

Dementia-Friendly Community Initiatives:

Voices from Practice Leaders in Massachusetts

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SECTION 1: BACKGROUND



Introduction

Dementia-friendly community (DFC) initiatives aim to make localities more inclusive and supportive of persons living with dementia and their care partners. DFC initiatives work toward this aim through a variety of activities, such as by facilitating community programs to raise awareness about dementia and improving access to services. Central to the DFC movement is engaging residents living with dementia and their care partners in community decision-making, as well as forging multisectoral partnerships.

This report summarizes findings from a research project conducted in 2021 to understand the development and implementation of DFC initiatives in Massachusetts. Massachusetts is unique in its having a state-level network for municipal and regional DFC initiatives. The study's aim was to understand the perspectives of local DFC initiative leaders on how they and their collaborators are working toward DFC change at the local level.

Development of DFC Initiatives Worldwide

The concept of dementia-friendly communities is new to the 21st century. The timeline below highlights key developments in the dementia-friendly movement leading up to the founding of Dementia Friendly Massachusetts.

JAPAN

In 2004, Japan's government launched its *Ten-Year Plan to Understand Dementia and Build Community Networks*. This national campaign inspired the development of DFC initiatives worldwide.

UNITED KINGDOM

In 2012, the *Prime Minister's Challenge on Dementia* established the Alzheimer's Society's (United Kingdom) "Dementia-Friendly Communities" recognition program.

ALZHEIMER'S DISEASE INTERNATIONAL

Alzheimer's Disease International collaborated with the World Health Organization on a report, *Dementia: A Public Health Priority*, which emphasizes the importance of DFC initiatives.

DFC INITIATIVES EMERGE ACROSS THE GLOBE

Several countries, including Scotland, Australia, Canada, and Finland, established national dementia plans that helped to spur the development of DFC initiatives.

ACT ON ALZHEIMER'S

In the United States (US), the dementia-friendly movement took hold in Minnesota in 2009 with ACT on Alzheimer's, a statewide collaboration that promoted community-centered responses to better support persons living with dementia and their care partners.

DEMENTIA-FRIENDLY AMERICA

Building on the tools of ACT on Alzheimer's, the Dementia Friendly America (DFA) initiative launched in 2015 when 35 national organizations came together to spearhead a dementia-friendly movement across the US.

DEMENTIA FRIENDLY MASSACHUSETTS

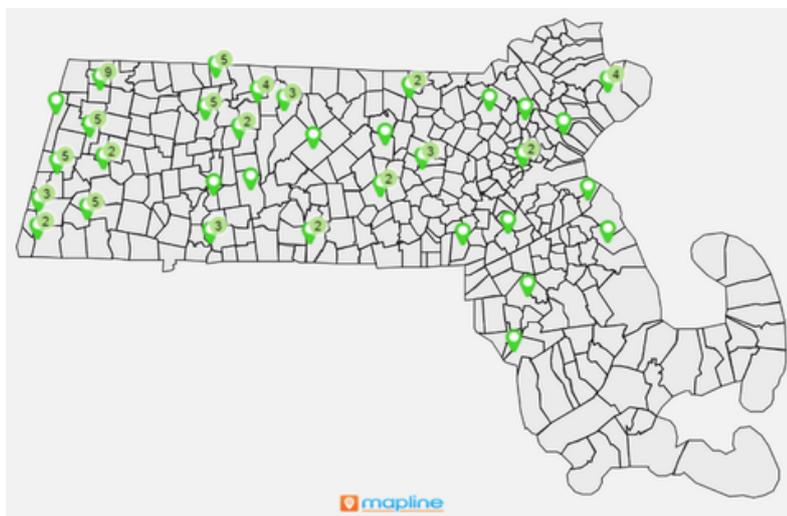
Through the collaboration of statewide partners, Dementia Friendly Massachusetts was established in 2016.

Background on Dementia Friendly Massachusetts

Dementia Friendly Massachusetts (DFM) is a multi-organizational program that supports a statewide network of localities that are working to make their communities more dementia friendly. With support from the Tufts Health Plan Foundation, DFM is currently administered by the Massachusetts Councils on Aging (MCOA). MCOA is a nonprofit membership association for 350 local Councils on Aging (COAs). With guidance from a team of professionals across the private nonprofit, public, and academic sectors, DFM provides educational opportunities, networking events, online resources, and one-on-one guidance for member communities.

As of January 2022, three regions representing a total of 58 municipalities, as well as an additional 24 municipalities, are pledged members of DFM. Elected leaders in these communities have signed a pledge or sent a letter that formalizes their commitment to DFC progress. Pledged members have committed to:

- Creating an action team and identifying a leader or co-leaders
- Identifying the community's dementia-friendly needs
- Developing an action plan and beginning implementation
- Signing and submitting the DFM pledge and an action plan
- Celebrating progress and looking for ways to continue to improve



Map of communities in Massachusetts that have signed the DFM pledge or sent a letter indicating their commitment (map courtesy of DFM)

Overview of the Research Project

This report presents findings from a research project to advance understanding of the development and implementation of DFC initiatives at the local level in Massachusetts. The researchers conducted qualitative interviews with leaders of DFC initiatives that were part of DFM as pledged members as of March 2021. They sought to answer the following question:

How do local leaders describe the development and implementation of DFC initiatives?

Study Details By The Numbers

24

Total number of individuals who participated in an interview. They represented 19 localities out of the 24 that were invited for an interview. All participants identified as White (100%), and most were female (91.7%). Almost all participants (95.8%) reported having an associate's degree or more, and most participants (58%) were staff of the local Council on Aging.

60

Number of minutes for each interview. We asked questions such as "How did the idea for having a DFC initiative in your community first come about?" and "How does your work with the DFC initiative fit in with your other professional responsibilities?" We conducted a qualitative descriptive analysis around primary topic areas, as presented in this report.

Demographic Characteristics of Localities

	Minimum	Maximum	Median
Total Population Size	2,630	185,428	19,865
Median Household Income	\$48,139	\$148,854	\$103,228
% Ages 65+	9%	33.7%	17.5%
% Non-Hispanic White	31%	99%	82.9%
% Bachelors Degree or More	15.4%	85.3%	55.7%

SECTION 2: FINDINGS

1. Influences on Getting Started

"We got a grant through our local Aging Services Access Point. We traveled out to Minnesota because we initially modeled our dementia-friendly work after Minnesota. We spent three days there taking classes, meeting with people, figuring out how they did it, and then we came back and started implementing it in our own communities."

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1. Influences on Getting Started

What leads communities to take on the work of a DFC initiative, especially without any dedicated state or federal funding streams? Our findings indicated two motivating factors: ready leaders within the municipality and catalysts from outside the municipality.

Key Influences on Getting Started



Ready Leaders Within the Municipality

- Leaders have worked with individuals living with dementia, professionally or personally, and are passionate about the work
- Leaders have prior experience working together and are motivated for inter-organizational collaboration at the outset of the DFC initiative
- Key municipal leaders (e.g., town administrators, elected officials, and Councils on Aging directors) deeply understand the need to better support residents with dementia



Catalysts from Outside the Municipality

- Financial support from regional funders, including Aging Services Access Points and local foundations
- Inspiration from the broader age- and dementia-friendly communities movement across Massachusetts
- Learning about the model as implemented through Act on Alzheimer's in Minnesota

2. Focal Activities

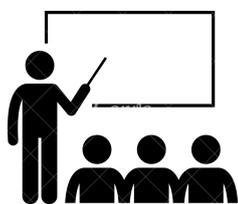
"I think memory cafes are a phenomenal way for a caregiver to have an hour and a half to be with other caregivers in a very comfortable space so they can share their anxieties, their thoughts, and their resources. The memory cafe is a great way to support our caregivers and their loved ones with dementia."

”

2. Focal Activities

DFC initiatives are designed as a community-centered approach to benefit persons living with dementia and their care partners. Unlike traditional health and social services initiatives, DFC initiatives do not primarily focus on the delivery of services. So what exactly do DFC initiatives offer? Our findings indicated three broad categories of activities related to community-level goals: greater awareness of dementia, enhanced local services, and improved public facilities and outdoor spaces.

Goals and Activities



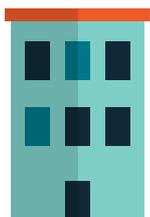
Greater Awareness of Dementia

- Trainings for the public at large
- Trainings for sector-specific groups (e.g., banks, police and fire, libraries, public transportation, etc.)



Enhanced Local Services

- Developing memory cafes that provide socialization and a sense of community for individuals living with dementia and their care partners
- Coordinating services with other organizations, both within the locality and regionally
- Connecting individuals living with dementia and their care partners to resources



Improved Public Facilities and Outdoor Spaces

- Planning for improvements in public spaces and housing options, often in conjunction with local age-friendly efforts
- Improving the accessibility of Council on Aging facilities

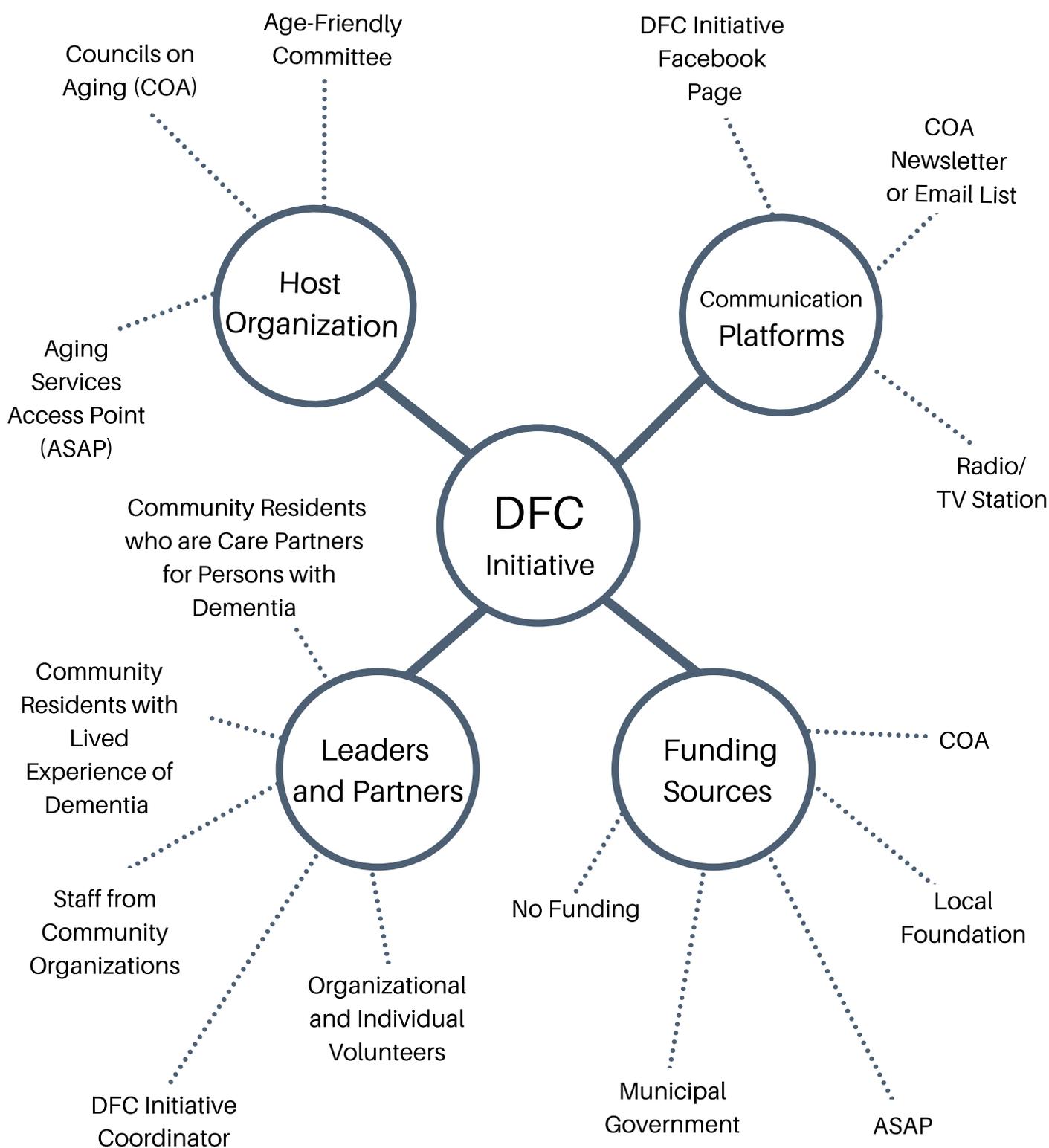
3. DFC Initiative Structure

"There is no staff member, as in paid staff or grant-sponsored, for the initiative. It's our other social worker and outreach coordinator, who have taken the lead and gone to most of the meetings for dementia- and age-friendly. The number of hours they devote to the initiative is based on their availability."

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3. DFC Initiative Structure

Participants described their DFC initiative structure according to the following categories: host organization, communication platforms, leaders and partners, and funding sources. The graphic below summarizes the major themes that came up within each of those categories.



4. Action Teams

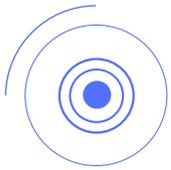
"Our action team includes representatives from a memory care unit, Chamber of Commerce, police department, library, bank, and local school. We have a standing meeting every month that is very well attended. We used to host the meetings at the library, but we've moved to virtual meetings since COVID."

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4. Action Teams

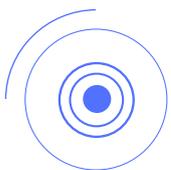
Action teams are a central component of DFC initiatives in the US. Action teams can include residents, organizational representatives, local government officials, or anyone in the community interested in shaping the DFC initiative in their city or town. Action teams have a leader or co-leaders responsible for convening and leading the team's collaborative work. While most initiatives in our study described having a team of people providing oversight, the nature of this team varied greatly. Action teams, as described by study participants, belonged to one of three categories: active multisectoral action team, disbanded multisectoral action team, and no standalone action team.

Variation in DFC Initiative Action Teams



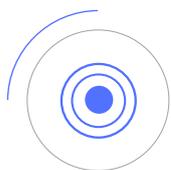
Active Multisectoral Action Team

- The leaders with active multisectoral actions teams convened meetings and ran dementia-friendly programs during the COVID-19 pandemic
- Examples of sectors included police and fire departments, libraries, banks, assisted living residences, and residents living with dementia and their care partners
- Many DFC Initiatives drew on the Act on Alzheimer's model in Minnesota to create their multisectoral action team



Disbanded Multisectoral Action Team

- The action team no longer convened for a variety of reasons such as:
 - Dementia-friendly work was put on pause during COVID-19
 - Action team had achieved its initial aims (e.g., conducting a survey and creating an action plan)
 - Grant funding ended, and staff time was no longer supported



No Standalone Action Team

- Dementia-friendly work was discussed at COA staff meetings
- Dementia-friendly was embedded as part of age-friendly committees
- Dementia-friendly work was infused into COA staff members' other job responsibilities without the formation of a team

5. Connections with State and Regional Organizations

"We were recognized at the Select Board meeting. We were presented that certificate from DFM. It was a special moment. I think there were a lot of people who were very proud of the work we did. We were really just getting started, but just to be congratulated for those grassroots efforts to get us going, in part, laid our programming after that."

”

5. Connections with State and Regional Organizations

Although DFC initiatives in Massachusetts conduct their work within local communities, many receive assistance and utilize resources from statewide organizations. Examples include the Massachusetts Councils on Aging and DFM, the Massachusetts/New Hampshire Chapter of the Alzheimer’s Association, Jewish Family and Children’s Service, local Area Agencies on Aging or ASAPs, the Massachusetts Healthy Aging Collaborative, and the Commonwealth of Massachusetts (state government). Our findings indicated that these organizations support DFC initiatives in two primary ways: by connecting local efforts with a statewide network and providing direct assistance with local implementation.

Categories of Connection

Connecting Local Efforts with a Statewide Network

- Formalizing the DFC initiative as part of a statewide movement
 - **Example:** Hosting a pledge acceptance or "kick-off" ceremony for the DFC initiative
- Spreading awareness about the DFC initiative across regional and statewide networks
 - **Example:** Promoting the DFC initiative's work through the organization's communications platforms



Direct Assistance with Local Implementation

- Providing content for incorporation within local DFC initiative dissemination and outreach efforts
 - **Example:** Providing materials for DFC initiative leaders to use for dementia awareness trainings in their communities
- Working with the DFC initiative to co-create or collaborate on an event, program, or training
 - **Example:** Collaborating on a community forum in a DFC initiative's locality about topics related to dementia
- Fielding questions and providing one-on-one support



6. Challenges During COVID-19

"During the pandemic, it became challenging to get the group together. So we have not met regularly during the course of the pandemic. When you look at the responsibilities of the folks who are on the steering committee, their time was consumed. Dementia-friendly meetings just couldn't be their priority."

”

6. Challenges During COVID-19

Participants described ways in which the pandemic affected all aspects of community life, and many organizations affiliated with DFC initiatives had to pivot to address residents' health and social needs. Individuals living with dementia were among the most vulnerable during the pandemic given that they were at increased risk of developing COVID-19 and worsening symptoms due to social isolation. In light of these difficult circumstances, DFC initiatives faced many challenges, as listed below.



Work Put on Pause to Manage the Crisis

DFC leaders and partners shifted their focus to address residents' most pressing needs such as food security and health care.



Partners Were Less Available

As a result of the shift to crisis management, many DFC initiative partners and action team members had less capacity to engage in dementia-friendly collaboration.



Social Distancing Limited In-Person Events

Social distancing protocols prevented in-person events, which resulted in fewer dementia-friendly programs.



Difficulties with Virtual Programming

Virtual programs were less attended, in part, because it was challenging for individuals living with dementia to participate virtually.



Changes in Leadership and Staffing

Some DFC initiative staff had to leave the initiative due to circumstances such as family concerns.

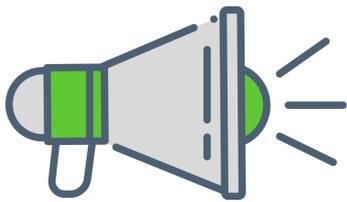
7. Opportunities During COVID-19

"The pandemic gave us the chance to network with other communities. It has helped us reach out to other centers and say, 'Is this something once we're up and running that you guys would like to do?' If we do it together, we may reach more individuals living with dementia."

”

7. Opportunities During COVID-19

While the pandemic posed significant challenges for DFC initiative leaders, it was also a time for growth and restructuring. Some participants noticed that community members became more aware of the needs of older adults living with dementia and their care partners during the crisis. In addition, leaders capitalized on new partnerships, additional planning time, and virtual programming.



Increased Awareness of Needs

The pandemic resulted in a heightened awareness among community leaders and the public at large of the needs of older adults living with dementia and their care partners.

New Partnerships Formed

The crisis accelerated the development of new partnerships across organizations within the community on dementia-friendly work.

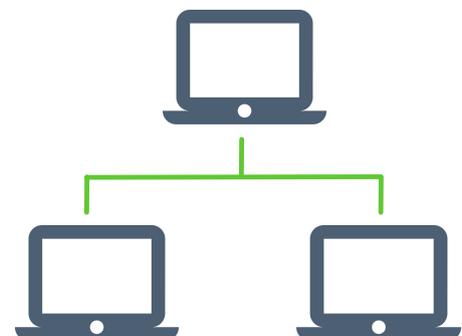


Additional Planning Time

Because day-to-day work was put on pause during periods of the pandemic, some leaders found additional time for DFC initiative planning.

Utilization of New Platforms

DFC initiatives used virtual programming, radio, and cable TV to raise awareness about dementia, engage a greater number of residents, and improve outreach strategies.



8. Hopes for the Future

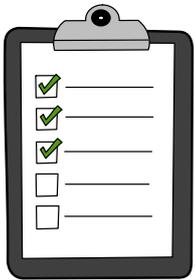
"My hope is that we can continue to push this movement forward to the point where you walk down the main street, and you see every window with our decal on it, and it makes people think about, 'Well, what is [Name of DFC initiative] or what does it mean to have dementia? What does this mean for our community?'"

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8. Hopes for the Future

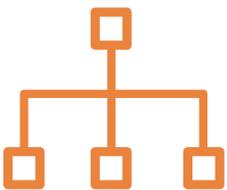
We asked participants to share what they view as the most important action steps moving forward for their DFC initiatives. For many, the COVID-19 pandemic put dementia-friendly community work on pause, and leaders hoped to revisit the work they were doing before the crisis. The three main goals that leaders described were advancing dementia-friendly goals and programs, improving the structure of the DFC initiative, and ensuring the DFC initiative's sustainability.

Advance Dementia-Friendly Goals and Programs



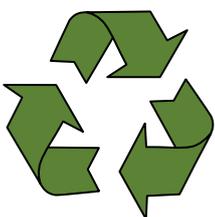
- **Examples:**
 - Build awareness around dementia (e.g., by hosting additional Dementia Friends trainings)
 - Greater outreach to older adults living with dementia from historically marginalized groups (e.g., by race/ethnicity, language, LGBTQA+ identification)
 - Develop or build upon dementia-friendly programs (e.g., plan for the addition of a supportive day program within the Council on Aging)

Improve the Structure of the DFC Initiative



- **Examples:**
 - Develop or reinstate the action team
 - Foster multisectoral partnerships
 - Include individuals living with dementia on the action team
 - Hire a paid staff member for the DFC initiative

Ensure Sustainability of the DFC Initiative



- **Examples:**
 - Continue to develop the action plan toward long-term goals
 - Evaluate the impact of dementia-friendly work
 - Identify a host organization for the DFC initiative
 - Secure funding

SECTION 3: CONCLUSION

Shared Aspirations, Different Approaches

This report presents findings from interviews with leaders of 19 DFC initiatives that were pledged as part of Dementia Friendly Massachusetts as of March 2021. The project's aim was to understand how DFC initiatives have developed in the context of a unique statewide network. All participants reflected on their desire for their locality to become more dementia friendly. They broadly described their initiative's aspiration to make local organizations and community leaders more aware of, responsive to, and supportive of persons living with dementia and their care partners. They generally emphasized ways in which their dementia-friendly work involved educating service providers, organizational leaders, and the public at large about aging in the community with dementia and cognitive impairment.

While similar in focus, the participants' descriptions of their initiatives differed from each other with respect to several key aspects. For example:



Many initiatives described maintaining a standalone multisectoral action team, yet others had disbanded their teams, or never had such a team.



Some initiatives described having paid staff with allocated time to work on the DFC initiative as a distinct program. Others described their initiatives as a framework to help guide existing programs.



Some initiatives' community outreach was extensive and involved systematically connecting with a large diversity of partners. Others' outreach efforts were more focused and smaller in scope, such as focusing on training for key municipal departments.

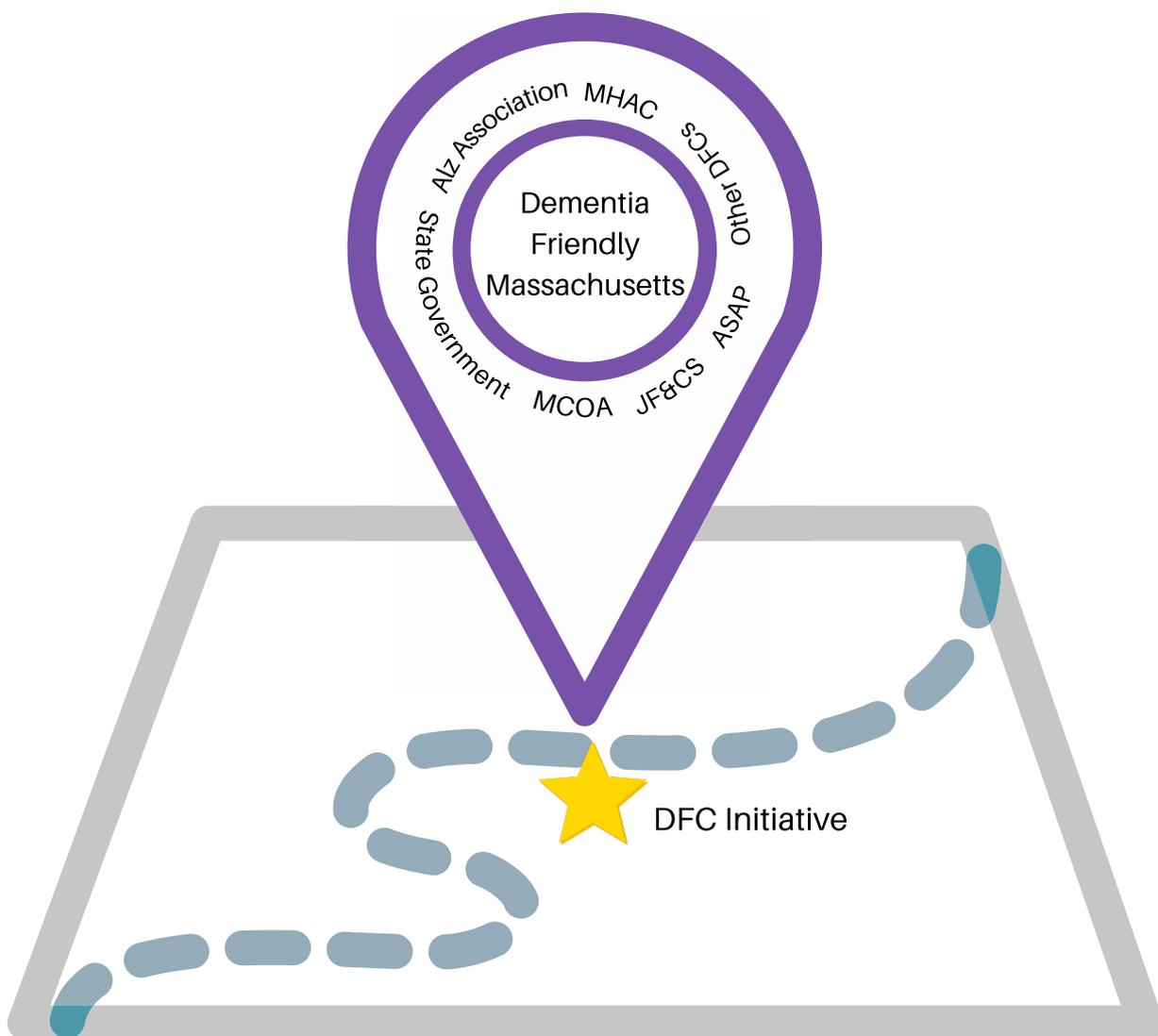


Some initiatives' work on improving services for persons living with dementia centered on educating the community about the availability of existing services. Others were also working to create new services for persons living with dementia and their care partners as part of the DFC initiative.

This variation suggests that there is perhaps more than one program model underlying DFC initiatives in Massachusetts. Additional research is necessary to further identify and delineate multiple approaches to dementia-friendly community work. Advancing understanding of multiple program models holds great promise for guiding more theory-driven evaluation, technical assistance, community practice, and policy on DFC initiatives—all of which can help to strengthen the effectiveness and solidify the sustainability of DFC initiatives in Massachusetts and beyond.

Local Focus as Part of Statewide Efforts

Findings from this study further indicate ways in which local dementia-friendly community work is embedded within a broader ecosystem of other local, regional, and statewide organizations working toward similar goals. While all participants described their local geographic communities as their initiatives' primary target for action and change, each participant also discussed ways in which organizations outside of their municipalities enhanced or informed their efforts. Especially because participants described drawing on these organizations for different reasons and at different points in their initiatives' development, findings suggest the importance of continuing to develop a robust network of age- and dementia-friendly leaders throughout Massachusetts across diverse systems-levels and sectors.



Note: This figure lists the organizations that DFC initiative leaders discussed most frequently in the interviews. It is not an exhaustive list.

ASAP = Aging Services Access Point

JF&CS = Jewish Family & Children's Service

MCOA = Massachusetts Councils on Aging

MHAC = Massachusetts Healthy Aging Collaborative

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