



# ***Best Practice Caregiving: Guiding Organizations to Dementia Programs for Family Caregivers***

**Donna Barrett**

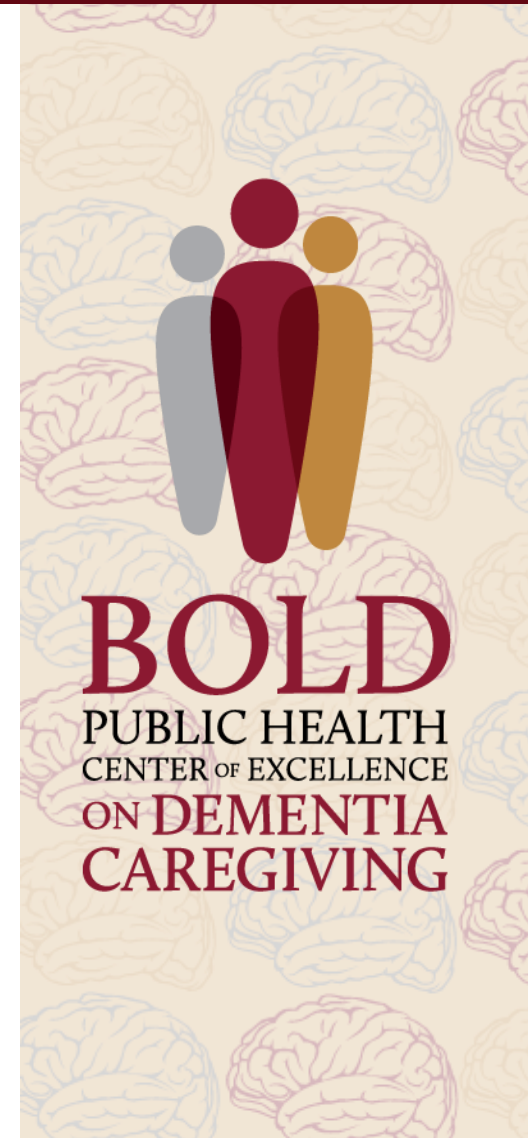
Program Manager,  
Senior and Adult Services  
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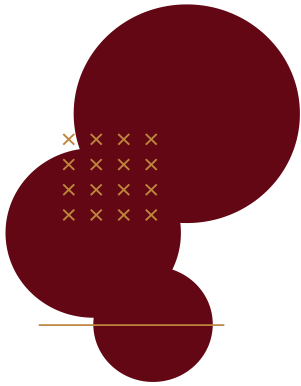
**Rachel Cannon**

Senior Research Analyst  
Benjamin Rose Institute on Aging

**David Bass**

Senior Vice President  
Senior Scientist  
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# Best Practice Caregiving: Partners and Collaborators

## Partners

Benjamin Rose Institute on Aging

Family Caregiver Alliance

Gerontological Society of America

## Collaborators

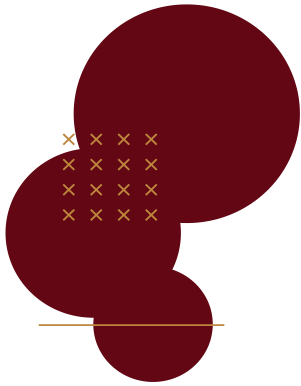
Bridge Builder Strategies

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



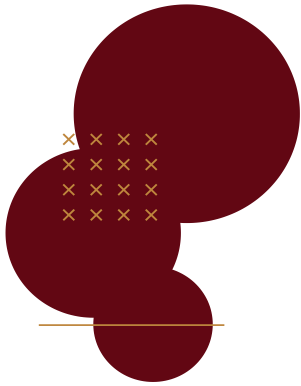
The  
John A. Hartford  
Foundation



RRF | Foundation  
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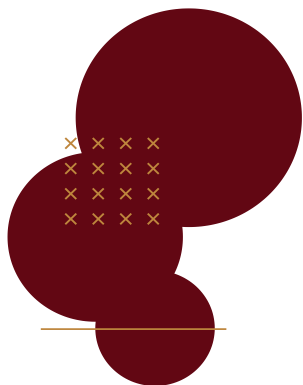


# Welcome and Introduction

**Rani Snyder**  
**Vice President, Program**  
**The John A. Hartford Foundation**



The  
**John A. Hartford**  
Foundation

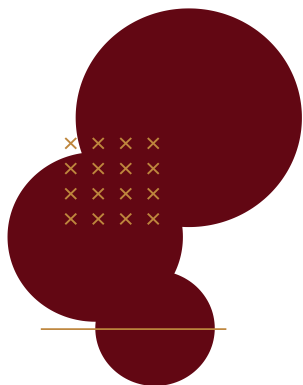


# Why a Health Department is Providing Programs for Family Caregivers

**Donna Barrett, MSW, LSW**

Program Manager, Senior and Adult Services

Summit County Public Health



# About Summit County Public Health

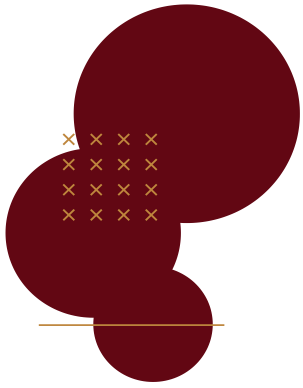
## Our Mission

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...

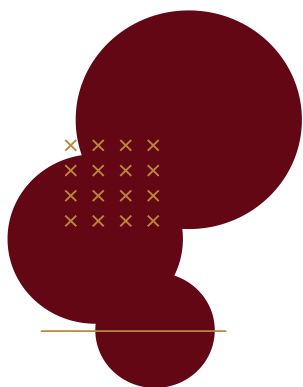
**HEALTHY PLACES, HEALTHY PEOPLE, AND HEALTHIER TOMORROWS.**



# Reasons Why?

1. Role of Public Health to address gaps in public health needs
  - System, Environmental and Policy Change
2. Aging Population
3. Support Caregivers
4. Personal Experience
5. Professional Experience
6. Passion





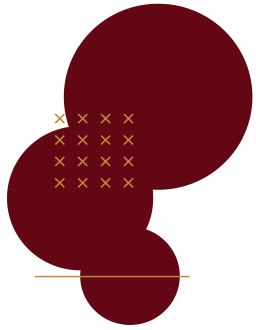
# Administration on Aging Grant (Grant #90APDI0045)

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.

Project Period: 9/30/2019 through 9/29/2022.

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

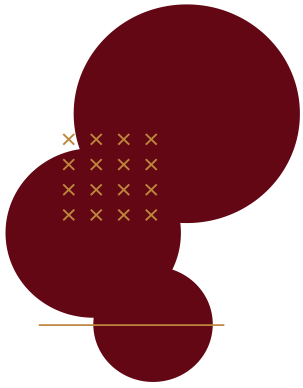
Goal	Intervention
Develop and deliver supportive services to persons living alone with Alzheimer's disease and related dementias (ADRD). Applicants must describe actions they will take to identify and support individuals living alone with ADRD	Gatekeeper Program –Train and receive referrals
	Dementia 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

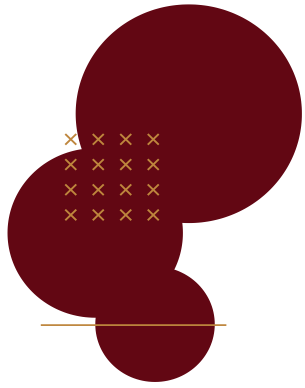
## Why did we choose this program?

- ✓ 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



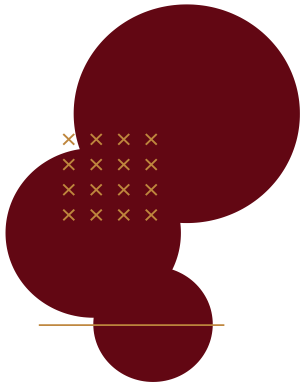
# Steps to Implementation

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



# Outcomes

- 18 Referrals
- 08 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



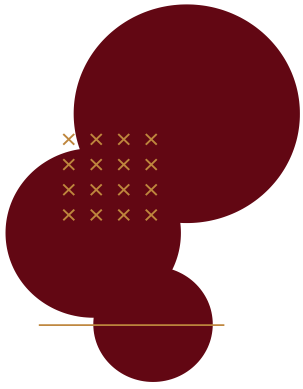
# Successes and challenges

## 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



# Contact Information

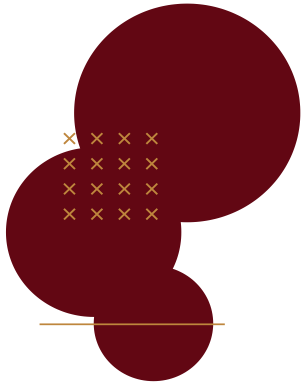
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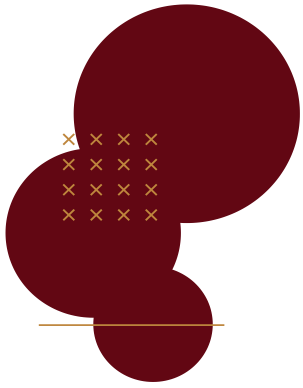


# Best Practice Caregiving to Find and Compare Evidence-Based Dementia Caregiving Programs

**David Bass, PhD**

Benjamin Rose Institute on Aging

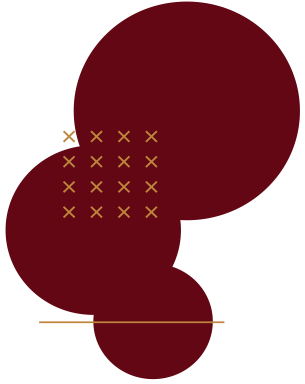
[dbass@benrose.org](mailto:dbass@benrose.org)



# Persons Living with Dementia

- 6.5 million US adults 65 and over are living with Alzheimer's disease
  - Low estimate because of under-diagnosis
  - Does not include people with other types of dementia
- Percentage of people with dementia increases with age
  - Number of persons with Alzheimer's and other dementias will double by 2060 as the oldest segment of population increases

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

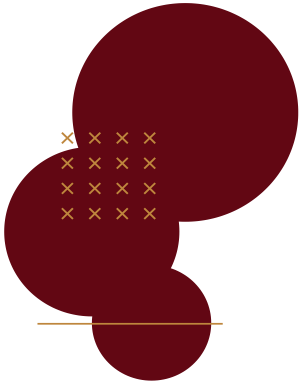


# Caregiving for Persons Living with Dementia

- More than 11 million US family/friend caregivers of persons living with dementia
- Unpaid caregivers (family and friends) provide more than 80% of total care to persons living with dementia
- Compared to other caregivers, 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).*

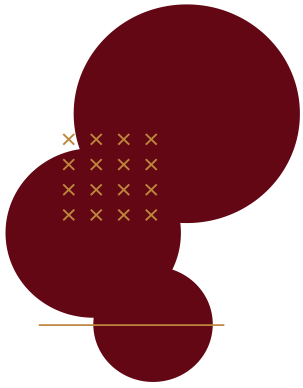
<https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf>



# Evidence-Based Programs: Major Advance in Caregiving

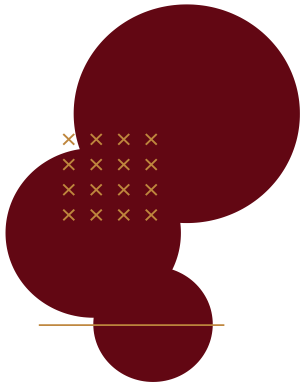
- Many non-pharmacological programs with research-proven benefits for family/friend caregivers
- Some programs also have proven benefits for persons living with dementia
- Some programs are ready for scaling in communities

*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).*



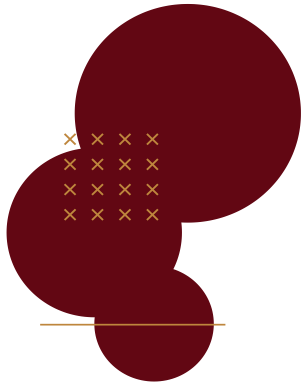
# Strengths of Evidence-Based Programs

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



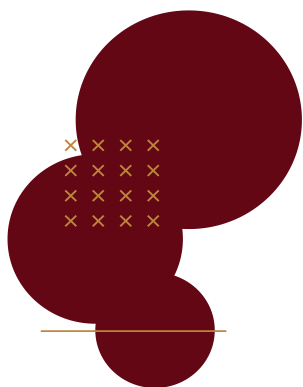
# Evidence-Based Programs Are Not All the Same

- Variation in research base – number of studies, methodology, outcomes.
- Number of program sessions and time to complete.
- Mode of program delivery – in-person, telephone, online, combination.
- Designed for certain caregiving situations – stage of disease, level of strain, caregivers from diverse communities.
- Degree to which content and delivery is tailed to individuals .
- Number of non-research implementations.
- Availability of ongoing technical assistance.
- Cost to deliver program – license, staffing, software.



## Not All the Same, cont. – Types of Assistance Provided

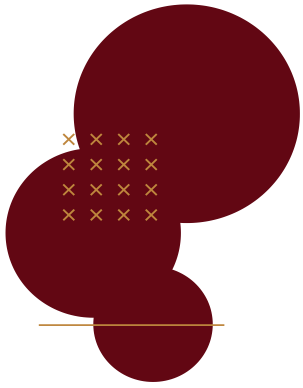
- Caregiver-Person Communication
- Coping
- Healthy Behaviors
- Positive Activities for Caregiver & Person
- Symptoms of Dementia
- Stigma or Isolation
- Daily Tasks
- Preventing Emergencies & Harm
- Assessment of Problems
- End-of-Life Support
- Care Transitions
- Advance Directives
- Finances
- Coordinating Home & Family Care
- Accessing Medical Care
- Coordinating Medical Care
- Pain Management
- Dementia Diagnosis
- Ongoing Monitoring of Services



# 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.



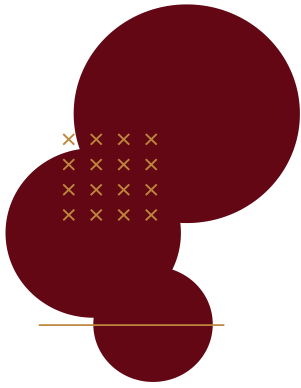


# Best Practice Caregiving: Learn about and Compare Evidence-Based Programs

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

44 Evidence-based dementia caregiving programs (more being added), with

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



# Best Practice Caregiving Inclusion Criteria

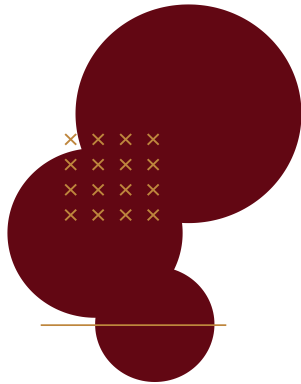
## 1. Research Evidence

- 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.

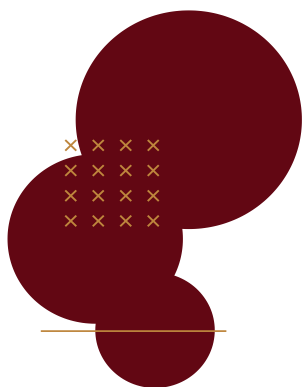
## 2. At least 1 “real world” delivery by a healthcare or community organization.

## 3. Available for replication

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

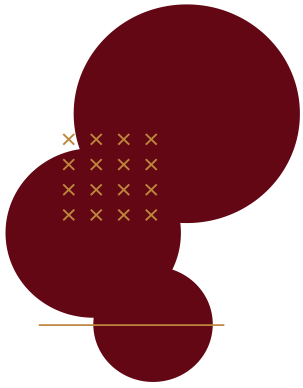


44 Programs in the Best Practice Caregiving (2021)		
ANSWERS	Inner Resources for Stress	Rosalynn Carter Institute REACH (RCI REACH)
Active Caregiving: Empowering Skills (ACES)	Mindfulness Training for Patients with Progressive Cognitive Decline and their Caregivers	Savvy Caregiver
Adult Day Services Plus (ADS Plus)	Mindfulness-Based Alzheimer's Caregiving	Skills <sub>2</sub> 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)	



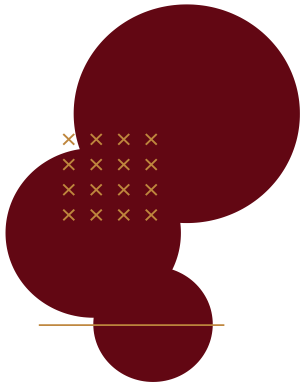
# Organizations Delivering Best Practice Caregiving Programs

- 324 organizations delivered 350 programs – 25 organizations delivered more than one.
- Larger number of community implementations than anticipated.
- This is an undercount, with many more expected in our 2022 update.
- 2022 update will include the service area targeted by programs being delivered in communities.



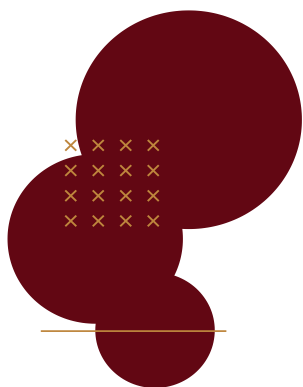
# Organizations Delivering Best Practice Caregiving Programs

- 16 Different types of organizations (no public health organizations in 2019)
- Most common delivery organizations:
  - Healthcare systems (24%; n =77)
  - Area Agencies on Aging (24%; n = 77)
  - Alzheimer's or Dementia Associations (12%; n = 39)
- These 3 types accounted for 61.4% delivery organizations



# Most Widely Delivered Programs in 2019 (>11 sites)

1. BRI Care Consultation
2. Building Better Caregivers
3. New York University Caregiver Intervention
4. Powerful Tools for Caregivers
5. RCI REACH
6. REACH Community
7. REACH VA
8. Savvy Caregiver
9. Skills2Care
10. TCARE



# Common Funding Sources for BPC Programs

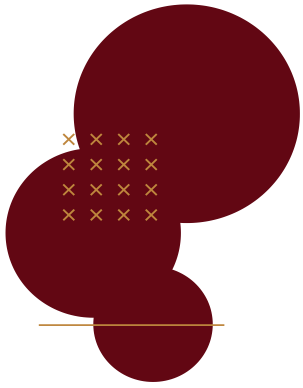
Title III-E Older Americans Act (National Family Caregiver Support Program)	34%
Grants other than Administration for Community Living	28%
Participant Payments or Donations	27%
Organization Operating Funds	25%
Administration for Community Living, Alzheimer's Disease and Dementia Grants	11%
Title III-B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



# Most to Least Common Challenges to Program Success

Marketing Program	70%
Engaging Caregivers to Participate	66%
Staffing Programs	52%
Costs for Delivery	41%
Convenience for Participants to Use	39%
Internal Organizational Support	35%
Getting Supplies/Equipment for Delivery	30%
Offering in Different Languages	29%





# Consumer Version: Best Practice Caregiving

- **Best Practice Caregiving for family and friend caregivers – launch 2023.**
- Information caregivers need to find, compare, and enroll in Best Practice Caregiving 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 for caregivers from diverse communities.
- Partnering with Diverse Elders Coalition and its six member organizations.
- Program culture adaptations, translations, and research with diverse caregivers.

# Demonstration – Using Best Practice Caregiving to Find the Right Dementia Caregiving Program

Rachel Cannon, MPH  
Benjamin Rose Institute on Aging

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