

Choosing the Right Evidence-Based Dementia Caregiving Programs for Your Community and Organization

O4A Pre-Conference 2022 Annual Meeting

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Why a Health Department is Providing Programs for Family Caregivers

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About Summit County Public Health

Our Mission

The mission of Summit County Public Health is to protect and promote the health of the entire community through programs and activities designed to address the safety, health and well-being of the people who live in Summit County. The Health Department seeks to create a healthful environment and ensure the accessibility of health services to all.

Vision Statement

We envision a community where all can achieve optimal health where they live, work and play, resulting in...

HEALTHY PLACES, HEALTHY PEOPLE, AND HEALTHIER TOMORRO



Reason's Why?

- Aging Numbers
 - AD 5.8 Million Adults U.S.
 - 54 Million older adults live the US; 16.5 %
 - 85.7 estimate by 2050
- Alzheimer's is a Public Health Crisis
 - Historically viewed as an medical or aging issue
 - Growing recognition of public health crisis
 - Large and growing epidemic
 - Significant impact
 - There are ways to intervene

<https://www.americashealthrankings.org/learn/reports/2021-senior-report/introduction>



Reason's Why?

- Support Caregivers
 - 83% of care provided to older adults is by family, friends and other unpaid caregivers
 - Over 16 Million caregivers
 - 18 billion hours of unpaid care annually
 - Hardships: health, emotional and financial
 - Unpaid care valued at \$233.9 billion (2018)



Role of Public Health

- System
 - Early diagnosis
 - Programming
- Policy
 - Use Surveillance Data to inform public policy and planning
- Environmental Changes
 - Education



Administration on Aging Grant (#90APDI0045)

In 2019, Summit County Public Health received funding from the Health and Human Services, Administration for Community Living/Administration on Aging to improve Summit County, **Ohio's Dementia Capability**

August 2022, Received a No-Cost One Year Extension

Project Period: 9/30/2019 through 9/29/2023

Target Population/Location = People with Dementia and Caregivers in Summit County, Ohio

The view and opinions expressed in this Power Point presentation are those of the presenter and not necessarily of the presenter's organization including the U.S. Department of Health and Human Services and the Administration for Community Living/Administration on Aging.



Partners





Grant Goals and Interventions

Goal	Intervention
Develop and deliver supportive services to persons living alone with Alzheimer's disease and related dementias (ADRD). Applicants must describe actions they will take to identify and support individuals living alone with ADRD	Gatekeeper Program –Train and receive referrals
	Dementia Friends Trainings -- DF LA, DF IDD, DF Champions
	Brain Health and Medicine, Age and Your Brain
Improve the quality and effectiveness of programs and services dedicated to individuals aging with intellectual and developmental disabilities (IDD) with ADRD or those at high risk of developing ADRD. Program activities should focus on the unique circumstances of this population	DF IDD
	Supplemental ADRD/IDD Training
	Trained Mentors and Coaches
	Sustainability within the DD system
Deliver behavioral symptom management training and expert consultation services to family caregivers using evidenced based programming. Focus is on impacting disease progression, quality of life for the caregiver and receiver, function decline etc. Programming should focus on symptom management training, caregiver stress, education demonstrated to have positive outcomes	Required Evidenced Based Programming to support caregivers
	BRI Care Consultation
	Behavioral Interventions



BRI Care Consultation

- Why did we choose this program.
 - Researched list provided by ACL and AoA
 - EB Dementia AD Interventions
 - Name of Program
 - Target Population
 - Description of the Intervention
 - Background Publications
 - Contact Info/Access to Intervention Materials
 - Current Site Implementing the Intervention
 - Previous Sites
- Assesses both caregiver and PWD (domains)
- Local Support
- Best Practice Caregiving was not available



Steps to Implementation

- Researched all of the various programs (site research)
- Calls to developers
 - To determine costs
 - Population to served
 - Outcomes





Outcomes

- 21 Referrals
- 10 Enrolled
- 08 Dis-enrolled
- 02 Never Enrolled
- Preliminary outcomes indicate that there have been decreases in triggers from the first assessment to the re-assessment
- Improvements in Geriatric Depression, Caregiver Wellbeing and Quality of life for the PWD



Challenges and Successes

Successes

- Implementation
- Staff Trainings
- Positive Fidelity Reviews
- BRI is approachable and helpful
- Monthly BRI Marketing Meetings
- Networking and New Partnerships

Challenges

- COVID
 - Limited Outreach to the community and to physicians
- Marketing
- Numbers being served
- Financial Sustainability
 - SAPA
 - ODA



QUESTIONS



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- Alzheimer's Association. (n.d.) *Prevention*. Retrieved from https://www.alz.org/alzheimers-dementia/research_progress/prevention
- U.S. Department of Health and Human Services. (2018) *National Plan to Address Alzheimer's Disease: 2018 Update*

Best Practice Caregiving: Partners and Collaborators

Partners

Benjamin Rose Institute on Aging

Family Caregiver Alliance

Gerontological Society of America

Collaborators

Bridge Builders Strategies

Quality Process

Diverse Elders Coalition & member organizations:

- National Caucus and Center on Black Aging
- National Hispanic Council on Aging
- National Indian Council on Aging
- SAGE, Advocacy and Services for LGBT Elders
- National Asian Pacific Center on Aging
- Southeast Asian Resource Action Center

Best Practice Caregiving: Funders



The
John A. Hartford
Foundation



RRF | Foundation
for Aging



ARCHSTONE
FOUNDATION

**best practice
caregiving** | *Guiding organizations
to dementia programs
for family caregivers*

A partnership between
Benjamin Rose Institute on Aging and Family Caregiver Alliance

Funded by The John A. Hartford Foundation, Archstone Foundation, and The Retirement Research Foundation

Caregiving for Persons Living with Dementia

More than 11 million US family/friend caregivers of persons living with dementia

Unpaid caregivers (family and friends) provide more than 80% of care

Caregivers of persons living with dementia:

- More adverse caregiving consequences (e.g., emotional and physical strain)
- Higher prevalence of depression
- Provide more hours of care
- Deal with more stressful symptoms (e.g., behavioral symptoms)
- Pay more out-of-pocket costs for care

Alzheimer's Association. (2022). *2022 Alzheimer's Disease Facts and Figures* (No. 18). <https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf>

Major Advance in the Field of Caregiving

- Many non-pharmacological programs with research-proven benefits for family/friend caregivers
- Some programs also have proven benefits for persons living with dementia
- Some programs are ready for scaling in communities

National Academies of Sciences, Engineering, and Medicine, Committee on Family Caregiving for Older Adults, Board on Health Care Services, Health and Medicine Division (2016). Schulz R. and Eden J., editors. Families Caring for an Aging America. Washington (DC): National Academies Press (US).

Strengths of Evidence-Based Programs

- Based on a theoretical framework – why it should work, expected outcomes
- Standardized protocol for consistent program delivery
- Beneficial outcomes in controlled research
- Qualifications of delivery staff
- Manuals and training for delivery staff
- Tools for delivery and marketing
- Tools for monitoring fidelity

Evidence-Based Programs Are Not All the Same

Variation among programs:

- Strength of research evidence – # studies, methodology quality, impacted outcomes
- Number of sessions and time to complete
- Mode of delivery – in-person, telephone, online, combination
- Target population – disease stage, level of strain, diverse communities
- Whether content is tailored to the individual
- # Non-research implementations
- Cost to deliver program – license, staffing, software
- Types of help provided

Many Options – Challenging to Find the Right Program

- Best match for your organization, mission, and workforce
- Best match for your community
- Programs that are ready for non-research delivery
- Programs that have already worked well in other communities

Best Practice Caregiving: Learn about and Compare Evidence-Based Programs

Easy-to-use free online tool for professionals (Consumer Version under construction)

45 Evidence-based dementia caregiving programs (more being added)

- Complete program descriptions
- Basics of research methodology and results
- Real-world experiences of organizations that delivered programs
- Complete bibliographies
- Who to contact for more information

Inclusion Criteria for Best Practice Caregiving

1. Research Evidence

- Controlled research with at least 1 published, positive outcome for family or friend caregivers
- Caregivers of Persons living with dementia in the community
- US-based research

2. At least 1 “real world” delivery by a healthcare or community organization

3. Available for replication

- Permission or license to deliver
- Manuals, training, and delivery tools

45 Programs in Best Practice Caregiving (2022)

ANSWERS	Inner Resources for Stress	Rosalynn Carter Institute REACH (RCI REACH)
Active Caregiving: Empowering Skills (ACES)	Mindfulness Training for Patients with Progressive Cognitive Decline and their Caregivers	Savvy Caregiver
Adult Day Services Plus (ADS Plus)	Mindfulness-Based Alzheimer's Caregiving	Skills ₂ Care
African-American Alzheimer's Training and Caregiver Support (ACTS-2)	Mindfulness-Based Dementia Care	STAR Caregiver (STAR-C)
Aging Brain Center (Collaborative Care)	Mindfulness-Based Stress Reduction for Dementia Caregivers	Stress-Busting Program
Alzheimer's Disease Coordinated Care for San Diego Seniors (ACCESS)	Minds in Motion	Support Health Activities Resources Education (SHARE)
At the Crossroads	New Ways for Better Days: Tailoring Activities for Persons with Dementia and Caregivers (TAP)	Tailored Caregiver Assessment and Referral (TCARE)
Behavioral Treatment of Insomnia in Caregivers	New York University Caregiver Intervention (NYUCI)	Telehealth Education Program for Caregivers of Veterans with Dementia (SUSTAIN)
BRI Care Consultation	Powerful Tools for Caregivers	Telenovela Mirela
Building Better Caregivers	Progressively Lowered Stress Threshold Intervention (PLST)	The Memory Club
Building Better Caregivers Online	REACH Community	The Unforgettables
Care of Persons with Dementia in their Environments (COPE)	REACH TX	Together We Can!
Care Partners Reaching Out (CarePRO)	REACH VA	UCLA Alzheimer's and Dementia Care (UCLA ADC)
Dealing with Dementia	REACH to Caregivers (CALMA)	Yogic Meditation
Early- Stage Partners in Care (EPIC)	Reducing Disability in Alzheimer's Disease (RDAD)	Care Ecosystem

Organizations Delivering Best Practice Caregiving Programs

324 organizations delivered BPC programs in 2019

Larger number of community implementations than anticipated

Increase in number of organizations projected in our 2022 update

Most common delivery organizations:

- Healthcare systems (24%; n = 77)
- Area Agencies on Aging (24%; n = 77)
- Alzheimer's or Dementia Associations (12%; n = 39)

Most Widely Delivered Programs in 2019 (≥ 11 sites)

- BRI Care Consultation
- Building Better Caregivers
- New York University Caregiver Intervention
- Powerful Tools for Caregivers
- RCI REACH
- REACH Community
- REACH VA
- Savvy Caregiver
- Skills2Care
- TCARE

Common Funding Sources for BPC Programs

Title III-E Older Americans Act (National Family Caregiver Support Program)	34%
Grants other than Administration for Community Living	28%
Participant Payments or Donations	27%
Organization Operating Funds	25%
Administration for Community Living, Alzheimer's Disease and Dementia Grants	11%
Title III-B Older Americans Act (Supportive Services)	11%
Title III-D Older Americans Act (Health Promotion and Disease Prevention)	9%

Consumer Version: Best Practice Caregiving

Best Practice Caregiving for family and friend caregivers – launch 2023

Designed for caregivers to find, compare, and learn how to enroll in BPC programs in their communities

- When, where, and how programs are delivered
- Cost, waiting lists, how to enroll
- Program features, types of assistance, expected benefits
- Expanded information on programs for caregivers from diverse communities

Best Practice Caregiving: Reaching Caregivers from Diverse Communities

Sara Powers, PhD

Research Scientist

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The U.S. is becoming more ethnically diverse...

The lived experiences of dementia caregivers is greatly impacted by one's culture

Research has found cultural differences in caregiving experiences

- Physical functioning, psychosocial health, caregiver burden/appraisals, social connections, spirituality, coping, self-efficacy, filial responsibility/familism, use of formal services/healthcare

Still, access to evidence-based programs is limited and dementia caregiver intervention studies are needed to understand programmatic outcomes and the process of cultural tailoring for diverse groups.

Cultural Tailoring and Adaptations for Development and Implementation

Evidence-based dementia caregiving programs need to be adapted and/or developed to meet the growing needs of diverse communities...

- Language (e.g., program delivered in-language, program/marketing materials in-language)
- Delivery Staff (e.g., staff are bi-cultural/bilingual, cultural competency training)
- Logistical barriers (e.g., transportation services, adult/childcare, technology access)
- Community Partners or Consults (e.g., help develop, deliver, and/or promote the program to diverse communities)

Engaging Diverse Caregiving Communities – Project Activities

- Identify new data elements to collect information to help support the quality of cultural tailoring and/or adaptations among programs
- Test early iterations of the Best Practice Caregiving Consumer Version by diverse caregivers
- Identify and add new programs being used by caregivers from diverse communities that are not currently in Best Practice Caregiving but meet the eligibility requirements

Diverse Elders Coalition and Member Organizations



Additional Data Elements for Consideration

- Content Adaptations
 - Photos, images, or pictures inclusive? Content translated?
- Types of Consultations
 - Stakeholders, experts, or champions in the field involved in development/implementation?
- Program Training or Delivery Methods
 - Deliver the program in-language? Add special sections on training?
- Program Outreach and Marketing
 - Marketing tools designed to reach diverse groups and/or translated?
- Research and Evaluation Activities
 - Testing of benefits for diverse groups?

Focus Group Findings

- Important to have disaggregated data
 - Collect inclusive demographics/sample information

☒ Asian American

<input type="checkbox"/> Asian Indian	<input type="checkbox"/> Chinese	<input type="checkbox"/> Iwo Jiman	<input type="checkbox"/> Maldivian
<input type="checkbox"/> Bangladeshi	<input type="checkbox"/> Taiwanese	<input type="checkbox"/> Japanese	<input type="checkbox"/> Mongolian
<input type="checkbox"/> Bhutanese	<input type="checkbox"/> Filipino	<input type="checkbox"/> Korean	<input type="checkbox"/> Nepalese
<input type="checkbox"/> Burmese	<input type="checkbox"/> Hmong	<input type="checkbox"/> Laotian	<input type="checkbox"/> Okinawan
<input type="checkbox"/> Cambodian	<input type="checkbox"/> Indonesian	<input type="checkbox"/> Malaysian	<input type="checkbox"/> Pakistani
<input type="checkbox"/> Singaporean	<input type="checkbox"/> Sri Lankan	<input type="checkbox"/> Singaporean	<input type="checkbox"/> Thai
<input type="checkbox"/> Vietnamese	<input type="checkbox"/> Other not listed: Specify _____		

Focus Group Findings

- Even if a dementia caregiver program was adapted for one culturally diverse group, other culturally diverse caregivers may identify that program as useful/beneficial
- Having a cultural champion in the development/implementation of a program is key

Next Steps: Engage caregivers from diverse communities to pilot test the newly designed resource in 2023 and continue to add programs that have been developed for or implemented with diverse groups.

Resources & Supports

- Resources to support cultural competency and the tailoring of programming to meet the needs of caregivers from diverse communities
 - [A Toolkit for Serving Diverse Communities](#) (U.S. Administration on Aging)
 - [Training on Caregivers from Diverse Communities](#) (Diverse Elders Coalition)
 - [Cultural Competence Self-Assessment Questionnaire](#) (Example from Portland State University)
 - [Toolkit for Modifying Evidence-Based Practices to Increase Cultural Competence](#) (Example from Mental Health Services - Research Foundation for Mental Health)
 - [Evidence-Based and Culturally Relevant Behavioral Health Interventions in Practice: Strategies and Lessons Learned](#) (SAMHSA)

Demonstration - Best Practice Caregiving: Finding the Right Programs

<https://bpc.caregiver.org/#home>