Alzheimer's Advisory Council

Executive Office of Elder Affairs
Elizabeth Chen, Secretary

September 1, 2021
3:00-5:00 pm
Video Conference

Agenda

1. **Welcome, Meeting Logistics, Introductions (10 min)**

2. **Diagnosis & Services Navigation Workstream (50 min)**

   a) Diagnosis Implementation Team (25 min)

   b) Services Navigation Implementation Team (25 min)

3. **Council Member Roundtable: Updates & Discussion (35 min)**

4. **Closing Remarks and Final Roll Call (10 min)**

Alzheimer's Advisory Council
Moving from Planning to Action, 2021

Workstream: Diagnosis & Services Navigation

Implementation of Recommendations - Status and Discussion

September 1, 2021

Workstream Leads
Representative Tricia Farley-Bouvier
James Wessler

Implementation Team Members

Representative Tricia Farley-Bouvier (Workstream Co-lead)
Council Member

James Wessler (Workstream Co-lead)
Council Member
Chief Executive Officer, Alzheimer's Association,
MA/NH Chapter
and New England Regional Leader

Kathryn C. Burns, MHA
Chief Executive Officer
Greater Lynn Senior Services, Inc.

Hollis D. Day, MD, MS
Chief of Geriatric Medicine, Boston Medical Center and Associate Professor of Medicine, Boston University School of Medicine

James Lavery
Council Member
Director, Bureau of Health Professions Licensure
Massachusetts Department of Public Health

Liz McCarthy
Health Systems Director
Alzheimer's Association, New England Region

Ellen M McDonough
Former Director of Clinical Services
Elder Services of Cape Cod & the Islands

Nicole McGurin, MS, CDP
Family Services Director
Alzheimer's Association, MA/NH Chapter

Molly Purdue, PhD
Executive Director
Cape Cod Alzheimer's Family Support Center

Caitlin Roy
Options Counselor
Aging Services of North Central Massachusetts

Rebecca Starr, MD, AGSF
Medical Director, Geriatrics
Cooley Dickinson HealthCare

Karyn B. Wylie, MS, LSW
MA Aging & Disability Resource Consortia (ADRC) Coordinator
MA Executive Office of Elder Affairs

Hagen Yang, MD
Neurologist
Atrius Health
Braintree - Harvard Vanguard

Diagnosis and Services Navigation

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

Recommendation #1 (Diagnosis)

Significantly increase the numbers of undiagnosed or cognitively impaired residents who are diagnosed with dementia and informed of their diagnosis

Recommendation #2 (Services Navigation)

Ensure that after a dementia diagnosis, individuals and their families have access to comprehensive information and care planning services

Recommendation #1 (Diagnosis)

Team Lead: James Wessler

Significantly increase the numbers of undiagnosed or cognitively impaired residents who are diagnosed with dementia and informed of their diagnosis

Clinician Toolkit

- Available online
- Full complement of resources

Disclosure to Caregiver(s)

- Increase awareness of mandate

Practice Change in Primary Care

- Pilot implementation
- Measurement and evaluation

Diagnosis Implementation Status

Updates & Accomplishments

Clinician Toolkit: reviewed existing resources, including assessment tools for low-literacy/IDD populations

Identified pilot in primary care as best method to evaluate practice change

Collaborated with DPH to inform Health Systems of ACOP deadline extension to 10/1/2022

Next Steps

Identify & recruit PCP practice(s) to implement change in diagnostic process

Develop Clinician Toolkit, possibly collaborating with MHA for distribution

Work with BORIM to drive adoption of diagnosis/treatment plan disclosure requirement

Challenges

- Engaging BORIM
- Engaging MHA
- Pilot site recruitment

Solutions

- Initial meeting held with MHA
- Identified existing template for pilot recruitment
- Continue to seek engagement with BORIM

Questions

- Are there examples of successful practice changes? How were those successes achieved?

- How can we measure adherence with diagnosis/treatment plan disclosure?

Advice

- With which organizations/stakeholders should we collaborate to distribute Clinical Toolkit?

- What resonates with Primary Care to change practice?
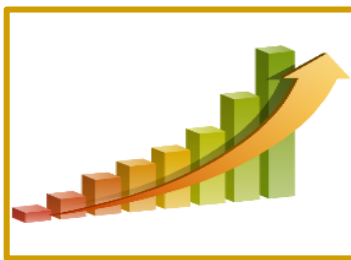
Recommendation #2 (Services Navigation)

Team Lead: Representative Tricia Farley-Bouvier

Ensure that after a dementia diagnosis, individuals and their families have access to comprehensive information and care planning services

I. Road Map

II. Dementia Care Coordination Program Expansion

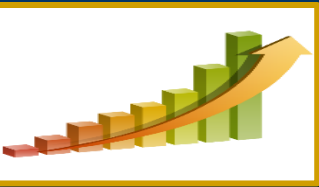**III. PCP Interactions with Unsupported Individuals**
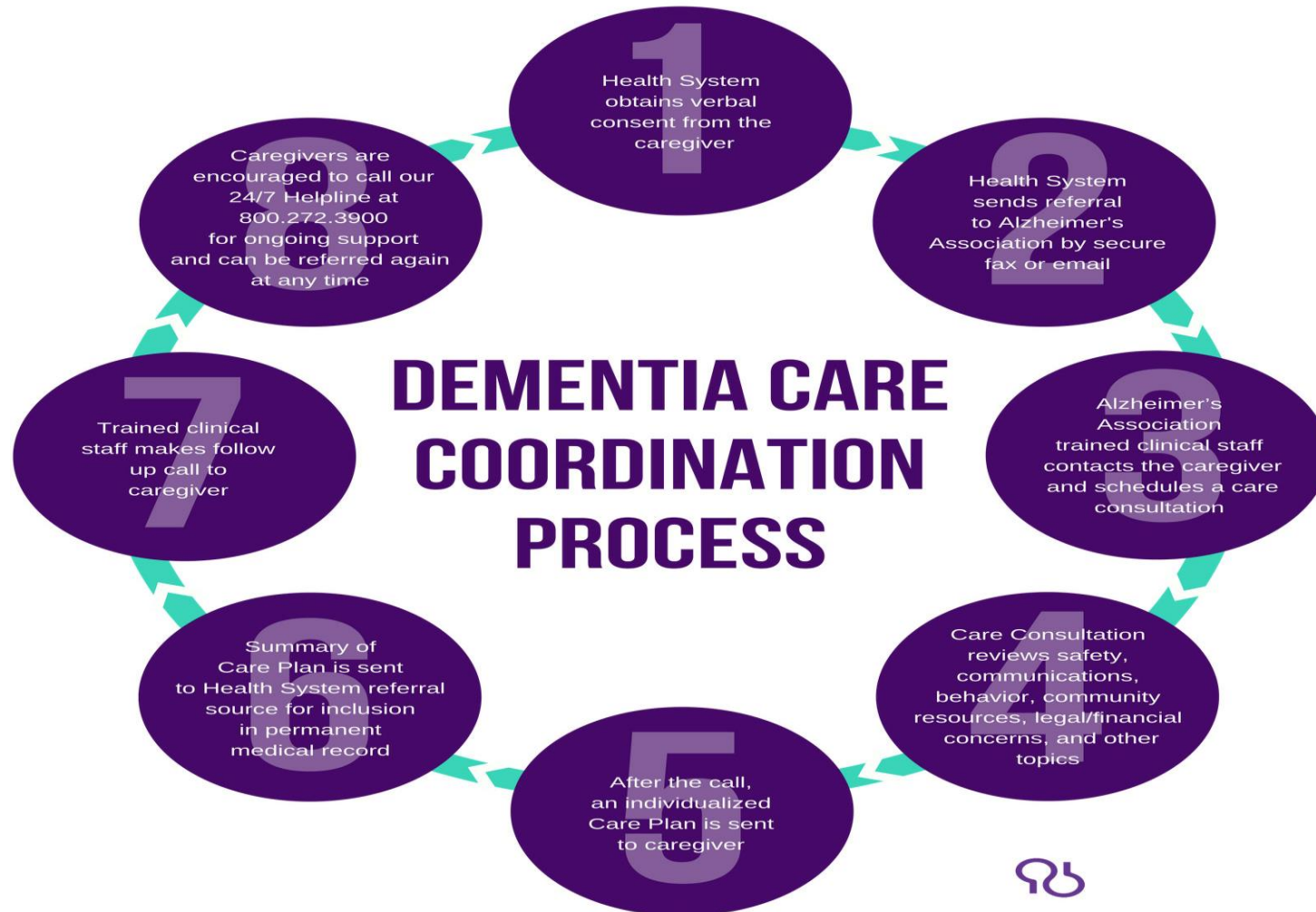
I. Road Map

Updates and Accomplishments

- Identified two-page document entitled, "**Next Steps After an Alzheimer's Diagnosis**" from the National Institute on Aging (NIA) of the National Institutes of Health (NIH)
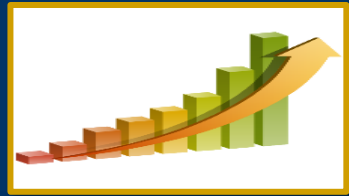
Next Steps

- Interview PCPs to determine the most helpful information in a road map

- Determine how to best make the "Next Steps" document available to PCPs

- Determine how to integrate local resources

- Explore placing dementia information and links on electronic medical records (EMRs)

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DEMENTIA CARE COORDINATION PROCESS

1. Health System obtains verbal consent from the caregiver

2. Health System sends referral to Alzheimer's Association by secure fax or email

3. Alzheimer's Association trained clinical staff contacts the caregiver and schedules a care consultation

4. Care Consultation reviews safety, communications, behavior, community resources, legal/financial concerns, and other topics

5. After the call, an individualized Care Plan is sent to caregiver

6. Summary of Care Plan is sent to Health System referral source for inclusion in permanent medical record

7. Trained clinical staff makes follow up call to caregiver

8. Caregivers are encouraged to call our 24/7 Helpline at 800.272.3900 for ongoing support and can be referred again at any time

II. Dementia Care Coordination Program Expansion

Updates and Accomplishments

- 23 referring partners

- 1,739 referrals in FY 2021; more than 12,000 referrals since the start of the program in 2014

- Final year of 4-year program evaluation providing outcomes for providers and caregivers and recommendations for program improvement

Next Steps

- Expand funding to increase capacity of the program

- Add new referring partners with focus on underserved populations

- Implement program improvements from the evaluation

Challenges

- Being able to engage with PCPs because of their tight schedules

- Balancing the need for information about local resources with information from statewide and national organizations

- Having printed information for PCPs that will be changing

- Time constraints delayed work on our third recommendation - to identify best practices in addressing the needs of unaccompanied or unsupported individuals diagnosed with dementia

Solutions/Potential Strategies

- Team members will have individual conversations with PCPs

- Direct people to Alzheimer's Association and MassOptions

- Create a digital version of "next steps after diagnosis" document with links to local resources

Questions

1. How can we best reach PCPs?

2. Do you know of any best practices or guidance for providers around addressing the needs of unaccompanied and/or unsupported individuals diagnosed with dementia?

Updates & Discussion

1. **Quality of Care** (M. Brennan & L. Pellegrini)

2. **Caregiver Support & Public Awareness** (B. Meehan & H. Montesino)

3. **Physical Infrastructure** (E. Chen)

4. **Research** (E. Chen for A. Budson in absentia)

5. **Public Health Infrastructure** (J. Dave and J. Lavery)

6. **Equitable Access & Care Workstream: Equity & Inclusion Consultancy** (E. Chen for J. Jackson in absentia)

Next Council Meeting – December 7, 2021, 3:00 to 5:00 pm

1. Presentation and Discussion on the Physical Infrastructure Workstream

2. Council Member Roundtable: Updates & Discussion