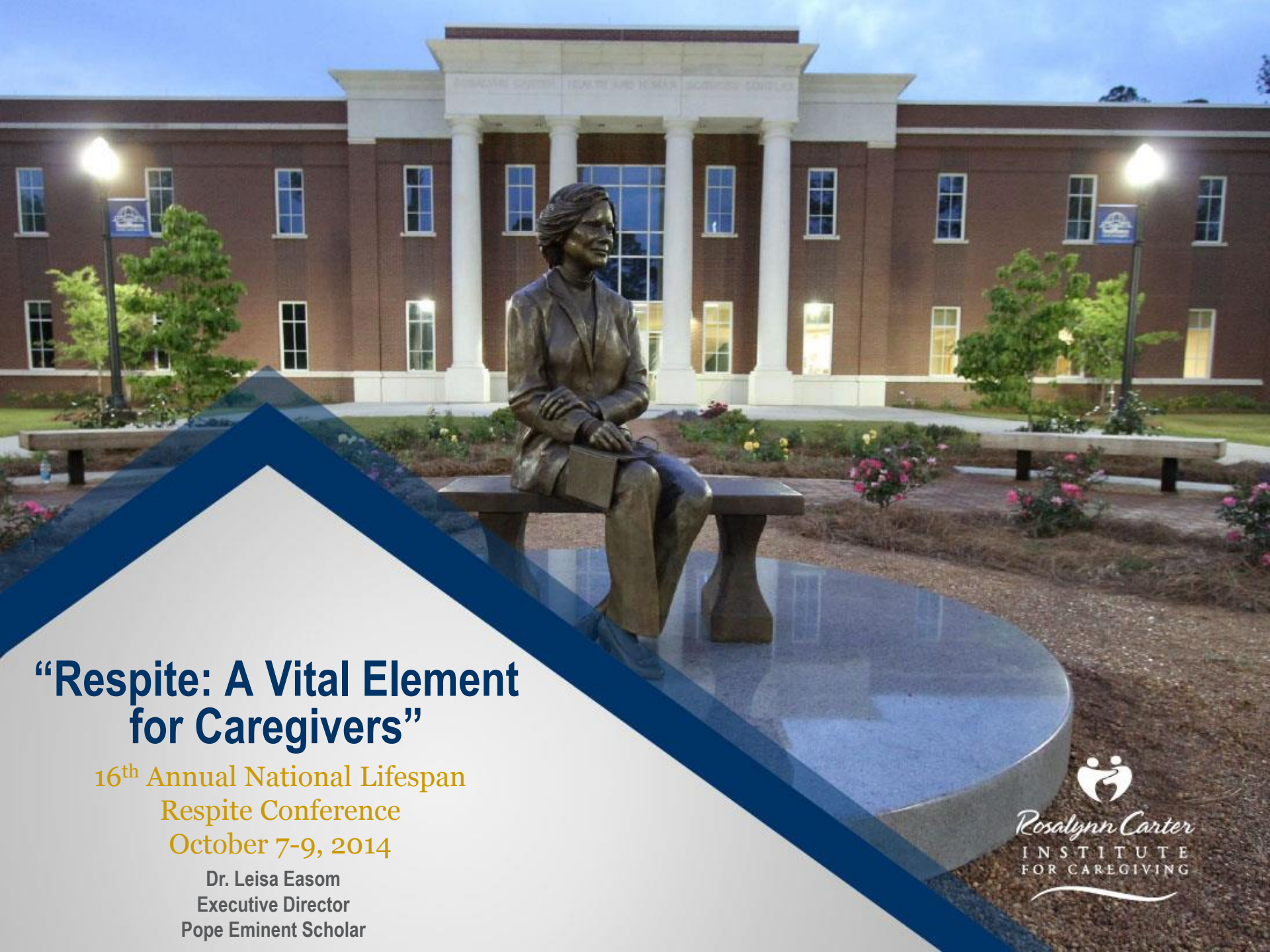




*Rosalynn Carter*

INSTITUTE  
FOR CAREGIVING





# “Respite: A Vital Element for Caregivers”

16<sup>th</sup> Annual National Lifespan  
Respite Conference  
October 7-9, 2014

Dr. Leisa Easom  
Executive Director  
Pope Eminent Scholar



# PIONEER IN CAREGIVING

“ *There are only four kinds of people  
in the world:*

*Those who have been caregivers*

*Those who currently are caregivers*

*Those who will be caregivers*

*Those who will need caregivers ”*

**-Rosalynn Carter**

**Former First Lady**





# ABOUT US



## *RCI: Supporting Caregivers through Advocacy, Education, Research, and Service*

The RCI was established in 1987 at Georgia Southwestern State University (GSW) in Americus, Georgia. The Institute was formed in honor of Former First Lady Rosalynn Carter, an alumna of GSW, to enhance her long-standing commitments to human development, caregiving and mental health through its Advocacy, Service, Research and Education Programs.

## *Mission and Philosophy*

The Rosalynn Carter Institute for Caregiving (RCI) establishes local, state, national, and international partnerships committed to building quality long-term, home and community-based services.

# RCI: SUPPORTING CAREGIVERS THROUGH ADVOCACY, EDUCATION, RESEARCH, AND SERVICE

## *Nationally...*

*Over 50 million family caregivers provide the largest proportion of care for dependent elderly individuals as well as adults and children with disabilities and chronic illnesses.*

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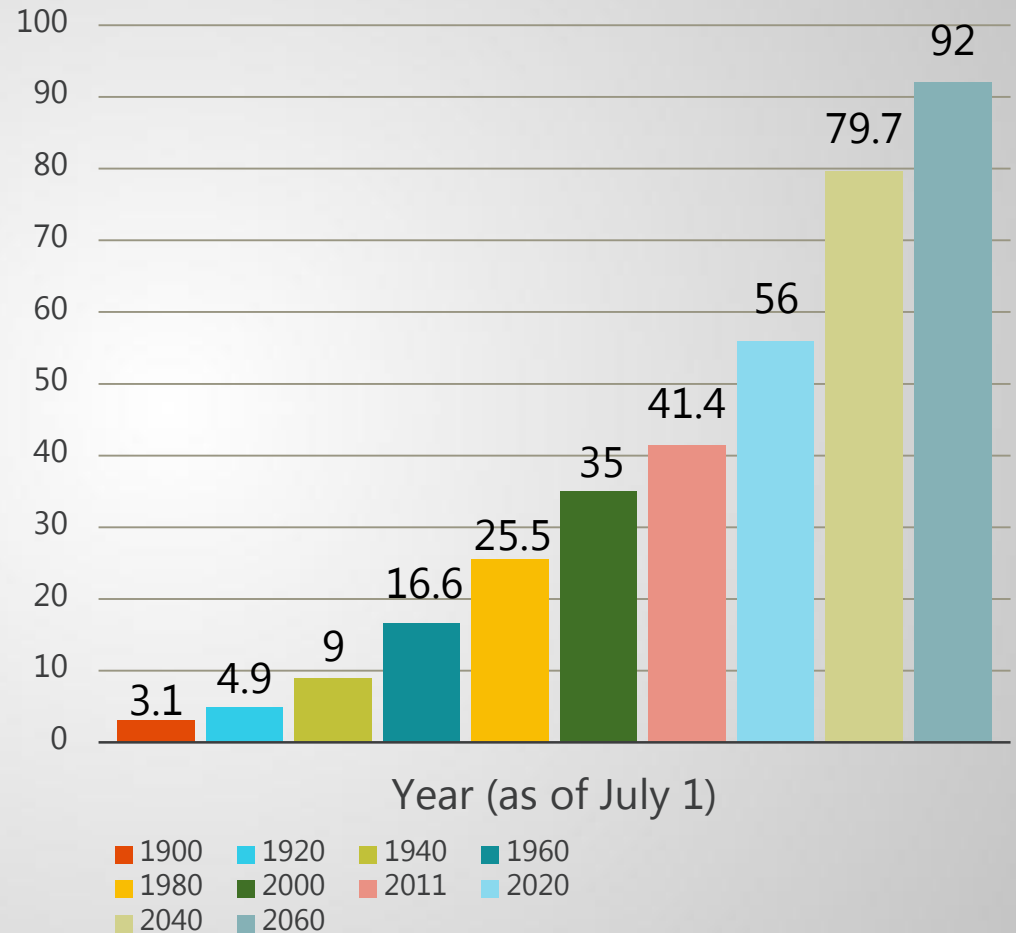
*The average senior today will spend two or more of their final years disabled enough to need someone to help with routine activities of daily living because of chronic illness.*



# AN AGING POPULATION

*Figure 1: Number of Persons 65+, 1900 - 2060  
(numbers in millions)*

- 35 million in 2000
- 36.9 million in 2009
- 79.7 million in 2040



# GENERAL ISSUES AND CONCERNS FACING ALL CAREGIVERS

- Today's family caregivers face an array of new challenges, including smaller, more geographically dispersed families, competing childrearing duties, and the need to balance work and caregiving.

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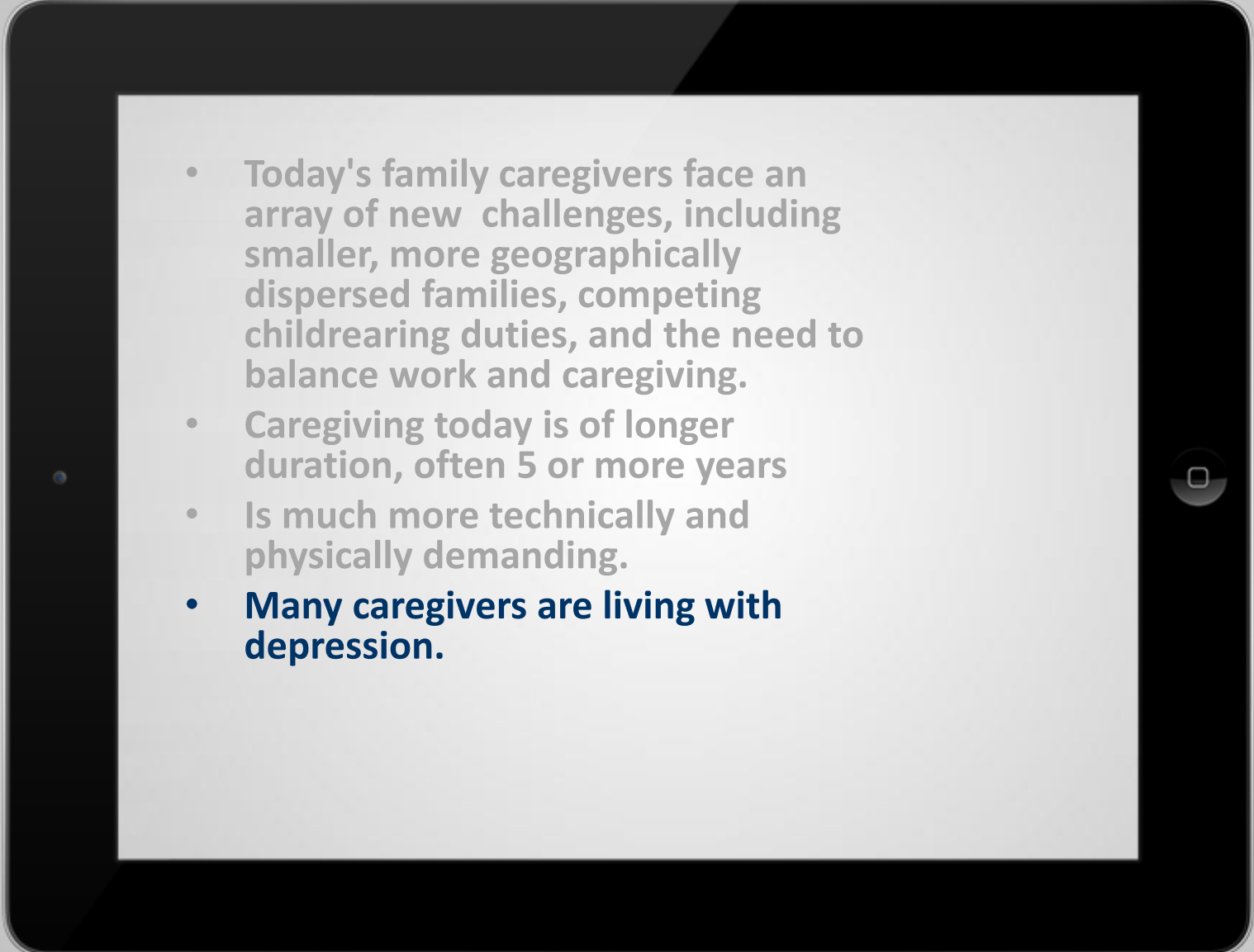
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- Caregiving today is of longer duration, often 5 or more years
- Is much more technically and physically demanding.
- Many caregivers are living with depression.
- **Caregivers have twice the rate of chronic health conditions as opposed to non-caregivers.**



# ISSUES AND CONCERNS OF SPOUSAL CAREGIVERS



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- **Many spousal caregivers are living with isolation and stress.**

# THE GROWING CARE GAP

*68% of Americans believe  
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meet LTSS needs*





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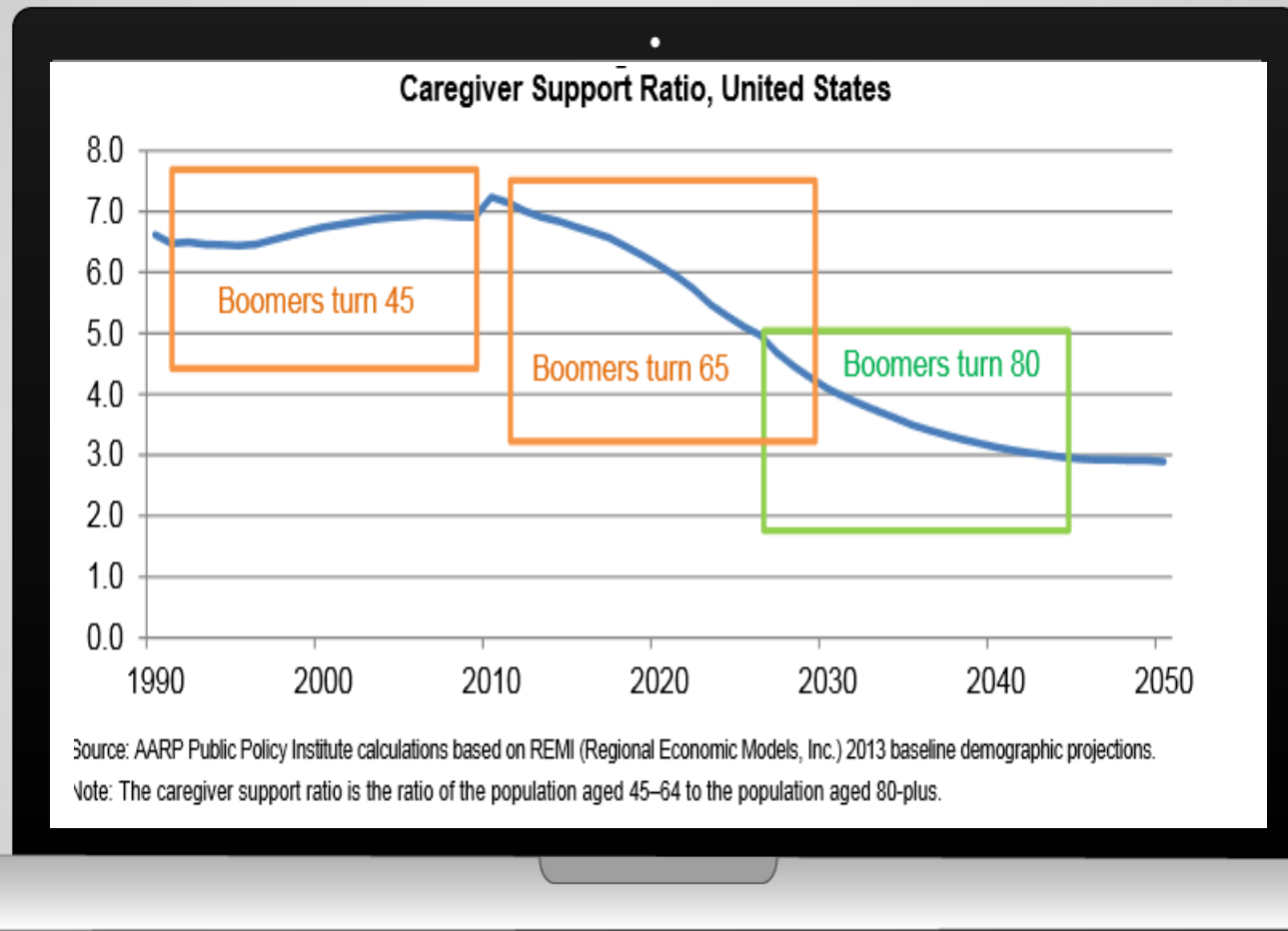
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*2030: 4 potential caregivers  
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# THE GROWING CARE GAP





# RESPITE: A VITAL ELEMENT

- Caregiving can be like a marathon



# RESPITE: A VITAL ELEMENT

A blue-tinted photograph of a person running on a track. The runner is in the foreground, wearing a light-colored shirt and dark shorts, with their legs in motion. In the background, there are stadium bleachers and a modern building with a glass facade. The overall scene is dynamic and energetic.

- Caregiving can be like a marathon
- Respite provides those essential “stops” or “pauses” to revitalize and refresh



# RESPITE: A VITAL ELEMENT



- Caregiving can be like a marathon
- Respite provides those essential “stops” or “pauses” to revitalize and refresh
- **Respite can be beneficial, meaningful, and enjoyable for both the caregiver and the care recipient**

# RESPITE ADVICE FROM OTHER CAREGIVERS

- Let go



# RESPITE ADVICE FROM OTHER CAREGIVERS

- Let go
- Learn relaxation techniques





# RESPIRE ADVICE FROM OTHER CAREGIVERS

- Let go
- Learn relaxation techniques
- Maintain a life outside of the caregiving role



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- Learn relaxation techniques
- Maintain a life outside of the caregiving role
- Keep a daily “burnout log”
- Build a caregiving team
- Seek spiritual renewal
- Appreciate yourself
- Rely on your sense of humor



# VISION CENTER OF EXCELLENCE FOR CAREGIVING

## RCI Training Center

### **Evidence-Based**

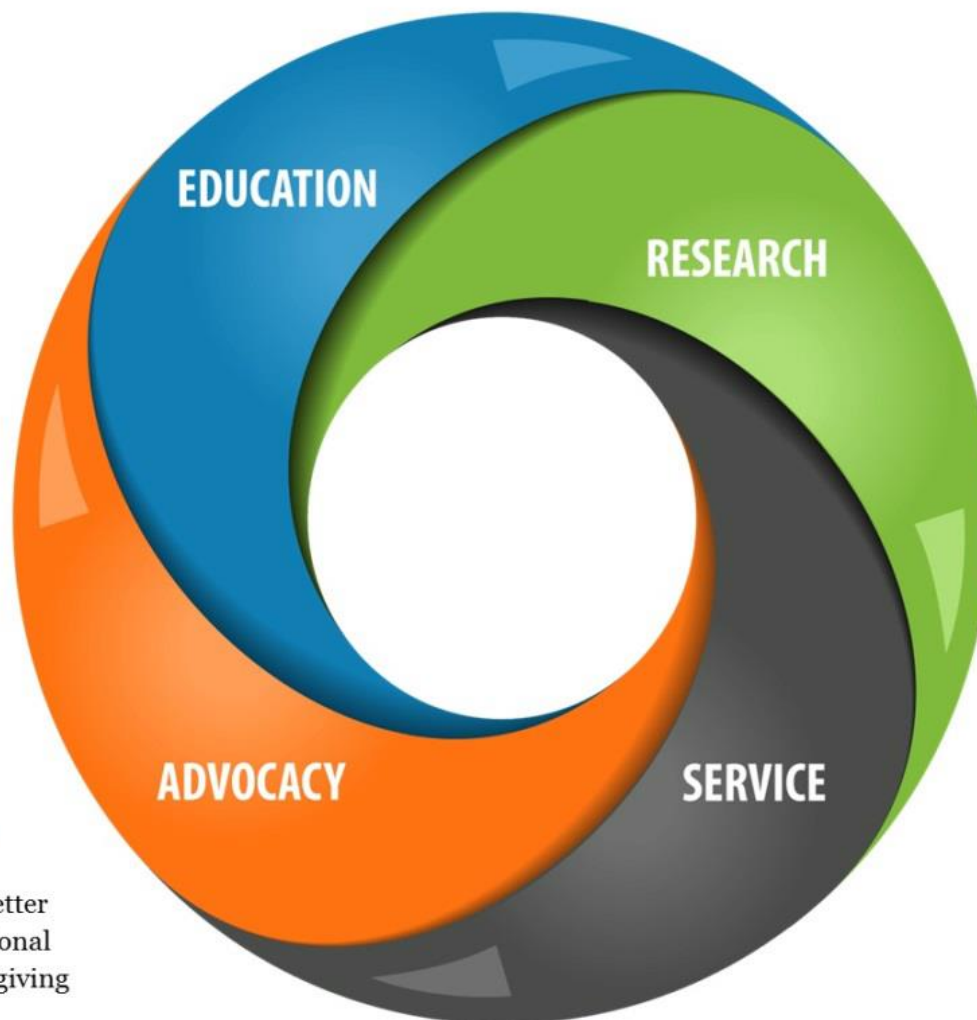
- Certification/Training
- RCI REACH
- Operation Family Caregiver
- BRI Care Consultation

### **Curriculum-Based**

- Caregiving Issues and Management Certificate
- Caring for You, Caring for Me (facilitator training)
- Educational webinars
- RCI-Korea

## Advocacy

- 4 RCI REACH sites (J & J)
- 4 OFC sites (J & J), 3 OFC sites (contract)
- RCI National Summit (J & J)
- Free Caregiver Workshops
- CARE-NET Coalition
- Caregiving Advocate E-Newsletter
- Webinars-Family and Professional
- Presentations to increase caregiving awareness & inform field



## Translational Research

- RCI REACH (4 J & J sites, 1 ADSSP site, 1 contract)
- Operation Family CG (4 J & J sites), 3 other
- Care Consultation (1 ADSSP site), 2 contract sites
- Publications/Presentations
- Future collaboration/partnerships
- Online repository of evidence-based and evidence-informed programs
- Metrics to Inform Field

## Service

- Caring for You, Caring for Me (caregiver training)
- Phoebe-Sumter Caregiver Support Center
- Pope Scholarships
- Pope Fellowships
- Reaching Out to Assess Dementia (ROAD program)
- Mattie Stepanek Awards





# CARE-NET COALITION

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- There are 12 regional CARE-NETs in the coalition throughout the state of Georgia, one in each Area Agency on Aging district.
- **Coalition members include volunteer leaders and advocates from community and state agencies, private corporations, churches and family caregivers who provide ongoing information, assistance, counseling, training and support groups for caregivers throughout Georgia.**

Lesson 01: Timings

Grid Compare Web Library

Grid Compare Web Library

Nothing selected.  
Select an object or text to fixate.

Size	Kind
1.6 MB	Micros
1.5 MB	Micros
1.5 MB	Micros
1.5 MB	Micros
345 KB	Pages
361 KB	Pages
324 KB	Pages
270 KB	Pages

Macintosh HD

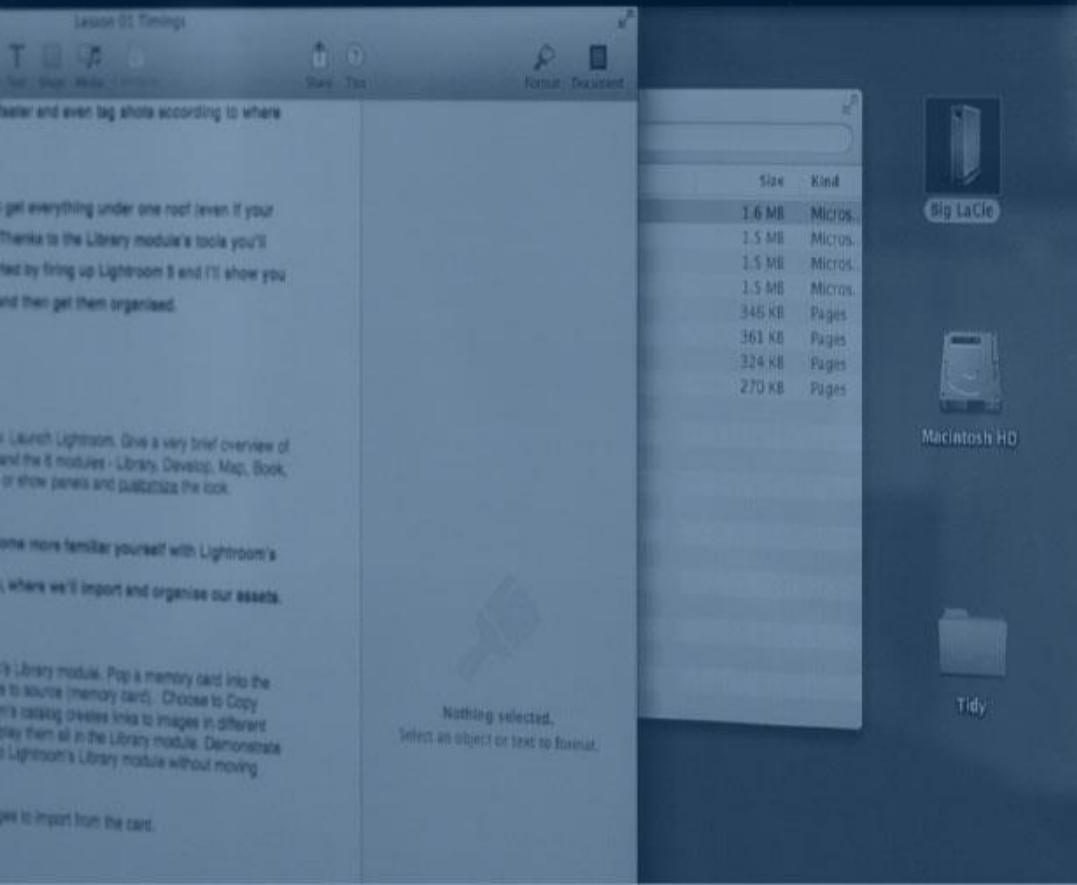
Tidy

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**Total of six courses – all online.**

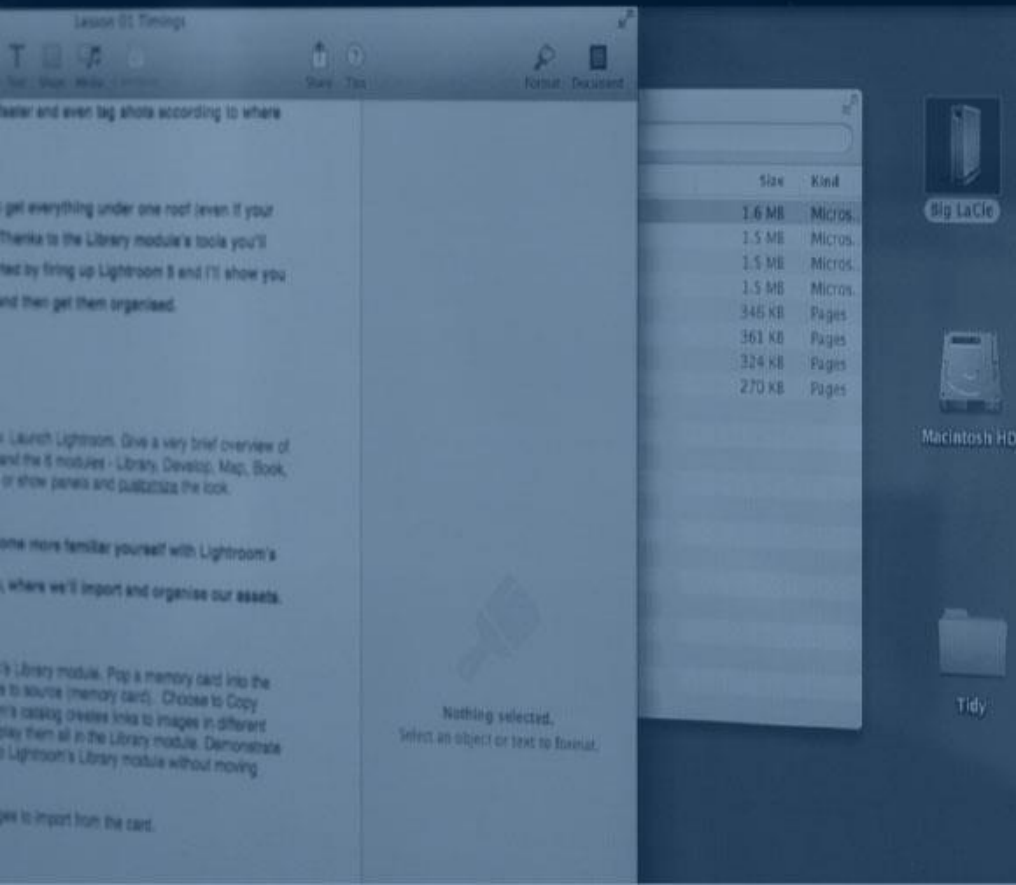


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This 18-credit certificate program can be earned as a stand alone certificate or in conjunction with a Bachelor’s Degree.



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Pope Scholarships.

- ☐ Focusing on Caregiving Certificate





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- ❑ Opportunities to work directly with caregivers



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Pope Fellowships

- ❑ Opportunities to work directly with caregivers
- ❑ Monthly meetings with a caregiving focus



# OTHER SERVICES/PUBLICATIONS

## Networking with State Units on Aging

- Creation of a seamless statewide access to supports for persons with dementia, chronic illnesses and their caregivers
- Georgia: Grant partnership
  - AOA Sustainable Systems -RCI role: Assessment survey, education
  - State wide BRI Care Consultation Roll Out
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- Caregiving for Alzheimer's Disease
- Caregiving Across the Lifespan
- Multiple Dimensions of Caregiving
- Challenges of Mental Health Caregiving
- Multidisciplinary Coordinated Caregiving

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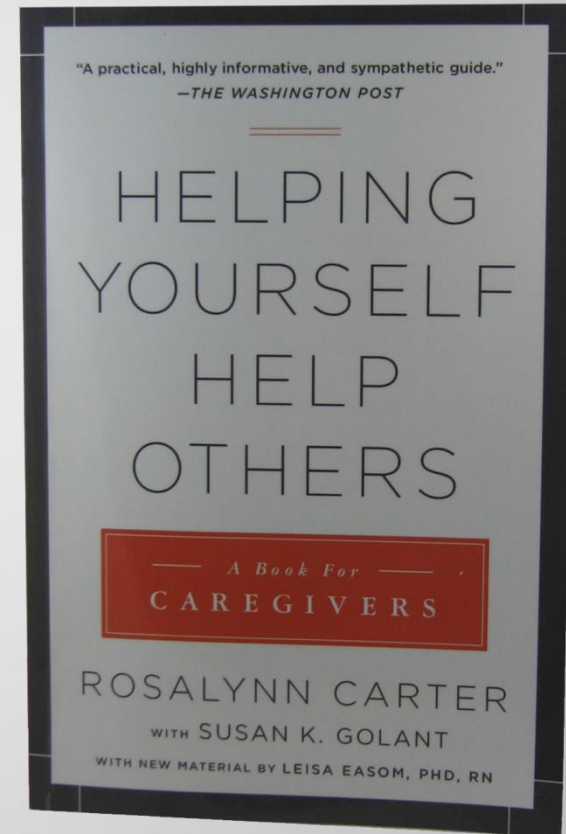
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## Helping Yourself Help Others, 2<sup>nd</sup> Edition, 2013

- A Book About and for Caregivers
- Speaks to Critical Need for Caregiving Respite





# THREE EVIDENCE-BASED PROGRAMS

Providing Effective Caregiver Support Offered Through the RCI Training Center of Excellence



# BRI CARE CONSULTATION IN GEORGIA



# BRI CARE CONSULTATION

- Telephonic/Internet



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- **Evidence-based** information and support service for adults with physical and mental health challenges and their family



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- **Prevents** crisis
- **Benefits:** Primary, secondary, and long-distanced caregivers as well as care receivers





# BRI CARE CONSULTATION



**For individuals,** BRI Care Consultation Provides Assistance With:

- Health and Care-Related Information
- Family and Friend Involvement in Care
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*Personal Testimony: “Thanks for all of your concern and knowledge. You have NO IDEA how important it is for me!”*

*-Care Consultation Caregiver*

# BRI CARE CONSULTATION

Caregiving Families served:  
**Over 600 in 40 Georgia  
Counties**



\*Cost based on Atlanta Regional Commission Care Consultant Salary Plus Fringe Benefits

This project was supported in part by grant number 90AE0349/01, from the U.S. Administration on Aging, U.S. Department of Health and Human Services

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Average Annual Cost of  
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Family:

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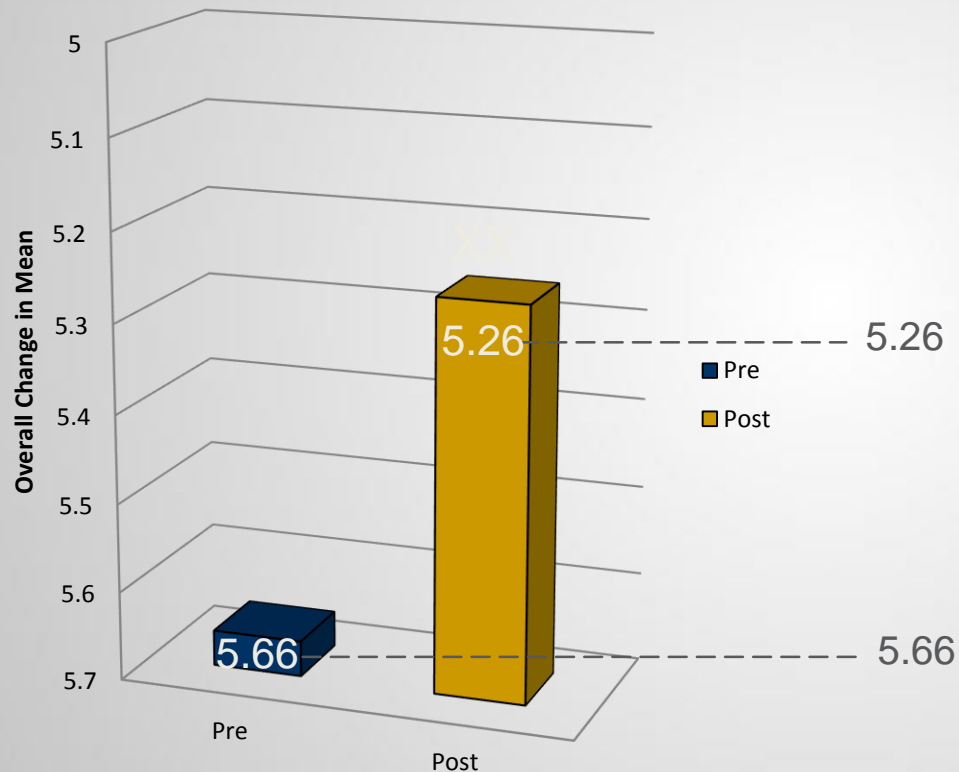
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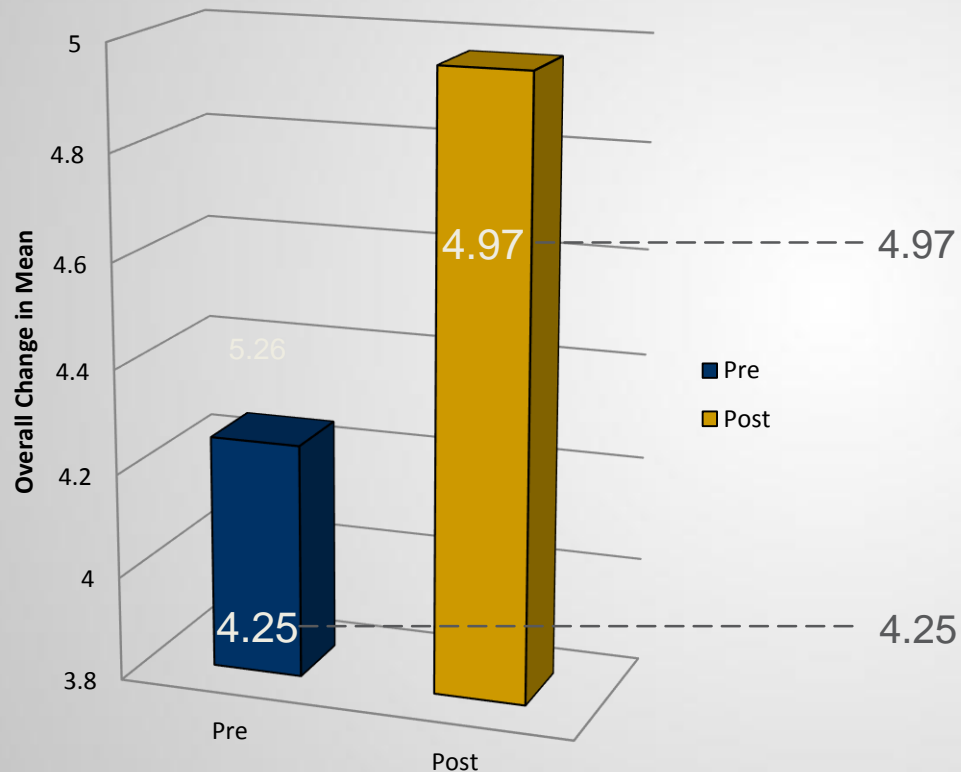
Increased Confidence in Managing Care



N=439

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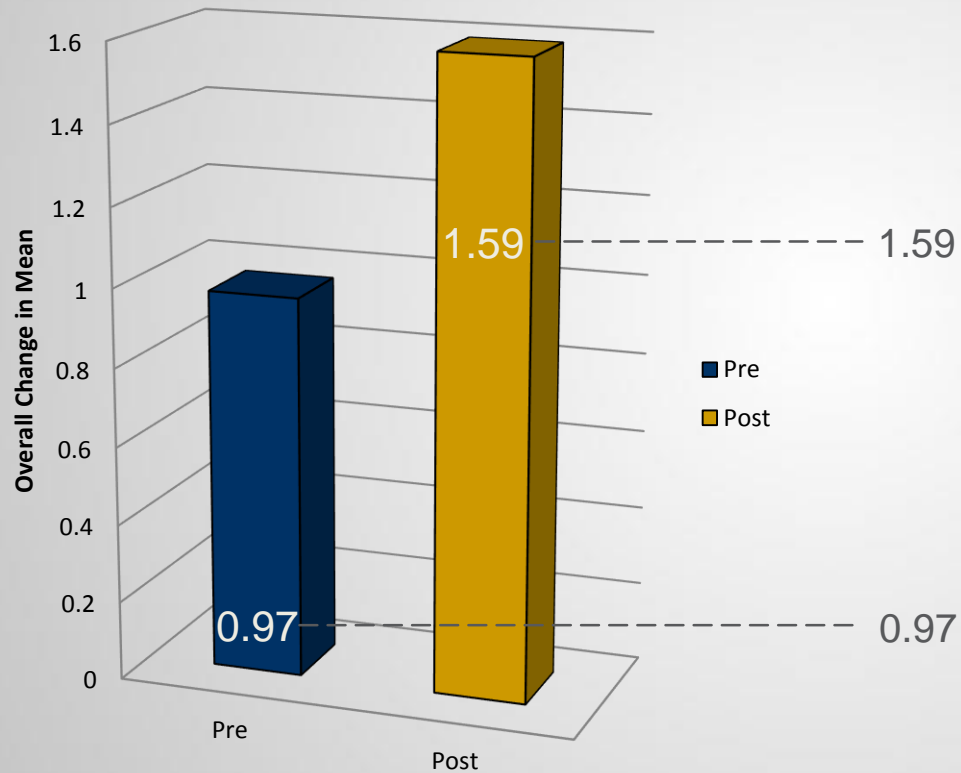
Increased Ability to Organize Family and Friend Helping Network



N=439

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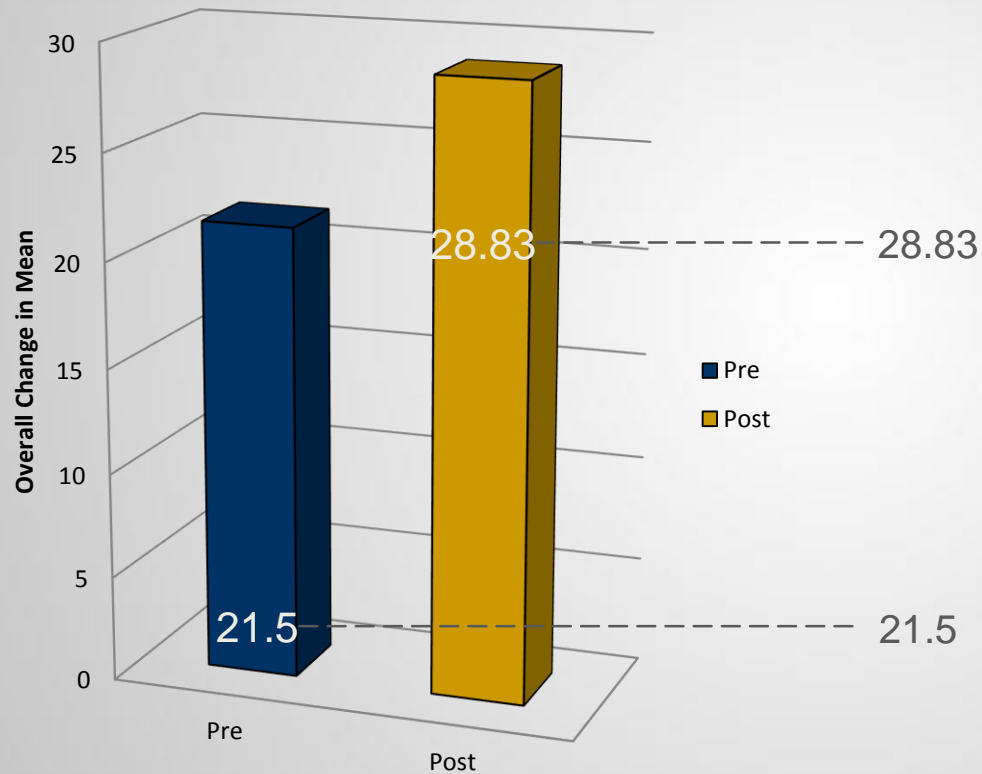
Increased Ability to Get Respite from Caregiving



N=439

# BRI CARE CONSULTATION RESULTS:

Overall Increase In Total Needs Met



N=439



# BRI REPORTS OTHER BENEFICIAL OUTCOMES IN OTHER RESEARCH STUDIES

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  - Reduced Relationship Strain
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- **Improved** Access to Information

RCI REACH



# **RCI REACH: RESOURCES ENHANCING ALZHEIMER'S CAREGIVER HEALTH**

- **Face-to-face, intensive**

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- **Supportive** in the caregiving journey

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Six month intervention delivered in up to twelve sessions in the home with the option of three sessions by phone:

- Education about dementia



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- Social support for dyad

# RCI REACH: RESOURCES ENHANCING ALZHEIMER'S CAREGIVER HEALTH

Six month intervention delivered in up to twelve sessions in the home with the option of three sessions by phone:

- Education about dementia
- Safety for dementia care recipient
- Emotional well being of dementia caregiver
- Health and self-care of dementia caregiver
- Social support for dyad
- Troubling dementia problem behaviors/ caregiver skills.



# RCI REACH: RESOURCES ENHANCING ALZHEIMER'S CAREGIVER HEALTH

## STUDY #1:

Caregiving Families  
served:  
**85 in eleven rural  
Georgia Counties**



This project was supported in part by grant number 90AE0320/01, from the U.S. Administration on Aging, U.S. Department of Health and Human Services.

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One Care Interventionist  
can effectively serve :  
**20 Caregiving Families**



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# RCI REACH: RESOURCES ENHANCING ALZHEIMER'S CAREGIVER HEALTH

## STUDY #1:

Caregiving Families  
served:

85 in eleven rural Georgia  
Counties

One Care Interventionist  
can effectively serve :  
20 Caregiving Families

Average Cost of Service  
per Caregiving Family:  
**\$7.00/day**



This project was supported in part by grant number 90AE0320/01, from the U.S. Administration on Aging, U.S. Department of Health and Human Services.

# RCI REACH: RESOURCES ENHANCING ALZHEIMER'S CAREGIVER HEALTH

## STUDY #2:

Caregiving Families  
served:

121 in Georgia Coastal  
Region

One Care Interventionist  
can effectively serve :  
20 Caregiving Families

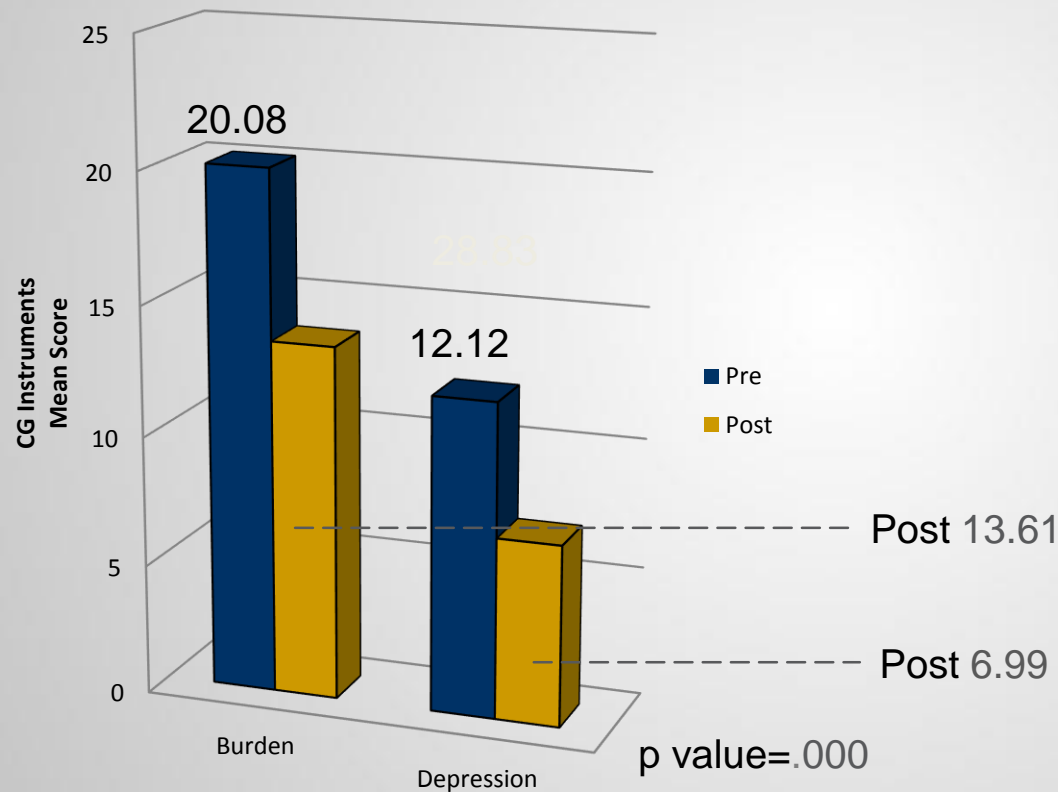


This project was supported in part by grant number 90AE0339/01, from the U.S. Administration on Aging, U.S. Department of Health and Human Services.



# STUDY II: PRELIMINARY OUTCOMES FOR COASTAL GA REACH PROGRAM

Decreased Burden and Depression

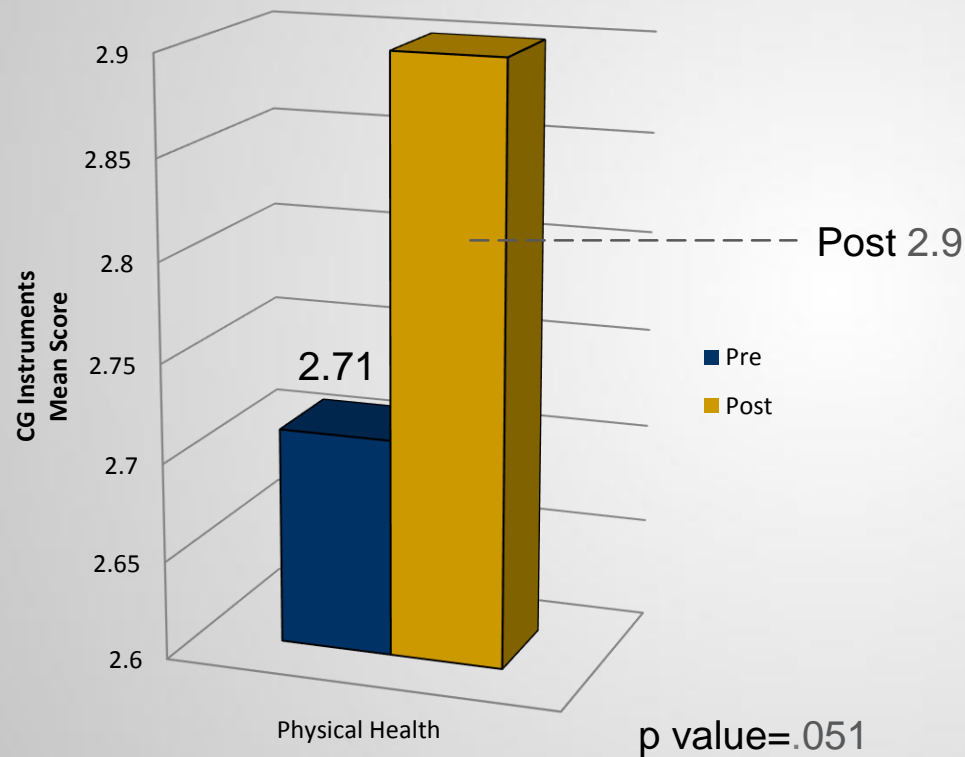


n=121

$\alpha = <.05$

# STUDY II: PRELIMINARY OUTCOMES FOR COASTAL GA REACH PROGRAM

## Increase in Physical Health



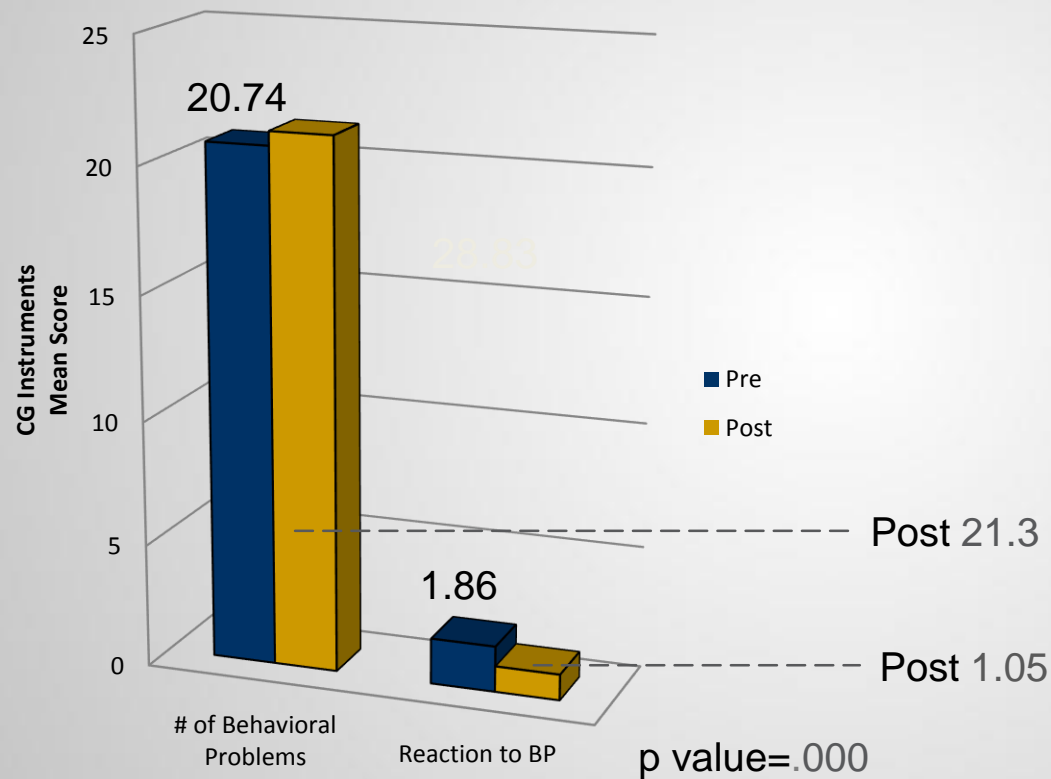
n=121

$\alpha = <.05$



# STUDY II: PRELIMINARY OUTCOMES FOR COASTAL GA REACH PROGRAM

Increase in Behavioral Problems and Decrease in Reaction to Behavior Problems



n=121



Ready to bring an evidence based  
caregiver support program to  
your community?

**RCI REACH**

Free training and technical  
assistance funded by ACL!

**Apply today!**

**RCI will provide training,  
technical assistance and  
consultation to 20 agencies  
around the nation.**

**To learn how to apply:**

**Email Gayle Alston**

**[Gayle.alston@gsw.edu](mailto:Gayle.alston@gsw.edu)**



## OPERATION FAMILY CAREGIVER:


- Pennsylvania
- New York
- Texas
- California



[www.operationfamilycaregiver.org](http://www.operationfamilycaregiver.org)

A program of the Rosalynn Carter Institute for  
Caregiving, generously funded by Johnson & Johnson





# **An Evidence Based Caregiver Support Program**



# Identifying the Need

- Since 2001, 2.4 million active duty and reserve military personnel were deployed to the wars in Iraq and Afghanistan - More than 63,000 service members have been medically evacuated from Iraq or Afghanistan.
- 30% of this group – nearly 730,000 men and women will have a mental health condition requiring treatment.
- 18.5% of all OEF/OIF veterans have post-traumatic stress (PTS) and/or major depression.
- 1 in 6 soldiers returning from deployment have traumatic brain injury
- Families of service men and women serve and sacrifice. Families are the support system to which the service member returns – they are struggling to cope with resulting depression and frustration

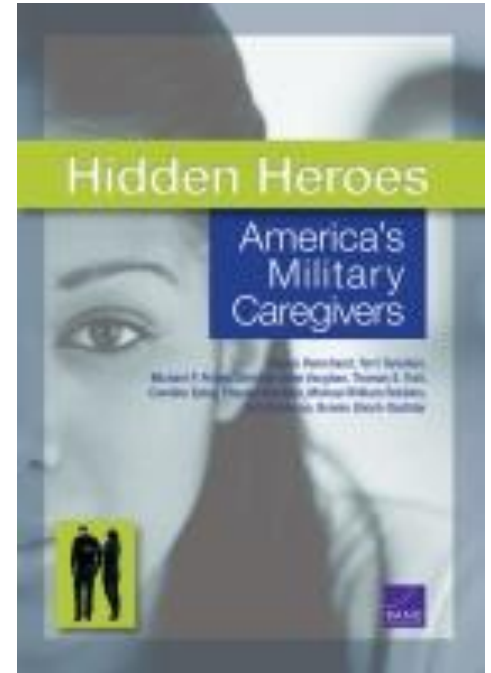
# A Soldier's Words....

“When these guys and gals deploy, they come back home with PTSD, TBI, whatever the issue may be - a lot of the spouses I’ve talked to have all said the same thing – they do not know how to deal with their husbands or their wives when they return...their families, whether it’s their wife, their husband, or their children suffer because they’re not prepared for that change...yeah, they get the nice little brief from ACS and the FRG group; ‘your husband is gonna come back changed’, but they aren’t given any tools or resources...for when I didn’t sleep, for when I woke up from the nightmares and I was punching her in her sleep because I didn’t know where I was or what I was doing...”

SPC Vic Bertrand, Wounded Warrior  
Attendee at the Military Family Summit  
Ft. Benning, GA, June 14, 2012

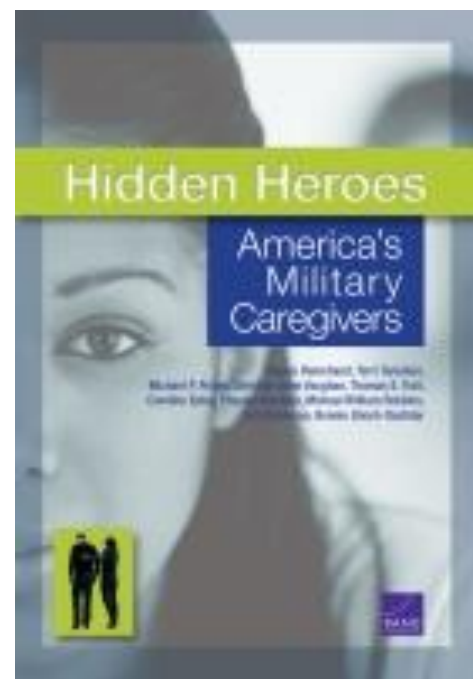
# New Research Findings

- Empower Caregivers
- Create Caregiver-Friendly Environments
- Fill Gaps in Programs
- Plan for Future Caregiving Needs



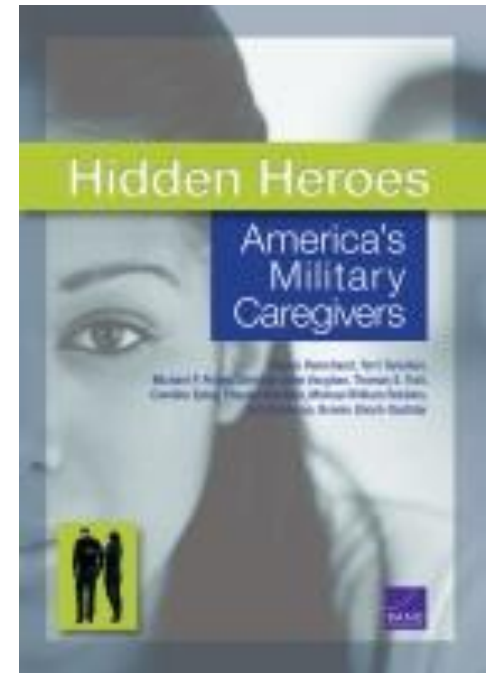
# 1.1 million post 9/11 military caregivers who are:

- Younger (more than 40% between 18 and 30)
- Caring for a younger individual with a mental health or substance abuse condition
- Nonwhite
- A veteran of military service
- Employed
- Not connected to a support network (53% lack support)



# Most relevant programs and policies serve caregivers only incidentally

- Targeted towards care recipient of military/veteran families
- Most programs limit eligibility to primary family members
- Many programs geared towards caregivers for older populations, younger caregivers not eligible



# Caregiving Imposes a Heavy Burden

Post 9/11 military caregivers

- Worse health outcomes
- Greater strains in family relationships
- More workplace problems
- Elevated risk of depression
- 33% lack health care coverage





# Why is Military Caregiving Unique?

A new cadre of caregivers...

- Multiple and severe injuries or illnesses
- Complex systems of care
- Invisible wounds
- Around-the-clock care
- A lifetime of care



## NIH Public Access Author Manuscript

*Arch Phys Med Rehabil.* Author manuscript; available in PMC 2008 August 19.

Published in final edited form as:

*Arch Phys Med Rehabil.* 2008 May ; 89(5): 931–941.

### Problem-Solving Training for Family Caregivers of Persons With Traumatic Brain Injuries: A Randomized Controlled Trial

Patricia A. Rivera, PhD,

*Birmingham Veterans Administration Medical Center, Birmingham, AL*

Timothy R. Elliott, PhD,

*Department of Educational Psychology, Texas A&M University, College Station, TX*

Jack W. Berry, PhD, and

*Injury Control Research Center, University of Alabama, Birmingham, AL*

Joan S. Grant, DSN, RN, CS

*University of Alabama School of Nursing, University of Alabama, Birmingham, AL*

#### Abstract

**Objective**—To test the hypothesis that a problem-solving training program would lower depression, health complaints, and burden, and increase well-being reported by community-residing family caregivers of persons with traumatic brain injuries (TBIs).

**Design**—Randomized controlled trial.

**Setting**—General community.

**Participants**—Of the 180 people who expressed interest in the study, 113 did not meet eligibility

# Operation Family Caregiver

## Strong Military, Stronger Families

- OFC is a non-clinical, supportive adjunct to any other support the family is receiving.
- A medical or mental health diagnosis is not required.
- Takes basic education a step further to help facilitate behavioral change. This problem-solving, skill-building program prepares the caregiver to be able to handle challenges over the long-term. Caregiver Notebook for each family.



# Eligibility criteria

Caregivers and families of OEF/OIF/OND service members/veterans living with Post Traumatic Stress Disorder, Traumatic Brain Injury, and/or a physical disability

**OFC** is an in-home, tailored, caregiver support intervention:

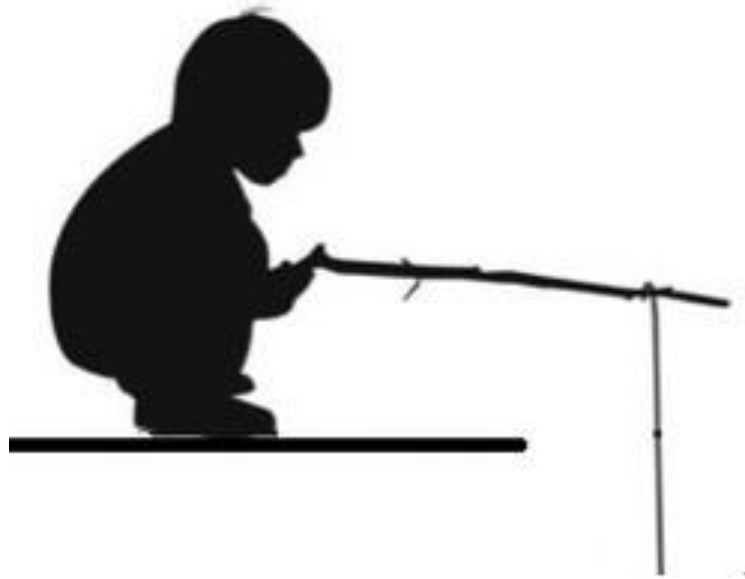
- 4 in-home visits- face to face or via SKYPE
- Monthly telephone availability
- Data collection at beginning and end
- Program length 4-6 months
- Must complete 75% of sessions to be considered a completer

# OFC

## Program philosophy

*“Give someone a fish and you feed him for a day. Teach someone to fish and you feed him for a life time.”*

*~ Lao Tzu*



# Why OFC

Confidential and Free



1. **Evidence-based** (has undergone rigorous scientific evaluation in a randomized control trial)
2. **Proven effectiveness** (has consistently demonstrated the ability to achieve outcomes of importance to family caregivers)
3. **Tailored** to each individual family's needs
4. **Location** - program comes to the caregiver (their home or other location that caregiver chooses, telephone or Skype )
5. **Minimizes stigma** – a diagnosis of PTSD reflects a mental illness/defect; service members may be wary that seeking help may jeopardize employment or job promotion opportunities; privacy of OFC service setting ensures confidentiality



# Outcomes

## Skill enhancement

### **Training improved caregiver self confidence:**

- Personal expectations - their goal setting improved once they understood the feasibility of their goals
- An approach – how to begin working with their loved one
- Promoting their loved one's desire for autonomy
- Better understood the importance of self care

### **Training caregivers improved knowledge:**

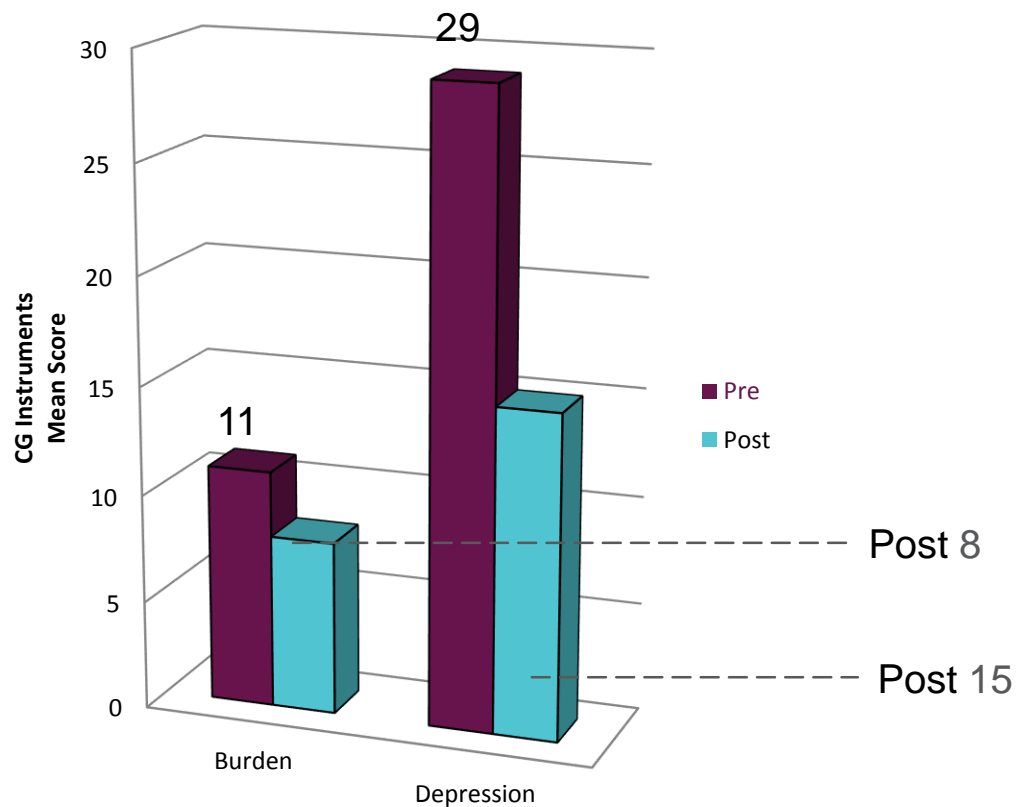
- Learning more about PTSD/TBI and possible triggers helped equip them to better respond to their loved one

### **Desired impact is measurable:**

- Reduction in caregiver depression
- Reduction in burden
- Increase in satisfaction of life
- Decrease in health issues

# OVERALL PRELIMINARY OUTCOMES FOR J & J OFC PROGRAM

## Decreased Burden and Depression



Burden p value=.027

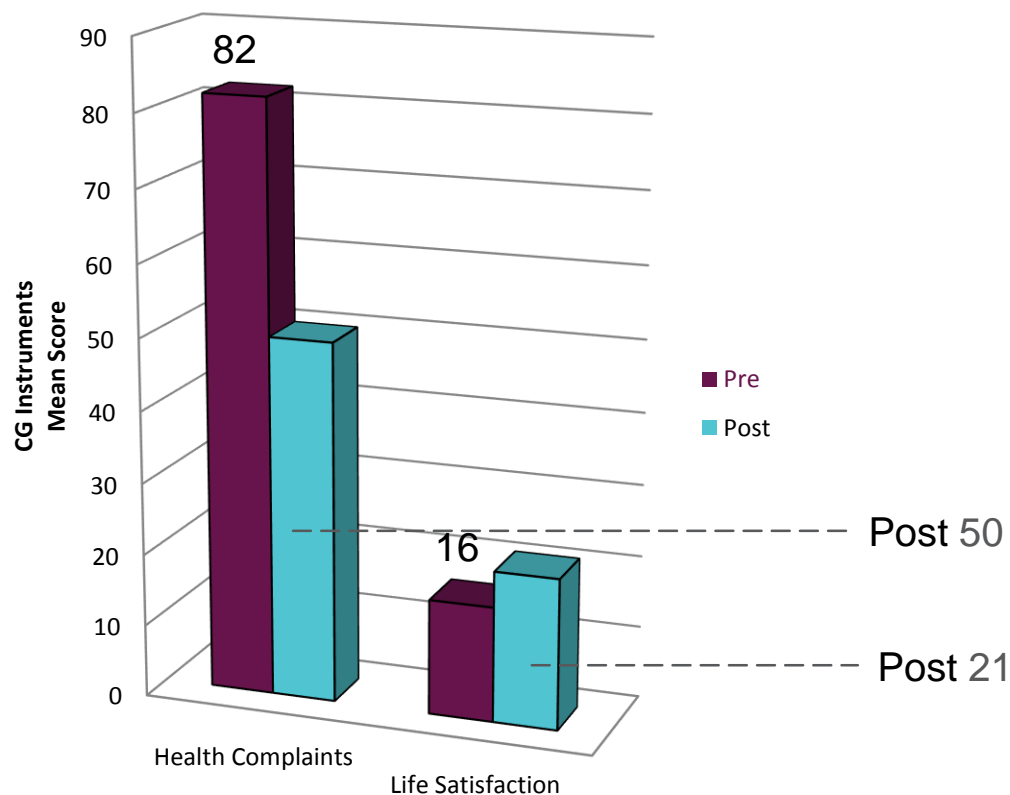
Depression p value=.045

$\alpha = <.05$

n=7

# OVERALL PRELIMINARY OUTCOMES FOR J & J OFC PROGRAM

Decreased Health Complaints and Increased Life Satisfaction



Health Complaints p value=.132

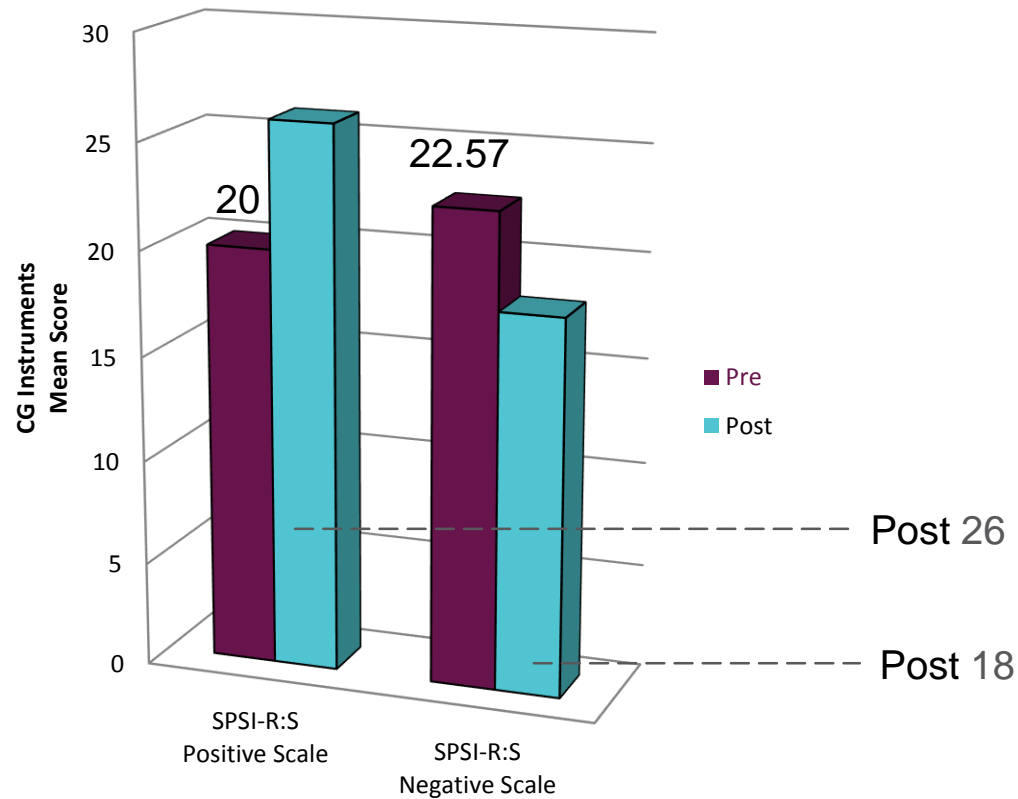
Life Satisfaction p value=.154

$\alpha = <.05$

n=7

# OVERALL PRELIMINARY OUTCOMES FOR J & J OFC PROGRAM

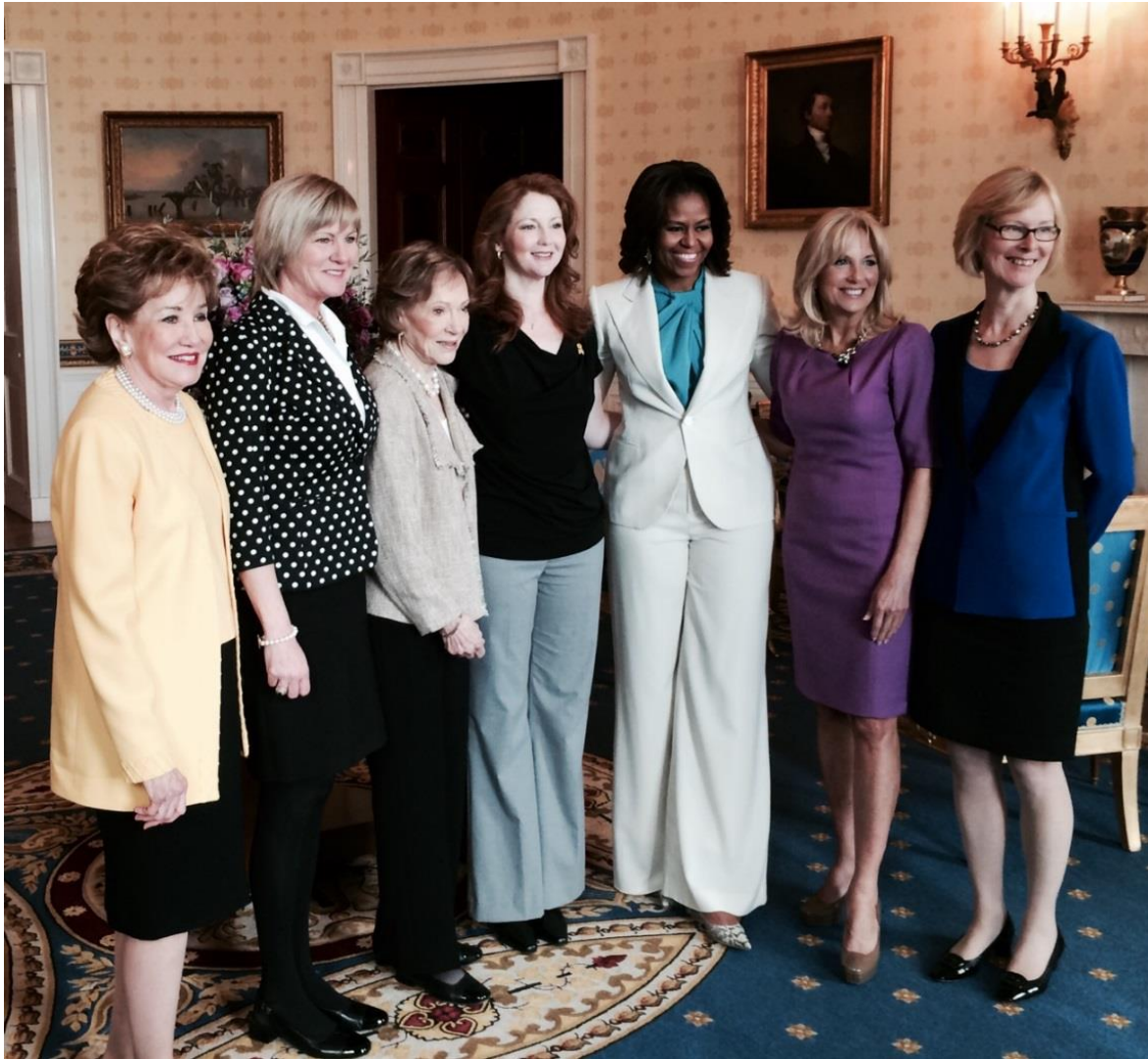
Social Problem Solving: Increased Positive Problem Orientation and Decreased Negative Problem Orientation



SPSI-R:S Positive p value=.129  
SPSI-R:S Negative p value=.281  
 $\alpha = <.05$

n=7

# Joining Forces to Support Military Caregivers



**April 11, 2014**



**Q&A**



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**Leisa Easom, PhD, RN**  
Executive Director



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[leisa.easom@gsu.edu](mailto:leisa.easom@gsu.edu)

A bronze statue of a woman, likely a historical figure, is seated on a circular, reflective pedestal. She is wearing a long coat and glasses. The background features a large, classical-style building with a portico supported by columns. The scene is illuminated by streetlights, and the overall tone is blue. The text "Thank You!" is overlaid in a large, white, serif font.

Thank You!