

# Grand Rounds: Translating Evidence-Based Dementia Caregiving into Real-World Practice

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# Current Challenges Facing Dementia Caregivers

## Physical and Emotional Burden

- Caregiver stress, depression, and burnout rates
- Health consequences for caregivers
- 24/7 nature of dementia care

## Knowledge and Skill Gaps

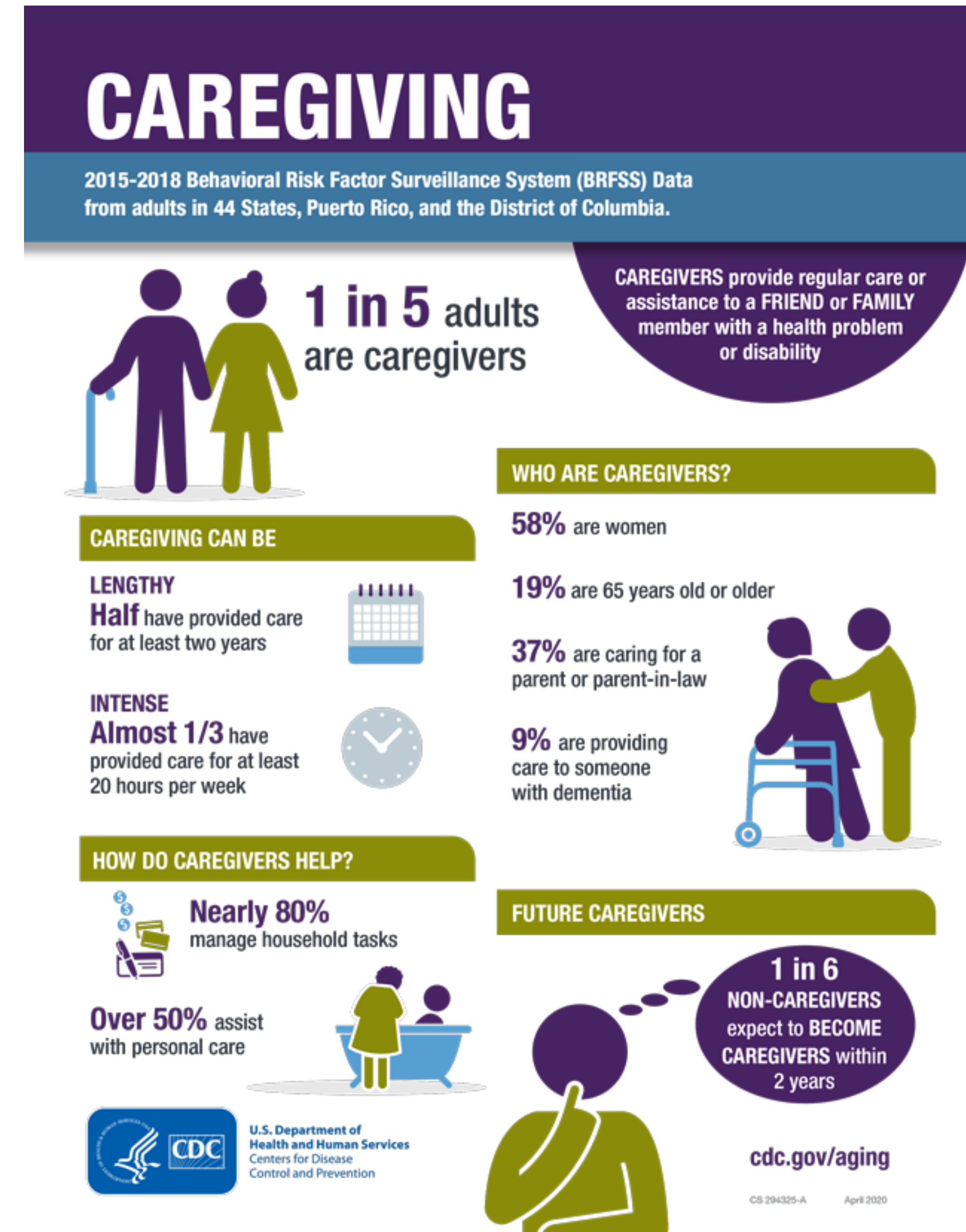
- Lack of dementia-specific training
- Difficulty managing behavioral symptoms
- Navigation of healthcare systems

## Resource and Support Limitations

- Limited access to respite care
- Financial constraints
- Geographic barriers to services
- Fragmented support systems

## Evolving Care Needs

- Progressive nature of dementia
- Changing behavioral and functional challenge





# The Rich Evidence Base: Over 200 Interventions

## Scope of Available Research

- Systematic reviews and meta-analyses
- Range of intervention types and approaches

## Categories of Evidence-Based Interventions

- Psychoeducational programs
- Support groups and peer support
- Skills training interventions
- Technology-assisted interventions
- Multicomponent approaches

## Demonstrated Effectiveness

- Effect sizes and clinical significance
- Cost-effectiveness data

TABLE. EVIDENCE-BASED CARE INTERVENTIONS THAT IMPROVE CAREGIVERS' QUALITY OF LIFE		
Program	Delivery model	Results of intervention
Active Caregiving: Empowering Skills (ACES)	Weekly 2-hour session for 4 weeks led by trained layperson professional or paraprofessional	Decreased caregiver depression symptoms and improved quality of life for caregiver
Adult Day Services Plus (ADS Plus)	Skills training and check-ins from trained professional or paraprofessional for skills-training education, and resources. Up to 8 sessions (15 minutes-1 hour) over 1-year	Decreased caregiver depression symptoms, improved caregiver confidence and skills, and improved caregivers' quality of life.
Mindfulness Training for Patients with Progressive Cognitive Decline and their Caregivers Program	Weekly 90-minute sessions for caregivers over 8 weeks led by professional or paraprofessional, focused on meditation, movement, yoga	Decreased depression symptoms, improved confidence and skills, quality of life, and health for caregivers; also improved depression symptoms, severity of other symptoms, stress, and quality of life for person with dementia
REACH TX	4 in-person sessions for caregiver and person with dementia with professional or paraprofessional over 6-month period	Decreased depression symptoms, improved confidence and skills, quality of life, and health for caregivers; decreased symptom severity and increased independence for activities of daily living for person with dementia
Savvy Caregiver	Weekly 2-hour session for 6 weeks in-person or online from trained layperson, paraprofessional or professional focused on caregiving knowledge and skills, coping with stress, and encouraging persons living with dementia to participate in daily tasks and activities.	Decreased depression symptoms, improved confidence and skills, quality of life, and health for caregivers; decreased symptom severity for person with dementia

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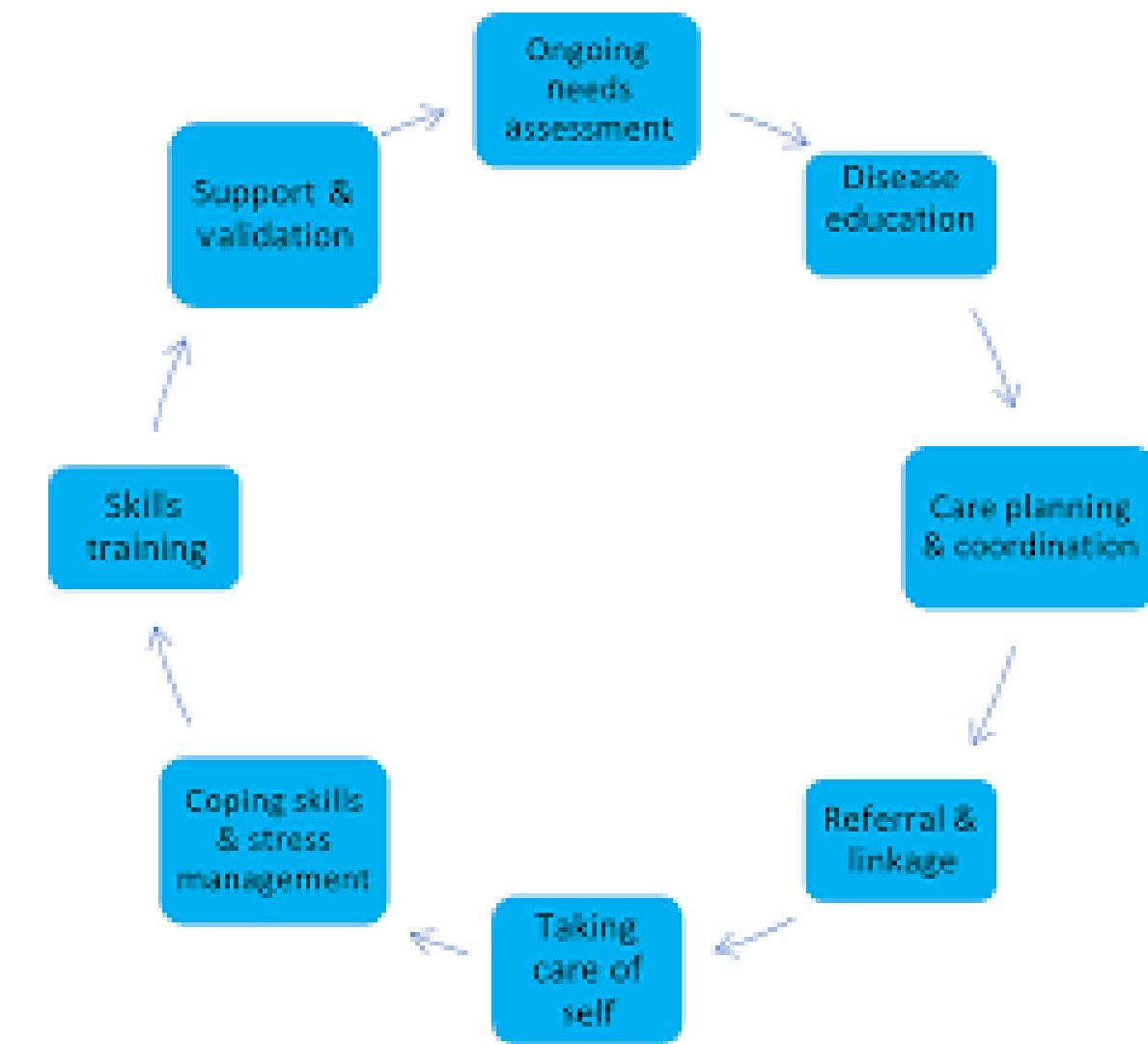


# Active Ingredients of Effective Interventions

- **Education and Information Provision**
  - Dementia knowledge and disease progression
  - Behavioral management strategies
  - Communication techniques
- **Skill Building and Problem-Solving**
  - Practical caregiving skills
  - Stress management techniques
- **Emotional Support and Validation**
  - Peer connection and shared experiences
  - Professional counseling components
- **Resource Navigation and Advocacy**
  - Healthcare system navigation
  - Community resource identification
  - Legal and financial planning

## Delivery Characteristics

- Structured, multi-session formats
- Tailored to individual needs
- Culturally appropriate approaches
- Accessible delivery methods



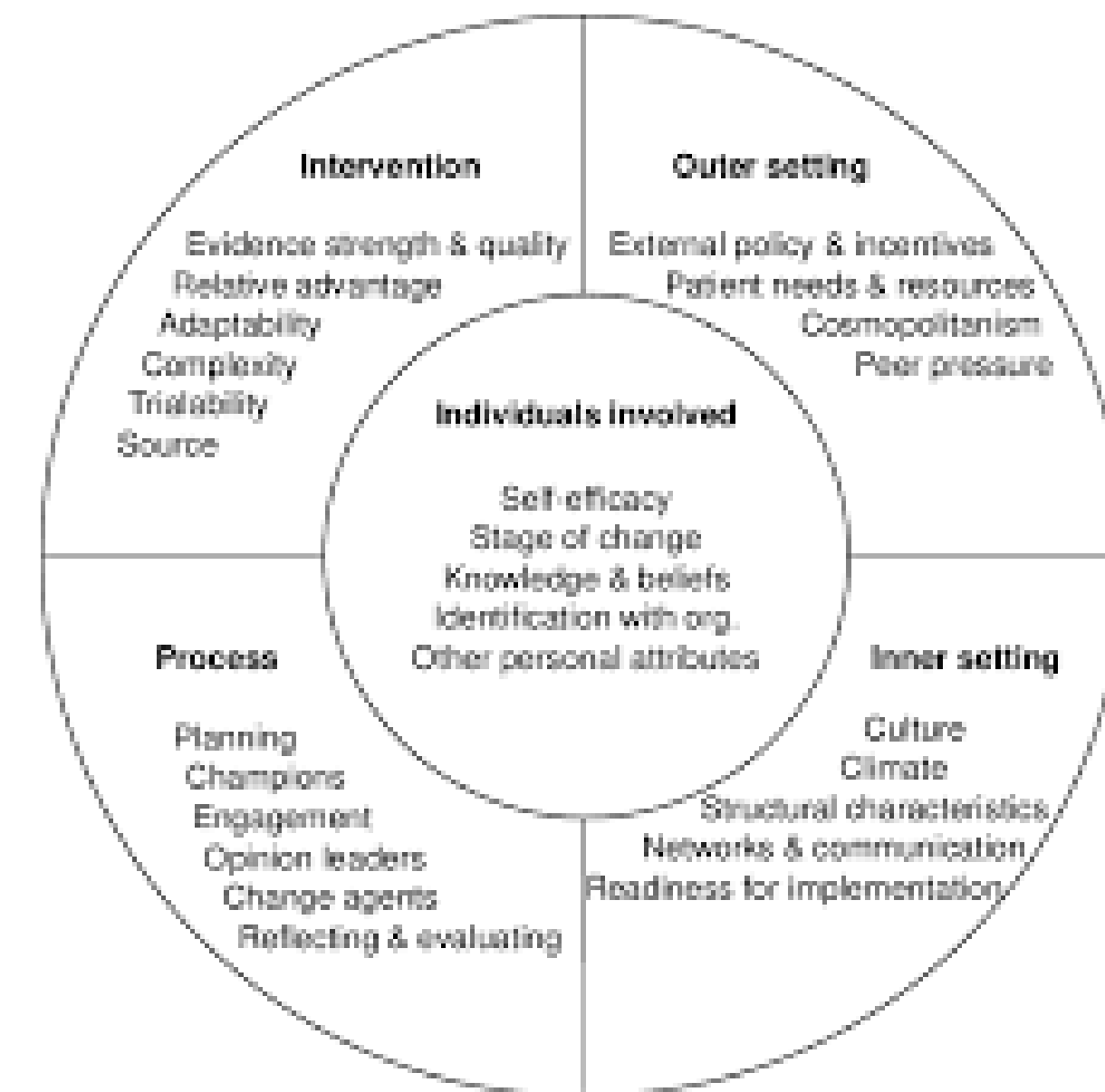


# The Challenge of Evidence Translation in Dementia Caregiving

- **Caregiver-Specific Factors**
  - Time constraints and competing demands
  - Caregiver reluctance to seek help
  - Stigma and isolation
  - Heterogeneity of caregiver populations
- **System-Level Barriers**
  - Lack of reimbursement mechanisms
  - Limited healthcare provider training
  - Absence of standardized screening and referral
  - Insufficient community infrastructure
- **Intervention Adaptation Challenges**
  - Maintaining fidelity vs. local adaptation
  - Scaling from research to practice settings
  - Training and supervision requirements

## Research-to-Practice Gap

- Controlled vs. real-world conditions
- Resource limitations in practice settings
- Sustainability challenges
- Outcome measurement difficulties





## Develop stakeholder interrelationships

Build a connection	<input type="checkbox"/>
Capture and share local knowledge	<input type="checkbox"/>
Develop academic partnership	<input type="checkbox"/>
Obtain formal commitments	<input type="checkbox"/>
Organize clinician implementation team meeting.	<input type="checkbox"/>
Use an implementation advisor	<input type="checkbox"/>

## Train and educate stakeholders

Conduct educational meetings	<input type="checkbox"/>
Develop educational materials	<input type="checkbox"/>
Distribute educational materials	<input type="checkbox"/>
Make training dynamic	<input type="checkbox"/>
Provide ongoing consultation	<input type="checkbox"/>
Work with educational institution	<input type="checkbox"/>

## Support clinicians



Remind clinicians	<input type="checkbox"/>
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## Engage participants

Involve participants and family members	<input type="checkbox"/>
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## Utilize financial strategies

Alert incentive/allowance structures	<input type="checkbox"/>
Use capitated payments	<input type="checkbox"/>

## Change infrastructure

Change record systems	<input type="checkbox"/>
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# YOUR TURN!



- **COPE in PACE** Evidence-based occupational therapy, nurse intervention
- Focuses on environmental modifications and caregiver training
- Proven effective in reducing caregiver burden and improving quality of life
- Originally tested in suburban, English-speaking populations
- **Your Setting: Urban Hispanic PACE Program**
- 85% Spanish-speaking participants
- Limited family caregiver availability due to work demands
- Small apartments with multiple generations
- Staff: 2 OTs, 1 bilingual social worker, PT RN limited budget
- Strong community ties but transportation challenges

- **National Dementia Care Coordination** in Rural Hospital
- Program: Comprehensive dementia care coordination model
- Evidence-based care planning and family support-precursor to GUIDE model
- Developed with Alzheimer's Association partnership
- Proven to improve care transitions and caregiver self efficacy
- Designed for integrated health systems with specialist access
- **Your Setting: 75-bed rural hospital**
- Serves 3-county area (population 15,000)
- Nearest neurologist 2 hours away
- Staff: 1 part-time social worker, rotating physicians
- Many patients uninsured or underinsured
- Strong community relationships but limited resources



# 3 Rounds- 3 minutes each

## **Round 1: Barriers Assessment (3 minutes)**

Identify the top 3 barriers to implementing your program:

- Resource Barriers (staffing, funding, space, technology)
- Cultural/Language Barriers (communication, cultural fit, health beliefs)
- Structural Barriers (geography, healthcare system, regulatory)

## **Round 2: Adaptation Strategies (3 minutes)**

Choose ONE barrier from Round 1 and develop a practical solution:

Consider:

- What would you modify about the original program?
- What partnerships would you need?
- How would you maintain program fidelity while adapting?
- What would success look like in your setting?

## **Round 3: Debrief (3 minutes)**

What surprised you most about the implementation challenges?

How might these real-world constraints actually improve the program?

What would you need to convince administrators to support this initiative?



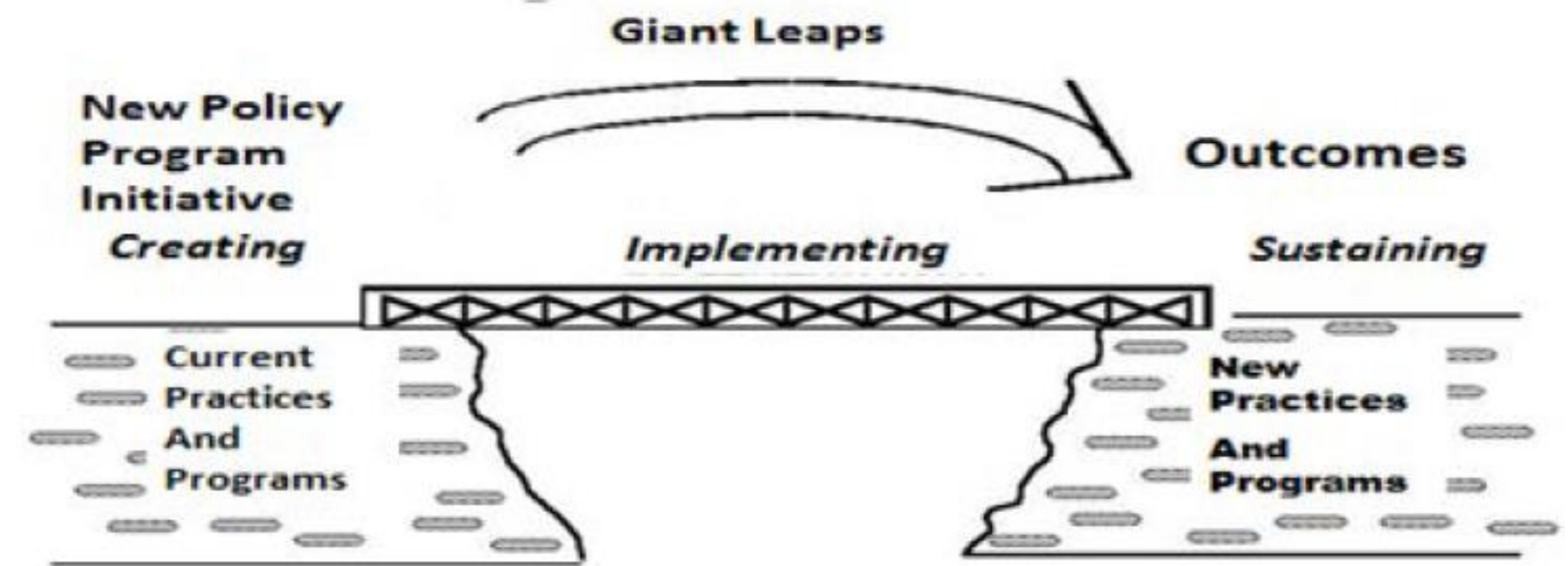
# Cross-Program Lessons Learned

## Common Implementation Challenges

- Recruitment and retention of participants
- Staff turnover and training
- Measuring and demonstrating impact

## Critical Success Factors

- Strong organizational leadership and commitment
- Adequate funding and resource allocation
- Local champions and ongoing enthusiasm
- Community partnerships commitment
- Flexible adaptation while maintaining core components





# Recommendations for Future Implementation

## **For Healthcare Systems/Clinicians**

- Integrate caregiver assessment into routine care
- Develop reimbursement pathways
- Address workflow concerns

## **For Researchers**

- Consider implementation science
- Develop pragmatic outcome measures
- Study adaptation strategies
- Evaluate cost-effectiveness in real-world settings

VALUE PROPOSITION: “COPE research demonstrates better dementia management for the person living with dementia, improved care partner well-being, and increased positive family communication.

Enhancing dementia competence in the clinical team through COPE is closely aligned with PACE site priorities.

Specialized training in this area can attract and retain top-tier talent while further strengthening PACE site reputations. Community relations can grow as a result, increasing participation in services by families looking for the best care.”



# Call to Action

- Moral imperative to support caregivers
- Economic benefits of prevention
- Opportunity to improve outcomes

## NATIONAL POLICIES

- Social institutions
- Public policies
- Regulations
- Research funding
- National dementia plans

## HEALTH AND HUMAN SERVICES SYSTEMS

- Insurers
- Health care organizations/ systems
- Payment mechanisms
- Training and preparedness of personnel

## NEIGHBORHOOD/COMMUNITY

- Safety/walkability/green
- Access to shopping, care, and services
- Social capital/memory cafes
- Community-based agencies
- Religious outlets
- Transportation
- Senior centers

## LIVING ENVIRONMENT

- Type of housing
- Accessibility
- Safety and security
- Level of stimulation
- Adaptive equipment
- Home repairs
- Persons in living space

## CAREGIVERS

- Health, physical, emotional, cognitive
- Knowledge, skills, motivation
- Social supports
- Employment and financial status
- Location in life course
- Relationship and closeness to individual with dementia
- Values, beliefs, style

## INDIVIDUAL WITH DEMENTIA

### Neuro-Biological

- Cognitive status
- Executive function
- Disease stage

### Health

- Comorbidities
- Health status
- Functional status
- Sensory changes

### Behavioral and Psychological

- Behavioral symptoms
- Affect/depression/anxiety

### Social

- Social comportment
- Interests, hobbies, occupations
- Socio-cultural background
- Sensitivity to context
- Living and marital status
- Lived experiences
- Exposures to discrimination

**Comprehensive  
Dementia  
Care to Support  
Aging in the  
Right Place**



# Next Steps

- Resources: <https://impactcollaboratory.org>;  
<https://embraceroybal.wisc.edu/>; <https://www.med.upenn.edu/PISCE>
- Hodgson, N., & Gitlin, L. N. (2021). Implementing and sustaining family care programs in real-world settings: Barriers and facilitators. *Bridging the family care gap*, 179-219.
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# Questions & Discussion

Thank you!

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