Overview of Presentation

• Personal Testimonies
• Mission of the Rosalynn Carter Institute for Caregiving
• Evidence-Based Programs
  Translation Into Communities
    • RCI REACH
    • BRI CARE CONSULTATION
    • OPERATION FAMILY CAREGIVER

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Families Living With...

Alzheimer’s Disease, Disabilities, Chronic Conditions

Post-Traumatic Stress and/or Traumatic Brain Injury

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**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 has spent over two decades working to accomplish this mission.

**Goals and Objectives**

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.
“There are only four kinds of people in this world:
Those who have been caregivers
Those who currently are caregivers
Those who will be caregivers
Those who will need caregivers”

- Former First Lady Rosalynn Carter
WHO IS A CAREGIVER?

• Those who:
  ❖ Help with grocery shopping, cooking, housework
  ❖ Provide transportation to health care providers
  ❖ Help with writing checks, paying bills
  ❖ Administer medications
  ❖ Provide emotional support for another
  ❖ Provide personal care
• May be spouses, parents, and more

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

An Aging Population
• 36.9 million in 2009
• 72.1 million in 2030
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.

• Approximately 6,000,000 adults over age 65 need daily assistance to live outside a nursing home today. That will grow to more than 12,000,000 by 2030.

• With longer life expectancy, comes higher rates of chronic illness, disability and need for care.

• 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.

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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.

Caregiving today is of longer duration, often 5 or more years.

Is much more technically and physically demanding.

Caregivers have a 63% higher mortality rate than non-caregivers.

At least 50% of caregivers are living with depression.

Caregivers have twice the rate of chronic health conditions as opposed to non-caregivers.
Three Evidence-Based Programs Providing Effective Caregiver Support Offered Through the RCI Training Center of Excellence
I. BRI Care Consultation

- Telephonic/Internet
- **Evidence-based** information and support service for adults with physical and mental health challenges and their family
- **Personalized** coaching up to 12 months
- **Empowerment** to manage care situations
- **Tailored** to client needs
- **Supportive** throughout caregiving journey
- **Prevents** crisis
- **Benefits:** Primary, secondary, and long-distanced caregivers as well as care receivers

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BRI Care Consultation

For individuals, BRI Care Consultation Provides Assistance With:

• Health and Care-Related Information
• Family and Friend Involvement in Care
• Awareness and Use of Community Services
• Coaching Support

For agencies, BRI Care Consultation Provides:

• Computerized Service Delivery System (CCIS)
• In-depth caregiver and care receiver assessment
• Capability to run multiple reports

Personal Testimony: “Thanks for all of your concern and knowledge. You have NO IDEA how important it is for me!”

-Care Consultation Caregiver

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BRI Care Consultation

Caregiving Families served:
**Over 600 in 40 Georgia Counties**
One Care Consultant can effectively serve:
**75 to 125 Caregiving Families**
Average Annual Cost of Service per Caregiving Family:
**$1.03/day or $376.00/year***

*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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BRI CARE CONSULTATION RESULTS: Improvement in Caregiver Self-Rated Health
BRI CARE CONSULTATION RESULTS: Decrease in Number of Emergency Room Visits
BRI CARE CONSULTATION RESULTS: Decrease in Number of Hospital Visits

![Bar chart showing decrease in hospital visits from T1 to T2.]

- T1: 2.25
- T2: 1.73
BRI Reports Other Beneficial Outcomes in Other Research Studies

- **Improved** Care
- **Reduced** Hospital Admissions
- **Delayed** Nursing Home Placement
- **Fewer** Emergency Department Visits
- **Decreased** Caregiver Depression and Strain
- **Improved** Quality of Life
  - **Reduced** Caregiver Stress and Burnout
  - **Reduced** Relationship Strain
  - **Decreased** Embarrassment and Isolation
- **Improved** Access to Information
II. RCI REACH: Resources Enhancing Alzheimer’s Caregiver Health

- Face-to-face, intensive
- **Evidence-based** information teaching problem-solving and stress management for families living with Alzheimer’s disease and related dementia
- **Six month** program **delivered in-home**
- **Tailored** to client needs
- **Caregiver Notebook** focusing on common issues faced
- **Supportive** in the caregiving journey

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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

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RCI REACH: Resources Enhancing Alzheimer’s Caregiver Health

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.

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Self rated health, compared to six months ago, showed improvement (mean score decreased from 3.1 to 2.8 on 5 point scale from 1 (Much Better Now) to 5 (Much Worse Now)). This decrease is significant at the 95% confidence interval.
RCI REACH Results – Decreased Burden and Depression

P < .05

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On a scale of 0 – 100 (with 0 being not at all confident and 100 being totally confident), participants were asked to rate their confidence in handling various caregiving situations. Overall scores rose from 71.8 to 75.3.
RCI REACH Results – Decreased Desire to Institutionalize

Caregivers are discussing less with the care receiver the possibility of nursing home placement (with 28% discussing this possibility before the program and 15% after).
Current RCI REACH Implementation and Data Collection Across Four Sites in United States

- The North Central Texas Chapter of the Alzheimer’s Association, Fort Worth, TX
- Child & Family Service Gerontology Program, Ewa Beach, HI
- Home Aides of Central New York, Syracuse, NY
- Nevada Senior Services, Inc., Las Vegas, NV

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III. Operation Family Caregiver-
Helping the Families of Veterans and Active Service Members

- Evidence-based information and support service for military families living with post-traumatic stress, traumatic brain injury or physical disability resulting from deployment
- Delivery Options: Face to face, Internet (Skype), or Telephonic
- 4-6 month program
- Personalized coaching
- Empowers and improves ability of family caregiver to utilize evidence-based problem-solving skills to reduce the burden of caregiving and enhance well-being

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Operation Family Caregiver

Specifically, Operation Family Caregiver is a caregiver support intervention that is:

• **Tailored** to client needs
• **Supportive** throughout caregiving journey
• **Prevents** crisis
• Involves 4 in-home visits: Face to face, Internet (SKYPE) or by telephone over 4 – 6 months
• Monthly **telephone availability** as needed
• **Data collection** at beginning and end
• Confidential – NO MEDICAL RECORDS ACCESSED

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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
“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 Army Community Services and the Family Readiness 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...”

The VA acknowledges that only 50% of those eligible for services are receiving them.

National Guardsmen and Reservists do NOT receive VA support.

Stigma attached to mental health issues a barrier to families receiving services.

Military caregivers must navigate a maze of policies, systems, eligibility requirements, information, and resources to care for their loved ones.

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Where should this care and support be provided?

IN THE COMMUNITY WHERE THE SOLDIERS AND FAMILIES LIVE. Of the 2.4 million OEF/OIF veterans, 40% are still active duty - but 60% have been discharged. Of those discharged, approx. 50% are using VA care while the rest are using private healthcare in communities in which they live.
Why the Problem-Solving Program Training for Veteran and Service Member Families?

- **Minimizes stigma** – a diagnosis of PTSD reflects a mental illness/defect; soldiers wary that seeking help may jeopardize employment or job promotion opportunities; privacy of the service setting ensures confidentiality
- **Flexibility** – caregiver coach works around the family’s schedule
- **Supportive adjunct to other services** – is not clinical in nature so does not compete with other counseling/psychological/rehab services the family may be receiving; by training the caregiver to effectively evaluate and respond to problems, helps to eliminate stress and emotional overload
- Support for **24/7 care**
OFC Outcomes- Increased Satisfaction with Life

OFC Pre/Post Sat with Life Analysis

T1: 18.67
T2: 20.33
OFC Outcomes - Decrease in Health Complaints/Symptoms

Pennebaker Inventory of Limbic Languidness Pre and Post Analysis

- $T_1$: 60.33, $n=3$
- $T_2$: 59.67

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Your staff can be trained and certified to provide clinically proven effective caregiver support services in your community.

Where does the training take place?
Training can be provided at your site or at the Rosalynn Carter Institute for Caregiving in Americus Ga. (148 miles south of Atlanta). Initial training is delivered in a classroom setting.

Who should be trained?
It is recommended that supervisors as well as service delivery staff attend the full training. Only the staff delivering the service will be required to attain certification.

What happens when there is staff turnover?
In the event of trained and certified staff leaving the agency, RCI will provide training and certification for up to four replacement staff in the first year. This training will be provided via the internet and the cost is included in the first year training package price.

Why Evidence Based Caregiver Interventions?
Published in the Annals of Internal Medicine, Covinsky & Johnston stated:
“If these interventions were drugs, it is hard to believe that they would not be on the fast track to approval. The magnitude of benefit and quality of evidence supporting these interventions considerably exceed those of currently approved pharmacologic therapies (for dementia).”
Thank You!

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