

**Collective Care When There Is No Cure:
An Evaluation of Dementia Friendly Initiatives**

by

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University of Pittsburgh, 2023

Abstract

Nearly seven million people in the United States live with some type of dementia such as Alzheimer's disease, vascular, Lewy body, and frontotemporal dementia. As dementia progresses, people increasingly struggle with daily activities because of symptoms that erode memory, communication, problem-solving, and other skills. Most people living with dementia reside at home in their communities, often thanks to the millions of family members and friends who provide unpaid care. Significant resources are poured into discovering a cure for Alzheimer's as it is the seventh leading cause of death in the United States. Yet while there is no cure for any type of dementia, there is care. Cities, towns, counties, and states across the U.S. are creating Dementia Friendly communities that strive to help people living with dementia and their care partners meaningfully participate in the community. Since 2015, USAging has overseen the Dementia Friendly America initiative which supports the country's network of over 300 Dementia Friendly communities. This study uses the RE-AIM model to evaluate the design and progress of seventeen Dementia Friendly initiatives with state leads. The findings suggest that communities' most common goals are increasing understanding of dementia through training and awareness efforts, establishing multisectoral partnerships, and creating more engaging social and cultural environments for people living with dementia and their care partners. By detailing and measuring their work, this study aims to highlight patterns of success, roadblocks, and potential ways forward for communities to meaningfully empower people living with dementia and their care partners.

Table of Contents

1.0	Background	1
1.1	Dementia	1
1.2	Caregiving in the Community.....	3
1.3	Evolution of Dementia Friendly	5
1.4	Alignment with the CDC’s Alzheimer’s Disease and Healthy Aging Program	10
1.5	State Plans for Alzheimer’s Disease and Related Dementias.....	12
1.6	International Context	13
1.7	Literature Review	15
1.8	Public Health Relevance.....	17
2.0	Study Design.....	18
2.1	Statement of Research Question.....	18
2.2	Methods.....	18
2.3	RE-AIM	19
3.0	Findings.....	23
3.1	Reach.....	25
3.2	Effectiveness	28
3.3	Adoption.....	29
3.4	Implementation	31
3.5	Maintenance	35
4.0	Discussion.....	38
4.1	Limitations.....	43
4.2	Recommendations	43
4.3	Conclusion	45
5.0	Appendix: Survey for Dementia Friendly State Leads	46
	Bibliography	50

List of Tables

Table 1. Dementia Friendly Initiatives with State Leads & CDC BOLD Funding	12
Table 2. RE-AIM Framework and Dimensions	20
Table 3. RE-AIM Applied to Dementia Friendly Community Model	22
Table 4. Information Sources for Dementia Friendly Programs	24
Table 5. Number of Dementia Friendly Communities in Each State.....	26
Table 6. State Leads' Organizations.....	31
Table 7. Examples of Dementia Friendly Programs.....	34
Table 8. State Plans for Alzheimer's Disease and Related Dementia.....	36

List of Figures

Figure 1. Timeline of Dementia Initiatives	6
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1.0 Background

1.1 Dementia

Today, an estimated seven million people are living with dementia in the U.S. (PRB, 2022). This number is expected to rise to nearly 12 million cases in 2040 (PRB, 2022). Dementia is the general term for over 100 chronic, terminal diseases that gradually weaken cognitive functions used in daily life including memory, thinking, and decision making (CDC, 2019). The CDC estimates that between 60 to 80 percent of people living with dementia are diagnosed with Alzheimer's disease, followed by vascular dementia, Lewy body dementia, and frontotemporal dementia (CDC, 2019). As of today, Alzheimer's disease is the seventh leading cause of death in the United States (CDC, 2023). While most people who live with dementia are 65 years and older, dementia is not a normal part of aging. Instead, aging is considered a non-modifiable risk factor for dementia followed by family history of the disease, being a woman, having Down syndrome, existing mild cognitive impairment, and prior traumatic brain injuries (Mayo Clinic, 2022). Education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, and social interaction are considered modifiable risk factors, according to a 2020 Lancet Commission on dementia prevention, although these factors are certainly hard to change for people who do not have the money and resources to do so (The Lancet, 2020). Nearly two-thirds of people living with Alzheimer's in the U.S. are women, with the most common explanation for this gender gap being that on average women live longer than men (Alzheimer's Association, 2022). Older Black individuals are twice as likely and Latinx individuals are one and a half times as likely to develop dementia as white individuals; the health equity issues associated with dementia and corresponding public health interventions are significant (Alzheimer's Association, 2020).

Most people associate dementia with memory loss, yet people living with dementia experience a range of symptoms including problems with attention, communication, reasoning, judgement, problem-solving, and visual perception (Mayo Clinic, 2022). Certain types of dementia also have characteristic progression and symptoms. For example, series of strokes worsen the symptoms of vascular dementia. People living with Lewy body dementia may experience challenges with movement, balance, and confusion such as visual hallucinations. Frontotemporal dementia can cause changes in an individual's personality and behavior, leading to inappropriate and potentially aggressive behavior (Mayo Clinic, 2022). All types of dementia are progressive and terminal, although it is often hard to anticipate how long an individual will live with dementia. After diagnosis, people living with Alzheimer's will live for another four to eight years on average (Alzheimer's Association, 2023). The wide variety and acuity of symptoms in combination with the progressive nature of dementias make it particularly challenging to create comprehensive public health interventions for this class of diseases, not to mention medical and pharmacological treatments. There is no known cure for any type of dementia, yet there are medications that can slow the progression of some symptoms.

The economic impact of caring for people living with dementia is hard to estimate given the range of health and social services required for this care, especially for individuals who have other comorbidities. As of 2020, the average annual spending for a person living with dementia was \$19,956. Inpatient, home health care, and prescription drugs account for 75% of these expenditures, especially for individuals living with dementia who also have other comorbidities (Milken Institute, 2022). Medicaid spending for older adults living with Alzheimer's disease is 22 times higher than those without the disease, as it is estimated that Medicare and Medicaid spent \$34 billion caring for those living with dementia in 2022 alone (Alzheimer's Association, 2023).

Considering the anticipated increase in the number of dementia cases, the Milken Institute projects that total expenditures for people living with dementia, including both medical and non-medical care costs, will reach upwards of \$100 billion in 2040. Treatment expenditures for women living with dementia is expected to grow from \$5 billion in 2020 to \$17 billion in 204 (Milken Institute, 2022).

1.2 Caregiving in the Community

Most people living with dementia reside at home in their communities, often thanks to the help of the nearly eleven million “informal” caregivers in the U.S. who are supporting individuals living with dementia (PRB, 2020). In fact, it is estimated that one in three caregivers of older adults 65 years and older are caring for someone with dementia (AARP, 2020). Daughters (39%), spouses (25%), other family and friends (20%), and sons (17%) provide the bulk of this unpaid care for their loved ones (PRB, 2020). The Alzheimer’s Association estimates that two-thirds of dementia care partners are women, most of whom live with the person with dementia, and over half of them provide care to their loved ones for four or more years, (Alzheimer’s Association, 2022). One analysis of NHATs data found that Black, Hispanic, immigrants, and those who do not have a high school diploma were the most likely to be living with dementia at home as opposed to a nursing home (AARP, 2020). When people living with dementia can remain in their communities, they can maintain a sense of independence, stay connected with their social networks, and enjoy the comfort and familiarity of home. However, these benefits often have mixed experiences for the caregivers themselves. While 45% of caregivers of people living with dementia say that providing help to their loved ones is very rewarding, the majority (59%) also rate the emotional stress of caregiving as very high. On a weekly basis, they provide care for an average of 48 hours, and this

time increases as the symptoms of dementia progresses (Alzheimer's Association, 2023). Numerous studies indicate a strong relationship between dementia caregiving and anxiety, depression, and poorer quality of life than caregivers of people without dementia (CDC, 2019). As the person living with dementia's symptoms progress, caregivers' daily emotional, social, and physical responsibilities intensify as they also navigate fragmented health and social services for their loved ones. The emotional and physical labor occurs alongside serious financial burden. During the last five years of life, out-of-pocket healthcare costs for people living with dementia averaged \$62,000, which is 80% higher than average costs for heart disease or cancer. Family and friends shoulder most of their loved ones' health care costs since Medicare does not cover many amenities and services needed to age in place with dementia; this is particularly true among minority communities (PRB, 2020).

Not only do people living with dementia and their care partners endure physical, emotional, and financial challenges, but they also navigate social and physical spaces that often do not consider or include dementia. For example, although most people living with dementia live in the community, every day they can experience barriers to safe, accessible public transportation, visit grocery stores or banks that do not adapt their services or environments for dementia, and even encounter first responders who may not understand how to identify and intervene when someone with dementia is wandering or exhibiting aggressive behavior. On an interpersonal level, they can come across others in the community who are unkind or avoidant because of a person living with dementia's cognitive or physical symptoms. Instead of adapting to meet their unique needs, people living with dementia and their care partners are all too often expected to adapt to the world around them. Inaccessible or unfriendly environments can make every day living seem like an insurmountable feat for people living with dementia and their care partners.

1.3 Evolution of Dementia Friendly

Numerous organizations and funding streams are dedicated to discovering a cure for cognitive decline and Alzheimer's disease. Yet while a cure is sought after, governments, organizations, and individuals are focused on innovating and improving care for people who are living with dementia today. This and the following sections will explore the evolution of policies and programs centered around meeting people living with dementia and their care partners where they are – in their communities.

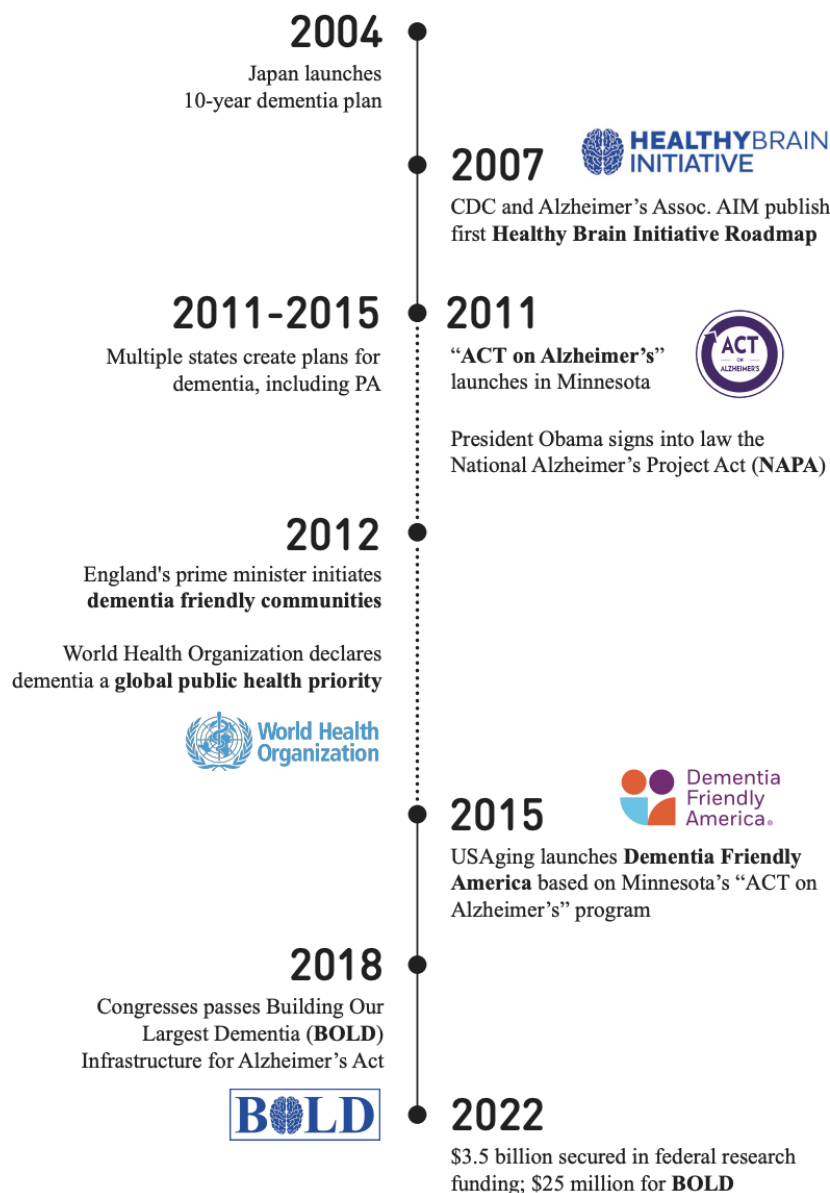


Figure 1. Timeline of Dementia Initiatives

In 2011, a new program called “ACT on Alzheimer’s” was developed in Minnesota with the goal of giving communities the resources to help people living with dementia and their caregivers meaningfully and safely participate in everyday life. The program was developed in

response to the state’s 2011 plan for Alzheimer’s disease, which listed community preparation as a goal (ACT on Alzheimer’s, 2023). The original ACT on Alzheimer’s model focused on establishing partnerships across industries to help organizations better serve people living with dementia and their care partners, enhancing support services for care partners, and training health care providers on best practices for early diagnosis and dementia care. Memory cafes and dementia education seminars for various sectors, such as banks and churches, were key components of the initial program, along with many other awareness and training efforts (ACT on Alzheimer’s, 2023). After four years, the ACT on Alzheimer’s program was shifted to the oversight of USAging during the Obama administration’s White House Conference on Aging in 2015 (The White House, 2015). At the conference, it was announced that USAging would help expand the ACT on Alzheimer’s model across the country through pilot communities in Colorado, Maryland, California, Arizona, and West Virginia. Since then, USAging has rebranded the “ACT on Alzheimer’s” model to “Dementia Friendly”.

USAging, formerly known as the National Association of Area Agencies on Aging (n4a), represents and supports the country’s hundreds of Area Agencies on Aging and Title VI Native American Aging Programs. The primary focus of USAging is to support older adults who are “aging in place” in their communities through advocacy and resources at local Area Agencies on Aging, which provide home and community-based services for older adults with funding from the Older Americans Act (USAging, 2023). USAging’s “Dementia Friendly America” team oversees the network of state and local Dementia Friendly communities along with Dementia Friends, a separate program that provides free information sessions about dementia to the public in communities across the country. USAging’s Dementia Friendly America program (2023) describes their community model as the following:

“A dementia friendly community is one that is taking action to foster quality of life for people living with dementia and their care partners by decreasing stigma, increasing opportunities for meaningful social interaction, and offering support in addressing the changing needs of people living with dementia.”

The Dementia Friendly model is designed to be a grassroots effort, meaning any individual or organization in a community, regardless of size, that’s willing work toward the model’s goals can apply to become part of the Dementia Friendly network. Cities, towns, counties, and states are all part of this network. Many communities first establish a Dementia Friends program and then pursue the Dementia Friendly community initiative. As of today, there are more than 360 Dementia Friendly communities and 131,000 Dementia Friends across the country (USAgings, 2023).

To join the national network of Dementia Friendly Communities, the lead organizers must submit information to USAgings that pledges their community will be able to meet the “Readiness and Recognition Criteria” when they join, which includes the following criteria (USAgings, 2023):

1. People living with dementia will be included as leaders and members during the design and implementation of Dementia Friendly community efforts.
2. The champion organization has the capacity to establish Dementia Friendly efforts in their community, whether that be through creating partnerships with local government or through funding.
3. The community can create and maintain a team that includes at least local/state government, clinical and community-based organizations, and people living with dementia in the community along with their care partners.
4. The initiative’s team encourages various stakeholders throughout their community to adopt dementia friendly practices, such as first responders learning how to interact with people

living with dementia who wander from their homes or restaurants making small modifications to better accommodate people living with dementia.

5. The initiative will track progress and share updates both in their self-evaluation reports and if requested by Dementia Friendly America.

Once the Dementia Friendly America team at USAging approves a community as part of the network, the lead individual or organization creates partnerships with various sectors that make up most communities including but not limited to: airports, banks and financial services, neighbors and community members, legal and advance planning services, local government, healthcare providers, libraries, faith communities, businesses of any industry, community-based services and supports, residential and specialty care, and hospitals (USAging, 2023). Individual and organizational leads are expected to establish and maintain a team that educates and empowers community partners so that they can understand and engage people living with dementia and their care partners. USAging (2023) lists the primary goals of Dementia Friendly communities as the following:

1. Increase awareness and understanding of dementia and of people living with dementia.
2. Increase awareness and understanding of brain health and risk reduction.
3. Collaborate with public, private, not-for-profit and health care sectors to better serve people living with dementia and care partners.
4. Address the changing needs of people with dementia and care partners.
5. Create social and cultural environments that are inclusive to those living with dementia.
6. Improve the physical environment in public places and systems (e.g., parks, transportation) so that it is dementia friendly.

USAgings Dementia Friendly team does not officially certify any community as being “dementia friendly” but instead recognizes communities that are constantly striving to better include and serve people living with dementia and their care partners. In terms of reporting results, communities are asked to complete a survey twice a year for the Dementia Friendly America team to track and organize the program’s impacts. Additionally, some Dementia Friendly state leads do require that their respective Dementia Friendly communities provide progress updates with their own methods and tools.

1.4 Alignment with the CDC’s Alzheimer’s Disease and Healthy Aging Program

USAgings Dementia Friendly community network operates within the larger context of public health programs in the United States that are focused on dementia. The CDC’s Alzheimer’s Disease and Healthy Aging program oversees the “National Healthy Brain Initiative” which “improves understanding of brain health as a central part of public health practice,” (CDC, 2020). Since 2007, the Initiative’s main function has been to design and support Healthy Brain Initiative Road Maps in close collaboration with the Alzheimer’s Association. These road maps are published every five years and set national goals for supporting people living with dementia and their care partners, research efforts to find a cure for Alzheimer’s, training public health professionals, brain health promotion activities, and progress updates on prior reports’ goals.

The Dementia Friendly community model is both explicitly and implicitly included in the current “State and Local Partnerships to Address Dementia: The 2018 – 2023 Road Map”. It includes twenty-five action items for state and local public health departments that are organized into four categories based on the four essential services of public health: “Educate and empower”, “Develop policies and mobilize partnerships”, “Assure a competent workforce”, and “Monitor and

evaluate” (CDC, 2018). The Road Map focuses on issues that occur throughout the lifespan, from pre-symptomatic through the early to late stages of the diagnosis, as well as issues affecting their care partners. The Dementia Friendly model aligns with action items listed in both the “Educate and Empower” and “Develop Policies & Mobilize Partnerships” sections. In particular, the Policy section states that the field of public health should “engage public and private partners in ongoing planning efforts to establish services and policies that promote supportive communities and workplaces,” (CDC, 2018). Additional action items in the policies and partnerships section that align with the Dementia Friendly model include (CDC, 2018):

- “Educate the public (E-1, E-3);
- Analyze the community support needs of people living with dementia and their caregivers (M-3, M-5);
- Promote the use of evidence-informed practices and educational resources (E-6, E-7); and
- Build the knowledge and skills of professionals who interact with people living with dementia and their caregivers (W-2, W-5, W-6).”

There is also a Healthy Brain Initiative Road Map for Indian Country, although this study does not examine this plan.

In tandem with the Healthy Brain Initiative Road Maps, the CDC’s Alzheimer’s Disease and Healthy Aging program also encompasses the BOLD program. In the winter of 2018, the Healthy Brain Road Maps received a funding increase when the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer’s Act was passed into law (CDC, 2021). The Act directs the CDC to: Establish Alzheimer’s and related dementias Public Health Centers of Excellence; provide funds to support public health departments; and increase data analysis and timely reporting on dementia. The BOLD fund receives approximately \$30 million per year, and several states’ and

cities’ public health departments have recently been granted BOLD funding that are also home to Dementia Friendly communities. There are two levels of BOLD funding. States and cities that receive “Core Capacity” designation will use the funds to create statewide dementia coalitions and develop or update the state plans for dementia by closely following the current Healthy Brain Initiative Road Map (CDC, 2021). Meanwhile, “Enhanced Capacity” recipients will use the funds to advance their already existing dementia coalitions and strategic activities outlined in their state plans for dementia. States with Dementia Friendly state-leads that received BOLD funding in 2021 are listed in Table 1 (CDC, 2021).

Table 1. Dementia Friendly Initiatives with State Leads & CDC BOLD Funding

Core Capacity	Enhanced Capacity
<ol style="list-style-type: none"> 1. Arkansas 2. City of Boston 3. Hawaii 4. Iowa 5. Maine 6. Nevada 7. North Carolina 	<ol style="list-style-type: none"> 1. Georgia 2. Minnesota 3. Virginia 4. Wisconsin

1.5 State Plans for Alzheimer’s Disease and Related Dementias

The CDC’s Healthy Brain Initiative Road Map also informs various state plans for Alzheimer’s disease and related dementias. State plans typically align with the Road Map’s strategy and goals, as the Alzheimer’s Association’s policy initiative (AIM) often threads the needle by supporting both the CDC’s Road Maps and having their individual state chapters be involved with the creation of state plans. This means Road Map’s implicit and explicit goals related to the Dementia Friendly community model are often funneled down into these state plans, whether

they have Dementia Friendly communities led at the state-level or by individual cities and counties. Since 2007, plans for dementia have been published by 49 states and the District of Columbia and Puerto Rico (Alzheimer's Association, 2020). The proliferation of these state plans was in part motivated by the passage of the National Alzheimer's Project Act, which was signed into law by President Obama in 2011. The first national plan to address dementia was published in 2012 in accordance with the new law, and the plan explicitly called for federal coordination with states to raise awareness of dementia, supporting caregivers, and providing dementia training to health care and public health professionals (HHS Assistant Secretary for Planning and Evaluation, 2021). In terms of sustainability, some states require by law that their plan be updated every three to four years and for the plan's task force to produce annual progress reports. Plans typically include four general focus areas: increasing education and awareness of the disease; promoting early detection and diagnosis; expanding access to home and community-based services; and addressing workforce shortages. Many states have also addressed other issues, including health care system capacity, quality of care, legal issues, funding for medical research, safety, and more (Alzheimer's Association, 2020).

1.6 International Context

The World Health Organization estimates that there are more than 55 million people living with dementia across the world and that dementia is the seventh leading cause of death internationally (WHO, 2023). Correspondingly, the concept of dementia friendly communities has also spread globally as dementia friendly activities are active in an estimated 40 different countries (Alzheimer's Disease International, 2016), although this may have changed because of the COVID-19 pandemic. Japan and the United Kingdom were at the forefront of shaping the

principles of the global dementia friendly movement, many of which originated in the form of the countries' plans and policies to address dementia. In 2004, Japan's anticipated aging population prompted the country to produce the "10-Year Plan to Understand Dementia and Build Community Networks", with one of its goals being to train professionals and the public about dementia to create more inclusive communities (Alzheimer's Disease International, 2023). In 2012, the World Health Organization declared dementia a global public health priority (WHO, 2012) while Alzheimer's Disease International published a recommended set of actions and policies for governments to address the growing prevalence of dementia. That same year, British prime minister's David Cameron ignited the dementia friendly community movement in the U.K. through the "Prime Minister's Challenge on Dementia". The document charged the Alzheimer's Society with taking the lead in creating a formal process for establishing Dementia Friendly communities, and the 2015 renewal of the Prime Minister's Challenge committed to establishing dementia friendly communities through half of England (Department of Health, 2016). As of 2020, there were 350 dementia friendly communities in England (NIHR ARC East of England, 2020). Across continental Europe, the coalition Alzheimer Europe represents Alzheimer's associations from 37 countries. Many of these countries' plans to address dementia as a public health policy priority include creating dementia friendly communities as a strategy, although alternative terms are also used such as "dementia inclusive" in Germany and "memory-friendly" in Finland (Alzheimer Europe, 2021). The World Health Organization's 2021 guidebook "Towards a dementia-inclusive society: WHO toolkit for dementia-friendly initiatives" acts as a supporting document for its "Global action plan on the public health response to dementia 2017–2025" (WHO, 2012). The concept of dementia friendly communities continues to gain traction across the globe.

1.7 Literature Review

Research about dementia friendly communities in the U.S. is relatively minimal yet growing. The few studies that have been published focus on specific aspects or initiatives. In 2022, one study conducted by the Mayo Clinic in Jacksonville, Florida consulted residents of a predominantly African American neighborhood about what could make their community more dementia friendly. Over one hundred Black residents living with dementia, informal and formal care partners, faith-based leaders, local business owners, and other residents of the neighborhood participated in focus groups. Multiple participants emphasized the need for more education on how to interact with people living with dementia as well as the importance of self-care for both formal and informal care partners (Bergeron, 2022). They suggested community presentations, formal training, workshops, informal support groups, and social media promotions as ways to increase community members' awareness and understanding of dementia. They also highlighted how their community's weak social cohesion could present challenges for dementia friendly work but offered that more social gatherings like block parties and potlucks could help neighbors form stronger connections. While not an evaluation of dementia friendly communities, a separate study (Ebert, 2020) surveyed nearly 650 people in Wisconsin about would make them feel more comfortable interacting with people living with dementia. The study aimed to capture how peoples' knowledge and perceptions of dementia shape how they communicate with people living with dementia. The survey results showed that sharing informal but meaningful experiences helped people feel more comfortable interacting with people living with dementia than simply learning about the biology of dementia, which the researchers suggested could help inform dementia friendly education and awareness activities.

Beyond the U.S., one integrative review examines dementia friendly community efforts in the U.K., Canada, Australia, and New Zealand (Shannon, 2018). The included studies focused on understanding the processes of building dementia friendly communities across these countries and identifying similar successes and challenges. The review concluded: “Strategies deemed to be successful for developing communities included steering groups with wide representation and particularly led by people with dementia, supportive action plans, partnerships with Alzheimer's groups, funding, and in-kind support. Challenges encountered included ensuring representation of marginalised groups on steering committees, and scarcity of resources, both financial and time.” A separate 2021 scoping review included 29 studies of communities’ social inclusion efforts for people living with dementia. The included studies were conducted in the U.S., U.K., Canada, Netherlands, Japan, Australia, Sweden, and beyond (Hung, 2021). This review specifically focused on how communities across these countries were addressing social inclusion for people living with dementia and their care partners. It identified how dementia friendly communities across the world recognize the importance of actively including people living with dementia in the design and implementation of dementia friendly work, yet many of these same community efforts shared that they lacked the structure to consistently, robustly include people living with dementia in this process. From 2017 through 2019, England’s Department of Health and Social Care conducted the national “DEMOCOM” mixed-methods study which evaluated the country’s hundreds of dementia friendly communities using a framework originally developed for age-friendly communities. The evaluation found that the country’s policy support for creating dementia friendly communities propelled this work forward, and that strong multisectoral partnerships were critical to ensuring their activation. Moreover, one of the papers (Buckner, 2018) that stemmed from this evaluation found that communities focused most often on raising awareness of dementia,

inconsistently involved people living with dementia, and that they struggled to thoroughly evaluate the impact of their activities.

1.8 Public Health Relevance

In the U.S., the current patchwork of approaches of formal and informal care must be strengthened to better serve people currently living with dementia and their care partners and expanded given the anticipated increase in number of dementia cases. There is an urgent need to develop alternative care solutions that are less costly, provide more robust support for care partners, and that are more focused on improving overall quality of life for people living with dementia in the community. Dementia Friendly is a relatively new model that is working to help more communities support people living with dementia so that they can meaningfully participate in everyday life. At its core, the Dementia Friendly model is a public health approach because its strategies are centered on cross-sector partnerships, community engagement, health promotion, and workforce capacity building. Public health can play a critical role in creating dementia friendly communities through promoting brain health and early diagnosis of dementia, creating awareness campaigns about dementia, educating the public health and healthcare workforce about dementia, and strengthening supports and services for both people living with dementia and their care partners. Additionally, public health program, policy, and evaluation experts also have an opportunity to help the Dementia Friendly model scale and strengthen its impact.

2.0 Study Design

2.1 Statement of Research Question

This study explores the design, implementation, and sustainability of Dementia Friendly initiatives in that have state leads. Multiple methods (emails, telephone interviews, surveys, and websites) were used to gather data from a sample of states that have Dementia Friendly programs. The RE-AIM framework was used to investigate the reach, effectiveness, adoption, implementation, and maintenance of Dementia Friendly initiatives with state leads.

2.2 Methods

This study focuses on the states and territories with Dementia Friendly state leads and does not examine the Dementia Friendly counties and cities in the 15 states without a designated state lead. Only initiatives with state leads were examined because of the time and resource constraints of this study. The twenty-six states listed with state leads on the Dementia Friendly America website were originally included in the analysis. A comprehensive list of Dementia Friendly communities was accessed on the Dementia Friendly America website (Dementia Friendly America, 2022). Programs with state leads, as opposed to individual cities or counties, were then identified. Multiple methods were used to collect qualitative and quantitative data about programs with state leads, including:

- **Emails:** The 14 state leads of Dementia Friendly initiatives that do not have a website were emailed in early November 2022. They were asked to share information about their initiative, including the same questions that were included in the survey described below.

Ten of the 14 states responded to the email with information about their initiative, although the breadth and depth of information varied across states.

- **Interviews:** One state lead agreed to be interviewed in November 2022. During the conversation, they shared background and information about their program, including how the program integrates with the states' other dementia efforts. Interviews were requested with two other states but pivoted to sharing questions and responses via email because of schedule conflicts.
- **Surveys:** USAging's Dementia Friendly America team agreed to distribute a survey to state leads in early January 2023. They emailed the survey to 26 state leads, five of whom completed the survey. The survey included 27 questions that aimed to capture information about the states according to the five domains of the REAIM framework. The full survey can be found in the appendix.
- **Websites:** Seventeen Dementia Friendly initiatives' websites provided much of the findings about their programs. The websites were first accessed beginning in August 2022. Most of the websites provide a history and overview of the Dementia Friendly initiative, information about the state lead's organization, general descriptions of their efforts and partners, and resources for training.

2.3 RE-AIM

The Dementia Friendly initiatives with state leads are evaluated using the integrative framework "RE-AIM". RE-AIM stands for Reach, Effectiveness, Adoption, Implementation, and Maintenance/Sustainment, which broadly encompass the following concepts (RE-AIM, 2023):

Table 2. RE-AIM Framework and Dimensions

Dimension	Technical Definition	Pragmatic Use
Reach	The absolute number, proportion, and representativeness of individuals willing to participate in each initiative, and the reasons why (qualitative).	Reach the target population: Who is intended to benefit and who participates or is exposed to the initiative?
Effectiveness	The impact of an initiative on outcomes, including potential negative effects, heterogeneity, quality of life, and economic outcomes as well as the reasons why (qualitative).	Effectiveness on targeted outcomes: What is the most important benefit you are trying to achieve and what is the likelihood of negative outcomes?
Adoption	The absolute number, proportion, and representativeness of settings and agents willing to initiate a program, and the reasons why (qualitative).	Adoption by target staff, settings, systems, and communities: Where is the program applied and who applied it?
Implementation	Fidelity to the intervention protocol, and including adaptations, time, and cost as well as the reasons why (qualitative).	Implementation consistency, costs and adaptations made during delivery of intervention: How consistently was the program delivered, how was it adapted, how much did it cost, and why did the results come about?
Maintenance/ Sustainment	The extent to which a program becomes institutionalized at the setting level or sustained at an individual level as well as the reasons why (qualitative).	Maintenance/sustainment of intervention effects in individuals and settings over time: When was the program operational and how long are the results sustained?

Originally developed in 1999, the RE-AIM framework was created to improve the approach to evaluating the public health impact of evidence-based interventions focused on health promotion and disease prevention. Moreover, Dr. Russ Glasgow created the RE-AIM framework to better understand how research is “translated” into programs, whether the programs were

replicated according to the original research, and if they had the same public health impact as the research. The RE-AIM framework has been widely used to evaluate interventions and applied research to improve their adoption and identify ways to sustain their implementation (RE-AIM, 2023). The RE-AIM model is an appropriate framework method to evaluate Dementia Friendly initiatives with state leads because the RE-AIM elements can assess both the organizational- and individual-level impacts of an intervention. The “Reach” and “Effectiveness” elements of the framework are meant to capture the impact on individuals, while the “Adoption” and “Implementation” are considered to measure organizational impact. Maintenance can measure both individual and organizational data. For Dementia Friendly communities with state leads, the RE-AIM framework was applied to the Dementia Friendly model in Table 3.

Table 3. RE-AIM Applied to Dementia Friendly Community Model

RE-AIM Dimension	Dementia Friendly Community Measures
Reach	<ul style="list-style-type: none"> • How many Dementia Friendly communities exist in the state • Number of people living with dementia and their care partners that have been impacted by the Dementia Friendly program • How the Dementia Friendly initiative engages people living with dementia in the organization of Dementia Friendly efforts • How the Dementia Friendly initiative engages women, Black, Latinx, LGBTQ+ and any other high-risk/ underserved populations
Effectiveness	<ul style="list-style-type: none"> • Evaluation outcomes of Dementia Friendly activities either through tools and measures recommended in Dementia Friendly America's Evaluation Guide or evaluation strategies developed independently
Adoption	<ul style="list-style-type: none"> • How many years the initiative has been active in the state • Organization that lead statewide Dementia Friendly initiative • Statewide partners • Funding sources and funding for partners • How many people are involved with building and maintaining the Dementia Friendly communities, including staff and volunteers • How state leads interact with Dementia Friendly communities
Implementation	<ul style="list-style-type: none"> • Programs or activities that have been implemented as part of the Dementia Friendly efforts • Fidelity to the Dementia Friendly community model, or to what extent the initiative embraces the Dementia Friendly community goals as set by Dementia Friendly America: <ul style="list-style-type: none"> ○ Increase awareness and understanding of dementia and of people living with dementia. ○ Increase awareness and understanding of brain health and risk reduction. ○ Collaborate with public, private, nonprofit and health care sectors to better serve people living with dementia and care partners. ○ Address the changing needs of people with dementia and care partners. ○ Create a supportive social, cultural and business environment that is inclusive of those living with dementia. ○ Improve the physical environment in public places and systems (e.g., parks, transportation) so that it is dementia-friendly
Maintenance/ Sustainment	<ul style="list-style-type: none"> • State plan for Alzheimer's Disease and Related Disorders, and whether it aligns with the Dementia Friendly initiative • Plans, funding, and goals to continue the Dementia Friendly Initiative over the next 5 years

3.0 Findings

Given the time constraints for this study, as much data as possible was collected about states' Dementia Friendly initiatives that pertains to these RE-AIM dimensions. There is wide variation in both the quality and quantity of states' data due to the different methods of data collection and differing availability of the data. Efforts were made to collect data from all twenty-six state leads listed on the Dementia Friendly America website. The table shows which state leads responded to the survey distributed by USAging, were responsive to email or interview queries, or had informational websites for their Dementia Friendly initiative, as well as those from whom no information was collected.

Table 4. Information Sources for Dementia Friendly Programs

State	Email	Interview	Survey	Website	No response
Alabama			X	X	
American Samoa					X
Arizona	X				
Arkansas	X				
Delaware	X				
Florida	X	X		X	
Georgia	X			X	
Hawaii					X
Illinois				X	
Indiana				X	
Iowa			X	X	
Maine	X				
Massachusetts			X	X	
Minnesota			X	X	
Nebraska				X	
Nevada				X	
New Hampshire					X
New York	X			X	
North Carolina	X			X	
Ohio			X	X	
Pennsylvania	X			X	
Utah				X	
Virginia	X			X	
West Virginia					X
Wisconsin				X	
TOTAL	10	1	5	17	4

Although most states did provide some sort of information, eight states were removed from the RE-AIM analysis for several reasons. Four state and territory leads from American Samoa, Hawaii, New Hampshire, and West Virginia did not respond to emails, did not complete the survey, and their programs did not have an informational website. For these reasons, they were excluded from the analysis. Delaware's state lead from the Delaware Department of Health and

Social Services shared via email that they had only just begun their Dementia Friendly initiatives before the COVID-19 pandemic completely derailed their efforts, thus they were only starting to plan their program in the fall of 2022 and did not have any helpful information to share. Maine's state lead from the Maine Council on Aging initially responded via email and shared that they technically did not focus on building Dementia Friendly communities but instead integrated the principles of the Dementia Friendly into many of their other dementia efforts. They did not respond to follow-up requests for more information and do not have a website, so they were excluded from the analysis. Two state leads from Arizona and Arkansas shared information that suggested their Dementia Friendly initiatives were much more akin to the Dementia Friends program, focusing more on holding Dementia Friends information sessions for the public and training Dementia Champions to hold these sessions in their own communities. Since they did not share information about Dementia Friendly efforts that fall outside the scope of Dementia Friends and do not have websites, Arizona and Arkansas were also excluded from the analysis. With the exclusion of these eight states, there are seventeen states included in this study. Data from these seventeen states have been organized in the following sections by applying the RE-AIM elements to different aspects of the Dementia Friendly model.

3.1 Reach

As previously stated, the Reach dimension applied to Dementia Friendly initiatives for this study captures who is intended to benefit and who participates or is exposed to the initiative. The most direct measurement of Reach is the number of Dementia Friendly communities that currently exist within each state. These communities are comprised of cities, towns, counties, and regions. Each state has a unique approach to identifying "communities", seemingly based on the state's

geography, the state lead's organizational capacity, and other unknown factors. For example, Nevada has divided the state into six different "Community Groups" comprised of five counties and regions across the state as well as a local Native American tribe's advisory council (Dementia Friendly Nevada, 2017). Meanwhile, the Massachusetts Dementia Friendly initiative includes 86 towns and cities that are considered Dementia Friendly communities, many of which are centered around local Councils on Aging (Dementia Friendly Massachusetts, 2018). This variation in how states define "community" is reflected in the wide range of numbers reported by states which are listed in Table 5.

Table 5. Number of Dementia Friendly Communities in Each State

State	Number of Dementia Friendly Communities
Alabama	13
Florida	16
Georgia	0
Illinois	26
Indiana	7
Iowa	5
Massachusetts	86
Minnesota	60
Nebraska	N/A
Nevada	6
New York	4
North Carolina	10
Ohio	5
Pennsylvania	8
Utah	N/A
Virginia	10
Wisconsin	13

Note: N/A indicates the number of communities was not available.

Another direct and important measure for identifying the "Reach" for Dementia Friendly initiatives is how many people living with dementia and their care partners were impacted by the

initiative's various efforts. This was difficult to estimate based off the initiative's websites, however the four state leads who completed the survey did provide rough estimates of how many people they reached in 2022. Alabama reported reaching 5,000 people, Florida reported 496,000 individuals, Iowa estimated reaching 5,000 people, and Ohio estimated reaching 2,750 people. Minnesota shared the following numbers related to reach: 325 people attended the Dementia Friendly Community Summit in 2022; 544 professionals participated in the Dementia Friendly for Healthcare training; and 2,295 people participated in theater arts and dementia program.

Regarding diversity, equity, and inclusion, initiatives' websites frequently shared little to no information about how they engaged two important populations: 1) people living with dementia and their care partners, and 2) women, Black, Latinx, LGBTQ+, and any other high-risk or underserved communities. Dementia Friendly America's "Readiness and Recognition" criteria includes having people living with dementia be engaged "as leaders and members during the design and implementation of Dementia Friendly community efforts," (Dementia Friendly 2022). Through the survey, Alabama, Iowa, Massachusetts, Minnesota, and Ohio did share ways they include people living with dementia in their community efforts, either by having them join action teams, advisory task forces, giving presentations and trainings, and requiring them to be involved with any organization that receives mini grants. Anecdotally, several state leads mentioned that they tend to involve care partners more consistently than people living with dementia in the process of communities' design and implementation. In terms of tailoring initiatives for marginalized and high-risk communities, several states in the survey mentioned they have formed partnerships with ethnic-minority and/or women-led businesses, given grants to community-based organizations that support underserved communities, offered Dementia Friends sessions in these communities, and invited people from minority or underserved communities to be a part of advisory task forces. One

state did acknowledge that they need to do more to engage and support minority and high-risk communities.

3.2 Effectiveness

The Effectiveness domain is meant to highlight the Dementia Friendly program's intended benefits and any potential negative outcomes of its implementation. Outcome measures would be the best way to capture this type of data for this study, although evaluation efforts vary widely across Dementia Friendly programs. Dementia Friendly America's Evaluation Guide provides resources, tools, and examples to help communities measure the outcomes and impact of their activities, such as surveys to capture changes in residents' understanding and perceptions of dementia (Dementia Friendly America, 2021). However, in an interview with the Dementia Friendly America team and throughout the data collection process, it became clear that most communities do not use the Guide. Many states have struggled to prioritize evaluation and how to identify the best measures for their activities, especially considering that so many communities are grassroots efforts led and supported by unpaid volunteers. The Evaluation guide explicitly states: "Based on a literature review of dementia-friendly community research conducted by DFA in the fall of 2020, dementia friendly community evaluations to this point have been largely descriptive and focused on the process of planning and implementing a dementia-friendly initiative. For example, currently available evaluations provide rich detail of how initiatives were set up, barriers and challenges to implementing activities, how many people participated in awareness raising activities and the number of activities offered in a community," (Dementia Friendly America, 2021). Moreover, it can often be difficult to ask people living with dementia and their care partners to donate more of their time toward evaluation efforts. Instead, the most common approach for

state leads to measure their Dementia Friendly efforts seems to be tracking the number of active Dementia Friendly communities, as outlined in the previous paragraph, as well as tracking the number of organizations who complete different Dementia Friendly sector trainings. However, some state leads have developed their own approaches to measurement while several have worked with local universities and organizations to evaluate their initiatives. For example, Iowa shared in their survey response that they partnered with the Iowa Geriatric Education Center to develop surveys for their Dementia Friends sessions and Dementia Friendly trainings for businesses and organizations. The Massachusetts Dementia Friendly initiative partnered with the Rutgers School of Social Work to report on its implementation and impact, although this report is no longer publicly available online (Dementia Friendly America, 2022). In their survey response, Minnesota shared that they have evaluated the impact of its trainings for different sectors.

3.3 Adoption

The Adoption measure encompasses where and who is applying the Dementia Friendly model. As mentioned previously, more than 360 Dementia Friendly communities have been established in 41 states and one territory over the past ten years (Dementia Friendly America, 2023). Established in 2013, Minnesota has the longest-standing Dementia Friendly initiative with ACT on Alzheimer's, which is the model for Dementia Friendly programs (ACT on Alzheimer's, 2023). After USAging assumed management of the Dementia Friendly model in 2015, three state leads (Florida, North Carolina, and New York) began their Dementia Friendly initiatives. In 2016, seven states followed: Alabama, Indiana, Iowa, Wisconsin, Nebraska, Nevada, and Massachusetts. The remaining states joined in the following years, with Pennsylvania and Ohio being the newest state leads in 2022. The ongoing COVID-19 pandemic certainly interrupted and altered all states'

Dementia Friendly efforts, and the two initial years of the pandemic likely reduced the scope and impact of their activities.

The state leads' organizations are also typically the main funders for the Dementia Friendly community initiative, with a few exceptions. Illinois' Dementia Friendly initiative is funded by Rush University Philanthropy, the Illinois Department of Public Health, and the HRSA Geriatric Workforce Engagement Program (Illinois Cognitive Resources Network, 2022). Indiana's initiative is funded by the Indiana University Health system and its Health Foundation (Alzheimer's and Dementia Resource Service, n.d.). Massachusetts' Dementia Friendly efforts receive funding from the Tufts Health Plan Foundation (Dementia Friendly Massachusetts, 2018), and Pennsylvania's Dementia Friendly efforts are funded by the Pennsylvania Department of Aging (Jewish Healthcare Foundation, 2022). As shown in Table 6, most state leads are employees of the state's Department of Health and/or Human Services or the state's Department of Aging. Three state leads work for regional or local Area Agencies on Aging, and another three state leads come from statewide coalitions of for- and non-profit coalitions, including research universities and health services providers, that are committed to supporting individuals with cognitive health issues and their care partners.

Table 6. State Leads' Organizations

	State Department of Health and/or Human Services or Aging	Regional/Local Area Agency on Aging	Nongovernmental Organizations
Alabama		X	
Florida	X		
Georgia	X		
Illinois			X
Indiana			X
Iowa		X	
Massachusetts			X
Minnesota		X	
Nebraska	X		
Nevada	X		
New York	X		
North Carolina	X		
Ohio			X
Pennsylvania			X
Utah	X		
Virginia	X		
Wisconsin	X		
TOTAL	9	3	5

Although most state leads work in state government agencies, many seem to collaborate closely with their local or regional Area Agencies on Aging by using them as hubs for Dementia Friendly communities across the state. Another frequent statewide partner are state or regional chapters of the Alzheimer's Association, which often provide community outreach, education, and training support for communities.

3.4 Implementation

The Implementation dimension considers the consistency and adaptations made during the program implantation; fidelity to the original model is the focus of this dimension. Since the

Dementia Friendly model is rooted in a grassroots approach, state leads have experienced a wide variety in the adaptation of the model. How state leads interact with and guide Dementia Friendly communities in their states shapes the variation among Dementia Friendly initiatives. Multiple states including Iowa, Indiana, Massachusetts, Nevada, and Illinois, among others, work with cities and towns throughout their states to help them apply for recognition from Dementia Friendly America. This includes drafting letters of support and reviewing their application to Dementia Friendly America, coordinating statewide meetings with all the communities, and providing more individualized support by helping communities define and advance their activities. More state leads seem to take a more “hands on” approach to helping define and implement the community’s priorities and efforts, while others allow communities to organically create activities on their own agendas.

Across the seventeen states, there are a few types of efforts that are somewhat consistently implemented in Dementia Friendly communities. Memory Cafes are one example of common social activities offered that provide opportunities for people living with dementia and their care partners to relax and connect with each other. Memory Cafes can include interactive activities like painting and crafts, educational sessions about different issues related to dementia, or informal gatherings centered around music and dancing. Training sessions are another significant activity for Dementia Friendly communities and were integral to the original ACT on Alzheimer’s model in Minnesota. The logistics of these trainings vary by state but can be offered in-person or through web-based educational modules. Dementia Friendly America has published free guides specific to various industries that are found in most communities, including: airports, arts and cultural activities, businesses, community-based services and support, communication and customer services, disaster planning, health care and hospitals, housing, legal resources and advanced

planning, libraries, local government, and transportation (Dementia Friendly America, 2022). Some Dementia Friendly communities use these resources from Dementia Friendly America while other have developed their own sector guides. The educational resources and trainings for businesses, healthcare workers, and banks and financial services seem to be most consistently used across initiatives with state leads. These guides generally cover the importance of understanding dementia and how it relates to their sector, communication tips for interacting with people living with dementia, and how they can modify their organization's environment and practices to better support people living with dementia and their care partners. Similarly, the free, one-hour Dementia Friends sessions are consistently offered to the public in most communities. Public libraries are another common partner for Dementia Friendly communities, as libraries can host memory cafes, support groups, Dementia Friends training, and create sections dedicated to books about cognitive decline and dementia. Resources, training, and support groups for care partners, including respite services, are another common activity for Dementia Friendly communities. In addition to these activities, several states have developed unique, robust Dementia Friendly programs that are highlighted in table 7.

Table 7. Examples of Dementia Friendly Programs

Program type	Examples
School curriculum	<ul style="list-style-type: none"> • The Dementia Friendly Alabama state lead shared in their survey response how they worked with the state’s Area Agencies on Aging to create the Dementia Friendly Alabama Schools Curriculum. The initiative’s representatives provided lesson plans to elementary school teachers about dementia, read dementia-related children’s books to students, provided educational materials about dementia, and showed students how robotic pets can provide comfort to people living with dementia.
Grants for community organizations	<ul style="list-style-type: none"> • In their survey response, the Georgia Gerontology Society shared that since 2018 they have award annual grants of \$2,000 to five different community organizations to help them lead Dementia Friendly efforts in their communities. • The Minnesota ACT on Alzheimer’s program shared in their survey that they award eight communities grants of \$8,000 each to support their Dementia Friendly efforts. Previously, grants awarded to communities had been as much as \$20,000.
Training for Businesses	<ul style="list-style-type: none"> • Iowa’s Dementia Friendly initiative offers training for businesses and organizations where the “trainers” will give a free, one-hour training session to at least half of the establishment’s employees. Staff are taught how they can engage customers living with dementia, spot the signs of dementia, and how to consider dementia in their businesses’ processes and environments (Dementia Friendly Iowa, 2023). • In 2018, the Dementia Friendly Indiana initiative collaborated with Indiana University’s School of Public Health to develop a-hour online course called “Dementia Friendly Business Training”, according to their website. The course teaches business owners and employees about dementia, why it’s important for businesses to learn about dementia, and how they can better serve people living with dementia and their care partners (Indiana University, 2018).
Training for Hospitals	<ul style="list-style-type: none"> • North Carolina’s Dementia Friendly Hospital Initiative is run by the University of North Carolina (UNC) Health Care’s Center for Aging and Health, funded with a grant from The Duke Endowment, and part of the state’s broader Dementia Friendly initiative. The Hospital Initiative plans to train 4,000 employees across its five hospitals, from doctors and nurses to food service workers and administrators, about how to communicate with patients with dementia and their range of potential symptoms (UNC School of Medicine, 2023).
Training for First Responder	<ul style="list-style-type: none"> • Nevada’s Dementia Friendly initiative collaborated with Cleveland Clinic Nevada to develop an online continuing education course called “Dementia Training for First Responders”. The Cleveland Clinic’s doctors and researchers lead the modules which Alzheimer’s disease, Frontotemporal dementia, and Lewy Body dementia and how first responders can safely, effectively interact with them (Dementia Friendly Nevada, 2017).
Advance Planning	<ul style="list-style-type: none"> • Dementia Friendly Massachusetts’ website describes its partnership with the nonprofit Honoring Choices Massachusetts which encourages communities to host “Pizza and Proxy” parties, where people living with dementia and their care partners gather to learn about advance care plans and directives as well how they can appoint a health care proxy (Dementia Friendly Massachusetts, n.d.).

3.5 Maintenance

The maintenance domain considers the institutionalization of a program, meaning which policies and systems are in place to ensure the sustainability of the program either by organizations or individuals. Many Dementia Friendly efforts have become “institutionalized” through state plans for Alzheimer’s disease and related dementias, as outlined in the table below. Thirteen of the seventeen states with Dementia Friendly state leads have state plans for dementia, although Alabama, Pennsylvania, and Nebraska have not updated them in the past five years. Nine of these state plans either explicitly or implicitly mention the goals of Dementia Friendly communities. For example, Georgia’s current state plan for dementia includes as a goal for outreach and partnerships the following: “Educate the public and organizations to become more "dementia-friendly" and dementia inclusive across all types of dementia,” (Georgia Alzheimer’s Disease and Related Dementias State Plan Collaborative Members and Advisory Council, 2020). Meanwhile, many of the goals from Florida’s 2020 state plan for dementia gesture toward the Dementia Friendly model without explicitly naming the program: “Engage public and private partners in ongoing planning efforts to establish services and policies that promote supportive communities and workplaces for people living with dementia and their caregivers,” (Florida Department of Elder Affairs, 2020).

Table 8. State Plans for Alzheimer's Disease and Related Dementia

State	State Plan for ADRD	Aligns with or Includes Dementia Friendly Goals
Alabama	2012-2015	
Arkansas	2021-2025	
Florida	2020	
Georgia	2020-2023	✓
Illinois	2020-2023	✓
Indiana	No	
Iowa	No	
Massachusetts	2021	✓
Minnesota	No	
Nebraska	2016	✓
Nevada	2021-2022	✓
New York	No	
North Carolina	2022	✓
Ohio	No	
Pennsylvania	2014	✓
Utah	2018-2022	✓
Virginia	2020-2024	✓
Wisconsin	2019-2023	✓

Although a state may have a plan for dementia, there may not be a regulatory mechanism to ensure the implementation and evaluation of the plan's intended strategies and goals. For example, Pennsylvania's State Plan for Alzheimer's Disease and Related Disorders was created in 2014 and includes Dementia Friendly communities but recent journalistic reporting has shown the state has made little progress on its goals due in part to the lack of regulatory enforcement and resources reserved for its strategies (Public Source, 2021). Additionally, some states have State Plans for Aging that may encompass goals and programs for supporting people living with dementia and their care partners, although they are not examined closely in this study. For example, the Alabama's "State Plan on Aging: Fiscal Years 2021-2024" includes supporting the Central Alabama Aging Consortium's Dementia Friendly Alabama program as a strategy (Alabama Department of Senior Services, 2021). Public information about funding to maintain the Dementia Friendly programs was not readily available, although in survey responses the state leads from Minnesota, Iowa, and Alabama shared that they plan to sustain their programs through grants, donations, and fundraising. Iowa, Nevada, North Carolina, Georgia, Minnesota, Virginia, and Wisconsin also receive BOLD funding from the CDC (CDC, 2021). This means they receive federal funding to support their dementia programs, which could include Dementia Friendly, although the exact allocation of these funds is not publicly available.

4.0 Discussion

The Dementia Friendly model has rapidly spread across the United States. In less than ten years, this program has been implemented in more than half of the fifty states, which is a strong indicator of the dedication of individuals, organizations, and state governments to actualize the goals of Dementia Friendly. The fact that many of the individuals who support the development of Dementia Friendly communities do so as unpaid volunteers demonstrates how much this concept means to people. The vision of creating communities where people living with dementia and their care partners can be understood, respected, and included has clearly resonated with so many Americans; there is power in the principles of Dementia Friendly. Yet the grassroots approach to many Dementia Friendly communities has also created challenges for consistently scaling and evaluating this model, which was accentuated with this study's RE-AIM evaluation. The states that seem to have the most comprehensive, dynamic Dementia Friendly programs rely on full-time professionals who have the time and the resources to promote, strengthen, and innovate the program in collaboration with volunteers throughout their state. Of course, states with policy and political support as well as dedicated funding tend to produce more robust Dementia Friendly programs. States that are truly committed to serving their residents living with dementia and care partners should strongly consider allocating funds and resources toward hiring professionals focused on implementing Dementia Friendly activities. Relying on unpaid labor to perform this work is not just or sustainable, especially in lower-income communities where people do not have the time to dedicate toward supporting this work for free. Of course, having Dementia Friendly communities maintain some of their grassroots efforts also comes with benefits. Communities of all sizes are allowed to adapt the structure and implementation of their Dementia Friendly programs to their unique geographic, cultural, and infrastructural aspects. The grassroots

structure also likely gives volunteers a greater sense of ownership, which can help sustain momentum for these efforts, but should be coupled with formal oversight to ensure the program can be sustained and integrated into communities that do cannot maintain grassroots efforts.

Many of the Dementia Friendly programs with state leads also seem to focus more on certain aims of the Dementia Friendly model over others. This study's findings suggest that communities' most common goals are increasing understanding of dementia through training and awareness campaigns, establishing partnerships with various industries, and creating more inclusive social and cultural environments for people living with dementia and their care partners. This focus on training and education may be a result of many states beginning their efforts with the Dementia Friends program before turning to Dementia Friendly community work. There was little information found that many of these initiatives explicitly, consistently prioritized the remaining goals of Dementia Friendly communities: promoting brain health and risk reduction, addressing the changing needs of people with dementia and care partners, and improving the physical environment of public spaces for people living with dementia and their care partners. Additionally, this study's findings suggest that Dementia Friendly community efforts will rarely be specifically designed for the populations who are disproportionately at higher risk of developing dementia: women, Black, and Latinx individuals. Additionally, the unique experiences of LGBTQ+ individuals who are living with dementia are not explicitly addressed in many of the states' efforts. This is not to say that women, Black, Latinx, and LGBTQ+ individuals do not benefit from existing Dementia Friendly initiatives, but that there is an opportunity to place more emphasis on meeting their unique needs and preferences, especially considering the expected rise of dementia cases in these populations.

Several states' Dementia Friendly initiatives are worth highlighting. Dementia Friendly Nevada began in 2016 when Nevada's Aging and Disabilities Services Division was awarded a federal grant from the Administration for Community Living to fund the initiative (Dementia Friendly Nevada, 2017). Nevada also receives BOLD funding from the CDC, which may support some of the state's Dementia Friendly efforts (CDC, 2021). The "Nevada State Plan to Address Alzheimer's Disease: 2021-2022" explicitly supports the expansion of Dementia Friendly communities (Nevada Department of Health and Human Services Task Force on Alzheimer's Disease, 2021). The state is divided into six Dementia Friendly "Community Groups" which cover several counties, cities, and one Native American tribe. Aging services professionals, community members, and people living with dementia are all members of these Community Groups which are overseen and supported by several full-time professionals from organizations involved with the initiative. The state's Dementia Friendly initiative has two main goals: 1) to establish dynamic multi-sectoral partnerships that help communities become more understanding and inclusive of people living with dementia and their care partners, and 2) to spread the implementation of evidence-based programs that support people living with dementia and their care partners. Nevada's partnership with the Cleveland Clinic Lou Ruvo Center for Brain Health has generated several unique resources, including the training for first responders mentioned in the "Implementation" section as well as various online content. For example, the Center collaborated with the Dementia Friendly Southern Nevada Team on a guide titled "Navigating the Dementia Journey" that is meant to help both people living with dementia and their care partners understand what to prepare for as dementia progresses and the range of services available to them. The Dementia Friendly initiative also raises awareness of modifiable risk factors for cognitive decline by promoting the Cleveland Clinic's Healthy Brains website, which encompasses a free online

“Brain Check-Up” for individuals who want to understand how strong their memory is and how they can adapt their lifestyles for better brain health. In Dementia Friendly Southern Urban Nevada, which encompasses Las Vegas, a grant from the Alzheimer’s Foundation of America funds free memory screenings for the community. Together, the structural support provided by Nevada’s state plan, funding streams, strong partnerships, and full-time professional management for Dementia Friendly Nevada has shaped its robust, organized programming.

In Alabama, the Central Alabama Aging Consortium (CAAC), which serves three counties, has been the lead organization for the state’s Dementia Friendly initiative since 2016 (Dementia Friendly Alabama, 2023). Funded by the Alabama Department of Senior Services, a full-time employee at the CAAC helps manage the initiative along with approximately 30 volunteers across the state. Although Alabama does not have a state plan for dementia, its State Plan on Aging mentions the initiative as a goal (Alabama Department of Senior Services, 2021). Partnerships with the state’s Alzheimer’s Association chapter, the Alabama Department of Senior Services, AARP, and the Alabama Cooperative Extension System, among other organizations, has helped the initiative scale and reach an estimated 5,000 people in 2022. The Dementia Friendly Alabama initiative awards mini grants to community organizations across the state that have helped develop programs in addition to the school curriculum detailed in the “Implementation” Section, including continuing education trainings for professionals and family caregivers, Dementia Friendly business trainings, a dementia resource guide, memory screenings, and access to Project Lifesaver’s tracking technology to help find individuals who are prone to wandering. In comparison with Nevada, Alabama’s initiative has taken a slightly more decentralized approach through these grants, which is noteworthy considering both states’ geographies span more rural areas than urban.

Interestingly, survey responses, interviews, and information found on initiatives' websites indicated that some states' dementia-related efforts could be considered "lookalikes" for Dementia Friendly programs. Florida and Georgia specifically attributed many of their efforts to their state plans and distinct dementia initiatives, even though they mirror Dementia Friendly's goals and tactics. Utah, New York, and North Carolina's Dementia Friendly initiatives also overlap with their state plans and programs. Many of these overlaps occur in states where the state leads are employees of their state's Department of Health, Human Services, or Aging. Future research should more closely examine how these "lookalike" efforts support Dementia Friendly's goals and whether they could be further integrated to strengthen impact.

To date, the core of Dementia Friendly efforts with state leads is raising awareness so that people can better understand dementia and how to interact with those living with dementia. Some may view this as a "soft" approach, yet if Dementia Friendly is to truly change people's attitudes and behaviors towards people living with dementia, then understanding is the first step toward greater social inclusion and engagement. Where the Dementia Friendly model becomes muddled is in its additional goals of promoting brain health and adapting physical spaces to be more accessible for people living with dementia. While these are valuable goals, they do not seem to have gained as much traction as the more straightforward partnerships and education objectives. These goals should be revisited to determine if they should be reframed or better served through separate, complimentary initiatives.

4.1 Limitations

This study has several limitations. First, the study focuses on Dementia Friendly initiatives with clearly identified state leads. Dementia Friendly programs and initiatives that are led by local communities but do not have a state lead were excluded because of the study's time and resource constraints. Second, while this study attempted to collect consistent information from multiple state leads, the responses varied in the depth and detail provided. Future research should focus on quantifying the implementation and reach of Dementia Friendly programs. It is also possible that some of the data collected from program's websites are outdated or incomplete. Moreover, this is by no means a comprehensive analysis of the seventeen states' activities, but rather a snapshot of the implementation and scaling of Dementia Friendly communities who have state leads. In terms of the evaluation framework, this study only analyzed numerators for each of the RE-AIM domains and did not include denominators, which are typically included in most RE-AIM evaluations. A full RE-AIM evaluation would include both numerators and denominators. Lastly, future evaluations should consider which industries have implemented robust dementia friendly efforts in states with more developed Dementia Friendly initiatives, such as whether health services systems have enhanced their diagnosis and care protocols for dementia or if airports have made their services and physical environment more accommodating.

4.2 Recommendations

Based on the findings of this study, recommendations to improve the Dementia Friendly model target various aspects of its design and implementation. First, the role and responsibility of the state lead should be defined to ensure a more consistent implementation and evaluation of

efforts. The Dementia Friendly America website could also highlight innovative, successful programs from Dementia Friendly communities that could be replicated in other areas, such as Massachusetts' "Pizza and Proxy" parties. This could encourage communities to think beyond the sector trainings when designing their programs.

For short-term solutions to the program's challenges with evaluation, Dementia Friendly America could provide quick evaluation tools since states seem to struggle with the logistics and resources needed for evaluation. For example, state leads could be sent an agnostic, web-based knowledge and attitude quiz with 10 questions relevant to all types of Dementia Friendly training that participants could immediately answer after different sessions. With responses from communities across the country, the national model could start to generate more quantitative data about the program's national impact, which could be used in marketing materials to further promote its adoption. Additionally, certain types of Dementia Friendly activities that are implemented by various states could be evaluated such as memory cafes and Dementia Friendly trainings for specific sectors (businesses, health care, etc.). In the long-term, Dementia Friendly America could partner with trained evaluation experts at research universities to conduct a formal, full-scale evaluation of the program.

Regarding equity, one immediate step toward reaching more diverse audiences would be to translate some of, if not all, Dementia Friendly America's resources into Spanish. One useful exercise could be to study how other initiatives that focus on specific diseases have engaged minority communities with public health and risk reduction efforts. Partnerships with national or state organizations that serve women, Black, Latinx, LGBTQ+ and other high-risk or underserved communities could help reach these communities at a larger scale, although this would need to balance with the grassroots ethos that many communities want to maintain. Integrating cultural

competency best practices into existing Dementia Friendly America resources could also help advance this equity work.

4.3 Conclusion

People who are living with dementia deserve understanding, respect, and accommodations from their neighbors and communities. The challenges experienced by these individuals and their care partners, as well as the anticipated increase of dementia cases in the U.S., necessitates both the behavioral and structural changes that the Dementia Friendly model promotes. This study highlights how the Dementia Friendly initiative has been embraced and adapted by states to meet their unique situations, initiated numerous multi-sectoral partnerships at both state and local levels, and been integrated into states' policy infrastructure for dementia through state plans and funding. Nevertheless, states with existing state leads should continue to refine and expand their initiatives while those without state leads should strongly consider appointing leads to reach as many communities as possible. The Dementia Friendly model is an ambitious, progressive concept that will likely require continual adaptations, but has already started to lay the foundation to make important, valuable changes needed to improve the lives of people living with dementia and their care partners.

5.0 Appendix: Survey for Dementia Friendly State Leads

Dementia Friendly States Survey

Thank you for taking the time to complete this survey! Your responses will be used by Chelsea Dickson for her master's essay on Dementia Friendly initiatives, which will explore successes and challenges across various states' efforts to support people living with dementia and their care partners.

Chelsea is a master's in public health student at the University of Pittsburgh's School of Public Health. Her essay topic was reviewed and considered exempt from the University of Pittsburgh's Institutional Review Board (IRB). The final essay will be published on the University's [D-Scholarship website](#) in the spring of 2023.

1. In which state do you currently reside?
2. What is your first name?
3. What is your last name?
4. What is your email address? This way, we can share the results of the survey with you.
5. What is the name of your organization?
6. What is your job title?
7. For how long have you held this position?
8. Does your organization lead the Dementia Friendly initiative for your state?

9. What year did the Dementia Friendly initiative for your state begin?
10. Who funds the Dementia Friendly initiative for the state?
11. How many Dementia Friendly communities are there in your state?
12. How many people have been impacted by dementia friendly programs over the past 12 months? Please estimate the number of participants in all public programs in all Dementia Friendly communities.
13. How many people are involved with building and maintaining these Dementia Friendly communities? (Consider staff and volunteers)
14. How do state leads interact with Dementia Friendly communities throughout the state?
15. Who are the statewide partners for the Dementia Friendly initiative? For example, is the Alzheimer's Association for your state a partner?
16. Which of the following sectors are involved in your state's Dementia Friendly initiative?
Please select all that apply.

- ☐ Airports (1)
- ☐ Banks and financial services (2)
- ☐ Neighbors and community members (3)
- ☐ Legal and advance planning services (4)
- ☐ Local government (5)
- ☐ Healthcare providers (6)
- ☐ Libraries (7)
- ☐ Faith communities (8)

- ☐ Businesses (9)
- ☐ Restaurants/Retail (10)
- ☐ Community-based services and supports (11)
- ☐ Residential and speciality Care (12)
- ☐ Hospitals (13)
- ☐ First responders (Police, fire department, EMS) (14)
- ☐ Other (15)

17. Please provide an example of a program or activity that has been implemented as part of your Dementia Friendly efforts.
18. Is any funding available to local partners? Do individuals and organizations that benefit from your state's Dementia Friendly programs and activities pay fees to your organization?
19. How does the state's Dementia Friendly initiative involve people living with dementia in the organization of Dementia Friendly efforts?
20. How does the state's Dementia Friendly initiative engage women, Black, Latinx, LGBTQ+ and any other underserved communities?
21. Does your state have a state plan for Alzheimer's Disease and Related Disorders, and if so, how does it align with the Dementia Friendly initiative?
22. Does your state currently have a plan to continue the Dementia Friendly Initiative over the next 5 years? If yes, how will it be funded and what are the overall goals?
23. Considering the implementation of Dementia Friendly in your state, to what extent has your initiative embraced each of the following goals:

	Degree			
	Not at all	To a small degree	To a moderate degree	To a high degree
1. Increase awareness and understanding of dementia and of people living with dementia.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Increase awareness and understanding of brain health and risk reduction.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Collaborate with public, private, nonprofit and health care sectors to better serve people living with dementia and care partners.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Address the changing needs of people with dementia and care partners.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Create a supportive social, cultural and business environment that is inclusive of those living with dementia.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Improve the physical environment in public places and systems (e.g., parks, transportation) so that it is dementia-friendly.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

24. How do you evaluate the impact outcomes of the state's Dementia Friendly initiative?

25. Are you open to talking further about your state's Dementia Friendly initiative with Chelsea? If yes, she will be in touch via email soon.

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