*Disseminating Evidence-Based Programs to Support Family Dementia Caregivers:*

*The Role of Public Health*

*July 24th, 2024*

# Welcome from...

**Joseph E. Gaugler, PhD**

Director, BOLD Public Health Center of Excellence on Dementia Caregiving

Professor and Robert L. Kane Endowed Chair in Long-Term Care & Aging, 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 BOLD 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.

Visit our website!

# Reminders for the Presentation Session

- **Submit your questions for the speakers into the Q&A feature.**

- Use the **CHAT to share comments, resources, links, and ideas.**

- The recording, slides and resources will be shared after the event.

- **Please complete the survey at the end of this event** (will pop up in Zoom when you leave this webinar). We greatly appreciate your feedback!

# We value your feedback!

*Please give us your feedback before you leave today's meeting!*

**Survey invitation** will pop-up when you leave the webinar
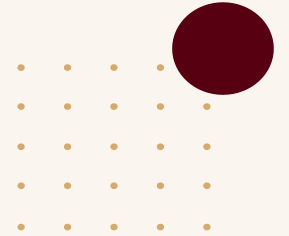
*OR* scan the QR code

*OR* visit bit.ly/EBP_publichealth

# Poll Question

## In what capacity are you attending this event?

- BOLD Public Health Agency

- Non-BOLD Public Health Agency

- Community organization/service provider

- Person living with dementia

- Interested caregiver and/or community member

- Care/clinical professional

- Other

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

# Toolkit Launch

- A resource and **guide for public health agencies** to build support networks and promote the **dissemination of evidence-based programs for dementia caregivers**.

- **Public health plays a role** in ensuring that a coordinated system of community based support and effective programs exist for dementia caregivers.

# Why Evidence-Based Programs (EBPs)?

*EBPs are tested through randomized controlled trials and are:
- ➢ **E**ffective at improving or maintaining health or functional status in people with dementia or their caregivers;
- ➢ **D**eployable through community-based organizations involving non-clinical workers or volunteers;
- ➢ **P**ublished in peer-reviewed journals; and
- ➢ **T**ranslated into practice and ready for distribution through community-based organizations.

*ACL'S DEFINITION OF EVIDENCE-BASED AND EVIDENCE-INFORMED PROGRAMS*

## 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.

# Recommendations for Public Health

7 Actions to Promote EBPs for Family Dementia Caregivers

| | | |
|---|---|---|
| ① | **Conducting a Landscape Assessment** | Perform an environmental scan to understand what programs are available to assist dementia caregivers and what services and supports might be missing across their jurisdiction. Mapping existing community assets and gaps can inform resource planning and allocation. |
| ② | **Promoting Programs and Facilitating Referrals** | Raise awareness about EBPs among local service organizations by offering informational sessions and program materials and referring them to Best Programs for Caregiving to find programs that best fit their community. Health agencies can also refer and connect dementia caregivers with local organizations delivering EBPs. |
| ③ | **Promoting Best Practices** | Identify organizations that are implementing EBPs and widely share their learnings to model how organizations can better serve dementia caregivers. They can synthesize the approaches and strategies that were key to successful implementation, identify opportunities for improvement, and develop tools and materials to aid with selecting and using programs. |
| ④ | **Providing Funding** | Promote existing funding opportunities and provide seed money grants for implementing EBPs to local organizations interested in growing their dementia caregiving programming. They can also provide technical assistance with grant applications and/or cover all or part of program launch, licensing, and training costs. |
| ⑤ | **Leveraging Partnerships** | Facilitate connections between healthcare systems and local service organizations offering EBPs for dementia caregivers to stimulate the development of coordinated dementia care systems. They can collaborate and pool resources with partners interested in or already delivering EBPs for dementia caregivers to raise awareness, increase program enrollment, and support other program-related activities. |
| ⑥ | **Centering Equity and Diversity** | Support local organizations serving older adults in ethnically and racially diverse communities and promote culturally adapted programs to improve caregiver access in underserved and minority populations. |
| ⑦ | **Monitoring and Evaluating** | Leverage their data collection and evaluation expertise to track population-level outcomes of EBPs and ensure that the programs reach and benefit caregivers in diverse communities. |

# Welcome to our presenters!

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

**Morgan Minyo, PhD**
Research Scientist,
Benjamin Rose Institute

**Erin Long, MSW**
Aging Services Program Coordinator, Team Lead,
Alzheimer's Disease Programs Initiative,
Administration for Community Living

# Best Programs for Caregiving – Public Version

**Morgan Minyo, PhD**
Research Scientist
&
**Rachel Cannon, MPH**
Senior Research Analyst

Benjamin Rose Institute on Aging
July 24, 2024

bpc.caregiver.org

# Developed to Fill a Need

- No comprehensive, updated source of information on evidence-based dementia caregiving programs.

- Lack of easy-to-find, detailed program descriptions made it difficult to know which programs:
  - o Best match for your organization
  - o Are being delivered as regular services with good results.

- Family and friend caregivers struggle to find proven support programs.
  - o Many people have no idea these programs even exist.

best programs for
**caregiving**
*guiding you to proven*
*support for dementia care*

bpc.caregiver.org

# Best Programs for Caregiving
### (formerly Best Practice Caregiving)

- Professional Version launched in 2020.

- 45 evidence-based dementia caregiving programs with

  o Beneficial research outcomes

  o At least one non-research, real-world implementation by a healthcare or community organization.

- First version was for professionals, policy makers, funders, and researchers.

  o Extensive information on program characteristics, delivery organization experiences, and research outcomes.

- Evaluation showed caregivers were using the site too – needed a Public Version.

best programs for
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# Best Programs for Caregiving for Family & Friend Caregivers

- Public Version launched in April 2024, a first-of-its-kind, free directory designed for family and friend caregivers of people living with dementia.

- Over 200 healthcare and community organizations delivering one or more of the 45 evidence-based BPC programs.

- Zip code search feature finds programs available in caregivers' communities.

- Some local in-person programs; others available to wider audiences via telephone or online delivery.

  o 18 programs offered nationally; reach rural and underserved areas.

- Special section on programs adapted or translated for diverse communities.

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**best practice caregiving**

*Guiding familes to dementia care programs*

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

## Dementia Care Programs for Family Caregivers

**I Care for Someone with Dementia** ▶

**Best Practice Caregiving** is a free online national database of proven effective dementia care programs for family caregivers and the organizations that provide them.

In Best Practice you 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
• Information on the program providers

## Dementia Care Program Info for Program Providers

**I'm a Program Provider** ▶

**Best Practice 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.
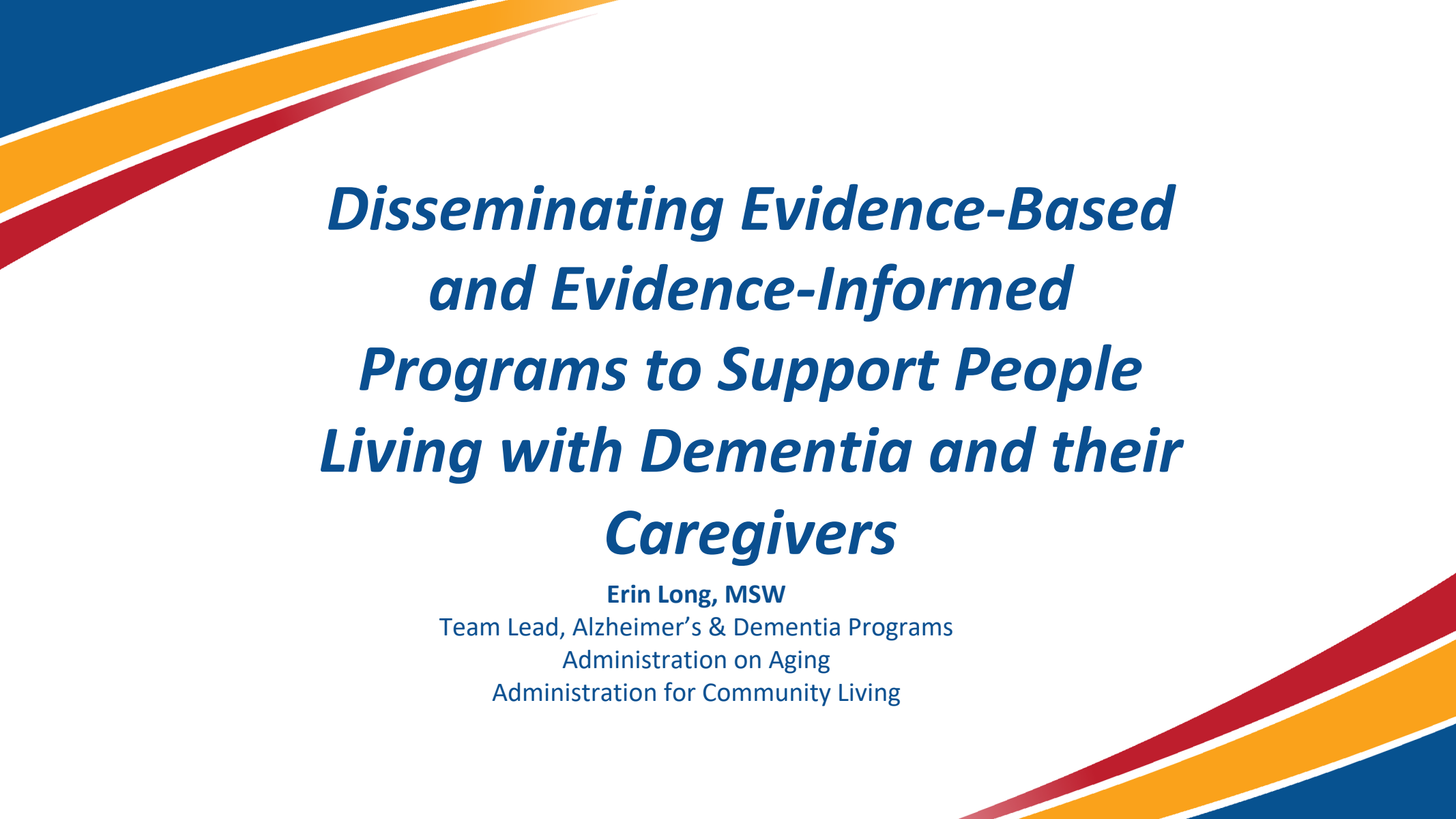
Please help us share this resource with caregivers!

Visit the website at bpc.caregiver.org

For more information contact
bass.onlineresource@benrose.org

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# *Disseminating Evidence-Based and Evidence-Informed Programs to Support People Living with Dementia and their Caregivers*

**Erin Long, MSW**
Team Lead, Alzheimer's & Dementia Programs
Administration on Aging
Administration for Community Living

# Alzheimer's Disease Programs Initiative (ADPI) Core Components

❖**State, Community and Tribe Grant Program**

Expand dementia-capability of **States, Communities and Tribes** through a single program;

Deliver **dementia-specific evidence-based and evidence-informed interventions** to support people living with dementia and their caregivers;
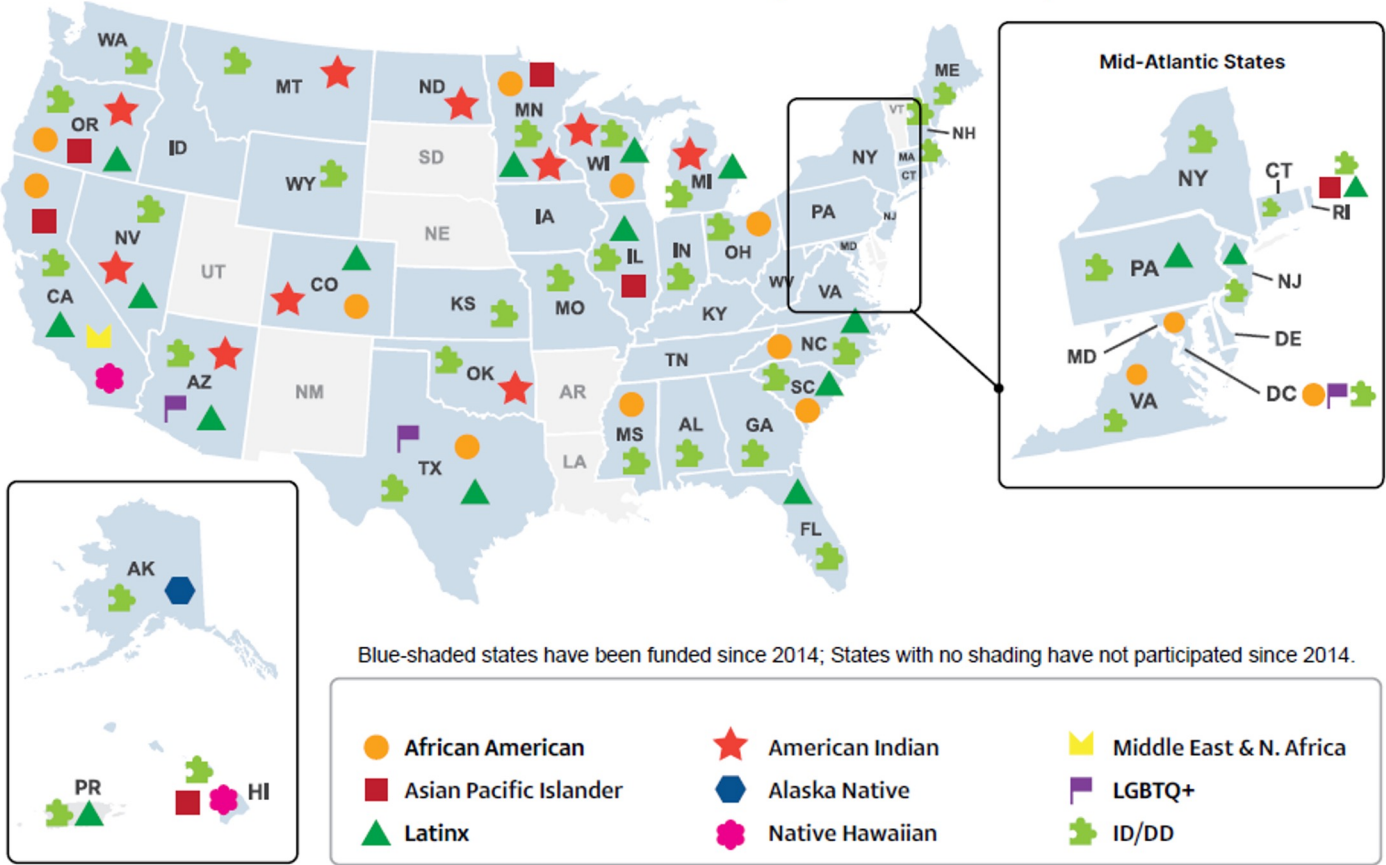
Improve and expand on **strengths-based, person-centered care** for people living with dementia and their caregivers;

**Support paid and unpaid caregivers** through provision of education, training and tools.

❖**Community Innovations in Dementia Specific Respite**

❖**National Alzheimer's Call Center**

**Current and Past Grantees (Funded Since 2014)**

Blue-shaded states have been funded since 2014; States with no shading have not participated since 2014.

Legend:
- 🟠 African American
- ⭐ American Indian
- 🟨 Middle East & N. Africa
- 🟥 Asian Pacific Islander
- ⬣ Alaska Native
- 🟪 LGBTQ+
- 🔺 Latinx
- ✿ Native Hawaiian
- ✿ ID/DD

Grantee Implemented Evidence-Based and Evidence-Informed Dementia Interventions

Link to Grantee Implemented Evidence-Based and Evidence-Informed Dementia Interventions on NADRC website

https://nadrc.acl.gov/home

# ADPI Evidence-Based and Evidence-Informed

| EVIDENCE-BASED | EVIDENCE-INFORMED |
|---|---|
| Tested through randomized controlled trials **AND**<br><br>1. Effective at improving, maintaining, or slowing the decline in the health or functional status of people living with dementia or family caregivers;<br>2. Suitable for deployment through community-based human services organizations and involve non-clinical workers and/or volunteers in the delivery of the intervention;<br>3. Research results have been published in a peer-reviewed scientific journal; and<br>4. Intervention has been translated into practice and is ready for distribution through community-based human services organizations. | Must 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.<br><br>**MUST:**<br>1. Have been tested by at least one quasi-experimental design with a comparison group, with at least 50 participants; **OR**<br>2. Have been adapted or translated from a single evidence-based intervention. |

Grantee-Implemented Evidence-Based and Evidence-Informed Interventions

## Evidence-Based Interventions

| Evidence-Based Intervention | Description of Intervention | Licensing and Materials Information | ADSSP, ADI-SSS, and ADPI Grants Implementing the Intervention |
|---|---|---|---|
| **Adult Day Services (ADS) Plus**<br><br>**Target Population:**<br>Caregivers<br><br>**Original Study**<br>Gitlin, L., Reever, K., Dennis, M. P., Mathieu, E., & Hauck, W. W. (2006). Enhancing quality of life of families who use adult day services: Short- and long-term effects of the adult day services plus program. *The Gerontologist, 46*(5), 630–639. | The ADS Plus model consists of five key components: (1) care management, (2) referral/linkage, (3) education about dementia, (4) situational counseling/emotional support/stress reduction techniques, and (5) skills to manage behavioral symptoms (e.g., rejection of care, agitation, aggression). Based on care challenges identified by family caregivers, an "ADS Plus Prescription" and a written document detailing easy-to-use strategies to address specified care challenges is provided and caregivers are trained in their use.<br><br>**Delivery Method:**<br>Full sessions = in-person<br>Check-ins = in-person, telephone, or email<br><br>**Session Length:**<br>Ranges from 15-minute check-ins to 60-minute full sessions.<br><br>**Program Length:**<br>52 weeks | **Website**<br>Program Details (caregiver.org)<br><br>**Licensing:**<br>No cost or fee to obtain license.<br><br>**Training:**<br>Initial training for delivery persons is 16 hours and includes 16 videos and 2 virtual sessions, 3 follow-up coaching calls, and 3 coaching sessions. Refresher training also provided.<br><br>**Materials:**<br>Program manuals included in training.<br><br>**Cost:**<br>Cost information available by contacting Laura Gitlin.<br><br>**Contact:**<br>Laura Gitlin, PhD at | **Current Grants**<br>– Athens Community Council of Aging Inc. (GA) |

https://nadrc.acl.gov/details?search1=20221214043701

# APPENDIX A: Choosing an Evidence-Based or Evidence-Informed Intervention: Considerations to Inform Decision-Making
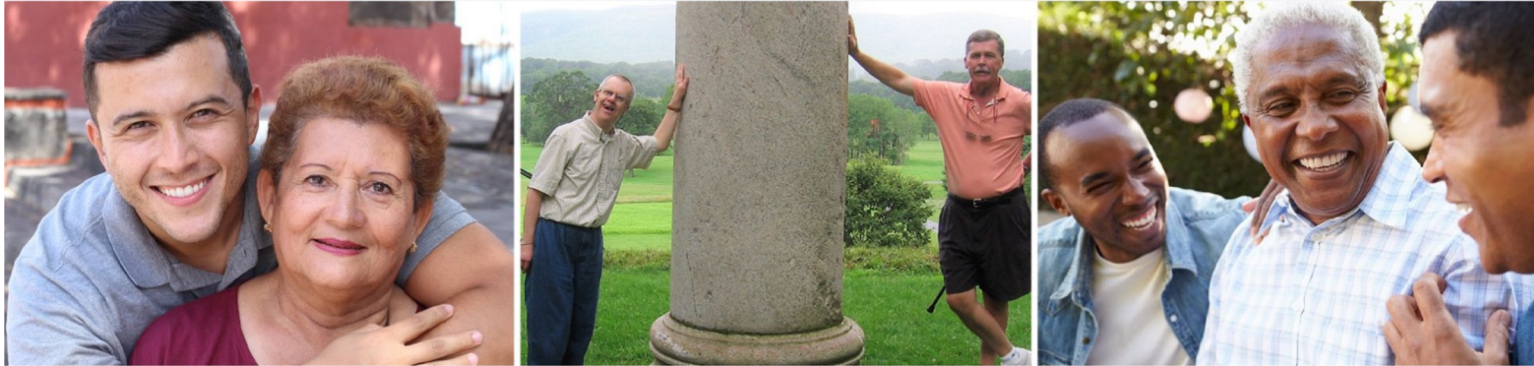
**TOPICS ORGANIZATIONS SHOULD CONSIDER BEFORE CHOOSING AN INTERVENTION FOR YOUR COMMUNITY!**

- **Readiness**
- **Program Characteristics**
- **Licensing**
- **Training**
- **Technical Assistance**
- **Data Management**
- **Program Fidelity**
- **Sustainability**

*MAKE INFORMED DECISIONS!*

*MOST IMPORTANT OF ALL!*

**ASK YOUR COMMUNITY WHAT THEY WANT/NEED!**

# National Alzheimer's and Dementia Resource Center

The NADRC provides expert technical assistance to AoA/ACL and its grantees, as well as making program information, program deliverables and resources available to individuals and organizations outside the Alzheimer's grantee community.

https://nadrc.acl.gov/

# Administration for Community Living/
## National Alzheimer's and Dementia Resource Center (NADRC) Resources

- **Grantee-Implemented Evidence-Based and Evidence-Informed Interventions**
- **Choosing an Evidence-Based or Evidence-Informed Intervention: Considerations to Inform Decision-Making**
- **Translations of Program materials into other languages – Japanese, Korean, Russian, Spanish, Vietnamese**
- **Resources to bring cultural competence to programs**

# Thank you!

Erin Long, MSW
Team Lead, Alzheimer's Disease Programs Initiative (ADPI)
Office of Supportive and Caregiver Services
Administration on Aging
Administration for Community Living

Email: Erin.Long@acl.hhs.gov

# Q&A

Please, submit your questions in the Q&A Zoom feature!

# 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 X  @PHCOE_DC

# Thank you for joining us today!

Please take a moment to complete a brief survey.

Scan the QR code, click the link in the chat, or click the link that displays when you close the webinar.

We appreciate your feedback!

*bit.ly/EBP_publichealth*