Strategies for Public Health:

Dissemination, Implementation and Adaptation of Evidence-Based Programs in Dementia Caregiving

November 12, 2021

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…
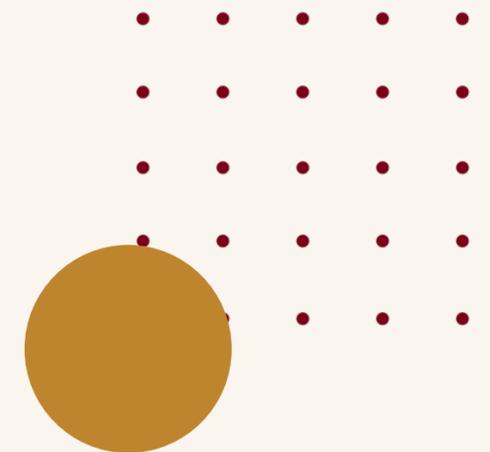
✓ Improving access to evidence-based programs and best practices

✓ 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
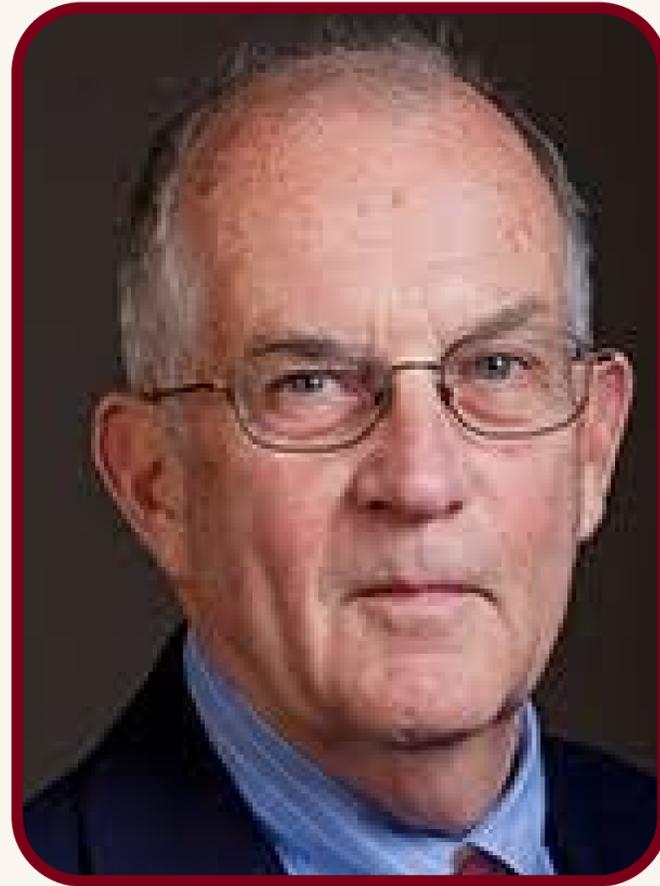
Welcoming our presenters...

Laura Gitlin, PhD, FGSA, FAAN
Dean and Distinguished University Professor, Drexel University College of Nursing and Health Professions

Ken Hepburn, PhD
PhD, Nell Hodgson Woodruff School of Nursing; Emory Roybal Center for Dementia Caregiving Mastery

John Hobday, MA
Founder and CEO, HealthCare Interactive

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

Knocking on One Door at a Time:

Dissemination Challenges Moving the COPE* Program to Practice

*(Care of Older People with Dementia in their Environments)

Laura N. Gitlin, Ph.D., FGSA, FAAN
Distinguished Professor
Dean, College of Nursing and Health Professions, Drexel University
Executive Director, AgeWell Collaboratory
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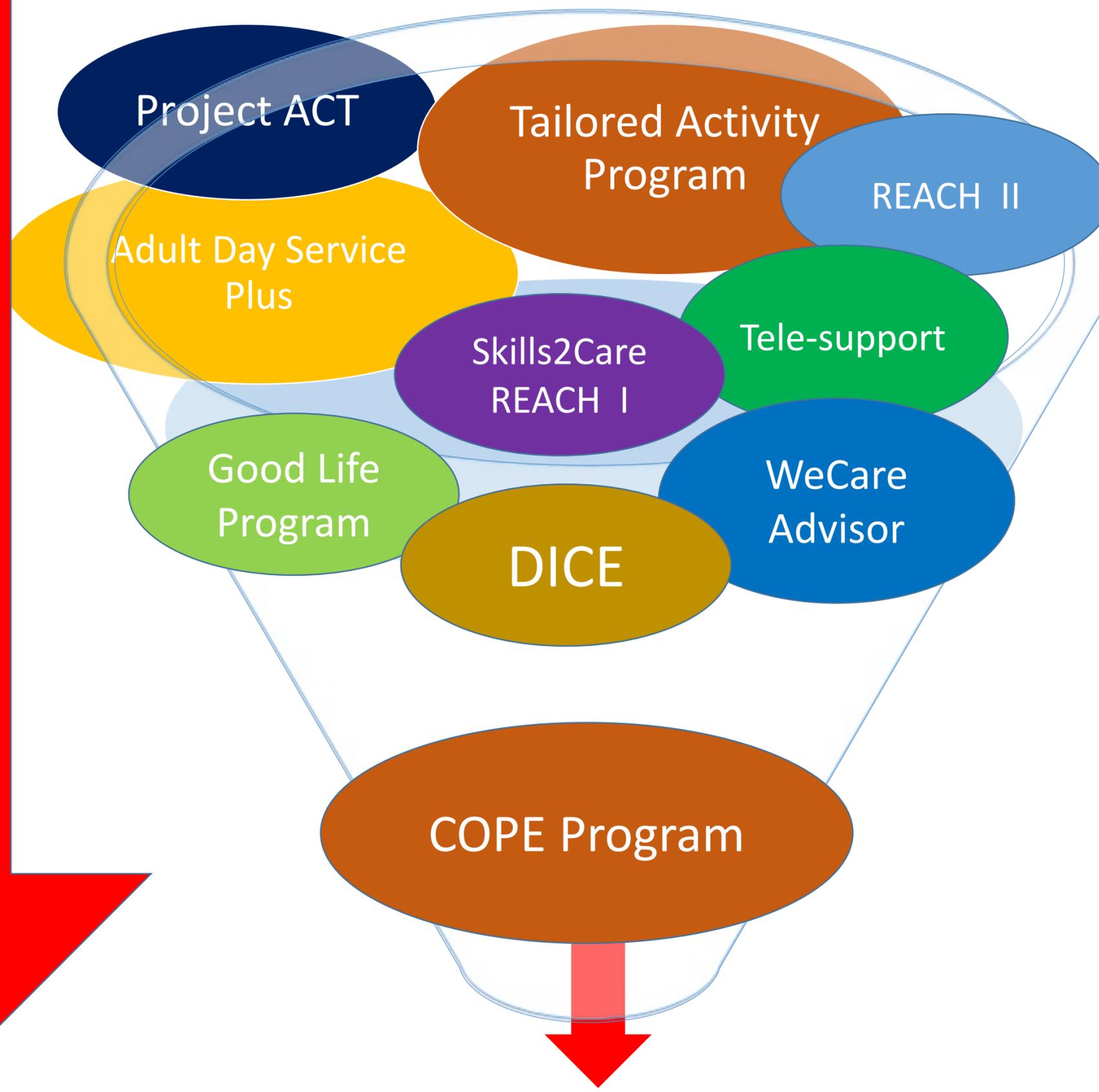Executive Director, AgeWell Collaboratory
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DREXEL UNIVERSITY
AgeWell
Collaboratory
College of Nursing and Health Professions

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Health Professions

17 - 25+ years From idea inception to practice if stars align

Project ACT

Tailored Activity Program

REACH II

Adult Day Service Plus

Skills2Care REACH I

Tele-support

Good Life Program

DICE

WeCare Advisor

COPE Program

Few families receive evidence-informed services

Considerations in Disseminating & Implementing Dementia Care

-What is level of evidence?
-Who does it work for?
-Relevance to stakeholders
-What is the need?
-Does it fit workflows within health systems?
-What is payment model?
-What is cost for training and delivery?
-Are staff available?
-What training is needed?
-Adaptations needed?
-Sustainability potential?
-Does developer have time, funds, & interest?

How COPE Works

- Flexible delivery :
  - Combination of home/phone
  - Number of sessions depends upon need (up to 10 OT sessions; 2-3 Nurse sessions)
  - Assessment tools used reflect agency preferences but all domains must be assessed
  - Built with home care, all inclusive care, billing potential

- 3 phases:
  - Assessment (caregiver needs/challenges, abilities of person living with dementia and home environment)
  - Implementation (CG identifies 3 care challenges and a prescription of nonpharmacological strategies are provided, demonstrated and practiced)
  - Generalization (modifying strategies for future declines)

- Content: Disease education, stress reduction techniques, skills training in communication strategies, task simplification, tailored activity use, management of common medical concerns)

Theory-based

Treatment Principles

COPE

1. Family Centered & Family Directed	• Program approach targets care challenges that caregivers identify as important to them.
2. Tailored to interests, abilities and preferences	• Education, strategies and activities reflect the living context, family needs, values and preferences of the person living with dementia and caregiver(s).
3. Culturally relevant	• Education, strategies and activities are consistent with previous/current roles and habits of the person living with dementia and family values and preferences.
4. Problem solving oriented	• Caregiver(s) participate in problem solving and brainstorming to identify strategies and activities that address care challenges.
5. Learning through active engagement	• Program approach employs adult learning principles, emphasizing experiential and learning through doing opportunities.

For People Living with Dementia

For Caregivers

And for Health Systems, cost savings

Detection of underlying treatable medical issues

Enhanced engagement

Reduced physical dependence

Reduced behavioral symptoms

Improved Caregiver confidence

Improved wellbeing

Less upset

Pizzi et al., in press, *Innovation in Aging*; Fortinsky et al., 2020, *Innovation in Aging*; Gitlin et al., 2010, *JAMA*; Clemson et al., 2020, *The Gerontologist;* ,

Getting Dissemination Ready

Develop on-line self-paced training program

- Identify training competencies and requirements
- Price structure for different settings, countries, independent providers
- Enrollment procedures
- Licensure
- Organize coaching calls (Who coaches, schedule, agenda)
- Determine how fidelity will be enhanced and monitored

Develop marketing and outreach strategy

- Brief introductory video
- Develop value propositions for different stakeholders

Specify allowable adaptations and targeted populations

Specify how agencies need to prepare, assure fidelity and associated costs for program delivery

Key Challenges

Human Factors – real life interferes
- Stakeholders, trained interventionists move, get sick, leave

Organizational Factors –readiness
- Mission alignment
- Value proposition
- Marketing and outreach

Historical Factors – COVID-19
- Agencies closed or capacity limited
- Redirection in focus
- Loss of staff

Scaling Factors
- Level of dependency on developer
- Clinical intensity can limit scaling
- Multi-component approaches most effective but challenging
- Work force may not be available
- Sustainability always challenging
- Methodology - In USA, one agency at a time; integrate in Alzheimer's Plans; national plan for training and outreach

What is the Future for the COPE Program?

- Who will "own" COPE and sustain it?
- Can COPE be integrated into health professional education?
- Is there a centralized organization who will take and run with COPE?
- How best to get COPE integrated into existing services and programs without knocking on one door at a time:
  - COPE can be integrated into care management, PACE, homecare, Adult Day, VA
- COPE protocols can be further developed
  - Sensory health protocols
  - End of life and bereavement

Adaptation and Fidelity Management of an Evidence-Based Behavioral Intervention

Ken Hepburn, PhD
Emory Roybal Center for Dementia Family Caregiving Mastery
Goizueta Alzheimer's Disease Research Center
Nell Hodgson Woodruff School of Nursing

Emory University

EMORY ROYBAL CENTER
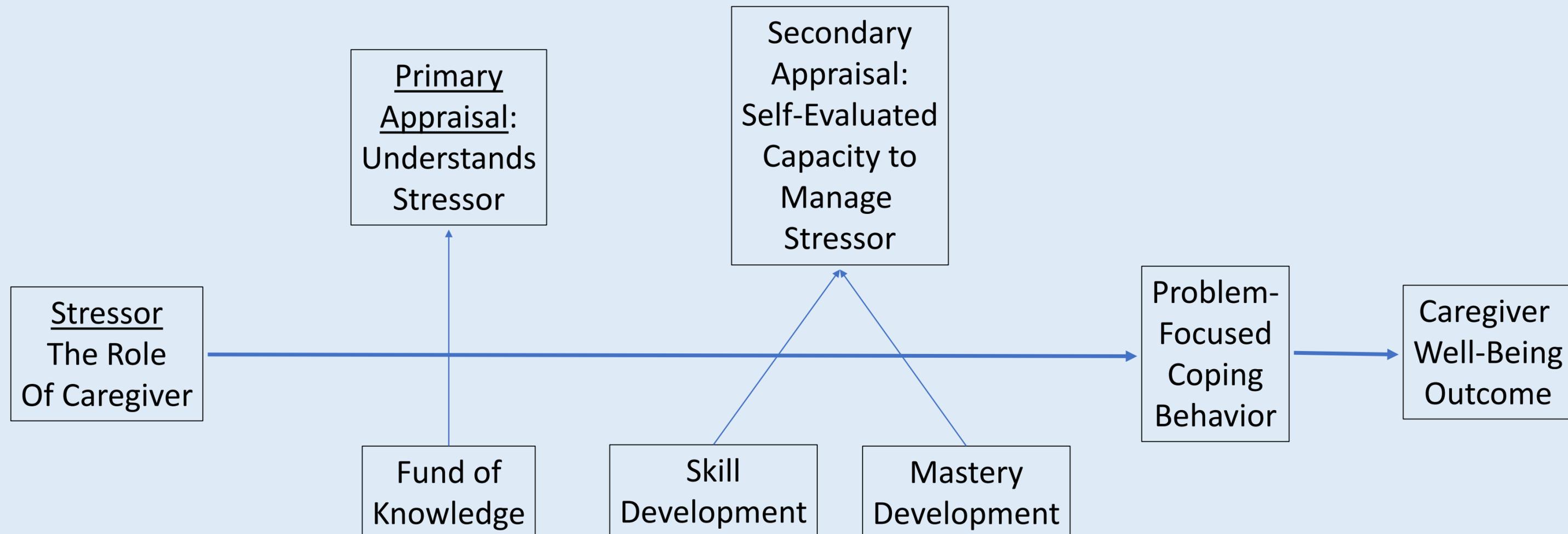FOR DEMENTIA CAREGIVING MASTERY

In What Does a Behavioral Intervention Consist?

- A Theoretical Framework or Basis

- A Behavioral Objective

- Core Principles/Tenets

- A Mechanism of Behavior Change

- An Intentional Structure/Curriculum Composed of Constituent/Contributing Parts

The Savvy Caregiver Example

Theoretical Framework: Social Cognitive Theory (Bandura, Folkman, Lazarus, Pearlin)

Savvy Example Continued

Behavioral Objective: Upon Completion of the Program, a Caregiver will be able to:

Frame and Enact Problem-Focused Coping Behaviors to manage the stress situations that day-to-day dementia caregiving produces

Savvy Example Continued

Core Principles

- Caregiving is a new life role – largely clinical in nature

- Personhood Persists

- Engagement is always possible

- Self-Care is Important

Savvy Example Continued

Mechanism of Change (How the Program Inculcates Caregiving Mastery (again, SCT)

- Instruction

- Successful Application with Coaching

- Vicarious Success – Observation of Successful Application by Peers

Savvy Example Continued

An Intentional Structure

- Deliberately sequenced Instruction
- Fund of Knowledge Leading to Application (Anchors of Contented Involvement)
- Active Learning Approach
  - Expectation for Home Application and In-Group Reporting
- Increasing Time Given to Coaching

Adaptation

Premise: Caregiving Occurs in Context

Challenge: How fit an evidence-based program (e.g., Savvy) to a particular context?

First Principle: Collaborate with Program Developers.

Start with Adherence to Theoretical Framework, Core Principles, Behavioral Objective, and Instructional Strategies

After That: Mold Surface Elements to fit the Context

Implementation and Drift in Savvy*

Adherence to Theoretical Framework, Core Principles, Behavioral Objective, and Instructional Strategies

- If it's not about achieving mastery in the caregiving role
- If the emphasis is not on developing knowledge and skills needed in the role
- If it's not an active learning program with adequate time and attention to group exercises, home application efforts, and coaching

Then it's not The Savvy Caregiver Program

* Copyright, Trademark, and "Use Only with Permission" appear to carry no weight.
Practice seems to be: "What's yours is mine, and I can do with it as I will."

Solution to Drift: Fidelity Management

Certification and Recertification of Savvy Leaders

- Standardized Training and Certification Program

- Regular Refresher and Recertification

Licensure and Re-Licensure

- Clear Organizational Understanding of and Commitment to Program

- Structured Fidelity Management and Program Evaluation

Strategies for Public Health: Dissemination, Implementation and Adaptation of Evidence-Based Programs in Dementia Caregiving

How CARES® Can Serve as an Model to Help Disseminate EBIs

Presenter: John Hobday, M.A.
HealthCare Interactive, Inc.
Savvy Systems, LLC.

HealthCare Interactive Background

- Founded 1997

- Online Training for HealthCare Workers (workforce employees) – 50+ hours

- Specialty Areas: Alzheimer's and Dementia

- 20 years of NIA funding / 20 journal articles

- "5-Step" Method, certification, and credentialing

- >350,000 trained throughout the U.S. and Canada, 1.5M modules completed, impact on care for more than 10 million PLWD

cares®
Online Dementia Training
HEALTHCARE INTERACTIVE®

How CARES Can Serve as a Model to Help Disseminate EBIs more Effectively

- Developing a Licensing Model

- Copyrighting/Trademarking Materials and Marks

- Defining Licensing Inclusions and Exclusions

- Ensuring Impact to Fidelity

- Promoting Sustainability Considerations

- Case Study: Savvy Caregiver™

Disseminating, Implementing and Adapting Programs Through Licensing

- ## Develop a Licensing Model
  - → Authorized use of CARES training and materials
  - → $99/user/program, or $159 any 2 programs (automatic 20% discount)
  - → $1,499 single-site "unlimited use" license
  - → $1,999 any 2 single-site "unlimited use" licenses

- ## Copyright and Trademark All Materials and Marks
  - → Copyright all materials and register all trademarks
  - → Word Marks: HealthCare Interactive® CARES®
  - → Design Marks:

HealthCare Interactive®

cares®

Disseminating, Implementing and Adapting Programs Through Licensing

- ## Define Licensing Inclusions
  - Access to the CARES® training
  - Ability to project CARES on-screen as a dementia curriculum, but not copy it
  - Access to a Free certification program for staff
  - Use of materials and downloads for staff

- ## Define Licensing Exclusions
  - Customers cannot copyright of any materials
  - Customers cannot use logos (without written authorization)
  - Customers cannot advertise CARES (without written authorization)

Disseminating, Implementing and Adapting Programs Through Licensing

- ## Ensure Impact to Fidelity

  1. Defined curriculum, certification process, credentialing process

  2. Standardized training, materials and distribution platform

  3. No "drift" occurs (if you talk about Marianne in one facility, you can discuss the very same example in the next with full understanding of the concepts taught.)

  4. No reliance on individual trainers' interpretation of concepts (e.g., educator who many not fully understand our "5-step method" are not subsequently teaching it to others)

  5. In Process: Case Write Ups for credentialing program

Disseminating, Implementing and Adapting Programs Through Licensing

- **Promote Sustainability Considerations**

  1. CARES is an asynchronous, defined curriculum that is scalable

  2. CARES is updated on a regular basis for:

     a. New state regulations

     b. Updated content and videos (i.e., COVID-19, care planning, etc.)

     c. Technical updates

  3. New product development extends sustainability

     (e.g. Serious Mental Illness version; Spanish language version)

  4. Long-term sustainability is likely due to an ongoing revenue stream

Summary:

- Develop a Licensing Model for your EBI
- Copyright and Trademark All Materials and Marks
- Define Licensing Inclusions and Exclusions
- Ensure Impact to Fidelity
- Promote Sustainability Considerations

Case Study: Savvy Caregiver™

Partnered with Technology Transfer Office (UMN/Emory)

- 2008: Licensing agreement with HCI
- 2021: Licensing Agreement with Savvy Systems

Developed a Licensing Model

- Created Flexible licensing model for each user and each version
- Established a home for licensing (www.savvycaregiver.com).
- Standardized Savvy Caregiver leader training (online training)

Case Study: Savvy Caregiver™

Copyright and Trademark

- Created authorized brand for Savvy Caregiver
- Continuing to copyright all materials
- Created of new "authorized" Savvy Caregiver manuals
- Started to make clear that Savvy Caregiver is not in the public domain
- Submitted trademark registration for Savvy Caregiver®

Case Study: Savvy Caregiver™

Define Licensing Inclusions

- Licensees can use authorized versions of Savvy Caregiver materials and branding

- Licensees can use authorized manuals, PowerPoints, and videos

- Licensees receive access to "Members Only" area on the www.savvycaregiver.com to access members-only materials, free ongoing webinars, follow-up trainings, etc.

Case Study: Savvy Caregiver™

Define Licensing Exclusions

- Licensees may not incorporate Savvy materials without permission and attribution.

- Licensees may not use alternative branding of Savvy Caregiver.

- Licensees may not independently distribute Savvy materials or training.

Case Study: Savvy Caregiver™

Ensure Impact to Fidelity

- Implemented a licensing agreement UMN/EDU

- Defined structures, inclusions, exclusions

- Eliminating master trainers to help limit "drift"

- Alternatively, considering process to ensure individuals trained by master trainers demonstrate equal knowledge and skills as via authorized trainers.

Case Study: Savvy Caregiver™

Promote Sustainability

- Established strong partnership with Tech Transfer
- Established Licensing as a path to fidelity and sustainability
- Created a revenue model to maintain program development, staffing, and training
- Created a commercialization model as a way to expand Savvy in the marketplace
- Created a structure to bring Savvy licensees together as a community

Conclusion

Licensing, copyright/trademark protection, fidelity, & sustainability structures

will allow your

Evidence-based program

to survive long-term.

Thank You and Questions

John Hobday

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Translation and Implementation of Dementia Specific Evidence-Based Interventions

Erin Long, MSW

Administration on Aging

Administration for Community Living

November 12, 2021

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.

Dementia Capability in Indian Country

- Grants to support federally recognized tribes, tribal organizations and/or consortiums representing federally recognized tribes in these target activities.

Where are we active NOW? (Fall 2021)

- State and HCBS grantees: State Units on Aging/Public Health/Social Service Departments, City & County governments, AAAs/COGs/ADRC, ADRD specific service providers, hospital systems, senior centers, and university based service providers.
- 32 States, District of Columbia and Puerto Rico
- Grantees have implemented 24 evidence-based and 12 evidence informed interventions.
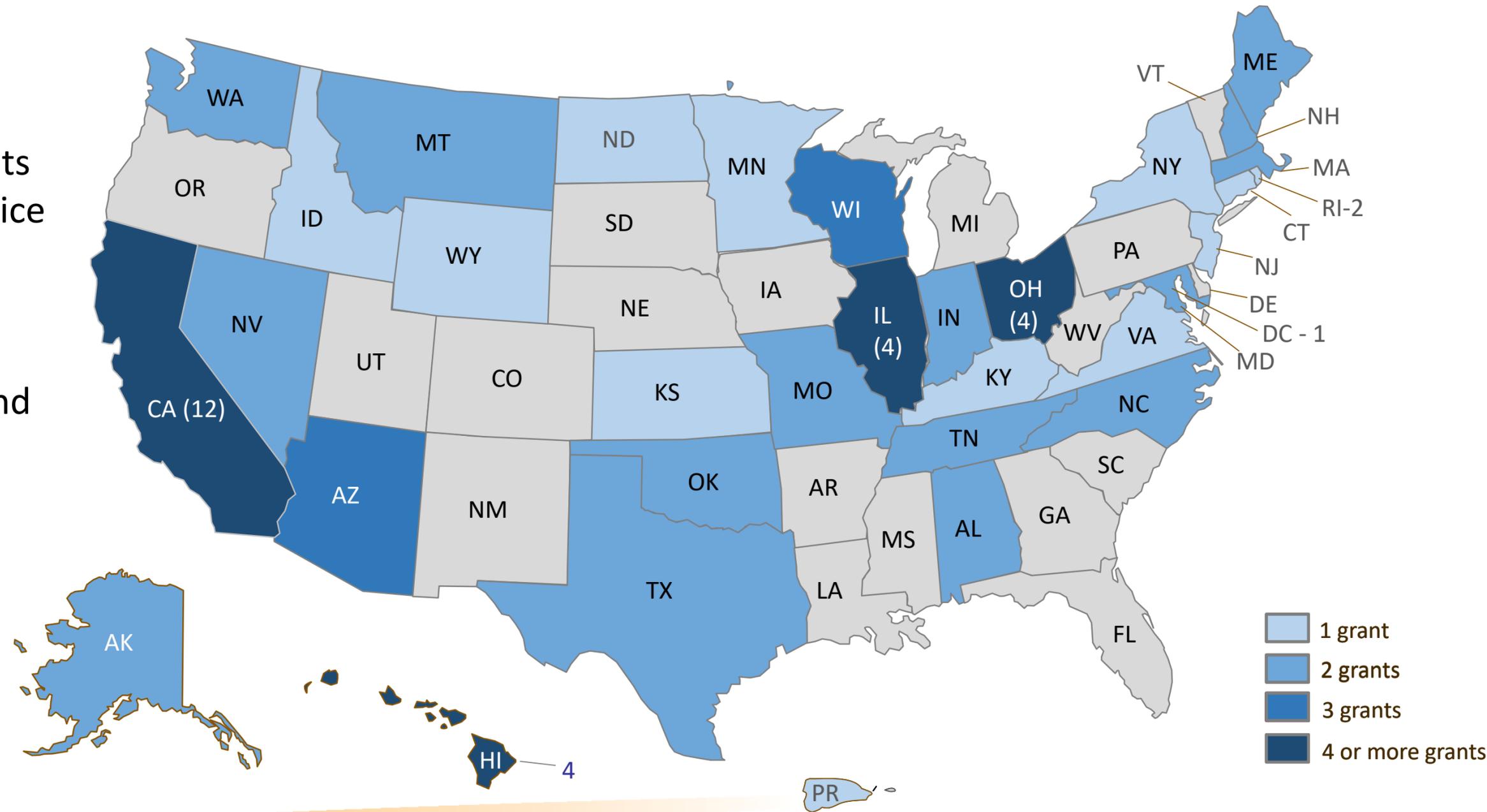
Evidence-Based Interventions Delivered through ACL Funded Programs

Evidence-Based Interventions	Person with Dementia Outcomes	Caregiver Outcomes
• BRI Care Consultations • BRIDGE Care Transitions • Care Ecosystem • Care of Older Persons in their Environment (COPE) • Cognitive Stimulation Therapy • NY University Caregiver Intervention • Powerful Tools for Caregivers • REACH Community • REACH Texas • Powerful Tools for Caregivers • SAVVY Caregiver • STAR-C	• Increased Perceived Quality of Life • Increased Enhance Self-efficacy (early stage) • Increased Meaningful Engagement • Decreased Emergency Room Visits • Decreased depression, • Decreased stigma • Increased independent functioning • Decreased unmet needs • Decreased behavioral symptoms • Delayed nursing home placement	• Improved Caregiver Stress • Improved Caregiver Burden • Improved Caregiver Coping • Caregiver Quality of Life • Improved Health • Improved Knowledge • Increased Self-Efficacy • Delayed Intent to Place • Positive Aspects of Caregiving

Decisions, Decisions

How do we choose the intervention that is right for our community?

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

Will choices meet the needs of community in terms of cultural competence? Including Rural vs Urban?

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

Make informed decisions!

Know your community!

Ask the right questions.

Think about now, the future?

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

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

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

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!!*

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

Is the intended service population likely to buy-in?

Administration for Community Living

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**
- **Best Practice Caregiving Database of Dementia Specific Evidence-Based Interventions (***at Benjamin Rose Institute website)*
- **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**

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.

LOOKING AHEAD

- ACL's continued commitment to translating evidence-based interventions into communities to support training and educating of caregivers (paid and unpaid).

- ACL's continued commitment to translating evidence-based interventions into communities to support.

- Bringing cultural competence, diversity to service delivery.

- Evaluating the impact of these interventions in the community.

Administration for Community Living

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 $31.5M
Expected Number of Awards:	33-35
Award Ceiling:	$1,000,000 Per Project Period
Award Floor:	$400,000 Per Project Period

QUESTIONS???

Erin Long, MSW
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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!

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at the end of this presentation.