



Executive Office  
Of Elder Affairs



## DEMENTIA FRIENDLY MASSACHUSETTS INITIATIVE

*May 9, 2016 Leadership Summit – Summary Report*

On May 9, 2016, leaders from 84 organizations and companies from across Massachusetts met at Tufts Health Plan Foundation in Watertown to share ideas and learn from national leaders about pathways by which Massachusetts communities can become more “dementia friendly.” Key to this effort is recognizing and building upon work that is already underway, both existing dementia friendly initiatives and complementary work such as age-friendly initiatives. This report summarizes the key learnings from the May 9 Summit, and next steps for moving this coordinated statewide effort forward.

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## CONTEXT

The number of people affected by Alzheimer's and related disorders is staggering. An estimated one in eight individuals age 65 or older has a diagnosable condition causing the symptoms of dementia. Thousands of Massachusetts residents under age 65 also live with dementia. Around each of these individuals is a circle of people – family members, friends, coworkers, neighbors – who are also affected. The cost of care due to dementia outstrips that of cancer and heart disease. As our society ages, these numbers will all continue to grow.

Numbers tell only part of the story. Each person living with dementia has his or her own culture, circumstances, and personal story. Symptoms that are now woven into daily life range from mild to life-limiting, and they change over time. As difficult as these symptoms can be, stigma, and lack of public awareness makes living with dementia much harder. Stigma and lack of awareness close off doors to community participation that could otherwise stay open. Stigma and lack of awareness end friendships. Stigma and lack of awareness isolate care partners as well as those living with dementia, so that loneliness and lack of meaningful activity become added burdens.

The scale of the problem is daunting. Yet, Dr. David Green, Board Member of Tufts Health Plan Foundation, opened the May 9<sup>th</sup> Summit by noting that “we come here with great hope.” This is because in Massachusetts and many other parts of the US and the world, the realization is growing that we can and must act together as communities to reopen doors that have been shut. Olivia Mastry, lead organizer of Dementia Friendly America and guest speaker at the Summit, emphasizes that much of the work ahead lies in identifying what she calls “cognitive ramps.” These are modifications that enable inclusion of those living with dementia and their care partners, much in the way that curb cuts, ramps and other physical modifications have enabled inclusion of individuals living with physical disabilities. As the disability rights movement and the growing age-friendly movement have shown, these modifications tend to produce a spillover benefit to community members of various ages and life circumstances.

While researchers make strides in seeking a cure for Alzheimer's and other conditions that cause dementia, living fully with these conditions is a compatible goal, and one that communities can pursue now. What does living fully with dementia look like? Sandy Halperin, a retired Florida professor of dentistry who became an advocate after he was diagnosed with younger onset Alzheimer's, put it in 139 characters, Twitter-style:

“Maintaining a fulfilling lifestyle under prevailing emotional and physical circumstances, being engaged in what gives me joy as I live in the gift of the present.”

Communities can help make a full life with dementia possible; national and international pioneers have demonstrated this. When communities remove needless barriers and provide supports to help those living with dementia to live out their lives fully, we all benefit – those currently living with dementia, and also spouses, children, grandchildren, neighbors, tax payers, businesses and service providers, and the many of us who will one day develop dementia or love someone who has.

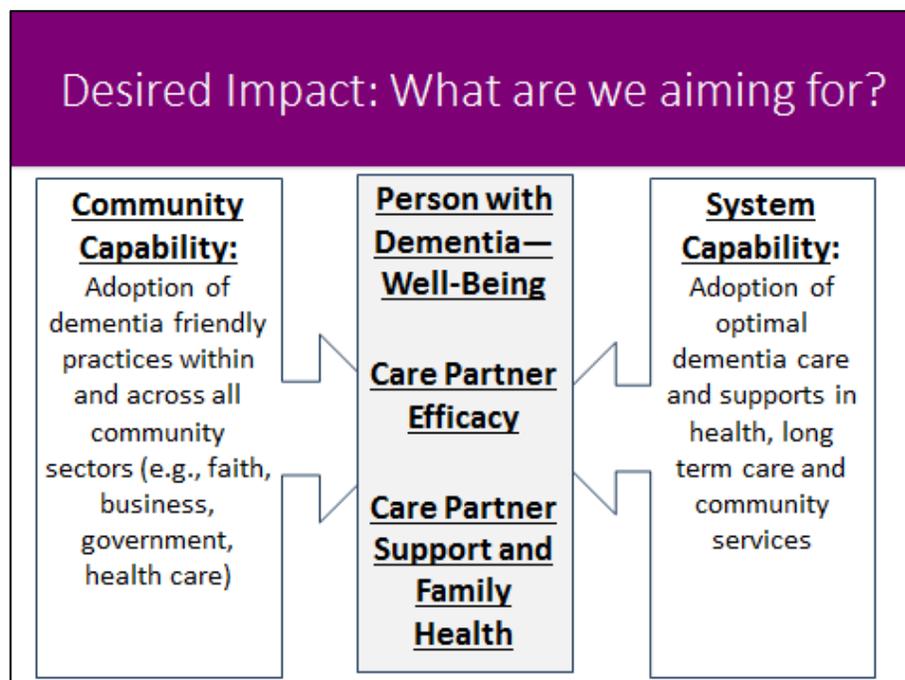
## KEY LEARNINGS FROM THE MAY 9<sup>TH</sup> SUMMIT

### Lessons from Minnesota

- The ACT on Alzheimer’s coalition of Minnesota was created by the team that developed the Minnesota State Alzheimer’s Plan. All states have Alzheimer’s Plans but few have been implemented.
- One of ACT on Alzheimer’s unique contributions is the development of an easy-to-use toolkit for geographic or cultural communities that want to implement dementia friendly initiatives. See either <http://www.actonalz.org/dementia-friendly-toolkit> or <http://www.dfamerica.org/toolkit-1/>
- The toolkit is structured *and* flexible. It breaks down tasks and provides tools; however, communities can start at different points, and adapt the tools as needed. One size does not fit all.
- The early steps of bringing key people to the table and analyzing current community strengths and gaps build a foundation for implementing meaningful dementia friendly initiatives with wide community support.
- Health equity has required a specific focus to ensure that the benefits of dementia friendly work reach communities experiencing greater stress or with fewer resources. See <http://www.actonalz.org/health-equity>
- For examples of what 43 Minnesota communities have already accomplished, click on “view a community directory” at <http://www.actonalz.org/action-communities>

### We are part of a nationwide movement guided by Dementia Friendly America

- Dementia Friendly America is replicating ACT on Alzheimer’s work nationwide. See [www.dfamerica.org](http://www.dfamerica.org)
- Dementia Friendly America’s nationwide goals are summarized here:





- Dementia friendly community work is underway in other parts of the state, including Westfield, South Hadley and Holyoke, and Cape Cod.
- Many Massachusetts communities are also engaged in the age-friendly movement, which brings together community members from many sectors to work for changes that benefit older adults along with people of all ages. Dementia friendly efforts should collaborate with age-friendly efforts wherever possible.

### The Dementia Friendly Massachusetts Initiative aims for efficiency, inclusion and scale

- **Summit attendees emphasized that they want to have a way to find out about work already being done, and to learn from others.** See Next Steps for plans to address this need.
- A statewide, coordinated approach to dementia friendly work aims to celebrate and encourage work already being done and to support action where it is needed. This includes not only initiatives that are explicitly focused on dementia, but also age-friendly initiatives, to which a dementia-friendly component can often be added, in order to leverage the wisdom and resources of existing multi-sector coalitions.
- The statewide effort will also reach out to communities where the need is significant but resources may be needed to take action.

### Professional associations and sector champions have a powerful role to play

- Not only geographic and cultural communities but also sectors can make a big difference.
- Professional associations can make a commitment to educate their membership.
- Entities such as supermarket chains, commercial banks, religious denominations and others that cross community boundaries can reach thousands by implementing dementia friendly initiatives. There is an opportunity for those who step up first to become “sector champions,” helping others in their sector to learn from their example.

### Language matters

- Like any learning process, the process of becoming more dementia friendly doesn’t have an endpoint. We can say that communities are “moving toward” becoming dementia friendly, but no community will ever be “certified” dementia friendly.
- Language can empower or add to stigma. For example, saying that someone is “living with dementia” emphasizes the person rather than the disease, whereas saying that someone “suffering from dementia” portrays them as a victim of the disease. Similarly, calling someone a “patient” when they are not in a medical setting makes it seem as if their life includes nothing but the disease.
- Alzheimer’s is the most common cause of dementia, but there are many other conditions that cause it as well. Each has its own trajectory and hallmark symptoms. It is important to use the terms “Alzheimer’s” or “Alzheimer’s and related disorders” or “dementia” appropriately, and not to use “Alzheimer’s” as a catch-all.
- Dementia is not the same as aging. Not all older adults have dementia, and many people with dementia are not older adults.

### One size does not fit all

- A repeated theme at the Summit was that geographic and cultural communities, and professional groups need to develop an approach to dementia friendly work that makes sense for their own culture, language, and particular assets and challenges.
- Leadership from within each community knows best how to do this; an approach shouldn't be imposed from outside.
- We can share what we learn with each other while respecting that each initiative will be unique in many ways.

### Sustainability

- Minnesota's experience has been that dementia friendly work helps to broadly reduce stigma and increase awareness. Dementia friendly philosophies then become embedded in organizational policies and culture. Therefore, once changes take place, they are often self-sustaining.
- To achieve real, lasting change, it is important to start with a broad, representative action team, and to take the time to learn together about strengths and gaps, so that there is strong support for the approaches that are implemented.

## NEXT STEPS FOR THE DEMENTIA FRIENDLY MASSACHUSETTS INITIATIVE

With support from Tufts Health Plan Foundation, JF&CS project managers Emily Kearns and Beth Soltzberg will work with representatives from many key organizations and businesses to take following steps during the remainder of 2016:

1. Reinforce and broaden the conversation about dementia friendly communities
  - a. Please share this report widely, along with resources such as the Dementia Friendly America sector guides.
  - b. JF&CS is planning a webinar this summer to share key themes from the Summit and how communities and sectors can get involved. Information to follow.
  - c. We will develop a plan for “learning communities.” These will be groups of people engaged in related dementia friendly initiatives who can share their ongoing work periodically via conference call or another convenient means of communication.
  - d. At every step, we will seek out existing dementia friendly and age-friendly activities and resources in order to avoid “reinventing the wheel,” and rather to honor the wisdom of those engaged in this process and to build upon it.
  
2. Link and support current and potential action partners
  - a. A research team at the University of Massachusetts Boston is working on an environmental scan with support from Tufts Health Plan Foundation. The environmental scan will identify and create an inventory of dementia friendly and age-friendly activities and assets throughout Massachusetts.
  - b. Those seeking information about other initiatives should contact Emily Kearns or Beth Soltzberg (see contact information below).
  
3. Collaboratively develop grant proposals for key initiatives requiring resources

During 2016, plans will be developed and funding sought for an ongoing coordinating structure to support dementia friendly initiatives across Massachusetts for the next several years.

## CONTACT INFORMATION

Dementia Friendly Massachusetts Initiative project managers:

Beth Soltzberg, MSW, MBA  
[bsoltzberg@jfcsboston.org](mailto:bsoltzberg@jfcsboston.org)  
781-693-5628

Emily Kearns, PhD, MBA  
[ekearns@jfcsboston.org](mailto:ekearns@jfcsboston.org)  
978-604-0830

JF&CS  
1430 Main Street  
Waltham, Massachusetts 02451  
[www.jfcsboston.org](http://www.jfcsboston.org)

## THANK YOU

To Tufts Health Plan Foundation for supporting and hosting the Dementia Friendly Massachusetts Leadership Summit, and for supporting ongoing planning work throughout 2016.

### To Summit Co-conveners

- Massachusetts Executive Office of Elder Affairs
- Jewish Family & Children's Service (JF&CS)

### To Summit Co-sponsors

- AARP
- Age-Friendly Boston
- Alzheimer's Association Massachusetts/New Hampshire Chapter
- BayPath Dementia-Friendly Hudson/Northborough/Marlborough
- Healthcentric Advisors
- Massachusetts Association of Councils on Aging
- Massachusetts Healthy Aging Collaborative
- Mayor's Alzheimer's Initiative, Boston
- Multicultural Coalition on Aging
- Tufts Health Plan Foundation

### To those who spoke at the Summit

- Christine Alessandro, MEd, MS, Executive Director, BayPath Elder Services
- Mike Belleville, Member, Alzheimer's Association Massachusetts New/Hampshire Chapter Board of Directors
- Alice Bonner, PhD, RN, FAAN, Secretary of the Executive Office of Elder Affairs
- Andrea Burns, Director, Age-Friendly Boston
- David S. Green, MD, Practicing physician and Member, Tufts Health Plan Foundation Board of Directors
- Erin Long, MSW, Aging Services Program Specialist, US Administration for Community Living
- Olivia Mastry, JD, MPH, Lead, Dementia Friendly America
- Patricia McCormack, Director, Mayor's Alzheimer's Initiative, Boston
- Beth Soltzberg, MSW, MBA, Manager, Alzheimer's/Related Disorders Family Support Program, JF&CS

To everyone who traveled to attend the Summit, and devoted a day to exploring how our communities can better include and support those living with dementia and their care partners.

Olivia Mastry closed the Summit with the words of the thirteenth century Persian poet, Jalāl ad-Dīn Muhammad Rumi: "We are all walking each other home."

## APPENDIX A

The following is a list of ideas that were suggested during Summit group discussions and brainstorming, or written on the “Moving Forward Together” forms collected at the Summit.

### **What are the most important next steps we can take across Massachusetts?**

- Break down fear/stigma through education, training, and dialogue about serving needs through dementia friendly initiatives
- Learn lessons from how the opioid crisis is being addressed
- Speak up and tell elected officials what we want. Begin to ask for federal, state and individual help/support (e.g. Beacon Hill)
- Hold “mini-summits” throughout state
- Leverage linkages from various advocacy organizations/associations that can share info, etc.
- Integrate health and human services; get out of silos
- Engage all people, families and communities: through broadening age- and dementia-friendly campaign
- Engage largest employers (especially customer service oriented) on how to better serve people living with dementia, and their care partners (e.g. Market Basket)
- Cultivate “first movers” in each sector. They can have the PR benefit of being “first,” and then can be role models for their peers.
- Emphasize multigenerational aspects of this movement in practices and policies
- Alzheimer’s and related disorders: “Name it, claim it, stop it” (thru research for a cure)
- Move to foster earlier diagnosis (see brainhealth.org)
- Environmental scan and inventory: What work is already underway in our state, and how we can share best practices?
- Creating more age-related priorities (e.g. through Mass Municipal Association)
- Bank Reporting Project – get this updated and deployed on more widespread basis
- Address wandering through more robust collaboration (e.g., Silver Alert, North Star). Align with dementia friendly emergency planning. Share info and coordinate efforts. State first responder curriculum is already developed and needs to be utilized.
- Leveraging the Dementia Friendly America community toolkit to activate community action (senior living community champions)
- Awareness and dissemination of activities, via local cable TV, social media, daily newspapers
- Emphasizing the far reach of dementia: engaging the wide circle of those surrounding each person living with dementia (family, friends, colleagues, employers, faith community, etc)
- Look to local communities to learn how best to move forward in that particular community to foster dementia friendliness. Understand culture, language, community assets, etc

- Identify what already exists to spread current assets, such as the New England Quality Innovation Network Quality Improvement (QIN-QIO) program
- Infrastructure to build support and momentum: leverage Mass Healthy Aging Collaborative, Councils on Aging, Area Agencies on Aging, Aging Services Access Points, senior centers, elder employment resources, which could conduct dementia friendly trainings (e.g., the ReServe, RSVP programs)
- Emphasize proper and respectful language/vocabulary: “living with dementia.” Make sure to speak of Alzheimer’s AND related disorders, not just use “Alzheimer’s” as a catch-all.
- Raise up personal stories to initiate conversations
- Pilot this work in a community that’s already undertaking an age-friendly effort
- Bank Reporting Project – get updated and deployed on more widespread basis
- Criss-cross the state through the Executive Office of Elder Affairs to support community change efforts
- Synthesize what’s been learned thus far (including output from today)
- Broaden the diversity of perspective and voice to shape and inform our collective work
- Position for collective funding opportunities (by year-end) that can scale all that communities are trying to accomplish
- Build a coalition that creates a no-wrong-door web of support – leverage those in the room today as peer champions
- Take on personal action in addition to our collective work – spread the word, initiate new dialogue/conversations
- No need to wait - - begin to share resources that you learned about today, e.g. the sector guides at <http://www.dfamerica.org/sector-guides-1/>

#### **What are ideas that you could pursue in your sector or community?**

- Educate pastor/visitors and faith community nurses
- Share info via North American Indian Center of Boston; start memory café for Native American community; educate youth to respect and understand elders’ needs
- Work via Elder Abuse Prevention Task Force (e.g., in Arlington)
- Expand NYU enhanced caregiver support model already being implemented in Cape Cod
- Share [www.alzheimersfriendlybusiness.com](http://www.alzheimersfriendlybusiness.com), an online training from Home Instead
- Incorporate dementia friendly into Age-Friendly initiatives (e.g., in Newton)
- Hold an early stage focus group, then a “dementia round table” – a community conversation
- Purple Angel business campaign
- Add dementia friendly info to police trainings
- Share materials with home care agencies through a professional association
- Introduce these ideas to students from grade school to doctoral

## APPENDIX B

The following is a list of businesses and organizations that participated in the Dementia Friendly Massachusetts Summit on May 9, 2016.

- AARP
- African Americans Against Alzheimer's (a network of UsAgainstAlzheimer's)
- Age-Friendly Boston
- Alzheimer's Association Massachusetts/New Hampshire Chapter
- Alzheimer's Family Support Center of Cape Cod
- Archdiocese of Boston
- BayPath Dementia-Friendly Hudson/Northborough/Marlborough
- BayPath Elder Services, Inc
- Blue Cross Blue Shield of Massachusetts
- Boston Commission on Affairs of the Elderly
- Boston EMS
- Center for Community Health Education Research and Service, Inc.
- Central Boston Elder Services
- Collective Action Lab, Minnesota
- Combined Jewish Philanthropies
- Connected Living, Inc.
- Cure Alzheimer's Fund
- Dementia Friendly America
- Departments of Critical Care Medicine and Pulmonary Medicine, Emerson Hospital
- Elder Services of Berkshires County
- FallonHealth
- FriendshipWorks
- Full Frame Initiative
- Goddard House Elder Care
- Greater Boston Chinese Golden Age Center
- Greater Boston Legal Services, Inc.
- Greater Springfield Senior Services
- Healthcentric Advisors
- Hebrew SeniorLife
- Home Care Aide Council
- Home Instead Senior Care
- Hope Dementia & Alzheimer's Services
- I'm Still Here Foundation/ARTZ
- Indian Affairs, Commonwealth of Massachusetts
- Jewish Community Housing for the Elderly
- Jewish Family & Children's Service
- John Hancock Long Term Care Insurance
- Latino Health Insurance Program, Inc.
- Lawrence Council on Aging/Senior Center
- Loomis Communities, South Hadley
- Masjid al-Qur'aan
- Massachusetts Association of Councils on Aging
- Massachusetts Commission for the Deaf and Hard of Hearing
- Massachusetts Department of Developmental Services
- Massachusetts Department of Mental Health
- Massachusetts Department of Public Health
- Massachusetts Executive Office of Elder Affairs

- Massachusetts General Hospital  
Alzheimer's Disease Research Center
- Massachusetts Hospital Association
- Massachusetts Municipal Association
- Massachusetts Restaurant Association
- Massachusetts State Legislature
- Massachusetts State Police
- Mayor's Alzheimer's Initiative, Boston
- McLean Hospital/Harvard Medical School
- Melrose Police Department
- MetroWest Health Foundation
- Mirick O'Connell Attorneys at Law
- Multicultural Coalition on Aging
- New England Regional Black Nurses Association
- Newton Department of Senior Services
- North American Indian Center of Boston
- Office of Congresswoman Niki Tsongas
- Office of Representative Denise Garlick
- Office of Senator Ed Markey
- Old Colony Elder Services
- Partners Health Care
- Preferred Therapy Solutions
- Raia and Associates
- ReServe
- Rita J. & Stanley H. Kaplan Family Foundation
- Rockland Trust
- Rotary International
- Senior Living Residences
- South Shore VNA
- Standish Village and Compass on the Bay Assisted Living
- The Conversation Project
- The University of Massachusetts Boston
- Town of Westborough
- Tufts Health Plan for Senior Products
- Tufts Health Plan Foundation
- US Administration on Aging,  
Administration on Community Living
- Ummah Health at the Islamic Society of Boston Cultural Center
- Wingate Healthcare