss-faq-cognitive.htm</u>

### Caregiver and Cognitive Decline Domains

### Caregiver module example domains

- % of adults who self-report as being a caregiver
- If the care recipient has dementia
- Relationship between caregiver and care recipient
- If caregiver assists with household tasks or personal tasks
- Average weekly hours of caregiving
- Length of time as a caregiver
- % of adults who are not caregivers, but expect to be in the next 2 years

### Cognitive Decline module example domains

- % of adults aged 45 years or older who experience:
  - subjective cognitive decline (SCD)
  - difficulties with daily activities due to SCD
- Health conditions and behaviors of adults aged 45 years or older experiencing SCD
- % of adults aged 45 years or older who experience SCD and live alone
- Reported need for assistance with activities due to SCD and whether individuals receive the help they need



### Massachusetts Department of Public Health

### **Thank You!**

Ben Wood ben.wood@mass.gov





# 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

August 25th, 2020

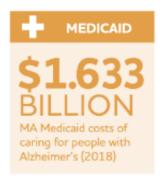




### Top Issues Facing the Commonwealth that Led to Legislative Action

- 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.













Americans are living with MILLION Alzheimer's **BY 2050**, this number is projected to rise to nearly MILLION





The Top Line



\$290 BILLION IN COSTS to care for people with Alzheimer's \$195 billion to Medicare and Medicaid 1 in every 5 Medicare dollars





### 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.







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



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

By Felice J. Frager State State, Aug. of Jr. 2018, 1937 p.m.





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Real Possibilities







#### 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.





### 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).





- 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)
  - Current MA CME Offerings
    - Mass Medical Society <a href="http://www.massmed.org/ALZ/">http://www.massmed.org/ALZ/</a>
      - 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: <a href="https://mhalink.thinkific.com/courses/alzheimer-s-and-related-dementias">https://mhalink.thinkific.com/courses/alzheimer-s-and-related-dementias</a>
    - 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

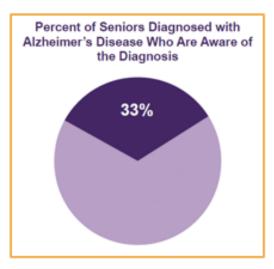


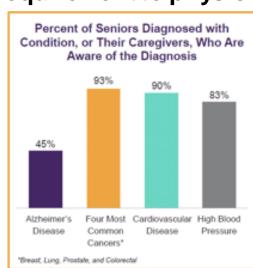


- 3. Requires doctors to share an Alzheimer's diagnosis and treatment plan to a family member or legal personal representative within the existing framework of federal and state privacy laws.
  - There is no penalty for a physician who does not comply with this requirement but the spirit of this component 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.









- 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 an action plan document including tools and resources. <u>Report</u> published in 2018.
  - Compliance is due October 1, 2021

\*Operational plans would be invaluable during pandemic protocol, however, much of the work was tabled because of COVID-19





### 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 EPS 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 PS workers has averaged about 5%
  - New workers take the online training within their first month



#### Alzheimer's Advisory Council Meetings Structure and Schedule



#### General structure of each meeting

- Workgroup leads update Council on progress and recommendations
- Council discusses, asks questions, gives feedback

**Council Meeting Timeline as of February 2020** 



#### COVID-19 outbreak caused a 4-month delay after February meeting

**Revised Council Meeting Timeline as of August 2020** 



To allow time to form & convene workgroups and report findings, we are proposing:

- an additional meeting in December 2020; and
- changing our January 2021 meeting to February 2021



### **Workgroup Schedule**



	Calendar Year 2020					2021			
WORKGROUPS	JUN	JUL	AUG	SEP	ОСТ	NOV	DEC	JAN	FEB
D. Caregiver Support, Education, and Respite									
F. Physical Infrastructure									
G. Research (to be scheduled)									
B. Quality of Care									
C. Public Awareness									
A. Equitable Access (to be scheduled)									
E. Diagnosis & Services Navigation									
Report & State Plan (Due on 3/1/21)									

#### **Council Meeting Dates**

- 1. August 25, 2020 (scheduled)
- 2. October 27, 2020 (scheduled)
- 3. December 1, 2020 (new)
- 4. February 9, 2021 (new)

LEGEND									
	Workgroup Meetings								
	(no more than 2 meetings in 2020)								
	Present to Council								





#### **Next Council Meeting**

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

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

Pam MacLeod – pam.macleod@mass.gov