Public Health Programs for Dementia Caregivers: Finding, Selecting and Implementing interventions that work

Feb 23, 2022

Presented by:

In collaboration with:

Welcome from…

Joseph Gaugler, Phd
Robert L. Kane Endowed Chair in LTC & Aging at the University of Minnesota. His research examines innovation in dementia care.

Land acknowledgement

The University of Minnesota Twin Cities is located on traditional, ancestral, and contemporary lands of Indigenous people. We acknowledge with gratitude the Land itself and the People. We take to heart and commit through action to learn and honor the traditional cultural Dakota Values: Courage, Wisdom, Respect and Generosity.

The Public Health Center of Excellence on Dementia Caregiving (PHCOE-DC)

Designed to support state, tribal and local public health agencies nationwide in developing their dementia caregiving-focused programs and initiatives, by...
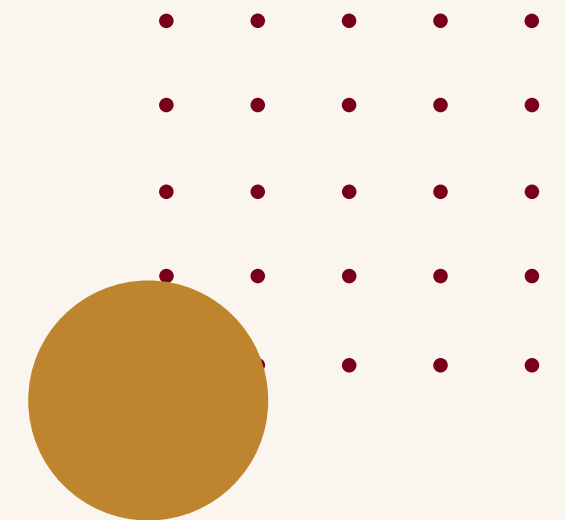
☑ **Improving access to evidence-based programs and best practices**
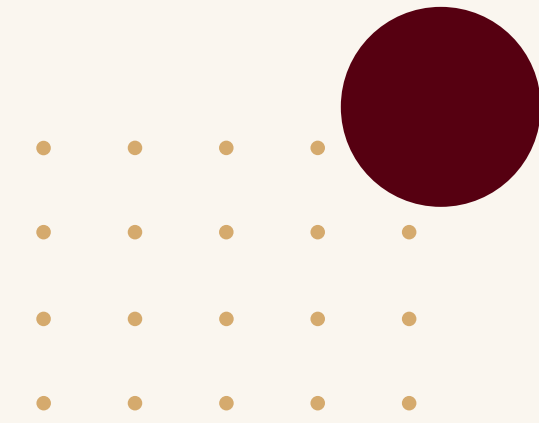
☑ **Facilitating connections and collaboration among public health agencies and a wide range of service organizations**

☑ **Providing technical assistance for identifying, selecting implementing effective public health interventions and strategies**

Introducing our presenters...

Donna Barret
MSW, LSW
Program Manager, Senior Services
Summit County Public Health

Katie Maslow
Visiting Scholar,
The Gerontological Society of America

David Bass
Senior Vice President,
Senior Research Scientist and Director
Center Research and Education
Benjamin Rose Institute on Aging

Rachel Cannon
MPH, Senior Research Analyst
Benjamin Rose Institute on Aging

Erin Long
MSW, Team Lead
Alzheimer's Disease Programs Initiative, Administration for Community Living

Summit County Public Health
- **Summit County Coalition for Health Improvement**

Community Health Assessment

Community Health Improvement Plan

Senior And Adult Services

Growing Crisis

HEALTHYBRAIN INITIATIVE

State and Local Public Health
Partnerships to Address Dementia:
The 2018-2023 Road Map

CDC

alzheimer's association

Statistics

- 5th Leading cause of death for those aged 65 or older

- Alzheimer's the most expensive disease in American with costs exceeding a quarter of a trillion dollars and by 2050 it is expected to $1.1 trillion dollars in 2018 dollars
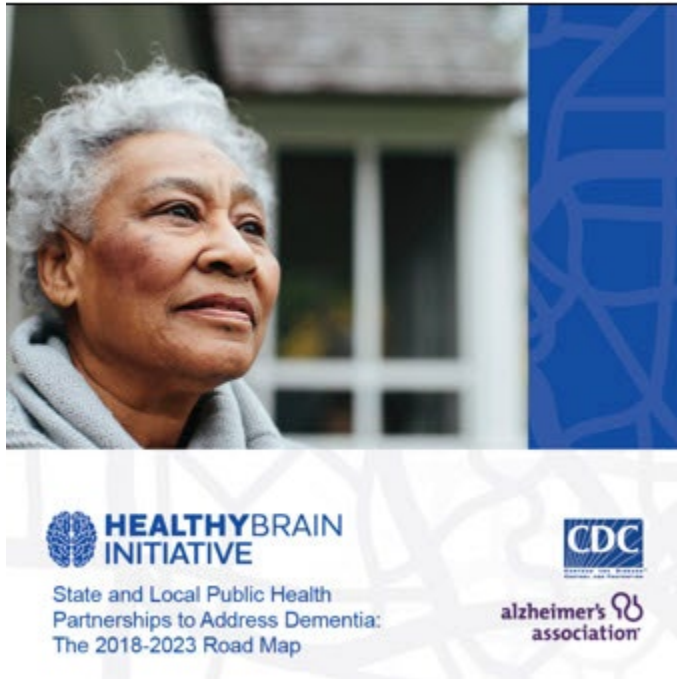
Caregiving

Caregiver Stress

Unpaid Caregivers

- **80% if caregivers provide all long-term care services.**

- **$5,220,000,000 is the estimated value of caregiving in the U.S. for ADRD support**

Goal 1. Ensure older people, adults with disabilities and caregivers have seamless access to information and services enabling them and their loved ones to age in the place "they call home".

Evidenced-Based Programming

Goal # 3-Educate, empower, and assure that older people, persons with disabilities and their caregivers have access to evidenced based programming focused on active, health and safe living enabling them to maintain their independence for as long as possible.

EBP Model

Administration for Community Living

- **ADRD Grant Number 90ADPI0045-01-11**

- **Purpose**
  - **Improve/Increase county dementia capability**
    - **People Living Alone with ADRD**
    - **IDD population and staff training (system change)**
    - **Evidenced Based Programming (behavioral intervention)**
      - **BRI Care Consultation**

BRI Care Consultation

- **Why did we choose this program.**
  - **Assesses both caregiver and PWD (domains)**
  - **Local Support**
- **How do we get referrals**
  - **Gatekeeper**
  - **Senior Network**
  - **Trainings**
    - **Behavioral Interventions**

Implementation

- **Press Release**
- **Web-page highlighting program with link to brochures**
- **Trainings**
- **Prescription Pad**
- **Outreach**

- **Interagency Partnership with other BRICC Providers**
- **Postcard**
- **Flyers**
- **Hotline**

Outcomes

- **15 Referrals**
- **13 Open**
- **05 Dis-enrolled**
- **12 Re-assessed**
- **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**

Barriers

- **COVID 19**
  - **Staffing**
  - **Outreach**
- **CBO's who have their own caregiver programs**
- **Funding for Sustainability**

Questions and Answers

- Healthy Brain Initiative., retrieved from www.cdc.gov/aging/pdf/2018-2023-Road-Map-508.pdf

Best Practice Caregiving:
Online Resource of Evidence-Based Dementia Caregiving Programs

David M. Bass
Senior Vice President
Senior Scientist
Benjamin Rose Institute
on Aging

Katie Maslow
Visiting Scholar
Gerontological
Society of America

Rachel Cannon
Senior Research Analyst
Benjamin Rose Institute
on Aging

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

Best Practice Caregiving:
Partners and Collaborators

Partners

Benjamin Rose Institute on Aging

Family Caregiver Alliance

Gerontological Society of America

Collaborators

Bridge Builders Strategies

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

Quality Process

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

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

Caregivers of Persons Living with Dementia

15 million US family/friend caregivers

Caregivers of persons living with dementia:

- More adverse consequences (e.g., relationship strain, depression)
- Assist with more tasks and more difficult tasks
- Deal with more stressful symptoms (e.g., behavioral symptoms)
- Person living with dementia may have limited ability for self-care

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).

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

Problem:
Limited Availability of Proven Programs

One Reason:

Professionals have limited knowledge about these programs, and it is challenging finding information

- Most healthcare and community service organizations offer none of these program

- Difficult to know:
    - Best match for an organization or community
    - Ready for non-research implementation
    - Which programs working well in other communities

Best Practice Caregiving (BPC)

Launched in Jan. 2020 to increase delivery of top evidence-based dementia caregiving programs

Easy-to-use

Online tool for <u>professionals</u>

44 evidence-based dementia caregiving programs

- Complete program descriptions
- Findings from research
- Experiences of delivery organizations
- Program bibliographies
- Developer contact information

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

BPC Inclusion Criteria

1. At least 1 randomized controlled trial, non-randomized controlled trial, or pre-post-test that was conducted in the U.S., and has:

   - At least one statistically significant, published, beneficial outcome for caregivers
   - At least 50% of the sample is dementia caregivers
   - Persons with dementia are living in the community

2. At least 1 "real world" implementation in which the program was offered by a health care or community agency as a regular service

3. Program is available for replication

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

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

Search Process and Decisions about Inclusions

- Gathered possible programs from journals, books, conference presentations, program developers, and other sources

- Searched for published articles and contacted the developer for each program to get information needed to determine program eligibility for inclusion

- Identified the 44 programs that met all 3 criteria

- Sadly excluded many good programs that lacked something needed to meet inclusion criteria

44 Programs in the Best Practice Caregiving Database in Jan. 2020

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)	

Early Look at Types of Assistance Provided by the 44 Programs

- Caregiver-PLWD Communication

- Coping

- Healthy Behaviors

- Positive Caregiver-PLWD Activities

- 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

Complexity of the Goal of Matching Dementia Family Caregivers with Programs that Will Help Them

- Heterogeneity of dementia family caregivers that affects the kinds of help they need and the kinds of programs that they will accept and use and that will be effective for them.

- Differences among health care and community organizations that affect the kinds of programs they can and will provide.

- Ongoing changes in caregivers and health care and community organizations

- Ongoing need for accurate, updated information about programs that are both effective and feasible for "real world" implementation

Programs to Help Family Caregivers from Diverse Groups

- Current list of 44 programs includes 4 programs that were developed originally for a particular racial or ethnic group.

- Additional programs in the current list have been adapted to create 10 additional programs that are intended for a particular racial, ethnic, cultural, or other diverse groups.

- Ongoing analysis of these programs will help us identify what's available and where there are gaps in this important program area.

best practice caregiving

Guiding organizations to dementia programs for family caregivers

A partnership between   13
Benjamin Rose Institute on Aging and Family Caregiver Alliance

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

bpc.caregiver.org

Key Finding 1:
Organizations Delivering BPC Programs

38 of the 44 programs were able to name the organizations delivering the programs in 2019

Key Findings:

More healthcare and community organizations than expected delivered a BPC program in 2019

- 324 organizations delivered 350 programs – 25 organizations delivered more than one

- This is an undercount; expect many more in 2022 update

Types of Organizations Delivering BPC Programs

16 Different types of organizations delivered BPC

Most common delivery organizations:

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

These 3 types accounted for 61.4%

Ten Most Widely Delivered Programs in 2019
(11 or more delivery sites; programs alphabetical)

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

Length of Delivery and Staffing

Number individuals served and months delivering program

- Average individuals served past 12 months: 94
- Average number of months programs delivered: 32 months
- 70% delivered programs for 5 years or less

Education degrees of program delivery staff

- 75% of programs had staff with graduate degrees
- 58% of programs had staff with bachelor's degree
- 24% of programs had staff with associate degree

Most Common Disciplines of Delivery Staff

- 62% social work
- 28% counseling
- 27% nursing
- 17% psychology

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%

Key Finding 2:
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%
Participants Paying for Program	27%

best practice caregiving

Guiding organizations to dementia programs for family caregivers

A partnership between

Benjamin Rose Institute on Aging and Family Caregiver Alliance

20

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

Key Finding 3:
Family/Friend Caregivers Use of BPC Professional Version

25% of BPC professional version users were caregivers - many caregivers searching online for support programs

Caregivers using BPC reported significant increases in program knowledge and familiarity

Almost all would encourage others to use BPC

Many caregivers said BPC would have been more helpful if it provided information on programs available in their communities

Next Phase: BPC Consumer Version

BPC for family and friend caregivers
- In development with launch in 2023
- Information for all US-based organizations delivering a BPC program

All the information caregivers need to find, compare, and enroll in BPC programs available in their communities
- Program features, types of help, expected benefits
- When, where, and how programs are delivered
- Costs, waiting lists, how to enroll

Expanded information about programs developed and adapted for caregivers from diverse communities
- Partnering with the Diverse Elders Coalition and its six member organizations as partners

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

CHOOSING SUPPORTS AND SERVICES FOR PEOPLE IN YOUR COMMUNITY LIVING WITH DEMENTIA AND THEIR CAREGIVERS

DECISIONS

INFORMED

DECISIONS

As You Consider Your Options: Consider Your Community!

- Did you ask them what they want and need?
  - *Is community interest sustainable?*
  - *Is your organization able to sustain, if the community accepts services?*
- Who is the target audience? Caregivers (Family/Paid)?
  - *What is in it for them? If paid caregivers, what is benefit to payers?*
  - *Expected outcomes.*
- How often will it be offered? How are you delivering? In-person, Virtual?
- What is the expected commitment for program participants?
  - *Is it reasonable?*

Making Informed Decisions:
Choosing the intervention that is right for your community

What professional resources do you have to implement the chosen intervention?

Who will implement? Your staff or will you train other orgs?

Will choices meet the needs of community in terms of cultural competence? Race, Ethnicity, Disability, even Rural vs Urban?

Know your community!

Ask the right questions.

Think about now, the future?

Who do you want to target? Caregivers? People Living with Dementia? BOTH?

What does it **cost**: initial training, annual license, boosters, TA?

What needs to happen for work to be sustained?

What is going on now in the community?

What does the community want/need? *ASK THEM!!*

How will services be delivered? In-person? Telephone? Computer?

What has been tried in the past, what worked, what didn't, why?

Is the intended service population likely to buy-in?

Choosing an Evidence-Based or Evidence-Informed Intervention: Considerations to Inform Decision-Making

You have made the big decision, now what?

BUT WILL THEY?

Getting People Engaged, it is a multi-step process!
PLAN TO BUILD YOUR "PIPELINE" OF PROGRAM PARTICIPANTS

Awareness

Interest

Consideration

Engagement

Be strategic in you marketing with messaging designed engage!

Know your audience

- ***Create a campaign that "speaks their language"!***
- Don't expect one size fits all.
- Use positive language designed to tell people how they can benefit from what you are offering.
- Engage partners that are trusted with the target audience.
- Sometimes you have to offer something a little less intimidating to earn trust and get people to engage more at a later date.

Design An Appropriate Marketing Strategy That:

- Will be seen and heard by the target audience.
- Uses "plain language".
- Uses authentic messaging from people who look like them and talk like them – particularly when working with diverse community members.
- Targets the media modes that intended audience uses most frequently.

MARKETING <u>WITHOUT</u> A BUDGET
GET CREATIVE TO GET THE WORD OUT!
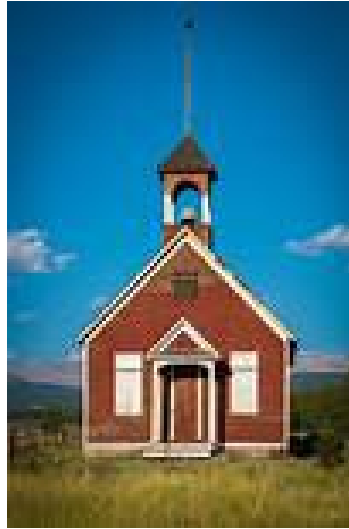
Try an Ambassador program with former participants

Radio Interviews

Social media

Libraries

Media interviews

- **Partnerships with Medical Practices**
- **Health Systems**
- **Gatekeeper programs**
- **Home Delivered meal volunteers**

Partner with Community Newsletter providers

Sometimes you need to go "old school"!

Marketing <u>with</u> a Budget

En esta temporada en la que estaremos con amigos y familiares, es importante conocer las señales de pérdida de memoria.

Llame hoy para recibir una evaluación gratuita

(520) 790-7262

Dementia Capable Southern Arizona

PIMA Council on Aging (PCOA), Tucson, Arizona

Public Service Announcements

Social Media Advertisements

Radio Advertisements

Newspaper Advertisements

Google

Google Ad Grants Attract donors, raise awareness for your organization, and recruit volunteers with in-kind advertising on Google Search

Closing Points

- Know your audiences, meet them where THEY are – not where you think they should be!

- Having a well thought out Marketing and Outreach before you launch a program will serve you well.

- Doing it right up front can support overall sustainability of a program down the road.

- **If you build it** - and then go out there and let them know you are there for them - **you have a better chance of them coming**!

Alzheimer's Disease Programs Initiative

State and Community Grant Program

- Expand dementia-capability of states and communities through a single program;
- Deliver dementia-specific evidence-based and evidence informed interventions to support people living with dementia and their caregivers;
- Improve and expand on person-centered care for individuals living with Alzheimer's and dementia,
- Targeting supports to those with the greatest social and economic need; and
- Support paid and unpaid caregivers through provision of education, training and tools.

FUNDING OPPORTUNITY FORECAST

Alzheimer's Disease Programs Initiative - Grants to States and Communities

HHS-2022-ACL-AOA-ADPI-0059

COMING in 2022!

Estimated Total Funding: Approximately $23,606,415

Expected Number of Awards: 23-26

Award Ceiling: $1,000,000 Per Project Period

Award Floor: $400,000 Per Project Period

National Alzheimer's and Dementia Resource Center (NADRC)
www.nadrc.acl.hhs.gov

- Technical Assistance to present, past and future grantees and stakeholders;
- Website makes issue briefs, toolkits, case studies, reports and grantee products, available to everyone;
- Facilitation of annual webinar series.

Helpful Resources for Identifying the RIGHT Dementia-Specific Evidence-Based Intervention for your community!

- **Choosing an Evidence-Based or Evidence-Informed Intervention: Considerations to Inform Decision-Making**
- **Grantee-Implemented Evidence-Based and Evidence-Informed Interventions**
- **Evaluating Dementia Services and Supports: Instrument Resource List, 3rd Edition**
- **Filling the Gaps in Dementia-Capable Home & Community-Based Services: Report on Completed Administration for Community Living ADI-SSS Grants to Communities and States**

QUESTIONS???

Erin Long, MSW
Office of Supportive and Caregiver Services
Administration on Aging/Administration for Community Living
U.S. Department of Health and Human Services
Erin.long@acl.hhs.gov

Q&A

Please use the Q&A feature to submit your questions!

Connect with us!

Visit us online at https://bolddementiacaregiving.org to....

- ✓ Find today's slides and recording
- ✓ Request Technical Assistance to support your public health work in dementia caregiving
- ✓ Access resources and materials
- ✓ Stay up to date with PHCOE-DC activities!

Follow us on Twitter!   @PHCOE_DC

Thank you for joining us today!

Please take a moment to complete our evaluation form at the end of this presentation.