

# Disseminating Evidence-Based Programs to Support Family Dementia Caregivers: **THE ROLE OF PUBLIC HEALTH**



**1** EVIDENCE-BASED PROGRAMS FOR DEMENTIA CAREGIVERS

**2** CONSIDERATIONS FOR PUBLIC HEALTH DISSEMINATING EVIDENCE-BASED PROGRAMS

**3** CONSIDERATIONS FOR ORGANIZATIONS DELIVERING EVIDENCE-BASED PROGRAMS

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# ABBREVIATIONS

<b>ACL</b>	Administration for Community Living
<b>ADPI</b>	Alzheimer's Disease Program Initiative
<b>ADRD</b>	Alzheimer's Disease and Related Dementias
<b>ASTHO</b>	Association of State and Territorial Health Officials
<b>BOLD</b>	Building Our Largest Dementia (BOLD) Infrastructure Act
<b>BPC</b>	Best Programs for Caregiving
<b>BRFSS</b>	Behavioral Risk Factor Surveillance System
<b>CARERS</b>	Coaching, Advocacy, Respite, Education, Relationship and Simulation program
<b>CDC</b>	Centers for Disease Control and Prevention
<b>CHW</b>	Community Health Worker
<b>CMS</b>	Centers for Medicare and Medicaid Services
<b>DAIL</b>	Department of Disabilities, Aging and Independent Living, Vermont
<b>DFCC</b>	Dementia Family Caregiver Center, Vermont
<b>DOH</b>	Hawai'i State Department of Health
<b>EBP</b>	Evidence-Based Programs
<b>EIP</b>	Evidence-Informed Programs
<b>EOA</b>	Hawai'i State Department of Health Executive Office on Aging
<b>GA DPH</b>	Georgia Department of Public Health
<b>HRSA</b>	Health Resources and Services Administration
<b>NADRC</b>	National Alzheimer's and Dementia Resource Center
<b>NCOA</b>	National Council on Aging
<b>OHA</b>	Rhode Island Department of Health Office of Healthy Aging
<b>PLWD</b>	Person (People) Living With Dementia
<b>RIDOH</b>	Rhode Island Department of Health
<b>SAMHSA</b>	Substance Abuse and Mental Health Services Administration
<b>TCARE</b>	Tailored Caregiver Assessment and Referral program
<b>TEACH</b>	Training, Education, and Assistance for Caregiving at Home program
<b>UCLA</b>	University of California, Los Angeles
<b>UVMHC</b>	University of Vermont Medical Center
<b>VT BRIDGES</b>	Vermont Broadening Resources in Developing Gerontological Education and Social Work
<b>VDH</b>	Vermont Department of Health

# OVERVIEW

Dementia caregivers, or *family caregivers*, are relatives, friends or other members of the community who provide care to people living with dementia (PLWD). Dementia caregivers provide help and support with a wide and increasingly complex range of tasks to meet the needs of the person with dementia. Thanks to such support, PLWD can remain at home, in their communities, and engaged in cherished activities. However, providing daily care and support for someone with dementia is difficult and often has negative consequences for the health and wellbeing of caregivers. Dementia caregivers are more likely than non-caregivers or caregivers of people without dementia to experience higher levels of anxiety and depressive symptoms<sup>1,2</sup>, see a reduction in their social networks<sup>3</sup>,

and professional activities.<sup>4</sup> Because of the responsibilities of care, dementia caregivers often deprioritize their own health and delay seeking the help and care they need. For these reasons, it is imperative that supportive services, programs, and resources are readily available and accessible to dementia caregivers within their community.

Public health has a role to play in ensuring that a coordinated system of community-based support and effective programs exist for dementia caregivers. The purpose of this document is to serve as a resource and a guide for public health agencies as they help build this support network, and, more specifically, as they promote the dissemination of evidence-based programs (EBPs) for dementia caregivers within their jurisdictions.

This document has three sections:

## 1 EVIDENCE-BASED PROGRAMS FOR DEMENTIA CAREGIVERS

Section 1 introduces EBPs for dementia caregivers, outlines program advantages, and provides information on how to access them.

## 2 CONSIDERATIONS FOR PUBLIC HEALTH DISSEMINATING EVIDENCE-BASED PROGRAMS








Section 2 describes the role of public health in disseminating EBPs, provides actions public health agencies can take to assist in the implementation of caregiving interventions, and showcases how state health agencies are supporting caregiver programs.

## 3 CONSIDERATIONS FOR ORGANIZATIONS DELIVERING EVIDENCE-BASED PROGRAMS

Section 3 focuses on public health agency partners, such as health systems and community-based service provider organizations that are serving PLWD and their family caregivers. This section also outlines organizational considerations and other resources to support the selection, implementation and sustainability of EBPs for dementia caregivers. Public health agencies can share this information with their community partners to guide and support them in implementing programs for dementia caregivers.

# 1 | EVIDENCE-BASED PROGRAMS FOR DEMENTIA CAREGIVERS

There are different types of strategies, or “interventions,” to support dementia caregivers. These interventions differ in their goals or areas of focus, as well as in their approach and delivery method. Table 1 describes the focus of different types of caregiver interventions. Supportive programs for dementia caregivers offered in communities across the country often include one or a combination of interventions.

TYPE OF CAREGIVER INTERVENTION	FOCUS
 <b>CASE MANAGEMENT</b>	Provides assessment, information, planning, referral, care coordination and/or advocacy for caregivers.
 <b>PSYCHOEDUCATIONAL APPROACHES</b>	Includes structured programs that provide information about the disease, resources and services, and information about how to expand skills to effectively respond to symptoms of the disease (for example, cognitive impairment, behavioral symptoms and care-related needs). Includes lectures, discussions and written materials and is led by professionals with specialized training.
 <b>COUNSELING</b>	Aims to resolve pre-existing personal problems that complicate caregiving to reduce conflicts between caregivers and care recipients and/or improve family functioning.
 <b>PSYCHOTHERAPEUTIC APPROACHES</b>	Involves the establishment of a therapeutic relationship between the caregiver and a professional therapist (for example, cognitive behavioral therapy for caregivers to focus on identifying and modifying beliefs related to emotional distress, developing new behaviors to deal with caregiving demands, and fostering activities that can promote caregiver well-being).
 <b>RESPIRE</b>	Provides planned, temporary relief for the caregiver through the provision of substitute care. Examples of this include adult day services and in-home or institutional respite care for a certain number of hours per week.
 <b>SUPPORT GROUPS</b>	Provides caregivers the opportunity to share personal feelings, concerns, and address feelings of isolation. They can also provide information on local resources, such as respite care, chore services, legal assistance, etc. Support groups are less structured than psychoeducational or psychotherapeutic interventions.
 <b>MULTICOMPONENT APPROACHES</b>	Involves intensive support strategies that combine multiple forms of intervention, such as education, support and respite, into a single, long-term service (often provided for 12 months or more).

Source: Alzheimer’s Association. 2024 Alzheimer’s Facts and Figures. 2024. Alzheimer’s Dement 2024; 20(5)



## INTRODUCTION TO EVIDENCE-BASED PROGRAMS

When selecting programs to assist dementia caregivers it is important to choose interventions that are supported by evidence demonstrating their effectiveness. On the continuum of evidence, evidence-based interventions—interventions backed by solid, rigorous research demonstrating positive results—are the gold standard. **Evidence-based programs (EBPs)** include evidence-based interventions, and aspects of the program responsible for those results have been identified.

A related term is **evidence-informed programs (EIPs)**. EIPs are also on the continuum of evidence, but unlike EBPs, they have not been as rigorously tested. For EIPs, it is not always clear what aspects of the programs

are responsible for their positive results, making it difficult to replicate in other community settings. Nevertheless, EIPs have the potential to work and may have a positive impact on people's lives.

To ensure that public resources are directed toward programs with the highest potential to deliver positive results to the largest number of people, public health agencies are encouraged to evaluate, compare, and select programs with a strong evidence base that are the best fit for the needs of caregivers in their communities.

For definitions and criteria for identifying EBPs and EIPs used by different federal agencies, see Appendix.

### ADVANTAGES OF USING EVIDENCE-BASED PROGRAMS

**Proven to work:**

Effectiveness has been demonstrated and there is a better probability that the program will produce successful results.

**Reliable:** Program elements responsible for the positive outcomes have been identified and can be reliably replicated.

**Address chronic disease:** EBPs that address chronic disease have the potential to reach many people.

**Ready to use:** EBPs are often “packaged” with instructions and tools for implementation, training, evaluation, and delivery, making them easier to implement and use.

**Help secure funding:** Funding agencies are more likely to support programs that have demonstrated benefits.

## FINDING EVIDENCE-BASED PROGRAMS

Often the biggest challenges public health agencies and service organizations face is finding programs that best meet the needs of caregivers in their community, and at the same time, wisely use their limited resources. The ability to compare programs and select those that are the best fit is therefore key. One tool that public health professionals can utilize for decision-making is *Best Programs for Caregiving* (formerly called Best Practice Caregiving).

Best Programs for Caregiving is a free, national database of EBPs for caregivers

of individuals with dementia. The database has two portals, one for professionals and one for caregivers. Its **professional portal** is designed for use by organizations and other professionals who work closely with caregivers and offers valuable information that organizations can use to compare and select the programs that can best meet the needs of caregivers in their community. The **caregiver portal** is intended for use by friends and family caregivers of PLWD. Searchable by zip code, the database makes it easy for caregivers to find local dementia care programs that meet their needs and preferences.

The screenshot shows the homepage of the Best Programs for Caregiving website. At the top left is the logo "best programs for caregiving" with the tagline "guiding you to proven support for dementia care". To the right are navigation links for "Caregivers" and "Professionals". Below the logo is a partnership statement: "A partnership between Benjamin Rose Institute on Aging and Family Caregiver Alliance". The main content area is split into two columns. The left column is titled "Dementia Care Programs for Family Caregivers" and features a collage of images showing caregivers and a yellow circular icon with hands holding a heart. Below the title, it states: "Best Programs for Caregiving is a free online national database of proven effective dementia care programs for family caregivers and the organizations that provide them." It then lists what users will find: "• Descriptions of dementia care programs that are available in your area", "• Languages programs are given in", "• How to know if you're eligible", "• Whether a program is offered online, in person, or hybrid", "• How to enroll", and "• Information on the program providers". At the bottom of this section is a blue button that says "I Care for Someone with Dementia". The right column is titled "Dementia Care Program Info for Program Providers" and features a collage of images showing people interacting and a blue circular icon with hands holding a heart. Below the title, it states: "Best Programs for Caregiving is a free online national database of proven dementia programs for family caregivers. It offers a searchable, interactive, national database of vetted, effective programs that offer much-needed information and support. The database is an invaluable tool for healthcare and community-based organizations, as well as funders and policy makers to discover and share high quality programs for caregivers." At the bottom of this section is a blue button that says "I'm a Program Provider". At the very bottom of the page, there is a small copyright notice: "© 2024 Best Programs for Caregiving. All right reserved."



## 2 | CONSIDERATIONS FOR PUBLIC HEALTH DISSEMINATING EVIDENCE-BASED PROGRAMS

Dozens of effective caregiver programs have been developed in the past few decades, and many are available in communities across the country. However, EBPs have not been widely disseminated and sustained, limiting their access and use by families and service providers. Factors impeding the large-scale dissemination of EBPs include limited applicability of programs to small groups of families, need for workforce preparation to deliver programs, dependence on external sources of funding to sustain programs over time, and mismatch between the program's focus on the caregivers and the healthcare organizations' focus on a single beneficiary, the patient, among others.<sup>5,6</sup>

There are several national efforts in place to increase access to EBPs. In 2019, the National Institute on Aging (NIA) funded the [NIA Imbedded Pragmatic AD/ADRD Clinical Trials \(IMPACT\) Collaboratory](#). In 2020, the Centers for Disease Control and Prevention

(CDC) established three Public Health Centers of Excellence, as part of the congressional [Building Our Largest Dementia \(BOLD\) Infrastructure for Alzheimer's Act](#), with one center focusing primarily on caregiving. More recently, in 2023, the CMS Innovation Center announced its new [Guiding an Improved Dementia Experience \(GUIDE\) Model](#). These efforts seek to accelerate the diffusion of EBPs in the research, public health, and healthcare sectors, respectively.

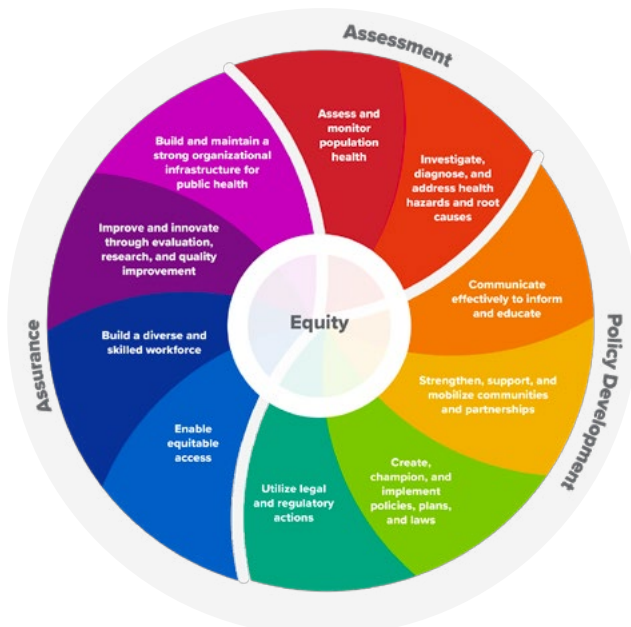
In this national context, there is a role for public health to strengthen these broader dissemination efforts. Public health professionals help build the capacity of community and aging service organizations through training, workforce development, and assistance with the adoption and implementation of new interventions. By doing this, public health can support widespread dissemination, adoption and use of EBPs across the U.S.



# WHAT CAN PUBLIC HEALTH DO TO PROMOTE THE ADOPTION OF EVIDENCE-BASED PROGRAMS?

Most public health departments do not implement programs or deliver services directly to caregivers. However, they play a central role in ensuring that supportive programs and resources are broadly available and that people in the community are aware of them.

Below we present *seven key actions* that public health agencies can lead to support wide dissemination, adoption and effective use of EBPs. These actions align with the 10 Essential Public Health Services<sup>7</sup>, as they raise awareness, increase access, and promote conditions in the community so that all *caregivers in all communities* can benefit from effective programs.



Source: 10 Essential Public Health Services Framework. Centers for Disease Control and Prevention. Available at <https://www.cdc.gov/public-health-gateway/php/about/index.html>

- 1 Conducting a Landscape Assessment:** As a first step, public health can conduct environmental scans to understand what programs are available to assist dementia caregivers in their jurisdiction. Knowing what types of services are missing, in what areas services are not available, and what organizations are already delivering elements of comprehensive dementia care will help inform later resource planning and allocation.

- 2 Promoting Programs and Facilitating Referrals:** Public health can identify and promote effective programs to local

service organizations serving older adults and their caregivers. Public health agencies can increase awareness by offering informational sessions and program materials and directing service organizations to Best Programs for Caregiving, where they can learn more about specific programs and find those that are the best fit. Health agencies can also use their existing outreach and recruitment platforms to refer and connect dementia caregivers with organizations delivering the programs.

- 3 Promoting Best Practices:** Public health can identify organizations that have implemented and sustained EBPs and widely share their learnings to model how organizations can better serve dementia caregivers. Public health departments can synthesize the approaches and strategies that were key to successful implementation of EBPs, identify opportunities for improvement, and develop tools and materials to aid with selection and use of EBPs.
- 4 Providing Funding:** To encourage adoption of EBPs, public health agencies can promote existing funding opportunities and provide seed money grants for implementing EBPs to local organizations that are interested in growing their dementia caregiving programming (e.g., to support training/certification in delivering a given

program). Public health agencies might also choose to cover part or all of the costs of program launch, licensing, or training.

**5 Leveraging Partnerships:** Public health departments can stimulate the development of coordinated dementia care systems in their jurisdictions by facilitating connections between health systems and local community-based organizations offering EBPs for dementia caregivers. They can collaborate and pool resources with partners already implementing or interested in implementing EBPs to raise awareness, increase program enrollment and support other program-related activities.

**6 Centering Equity and Diversity:** Public health agencies can help increase access to EBPs for caregivers in underserved and minority populations by promoting interventions that have been adapted for different cultural communities and by coordinating efforts and resources to adapt those that have not.

**7 Monitoring and Evaluating:** Given their expertise in data collection and evaluation, public health agencies can help track population-level outcomes of delivering EBPs and ensure that the programs are reaching and benefiting caregivers in diverse communities.



## EXAMPLES FROM PUBLIC HEALTH PRACTICE



### RHODE ISLAND: Powerful Tools for Caregivers

PROMOTING PROGRAMS | FACILITATING REFERRALS | LEVERAGING PARTNERSHIPS

#### PARTNERING FOR SUCCESS

The Rhode Island Department of Health (RIDOH) has supported the dissemination of *Powerful Tools for Caregivers* by joining broader outreach efforts to promote and raise awareness about the program across the state. In this work, RIDOH has leaned on its partnership with the Office of Healthy Aging (OHA). The OHA is a close collaborator of RIDOH on its dementia and caregiving initiatives, and funds *Powerful Tools for Caregivers*. By working closely with the primary program funder, RIDOH can help ensure that funding continues to be available and that the program is accessible to caregivers across the state.

**The Community Health Network**, Rhode Island's centralized system for referrals and data management that facilitates access to EBPs addressing chronic disease prevention and management, has been crucial to the success of the dissemination strategy. Funded by the various chronic disease programs at the RIDOH, the *Community Health Network* is a single portal for connecting caregivers across the state with available evidence-based supportive programs, including the National Diabetes Prevention Program, "Ready for Health," Chronic Pain Self-Management, and Tools for Healthy Living, among others. Using a shared platform allows the Alzheimer's Disease and Related Disorders

program to efficiently leverage shared resources with other chronic disease programs at RIDOH and at the same time help caregivers protect their own health.

#### THE CHALLENGE

A challenge for the dissemination of *Powerful Tools for Caregivers* has been staff capacity and maintaining staff certification to deliver the course among community-based organizations. To address this issue, RIDOH plans to engage community health workers (CHWs) to augment the capacity of the workforce. With the ability to [reimburse CHWs for service provision in Rhode Island](#), the opportunity to train CHWs to deliver EBPs, including *Powerful Tools for Caregivers*, will be explored. In the long term, CHWs and other key partners will continue to promote and connect caregivers to supportive EBPs.

#### POWERFUL TOOLS FOR CAREGIVERS

Powerful Tools is a group-based, education program for family caregivers designed to empower them to better care for themselves and reduce the negative effects of caregiving.

Read about this program at <https://www.powerfultoolsforcaregivers.org/>

To learn about the experience of organizations that have implemented it, visit <https://bpc.caregiver.org/#programDetails/powerful-tools>



## GEORGIA: Savvy Caregiver and Tele-Savvy

PROVIDING FUNDING | LEVERAGING PARTNERSHIPS | PROMOTING PROGRAMS

### PARTNERING FOR SUCCESS

The Georgia Department of Public Health (GA DPH) has long supported the implementation of evidence-based and evidence-informed programs for family caregivers. Most recently, the GA DPH launched and disseminated the *Savvy Caregiver* and the *Tele-Savvy Caregiver* programs. For *Savvy Caregiver*, the agency conducted an initial scan to determine program-associated costs, purchased the books and the program license, facilitated volunteer training, secured space for programming, and collaborated with its partners on promotion and marketing to raise awareness of the program among caregivers.

To promote, reach, and connect as many caregivers as possible with the program, the GA DPH has relied on its broad network of partners, including Area Agencies on Aging, local health departments, the Georgia Memory Net, the state Alzheimer's disease and related dementias (ADRD) coalition, and the University of Georgia Extension Offices. The partners also assist with program evaluation. Collaborative reporting by all organizations offering *Savvy Caregiver* will help avoid duplication and help identify areas of the state where programming is needed.

### THE CHALLENGE

A major challenge to wider and faster implementation of *Savvy Caregiver* has been the stringent training requirements and the high program cost. Because *Savvy Caregiver* is delivered by a wide network of volunteers,

obtaining individual program licenses may be cost prohibitive. Also, getting the training materials and books to partner organizations implementing the program has been difficult at times. Part of this burden has been alleviated by the GA DPH covering the licensure expenses, and some partners, like the Georgia Memory Net, are starting to take on the implementation of the program. But as the need for the program grows, finding ways to sustain it in the long term and reduce costs will be a priority for the GA DPH and its partners.

In addition to *Savvy Caregiver*, the GA DPH also supports *Powerful Tools for Caregivers*, a program traditionally offered by Area Agencies on Aging, as well as the [Virtual Dementia Tour](#) and the [Alter™](#) program. The *Virtual Dementia Tour* serves as an introduction for communities and the public health workforce to the challenges of living with dementia/cognitive decline. Once communities have completed this program, [Alter™](#) partners work with local churches to implement a dementia-friendly faith community and educate caregivers in churches on what other programs (e.g., *Savvy Caregiver*, *Powerful Tools for Caregivers*) are available.

#### SAVVY CAREGIVER

*Savvy Caregiver* is an educational program for family caregivers of community-based adults living with dementia. It focuses on building caregiving skills, coping with stress and engaging the person living with dementia in daily activities. To learn more about *Savvy Caregiver*, visit <https://savvycaregiver.com/>



## HAWAII: Savvy Caregiver

PROVIDING FUNDING | LEVERAGING PARTNERSHIPS | PROMOTING PROGRAMS

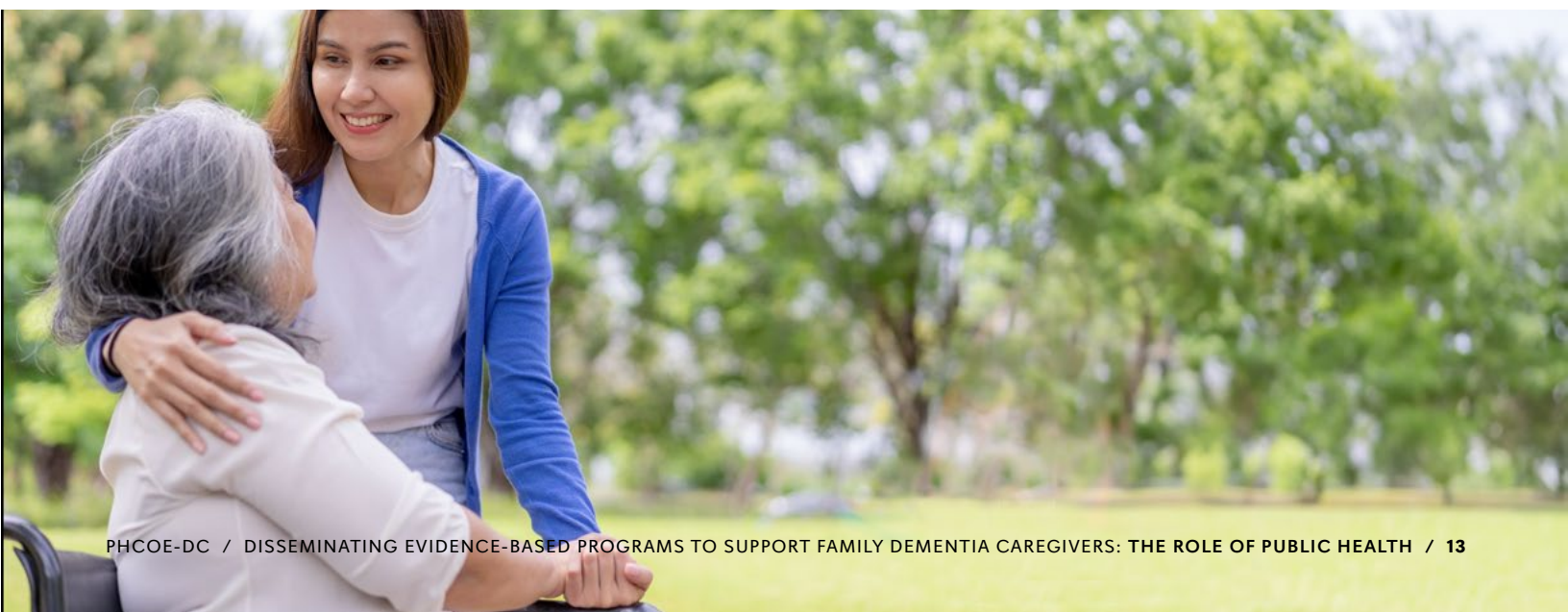
### PARTNERING FOR SUCCESS

As in Georgia, the Hawai'i State Department of Health (DOH) Executive Office on Aging (EOA) has supported the dissemination of the *Savvy Caregiver* program. With grants from the ACL, the agency provided funding for the initial program launch, offering stipends for new trainers and making Zoom accounts available for virtual training. The DOH EOA engaged a few local community partners, including Kula No Na Po'e Hawai'i, a Native Hawaiian beneficiary serving organization, adult day care centers, and a local church, to promote *Savvy Caregiver* and encourage their clients to enroll in the program. It also encouraged Area Agencies on Aging to refer caregivers to the program. Additional caregivers from other islands were able to attend the training once the program was offered virtually via Zoom during the Covid-19 pandemic. The team also added a "Class Zero" to allow participants to meet each other, share experiences and establish relationships, which were in line with social practices and preferences of the local Hawaiian culture.

### THE CHALLENGE

Challenges were faced in implementing the *Savvy Caregiver* in Hawai'i. As an island state, it was cost prohibitive to fly trainers weekly for the six weeks of classes. DOH EOA pivoted to delivering the training via Zoom. Changing to an online platform posed its own challenges and impacted recruitment and retention. Finally, like in Georgia, DOH EOA had difficulty sustaining the costs to cover licensing fees.

Thanks to [recent legislation](#), the DOH EOA was able to purchase the license creating the opportunity to continue to deliver the *Savvy Caregiver* program. The legislation will enable the Area Agencies on Aging to contract Savvy Caregiver trainers to deliver the program statewide, thus sustaining and expanding the program in Hawai'i. This, along with other strategies to make the training more accessible to caregivers, will be key to sustaining and expanding *Savvy Caregiver* in Hawai'i.





## VERMONT: TEACH, TCARE, CARERS, UCLA Alzheimer's and Dementia Care, and more

PROVIDING FUNDING | PROMOTING PROGRAMS | LEVERAGING PARTNERSHIPS

### PARTNERING FOR SUCCESS

The BOLD Program in Vermont is supporting the dissemination of multiple evidence-based and evidence-informed programs through its partnership with the VT Dementia Family Caregiver Center (DFCC). The Center, based at the University of Vermont's Medical Center (UVMCMC), offers several programs designed to support caregivers, including *CARERS*, *TEACH*, *TCARE*, *Peer to Peer Mentoring Program for Caregivers*, and the *VT BRIDGES* program for training gerontological social workers. The Center grew out of demand for meeting dementia caregivers' needs for training, support, and linkages to services (legal, respite, and others).

Vermont's BOLD Program is based at the VDH Alzheimer's Disease and Healthy Aging program, and collaborates closely with the Department of Disabilities, Aging and Independent Living (DAIL). Together, the two departments are funding the DFCC and the UVMCMC School of Nursing to conduct a pilot of a coordinated dementia care model, the Vermont Alzheimer's and Dementia Care Project. The care model is based on the UCLA Alzheimer's and Dementia Care Program, designed to benefit both individuals diagnosed with dementia and their caregivers.

The VDH regularly promotes information about all these initiatives in a number of ways, including its monthly newsletter, and the Alzheimer's Disease and Healthy Aging Coalition, which comprises a Hub and Spoke ADRD Workgroup, a Chronic

Disease and Brain Health Partnership, the Governor's Commission on Alzheimer's Disease and Related Dementias, and the DFCC. All coalition partners are invited to share their data and metrics with each other, which encourages regular dissemination of data and announcements about caregiving programs to the public. The VDH incorporates DFCC's dementia caregiver related data in its evaluation of collaborative dementia work across the state. It also plans to grant funds each year to support the mission of the DFCC.

### THE CHALLENGE

A challenge to increasing the use of programs has been the mismatch between the times at which the DFCC offers its programming and the times when family caregivers are available. Finding ways to increase staffing and secure resources to expand program hours at the center is critical for increasing the utilization of caregiving programs. The BOLD Program will provide partial funding for the VT BRIDGES program to assess the upfront causes of non-acute long-stay dementia patients in acute hospital beds. The assessment will examine services received/not received before admittance, contact points before admission (primary care provider, Home Health, mental health) and reason for admission. Based on the findings, a plan will be developed to connect caregivers to services and supports prior to hospitalization as a route to long-term care placement.



### 3 | CONSIDERATIONS FOR ORGANIZATIONS DELIVERING EVIDENCE-BASED PROGRAMS

As mentioned previously, public health departments do not normally implement caregiving programs. However, they can provide guidance and information to health systems, service organizations and other community partners to support them in selecting, implementing, and evaluating the implementation of EBPs. The following section highlights key considerations for community-based organizations and service providers when assessing their readiness to implement and sustain EBPs.

The recommendations presented below are based on the *Toolkit on Evidence-Based Programming for Seniors*, created by the Community Research Center for Senior Health at the Baylor Scott & White Center for Applied Health Research, and the *Choosing an Evidence-Based or Evidence-Informed Intervention: Considerations to Inform Decision-Making*, by the Administration for Community Living. For each topic, we list a few key questions service organizations can consider when assessing their readiness to implement programs. This list is not exhaustive, and organizations are encouraged to consult additional resources provided throughout this document.

**ADDITIONAL RESOURCES FOR PROGRAM IMPLEMENTATION**

- > [\*Implementation Science at a Glance: A Guide for Cancer Control Practitioners\*](#). While this workbook is focused on programs for cancer control, it can be a useful resource for dementia-specific programs.
- > The Community Toolbox, Chapter 19. [\*Choosing and Adapting Community Interventions\*](#) offers practical guidance for communities for selecting and adapting promising interventions.
- > [\*Choosing an Evidence-Based or Evidence-Informed Intervention: Considerations to Inform Decision-Making\*](#), by the Administration for Community Living National Alzheimer's and Dementia Resource Center (NADRC).
- > [\*Filling the Gaps in Dementia-Capable Home & Community-Based Services: Report on Completed Administration for Community Living ADI-SSS Grants to Communities and States\*](#), by the Administration for Community Living National Alzheimer's and Dementia Resource Center (NADRC)

## UNDERSTANDING CAREGIVERS' NEEDS

Before the right program can be selected for implementation, it is necessary to **understand the needs of dementia caregivers in the community** by conducting a needs assessment. To obtain as comprehensive a picture as possible, organizations can obtain baseline population-level data from existing, secondary data sources such as the Caregiving Module of the Behavioral Risk Factor Surveillance System (BRFSS), as well as other periodic assessments conducted by aging and health agencies across a state. This state- and regional-level information can be supplemented by *primary* data gathered directly by public health agencies and their partners. The tools and methods used to obtain these data can vary depending on the amount and type of information desired and the resources available, but the goal is to obtain a more nuanced understanding of the needs, experiences, and preferences of dementia caregivers in the local community. Informant groups should include caregivers and people living with dementia, who can share opportunities they may see for improving access to the support they need based on their personal experiences.

Finally, the information from the collected needs assessment can be combined with the learnings from the landscape assessments of community resources, assets, and programming available to caregivers. Mapping needs and assets together can help organizations identify local gaps in services and determine what kinds of programs they can implement to address these unmet needs.



### Q Questions to ask

Below are a few key questions to ask when conducting a needs assessment.

1. *What is the estimated number of dementia caregivers in your community of focus?*
2. *What are their demographic and socioeconomic characteristics, where do they live and what are their caregiving-related needs?*
3. *Where are caregivers in the community currently finding support and how are they accessing it?*
4. *Are there other organizations that offer the same or similar programs? If yes, where are they located and what is their reach?*

### ADDITIONAL RESOURCES

#### Specific to aging and/or dementia:

- > [Needs Assessment Toolkit for Dementia, Cognitive Health and Caregiving](#), by the Association of State and Territorial Health Officials (ASTHO)

#### General:

- > [The Community Toolbox: Community Health Assessment and Planning](#) tools.
- > The Community Toolbox: [Online Training Courses for Community Health Improvement](#) can support the community health need assessment process.





## SELECTING THE RIGHT PROGRAM

Once the organization has a good understanding of the needs of caregivers in their community, the organization can compare available programs and select those that would best match identified needs. The *Best Programs for Caregiving* database provides information about program implementation as well as utilization experience at other delivery sites. Organizations can also contact others that have implemented the same EBPs to learn about their successes and challenges with program implementation and how they overcame them.

### Q Questions to ask

Organized by different program features, below are a few key questions to ask when selecting a program for your organization and community.

#### Target population and conditions:

1. *Is the program designed to support caregivers of people living with a specific type of dementia, and/or any chronic conditions other than dementia?*
2. *Is the program intended only for the family caregivers or the person with dementia or both?*

#### Mode of delivery and program components:

3. *Do key delivery methods of the program (in person, phone, video, web-based, email, etc.) match the preferences of your community?*
4. *What types of assistance does the program provide to participants (e.g. financial, pain management, caregiver coaching, healthcare coordination, etc.) and how well does this match with what you learned in your community caregiver needs assessment?*

#### Program adaptations:

5. *Do any adaptations need to be made to the program in order to reach and serve your community?*
6. *Are program materials available in languages other than English?*

### ADDITIONAL RESOURCES

#### Specific to aging:

- > [The National Council on Aging \(NCOA\)](#) has a search tool for evidence-based programs that are approved for funding by the Older Americans Act Title III-D. Users can either download a spreadsheet of approved programs or search by a program title or “caregiving” search word.
- > The Administration for Community Living (ACL) maintains a list of all EBPs and EIPs that have been implemented by Alzheimer’s Disease Supportive Services Program, Alzheimer’s Disease Initiative Specialized Supportive Services, and Alzheimer’s Disease Program Initiative (ADPI) grantees. The list of programs can be found at [Grantee-Implemented Evidence-Based and Evidence-Informed Interventions](#).

#### General:

- > The Community Toolbox [Databases of Best Practices](#), provides links to many sites that promote best practices for community health and development.
- > [Guidelines for selecting an evidence-based program: Balancing community needs, program quality, and organizational resources](#), developed by the University of Wisconsin–Madison and University of Wisconsin–Extension, identifies several factors that should be considered when deciding which program is the most appropriate for a particular audience and sponsoring organization.

## ADAPTING PROGRAMS TO LOCAL COMMUNITIES

Programs are not always one-size-fits-all and they often need to be adapted to be meaningful and useful for caregivers in culturally and ethnically diverse communities. **Cultural adaptation** is defined as *“the systematic modification of an evidence-based intervention to consider language, culture, and context in such a way that it is compatible with the client’s cultural patterns, meanings, and values.”*<sup>8</sup>

Culturally adapting a program, therefore, is much more than simply translating materials into another language. Central to the adaptation process is maintaining program *fidelity*, or the extent to which the program is imple-

mented as originally intended. This means that the changes made to the program, such as adding new cultural content or changing the method of engagement, should not alter the core elements of the program and its principles that are responsible for its positive outcomes.<sup>9</sup>

If an organization is interested in culturally adapting a program for a community of focus, it is always best to consult with the program developer to discuss adaptations. As a rule of thumb, Table 2 shows the type of adaptations and the degree of caution that should be exercised when making them.

TYPES OF PROGRAM ADAPTATIONS	DO NOT ADAPT WITHOUT CONSULTATION	ADAPT FREELY
REMOVING OR CHANGING TOPICS	X	
REPLACING OR MODIFYING CULTURAL REFERENCES	X	
REDUCING THE NUMBER, LENGTH, OR FREQUENCY OF SESSIONS	X	
CHANGING FONTS AND FONT SIZE		X
REPLACING IMAGES TO REFLECT THE ETHNIC AND CULTURAL MAKEUP OF YOUR AUDIENCE	X	
ELIMINATING KEY MESSAGES OR SKILLS TRAINING	X	
USING PERSONNEL WITHOUT ADEQUATE TRAINING OR QUALIFICATIONS	X	
MODIFYING LANGUAGE (E.G., TRANSLATING OR CHANGING WORDS TO INCREASE READABILITY)	X	
REDUCING THE NUMBER OF MATERIALS AND RESOURCES GIVEN TO PARTICIPANTS	X	
ADDING CONTACT INFORMATION FOR YOUR ORGANIZATION AND LOCAL RESOURCES		X
FOCUSING ON A DIFFERENT AUDIENCE	X	
CHANGING AESTHETIC ELEMENTS TO MAKE THE PROGRAM MORE APPEALING TO YOUR AUDIENCE		X
UPDATING HEALTH STATISTICS AND OTHER SCIENCE-BASED INFORMATION TO REFLECT CURRENT FINDINGS	X	

Adapted from: *Toolkit for Evidence Based Programming for Seniors*. Community Research Center for Senior Health, Baylor Scott & White Research Institute Center for Applied Health Research. (2014)

## ASSESSING ORGANIZATIONAL CAPACITY AND READINESS

After selecting a new program, the organizations should consider assessing its overall readiness for the change. A helpful framework for assessing organizational readiness is proposed by Scaccia et. al (2015), which recommends evaluating three key components of organizational readiness: motivation to implement the new program, general capacities of the organization and the specific capacities that will be needed for the program.<sup>10</sup> Recognizing strengths and deficits across these three domains will enable the organization to allocate support and resources effectively, ensuring successful implementation and long-term sustainability of the new program.

### Q Questions to ask

Below are a few questions to ask related to each domain of organizational readiness:

#### Motivation:

1. To what degree do staff across the organization perceive the new program as a good fit for the needs of caregivers in the community?
2. Do staff perceive the new program as a valuable addition or as more significant compared to existing programs offered by the organization?

#### General organizational capacity:

3. Does the organization have the internal support to develop and implement the new program? If not, is there a “champion” in the leadership team who can help raise support and move the organization toward readiness?
4. How supportive has the organizational culture been in the past of similar innovations and new programs?

#### Program-specific capacity:

5. Are there any staff in the organization who are familiar with or have delivered this program in the past, and what were their experiences?
6. If the program will be focused on a specific cultural community, are there staff within the organization that identify as members of that community and who can serve as liaisons and program advocates in the community?

7. Will the organization need to purchase any program-specific equipment, manuals and materials for staff?
8. Does the organization have enough resources for operating costs for the first 1-3 years at least?
9. Will participants need to have access to technology, equipment, devices, transportation or other resources in order to participate in the program?
10. What professional expertise or roles will be needed on the team that will deliver the program, and do you have these within your organization?
11. Will new skills training or credentials be necessary for the staff delivering the program?
12. Is there a license fee for the program? How many people can be trained with the license?
13. Is the training included in the license fee or is it an additional cost? Are training materials included or will that be an additional cost?
14. Is there a “Train-The-Trainer” opportunity?
15. Are there data reporting requirements to the program developer?
16. Will additional staff need to be hired or does current staff have capacity to take on the activities of the new program?
17. Will technical assistance be available? If so what type of support will be included and what is the cost?

### ADDITIONAL RESOURCES

- > **Tip Sheet: Strategies to Improve Leader Retention for Chronic Disease Self-Management Education**, by the NCOA, summarizes best practices for identifying and retaining lay leaders, and provides links to recruitment and screening tools.
- > **A Practical Implementation Science Heuristic For Organizational Readiness: R = MC2**. This article by Scaccia and colleagues presents a three-dimensional framework – motivation, general capacity and innovation-specific capacity – for assessing organizational readiness for change. Available at <https://pubmed.ncbi.nlm.nih.gov/26668443/>



## BUILDING PARTNERSHIPS

Organizations can collaborate with others to deliver or help with certain aspects of new programs, from staff training to professional expertise on the team to evaluation of program outcomes, for instance. Partnering with other service organizations to deliver some aspects of the program can help reduce duplication, share costs, utilize partners' expertise, and extend the program's reach to new, diverse communities. Thanks to this, partnerships can strengthen the long-term sustainability of EBPs and make them available to more caregivers in diverse communities.

## Q Questions to ask

Below are a few questions to ask when identifying and selecting partners to deliver programs.

1. *Can you collaborate with organizations delivering the same program in other communities?*
2. *Can you partner with others to deliver parts of the program?*
3. *If new training for the staff will be necessary, do you have any partners who can provide the training?*
4. *Do you have a partner with the professional expertise you need on their staff from which you can subcontract?*
5. *If you are trying to reach caregivers in remote or small cultural communities, is there a cultural-service provider organization that already serves that community that you can partner with to deliver certain aspects of the program?*

## ADDITIONAL RESOURCES

> [Strategic Partnerships](#), by the NCOA

# APPENDIX

There is not a single definition of what constitutes an evidence-based intervention used across multiple disciplines, and criteria for what qualifies as an EBP might vary from one field or agency to another. The following are additional standards and criteria for EBPs used by leading federal agencies:

[Standards Required for the Development of CDC Evidence-Based Guidelines](#), CDC

[Community Guide Methodology](#), *The Community Guide*, CDC Community Preventive Services Task Force

[Health Promotion Eligibility Criteria and Definition of EBP](#), Administration for Community Living (ACL)

[Evidence Base Resource Guide Series](#), Substance Abuse and Mental Health Services Administration (SAMHSA)

[National Evidence-based/informed Strategy Measures \(ESMs\) Summary](#), Health Resources and Services Administration (HRSA)

## ACL'S DEFINITION OF EVIDENCE-BASED AND EVIDENCE-INFORMED PROGRAMS<sup>11</sup>

The Administration for Community Living (ACL) provides grants to states and communities to implement evidence-based and evidence-informed programs to people living with dementia and their family caregivers. In its ADPI funding announcements, the ACL provides the following definitions to its grantees:

**Evidence-Based Programs:** have been tested through randomized controlled trials and are: 1) effective at improving, maintaining, or slowing the decline in the health or functional status of people living with dementia or family caregivers; 2) suitable for deployment through community-based human services organizations and involve non-clinical workers and/or volunteers in the delivery of the intervention; 3) the research results have been published in a peer-reviewed scientific journal; and 4) the intervention has been translated into practice and is ready for distribution through community-based human services organizations.

**Evidence-Informed Programs:** have substantive research evidence that demonstrates an ability to improve, maintain, or slow the decline in the health and functional status of people living with dementia or family caregivers. ...an evidence-informed intervention is one that has: 1) been tested by at least one quasi-experimental design with a comparison group, with at least 50 participants; OR 2) is an adaptation or translation of a single evidence-based intervention.

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