

Resources for Enhancing Alzheimer's Caregivers Health in Tribal Communities (REACH into Indian Country)

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-
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Learning Objectives

1. Describe characteristics of and risks to caregivers of persons with dementia.
2. Explain characteristics of successful behavioral interventions for caregivers.
3. Explain the basic skills taught in the REACH program to empower Caregivers to improve patient care and caregiver self-care.
4. Discuss how a risk based approach can be used in targeting the stressful areas of caregiving.

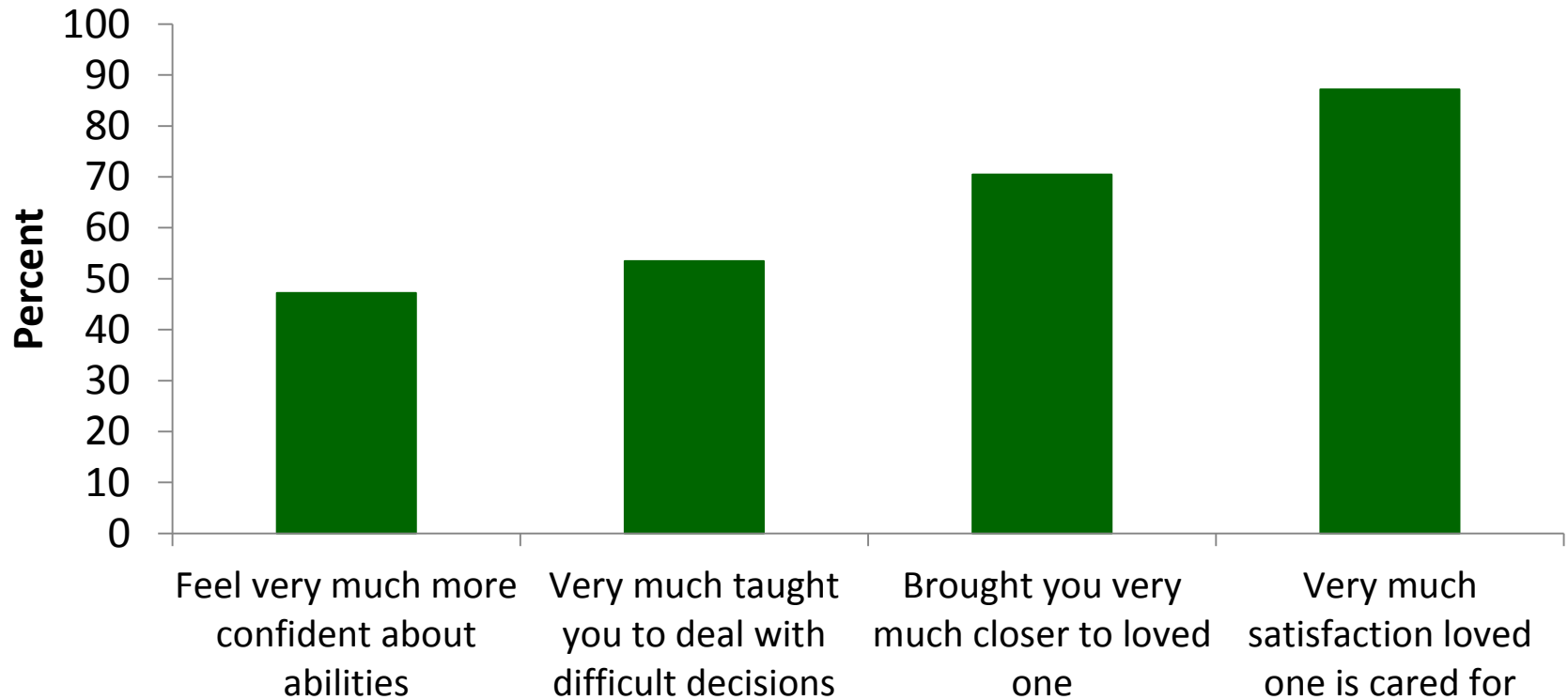
Caregiving Trends

- 43.5 million Caregivers (19% of U.S. adult population)
- 1.3 billion hours of care per month
- Value of informal care \$450 billion per year (2009)
- Demographic changes
 - Fewer children
 - More older adults
 - Diverse populations
- Family structures/dynamics
 - Fewer extended families available
 - Non-traditional families
 - Geographic distance
- Health care cost reductions
 - More transitions
 - Shorter stays
 - Greater reliance on families to provide complex clinical care in the home

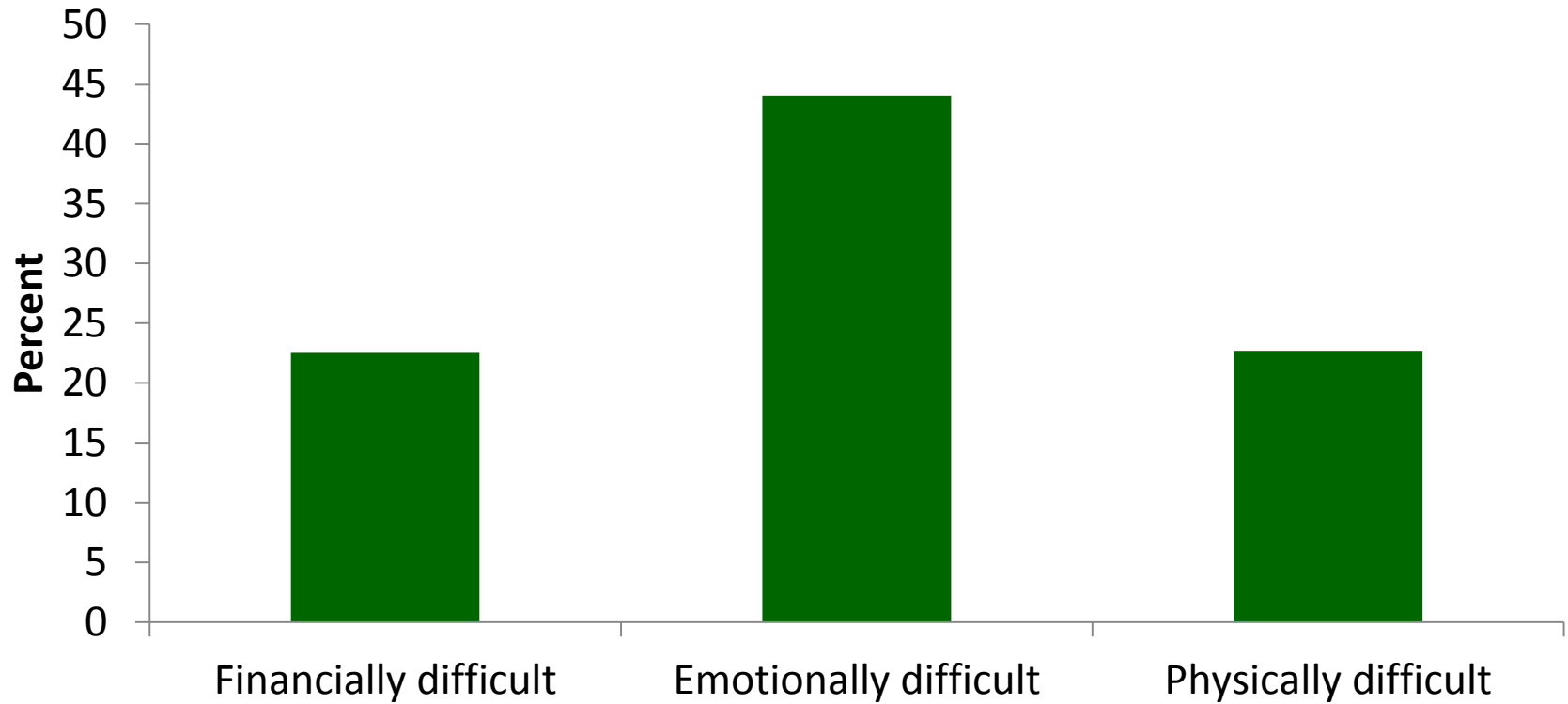
Domains of Care

- Household tasks
 - Shopping, laundry, housework, meals, transportation, help with bills, managing money
- Self-care/mobility
 - ADLs, behavioral problems, transferring
- Emotional and social support
 - Discuss ongoing life challenges, troubleshoot problems, help manage emotional responses, maintain normalcy
- Health and medical care
 - Manage and give medications, pills, or injections, wound care, operate equipment, manage acute changes and emergencies
- Advocacy and care coordination
 - Make appointments, speak to doctors, facilitate provider and patient understanding, insurance, arrange and supervise services
- Surrogacy
 - Treatment decisions, advanced planning, financial and legal matters

Benefits of Caregiving



Caregiving Risks



Caregiving Risks

- Psychological health
 - depression, anxiety, PTSD, burden, stress, morale, life satisfaction, marital satisfaction, resilience, grief
- Physical health
 - morbidity, mortality, blood pressure, insulin levels, impaired immune systems, CVD, health care use for both
- Caregiving/social
 - time spent on caregiving, social support, isolation, validation, efficacy, frustrations, safety

Economic Risks of Caregiving

- \$324,044 Social Security and wages lifetime loss for women (2008)
- Women caregivers 2.5 times more likely to live in poverty when old
- Economic hardships greater for
 - Low income families
 - Long distance caregivers
 - Disabled caregivers
 - Younger spousal caregivers
 - Long distance caregivers
 - Minority families
 - Caregivers with lower education
 - Families with more children at home
- Two-thirds of working caregivers caring for older person rearrange work schedule, decrease hours or take unpaid leave
 - 14% of caregivers of older adults left work due to inability to pay help (2015)
- American business lose approximately \$33.6 billion each year due to employees' need to care for loved ones 50 and over

Clinical Manifestations of Caregiving

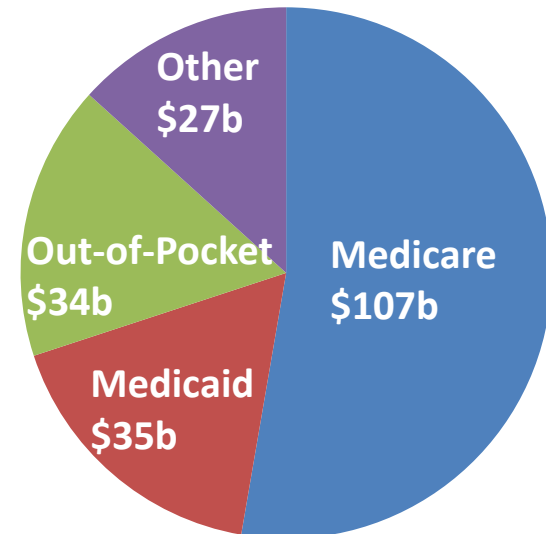
- Inability to provide care for patient
 - Making sure caregiver is in the loop
 - Medication errors
 - Lack of follow through on provider recommendations
 - Neglect
- Not taking care of self
 - Caregiver health status
 - Morbidity, mortality
 - Lack of caregiver assessment
- Burnout, stress
- Isolation
- Depression, grief



Health Care and Economic Impact of Dementia

- 5.4 million U.S. dementia patients
- Sixth-leading cause of U.S. deaths
- One-quarter of all older hospital patients
- More than three times as many hospital stays
- \$9.3 billion in additional caregiver health care costs due to physical and emotional toll of caregiving

2013 Costs of Alzheimer's \$203 Billion



AMA, *Dementia Performance Measurement Set*, 2011
Hurd et al., *NEJM* 2013, 368:1326-1334
2013 Alzheimer's Facts and Figures

Dementia Caregiving

- 5.8 million family and other unpaid dementia caregivers
- 532 million hours of help per month for dementia care
- 5.8 billion hours of unpaid care per year

Who identifies themselves as a caregiver?

Successful Caregiver Interventions

Common topics needed by all

- Disease and course
- Safety
- Caregiver physical well-being
- Caregiver emotional well-being
- Social support
- Management of patient concerns

Targeted to

- Specific needs of the dyad
 - Through assessment

Multicomponent

Focus on

- Education
- Support
- Skills building
 - Problem solving
 - Cognitive restructuring
 - Stress reduction
 - Communication
- Clinician-family alliance



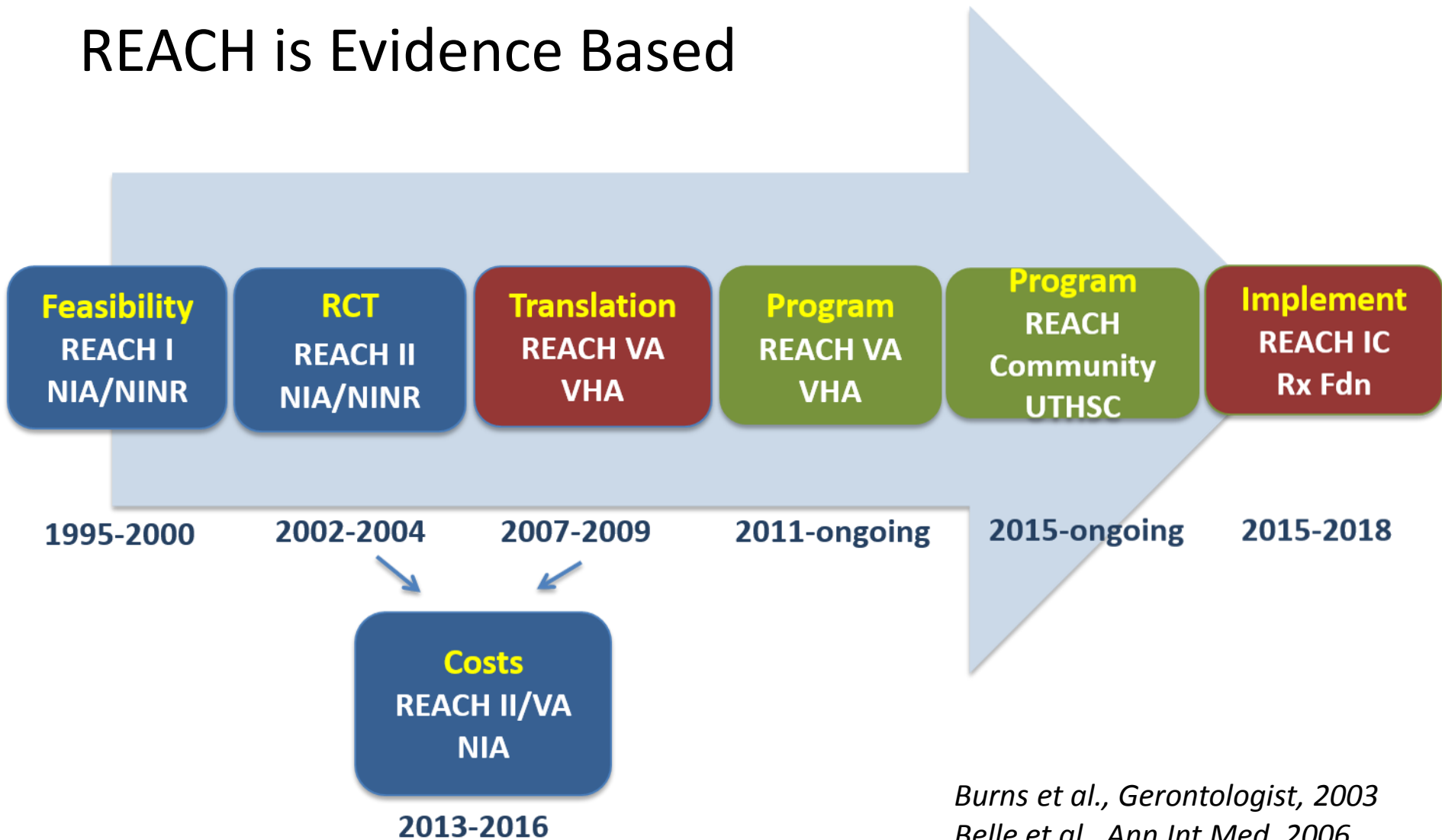
What is REACH?

Resources for Enhancing Alzheimer's Caregivers Health

REACH Intervention

- Individual behavioral intervention for caregivers
 - To help manage patient issues/concerns and their own stress and coping
- Active phase
 - Four individual core sessions over 2-3 months
 - Face to face or by telephone
 - Optional additional sessions based on caregiver need, desires and goal attainment, and Interventionist judgment
- Maintenance phase
 - Additional problems/stress issues as needed

REACH is Evidence Based



Burns et al., Gerontologist, 2003
Belle et al., Ann Int Med, 2006
Nichols et al., JAGS, 2008
Nichols et al., Arch Int Med, 2011
Nichols et al., Gerontologist, 2014

REACH into Indian Country Evolution

National Alzheimer's Project Act (NAPA) - 2013

Strategy 3.B: Enable Family Caregivers to Continue to Provide Care while Maintaining Their Own Health and Well-Being

Action 3.B.11: Pilot evidence-based interventions for caregivers in Indian Country

HHS and VA will partner to pilot REACH-VA in a small number of Tribes, focusing on American Indian and Alaska Native Veterans and their families. The IHS will invite IHS, Tribal, and Urban Indian health programs who serve American Indian and Alaska Native Veterans with dementia to obtain the REACH-VA training and materials for providing the caregiver support intervention. This cohort of programs and staff will provide us with insight to how well the REACH-VA program works in the IHS system.

REACH into Indian Country Evolution

National Alzheimer's Project Act (NAPA)- 2015 Update

Strategy 3.B: Enable Family Caregivers to Continue to Provide Care while Maintaining Their Own Health and Well-Being

Strategy 4.B: Work with State, Tribal, and Local Governments to Improve Coordination and Identify Model Initiatives to Advance Alzheimer's Disease Awareness and Readiness across the Government

REACH into Indian Country.

REACH into Indian Country. REACH (Resources for Enhancing Alzheimer's Caregivers' Health) into Indian Country is a 3-year project of the University of Tennessee Health Sciences Center REACH Training Center, which the Rx Foundation funds. The project will make the REACH intervention available to caregivers of elders with dementia, providing them with the tools and skills to manage challenges that arise in the course of caregiving. REACH is based on NIA-funded research, adapted and further evaluated by the VA system as REACH-VA. REACH-VA found that caregivers provided with this support experience significant decreases in burden, depression, anxiety, caregiving frustrations, and stress symptoms. In 2014, the REACH-VA intervention was piloted in three tribal communities. Continued coordination between ACL, IHS, and VA and funding by the Rx Foundation provides an opportunity and plan for implementation of the REACH intervention through IHS and tribal health programs and the Tribal Aging Network (NACSP) supported by ACL.

REACH into Indian Country Evolution

- REACH VA – ongoing
 - VA and IHS
- Rx funding – 02/01/2015
 - Implement REACH into at least 50 communities over the next 3 years
 - IHS PHNs
 - Tribal programs
 - ACL/AoA's Native American Caregiver Support Programs (NACSPs)



Why implement REACH?

REACH Goals

Empower staff

- Increase skills and knowledge
- Provide tools to work with Caregivers
- Maximize interactions

Empower Caregiver

- Increase problem or issue management and problem solving skills
- Increase coping skills

Improve Caregiver's life

- Decrease burden
- Decrease anxiety
- Decrease depression
- Decrease frustrations
- Decrease amount of time in tasks and on duty

Improve Care Recipient's life

- Improve management of problem behaviors and concerns
- Improve safety

REACH Works

Variable	Significance Time p -value	Clinical Significance d
Burden (0-16)	<.001	.33
Depression (0-6)	.006	.26
Anxiety (0-6)	<.001	.35
Safety (0-9)	<.001	.36
Caregiver frustrations (potential abuse) (0-4)	<.001	.33
General stress (1-10)	<.001	.46
Behaviors (0-25)	.001	.34
Decrease in time on duty, hours/day	.021	.24

d = effect size; difference in means/baseline standard deviation

REACH is Focused and Efficient

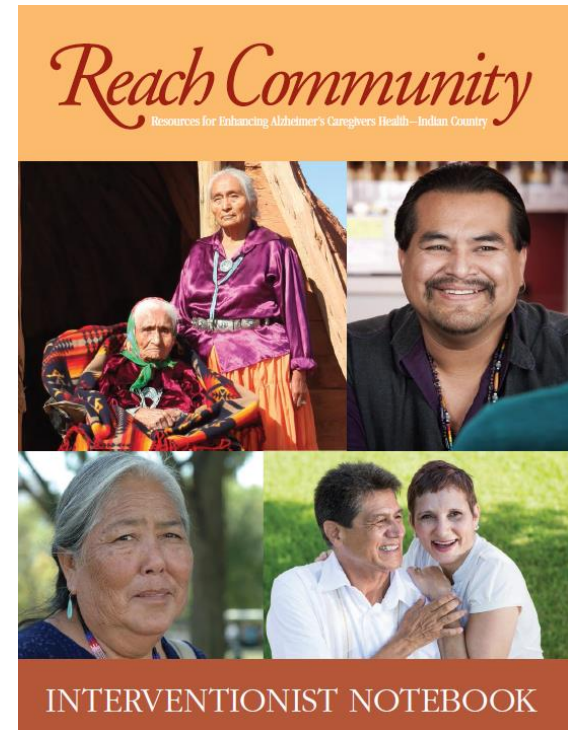
- Develops a working relationship quickly
- Maximizes staff time and interaction with the caregiver
- Gives staff a structure for interaction
- Gives the caregiver exactly what he/she needs
- Lessens caregiver dependence on staff

It got to the point I don't have to call her [interventionist] anymore.
(Caregiver)



REACH is Structured

- Protocol driven
- Simple to use
- Scripts, guidelines and talking points
- Grab and go materials
 - Caregiver Notebook
 - Interventionist Notebook
- Scripts are
 - Used as guides for interaction
 - Provide key vocabulary

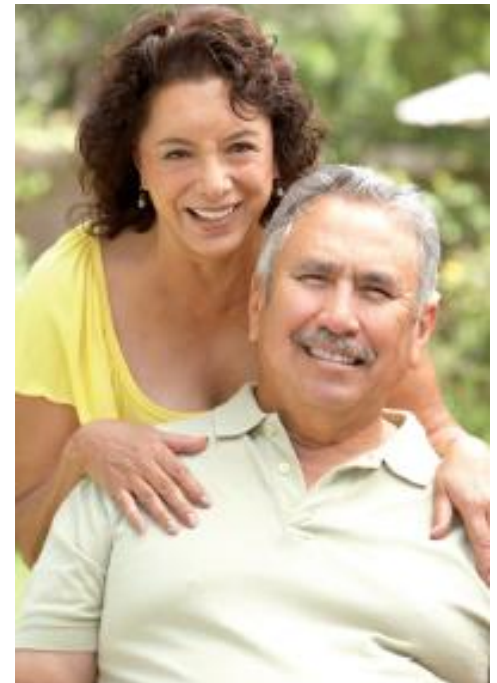




Why does REACH work?

REACH is Standardized

- Provides education, support, skills building
 - Problem solving
 - Cognitive reframing
 - Stress management
 - Communication
- Around risk areas that caregivers may experience:
 - Safety
 - Emotional well being
 - Self-care/healthy behaviors
 - Social support
 - Patient problem behaviors/caregiver concerns



REACH is Individualized

- Risk appraisal allows caregiving dyad concerns to be addressed
- Drives and customizes intervention
 - Identify major areas of high and moderate risk and alerts
 - Guide discussions and negotiate problem areas to address
 - Re-evaluate areas of risk periodically throughout intervention

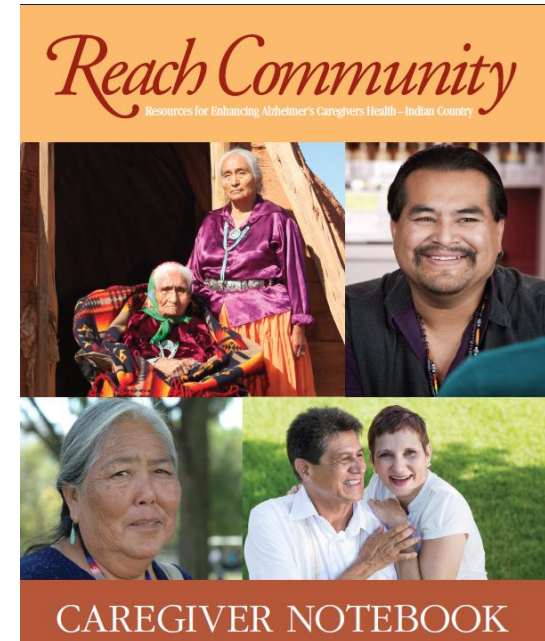
With the help of the risk priority inventory you were able to tailor it to their needs and that was great.
(Interventionist)



What does REACH look like?

REACH Materials

- For each caregiver
- Educational material (care recipient's condition, home safety)
- Stress and coping topics (health, well-being)
- Behavior/Issue topics
- Resource for now and after intervention ended



*CAREGIVER NOTEBOOK - EXCELLENT!
(Interventionist) The Caregiver
Notebook that is supplied. I could
refer back to it. Other home aides
saw it and said everyone (CG) should
have one. (Caregiver)*

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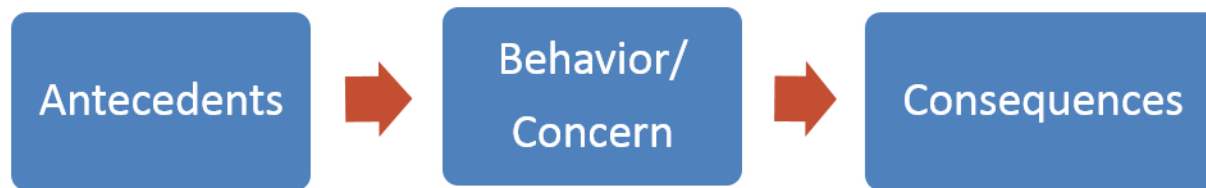
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Problem Solving Steps

- Determine/define/operationalize behavior/issue using ABC Process



- Assess previous attempts to address
- Set concrete and realistic goals
- Develop Target Behavior/Issue Plan
- Review and troubleshoot plan

The Reach program was a method to help the caregiver to deal with complex problems in a structured way. Our caregivers changed from viewing the issues with their loved ones as huge problems into thinking proactively by addressing small parts of the issues.

The REACH program was a method to help the caregiver to deal with complex problems in a structured way. Our caregivers changed from viewing the issues with their loved ones as huge problems into thinking proactively by addressing small parts of the issues. The book helped them to break thing down into a doable level.

(Interventionist, Cherokee)

Mood Management – Cognitive Reframing

- Managing the relationship between thoughts and feelings when the problem cannot be changed
 - Identify the situation
 - Identify current thoughts
 - Recognize current emotions/feelings
 - Challenge/replace unhelpful thoughts
 - Match milder feelings to milder thoughts



Mood Management Thought Record

<i>Identify the situation – describe the events that led to your unpleasant feelings</i>	<i>Identify your thoughts</i> * All or nothing (ought, must, should) * Awfulizing (awful, terrible, horrible evaluation) * Negative thinking	<i>Recognize your feelings and emotions</i>	<i>Challenge and replace or substitute unhelpful or negative thoughts with more helpful or milder thoughts</i>	<i>Match milder emotions to your milder thoughts</i>
Situation	Current Thoughts	Emotions	Substitute Thoughts	Substitute Feelings
What happened?	What are you thinking?	What are you feeling?	What is a different way of thinking about the situation?	What are you feeling?

Stress Management

- Stress Management/Relaxation Exercises
 - Signal Breath
 - Music
 - Stretching
 - Guided Imagery
 - Pleasant Events



Putting it Together to Help the Caregiver

- Active Phase
 - Four individual core sessions over 2-3 months
 - Face to face or by telephone
 - Optional additional sessions based on caregiver need, desires and goal attainment, and Interventionist judgment
- Maintenance Phase
 - Additional problems/stress issues as needed
- Key Tools
 - Structured, targeted to care dyad needs
 - Risk Priority Inventory
 - Interventionist Notebook
 - Caregiver Notebook
- Focus
 - Education
 - Problem solving
 - Mood management
 - Stress reduction



How can you become a REACH
interventionist?

UTHSC Caregiver Center Services

Materials

Training

Certification

Coaching

Contact

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REACH Coach

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