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## Providing Evidence-Based Programs for Caregivers:

**Yes, You Can!**

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## Over 80 is fastest growing group

**Figure 25. Population aged 80 or over: world, 1950-2050**

Year	Population (Millions)
2050	879.0
2025	153.4
2000	89.2
1975	31.4
1950	13.8

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## Aging and Need for Care

- 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 else to help with routine activities of daily living because of chronic illness.

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**Figure 2. Disability Prevalence and the Need for Assistance by Age: 2005**  
 (Percent)

Age	Any disability	Severe disability	Needs assistance
Under 15	8.8	3.6	0.4
15 to 24	10.4	5.0	1.3
25 to 44	11.4	7.5	1.9
45 to 54	19.4	12.8	3.4
55 to 64	30.1	20.8	5.7
65 to 69	37.4	26.1	7.6
70 to 74	43.8	27.6	9.4
75 to 79	55.9	37.8	16.1
80 and over	71.0	56.2	29.2

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## How Many Seniors Need Care?

**By 2030, approximately 13,000,000 adults over age 65 will need significant daily assistance to live outside of a nursing home.**

**Today, that number is approximately 7,000,000.**

**The caregiving households in which most of these individuals will live are truly the backbone of America's long-term care system.**

**Section 3 – The Impact of Chronic Conditions on Individuals and Their Caregivers**

### The Estimated Monetary Value of Family Caregiving Greatly Exceeds Spending on Formal Long-Term Care Services

- Family caregiving includes all unpaid services provided by family and friends.
- Because of gaps in the health care system and individual family preferences, much of the care for people with chronic conditions is provided by family and friends.
- One of people's greatest concerns is that they will become a burden to family and friends when they have a chronic condition.

**Value of Care, 1997 (in billions)**

Category	Value (in billions)
Formal health care	62
Family home care	120
Family caregiving	218

Source: Arno, P.S., Levine, C and Memmott, M.L. "The Economic Value of Informal Caregiving." Health Affairs, 18: 2, March/April 1999.

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## Updated in 2006 to \$350 Billion

The estimated \$350 billion is:

- As much as the total expenditures for the Medicare program (\$342 billion in 2005).
- More than total spending for Medicaid, including both federal and state contributions and both medical and long-term care (\$300 billion in 2005).
- Far more than the total spending (public and private funds) for nursing home and home health care in the United States (\$206.6 billion in 2005).
- More than four times the total amount spent on formal (paid) home care services (\$76.8 billion in 2005)

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## Facts About Caregiving Today


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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## Caregiving today is More Challenging:

- Longer Duration
- More Technically and Physically Demanding
- family caregivers today are often responsible for tasks that only skilled nurses performed just a decade ago



**The "Home Hospital" has become a reality.**

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## Adverse Outcomes for a Significant Minority of Caregivers

- High levels of stress, frustration
- High levels of depression, anxiety, PTSD
- Extreme fatigue
- Increased use of alcohol, smoking, other drugs
- Poor health behavior, diet, exercise, sleep
- Suppressed Immune system leading to frequent infection
- Increased risk of heart disease, diabetes, stroke

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## What No One Wants to Talk About...

- Poor care and elder abuse are often associated with caregiver stress and anger
- Growing rates of elder mistreatment are being reported
- Senate Special Committee on Aging estimated that as many as five million older Americans may be victims of abuse, neglect, and/or exploitation every year, often from family members.



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## Our Conclusion:

**Without significant investment in new programs and services for family caregivers, conditions that are extremely unfavorable for family caregivers, care-recipients, and professional caregivers will rapidly develop during the next two decades and family commitment to provide care may erode.**

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### First National Summit on EBP in Caregiving

- October, 2007, RCI and J&J convened 1<sup>st</sup> National Summit on EBP in Caregiving
- Invited leading Caregiver Researchers and Agencies providing caregiver supports.
- Examined Existing EBPs and the extent to which these were being practiced nationally.

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### Summit Findings:

- During past 20 years, we have learned a great deal about what works in supporting caregivers through rigorous evaluation.
- Caregiver Research has taken place largely in “silos”: e.g. cancer, NCI, Alzheimer’s, NIA, stroke, NINDS
- There exists a significant number of evidence-based programs and interventions for caregivers across a wide range of conditions.

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### 2007 Summit Findings:

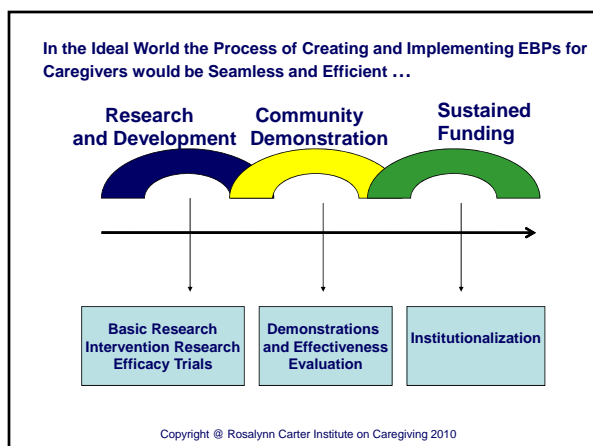
However, NONE of these Interventions have yet been integrated into:

- Aging network of services
- National Family Caregiver Programs
- Existing health services (e.g., home care, hospital discharge planning)
- Long-term, sustainable funding streams such as health insurance, HMOs, Medicaid, Medicare

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### Why are EBPs not Being Implemented?

- Lack of knowledge/ awareness
- Lack of funding to initiate & sustain services
- Little training available
- Programs have not been manualized
- Perceived and real difficulty of implementation



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### But... there are three problems

1. Program/ Interventions that show efficacy in trials require further refinement, modification and development of support materials.
2. Agencies, although motivated and in need, are typically not ready to adopt and implement a complex intervention without building internal capacity.

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### And....

- Host Systems typically do not support the new way of working without fundamental changes in policies, procedures, funding and thinking.
- In particular, sustainable funding is most often not available.

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### Three Simultaneous Change Processes

```

    graph TD
      System[System] <--> Agency[Agency]
      System --> Intervention[Intervention]
      Intervention --> Agency
  
```

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### Why are EBPs not Being Implemented?

- Because we have not addressed the complexity of the change process involved in creating and implementing EBPs.
- Because the change processes have been managed and conceived of separately when they are actually interdependent.

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### What we have done...

1. Created a pilot project: "NQC�"
2. Where the 3 change processes can be studied and managed as a whole.
3. As a learning community and laboratory specific to evidence-based programs for caregivers
4. Adopted models and approaches for EBP implementation (NIRN and others).

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### National Quality Caregiving Network

A network of community demonstration sites and research & development sites working to integrate and study three key change processes:

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    graph TD
      System[System] <--> Agency[Agency]
      System --> Intervention[Intervention]
      Intervention --> Agency
  
```


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### National Quality Caregiving Network


- Researchers and agency leaders and practitioners viewed as equal partners whose work informs and supports one another
- Serves as a learning community that generates "practice-based evidence"
- Draws upon a wide array of expertise including administrators, practitioners and researchers.
- Serves as a forum to build consensus about development and implementation of evidence-based programs and systems for caregivers.

### National Quality Caregiving Network

Community Demonstration Sites	Research & Development Sites
<ul style="list-style-type: none"> <li>• Fletcher Allen Health Care, NH</li> <li>• Met. Jewish Health System</li> <li>• Cleveland Clinic Lou Ruvo Center for Brain Health</li> <li>• Fox Rehab, PA</li> <li>• St. Johns Council on Aging, FL</li> <li>• Benjamin Rose Institute, OH</li> <li>• Middle Alabama AAA</li> <li>• Scott &amp; White Hospital and Central TX AAA</li> <li>• Southern Caregiver Resource Center, CA</li> <li>• Wellness Community SE Michigan</li> <li>• Middle Flint Council on Aging, GA</li> </ul>	<ul style="list-style-type: none"> <li>• New York U. School of Med.</li> <li>• Center for Applied Research on Aging &amp; Health/ Thomas Jefferson University</li> <li>• Margaret Blenkner Research Institute</li> <li>• U. of Mich/ School of Social Work and School of Nursing</li> <li>• Emory U. School of Nursing</li> <li>• Stanford U. School of Medicine</li> <li>• Veterans Admin. Coordinating Center on Caregiver Research</li> <li>• Rosalynn Carter Institute for Caregiving</li> </ul>




### NQCN Bridge from Science to Service





Five Elements to help address implementation challenges:

1. Online Resource Center
2. Education and Training
3. Implementation Grants
4. Targeted Technical Assistance
5. Rosalynn Carter Leadership Award in Caregiving




### EBP Online Resource Center






### Objectives of the Online Resource Center for EBP

- Collect Caregiver EBPs in one Location
- Track key translation and replication efforts
- Provide tools to assist agencies through each stage of adoption and implementation.
- Provide training materials for community agencies, practitioners, educators, and researchers



### Education & Training





### Free agency tools

- A series of reports / case studies on implementing specific EBPs in different systems; challenges, lessons learned, future prospects
- A professional development webinar series showcasing the current work of the Research and Development Sites.

**2010 Schedule – all webinars are scheduled for 11:00 a.m. EST**

**August 18** - The Environmental Skill-Building Program: What is it and how do I implement it in my agency?  
 Laura Gitlin, PhD, Thomas Jefferson University

**September 15** - The Importance of Cultural Adaptation in Implementing Evidence-Based Programs for Caregivers  
 Dolores Gallagher-Thompson, PhD, Stanford University  
 Sofia Vaksman, LCSW, HomeFirst

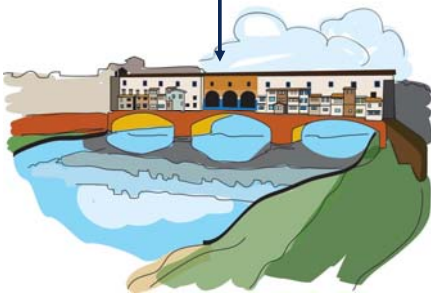
**November 17** - The Care Consultation Program: Our implementation experiences, successes, and challenges  
 David Bass, PhD, Benjamin Rose Institute

**December 15** - Implementing the FOCUS Program for Cancer Caregivers in a Community-Based Setting  
 Laurel Northouse, PhD, University of Michigan

**National Quality Caregiving Network**

- Technical Assistance Reports and Materials to help agencies successfully implement EBPs.
- Forums and Study Group Reports on key issues in Caregiver EBPs including a **Position Paper on Supporting Family Caregivers.**
- Annual Session at ASA/NCOA and the annual RCI National Summit.
- **[www.RosalynnCarter.org](http://www.RosalynnCarter.org)**

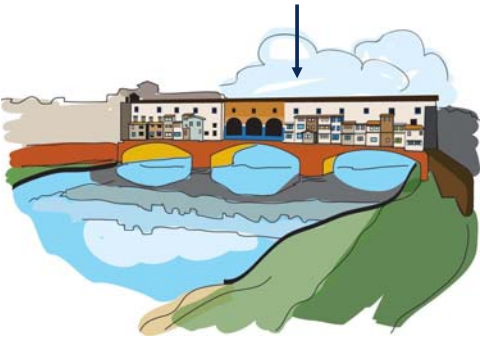
**Implementation Grant Program**



**New Grantees: 2009-2011**

- Benjamin Rose Institute (Cleveland, OH)  
 Care Consultation
- Lou Ruvo Center for Brain Health (Las Vegas, NV)  
 NYUCI
- Southern Caregiver Resource Center (San Diego, CA)  
 REACH-OUT
- St. Johns County Council on Aging, Inc. (St. Augustine, FL)  
 ESP
- The Wellness Community SE Michigan (Ann Arbor, MI)  
 FOCUS

**Targeted Technical Assistance**



**Targeted Technical Assistance**


- RCI's goal is to help agencies successfully implement their chosen EBP and help position them for mid and long-term funding.
- Assistance is targeted to the identified needs of each agency
- TA is both "generic" and "intervention specific"
- Research consultant delivers both on and off site training & support



**National Implementation Research Network**

Dr. Dean Fixsen and Dr. Karen Blase

We follow their model for both Intensive Technical Assistance and Implementation Drivers.



**Targeted Technical Assistance**


- done with a sharp focus on purpose and outcomes as well as considerable depth, breadth, coherence, and energy in relation to achieving those outcomes.
- takes responsibility for providing information and necessary supports and for doing whatever it takes to assure intended outcomes occur in a timely and effective manner.
- starts with the end in mind and works persistently to assure desired outcomes.



**Targeted Technical Assistance**

**CORE FEATURES:**

- Clarity
- Frequency
- Intensity
- Duration
- Integrity
- Accountability




**ADSSP**

Alzheimer's Disease Supportive Services Program

- In 2009, RCI entered into a Cooperative Agreement with the Administration on Aging (through ADSSP) for a three year project to implement a translation of the NYUCI through two Area Agencies on Aging in Georgia.
- This is the first test of this intervention that will include up to 1/2 African American clients and so represents an important national test.


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The Georgia Family Support Program ( RCI translation of NYUCI) will:

- Provide support services to Alzheimer's/dementia caregivers through a protocol that has been proven to be effective in random control trials.
- Develop a model for successful evidence based implementation that can be replicated by other agencies (and create a manual for that purpose)

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The Georgia Family Support Program will:

- Build the capacity of the partnering agencies to move forward with new evidence based programs.
- **Study the process of doing all the above**

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The New York University Caregiver Intervention (NYUCI) is a counseling and support program for spouse caregivers intended to improve their well-being and delay nursing home placement of persons with Alzheimer's disease.

The program helps spouse caregivers mobilize their social support network and better adapt to their caregiving role.

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The NYUCI has 4 components; the first 2 are delivered within 4 months of enrollment:

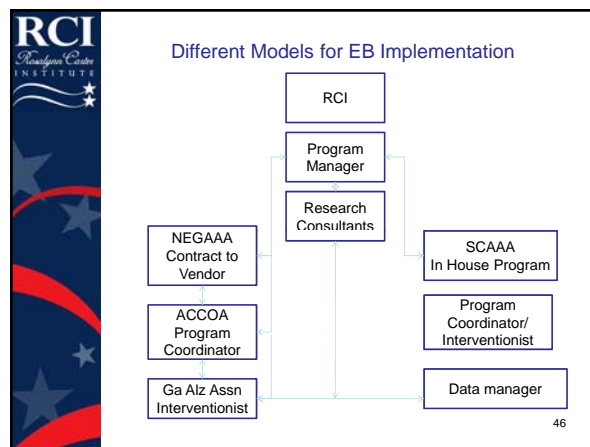
1. Two individual counseling sessions (one to begin, one to end)
2. Four family counseling sessions
3. Encouragement to participate in weekly, locally available support groups after participation in the intervention
4. Ad hoc counseling, provided by telephone whenever needed.

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**Outcomes of the NYUCI**  
 Caregivers who received the intervention reported:

- better physical health
- fewer depressive symptoms
- higher levels of satisfaction with their social support network
- being less troubled by their spouses' memory and behavior problems
- an average time from participation in the intervention to nursing home placement of care recipients that was **557** days longer

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**Readiness for Change**

Resistance occurs when people are asked prematurely to move to action. They are resistant to change because they are not ready for change.

What is needed is relevant and detailed information so those who are being asked to change are ready for change.

Accountability for readiness to change rests with those who are requesting the change, not those who are expected to change.

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**Readiness for Change Assessment**

- How do they usually do things?
- Why are they interested in this project?
- How do ALL the members of the staff feel about the project?
- How do they adapt to change?
- What procedures need to be adapted or adopted?
- What training is needed and for whom?
- OBSERVED OFFICE CULTURE

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## Implementation Teams

- Provide the infrastructure needed to use best practices in implementation.
- Helps integrate practice improvement initiatives at all levels.
- Establishes feedback systems to quickly identify strengths and address challenges.

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## Implementation Teams

- Identify and engage all agency staff involved in the project in any way.
- Include the entire team in all training and planning activities.
- Encourage feedback and ongoing communication.

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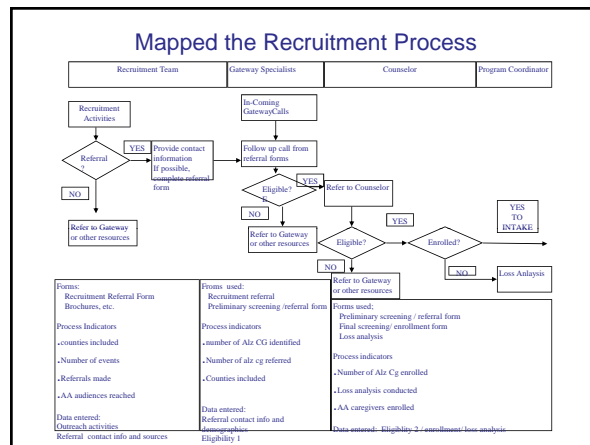
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## Training on IMPLEMENTATION

Provided training to the entire STAFF at each site on:

- The Intervention
- REAIM model
- NIRN model

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## Focus Groups

Conducted Focus groups with caregivers in both regions to better understand any barriers to recruitment and to ensure we are using the most appropriate language to promote acceptance.

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## Training the Interventionists

Dr. Mary Mittelman and Cynthia Epstein Smith provided training for interventionists and their supervisors on:

- Conducting the baseline assessment
- Addressing typical issues that arise during intervention sessions.
- Continued monthly consultations and ad hoc training/consultation.

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## Testing the Instruments

Piloted the baseline assessment with both staff and local caregivers to ensure instruments are appropriate for African American and Rural caregivers.

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- Installed comprehensive data collection systems.
  - Referral / Outreach
  - Service Delivery
  - Baseline and evaluation
- Create and install fidelity checkpoints.

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### Supervision/Feedback Plan

- Monthly Audio tapes of sessions
- Biweekly teleconferences
- Monthly site visits
- Monthly consultation with Research Consultants ( and Ad Hoc)
- Quarterly Cross Site Training and Feedback Sessions

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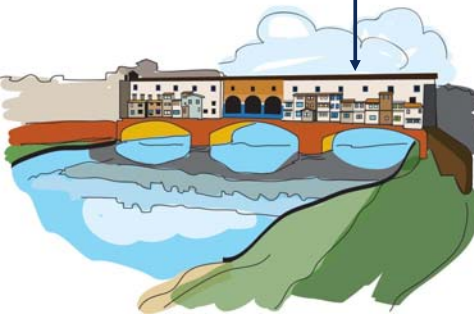
So far... so good.

Keep learning... keep sharing...

**DOCUMENT, DOCUMENT, DOCUMENT.....**

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### Rosalynn Carter Leadership in Caregiving Award



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### Rosalynn Carter Leadership in Caregiving Award






### What are our next steps?

- Issue a Position Paper reflecting the need to make EBPs widely available to caregivers
- Initiate a National Initiative to support and coordinate needed efforts



### National Quality Caregiving Initiative


- The goal is to provide an umbrella for disparate efforts in DHHS, NIH, CMS, CDC, VA, voluntary health organizations (Alzheimer's Association, etc.), private philanthropy and corporations.
- Focus on building a system of care constructed from EBPs as rapidly and expertly as possible.



### A Public Health Approach to Serving Caregivers

1. Focuses on the health of the population; tracks trends in population health through regular surveys, studies, analysis.
2. Identifies sub-populations and their needs.
3. Targets interventions and resources to address different levels of risk - those at greater risk receive more intensive, individualized services.
4. Focuses on prevention
5. Recognizes the caregiving dyad as the Unit of Service.

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### Elements of a Public Health Infrastructure for Caregivers that Need Rapid Development

1. Monitor Public Health
2. Outreach and Education, especially to most in need
3. Multiple, "natural" gateways to service
4. Assessment and "Triage"
5. Stepped Menu of Service Options with Increasing Intensity
6. Professional Development
7. Technical Assistance to Agencies / Service Providers
8. Accelerated Research and Development
9. Tax and Public Policy Changes
10. Targeted Investments and Sustainable Funding
11. Leadership and Coordination

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**October 20-22, 2010**  
**RCI National Summit & Training Institute**  
**Averting the Caregiver Crisis**

**REGISTER NOW!**



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 Assistant Secretary for Aging  
 U. S. Dept. of Health &  
 Human Services  
 Washington, DC

Anthony Rodgers  
 Deputy Administrator and Director  
 Center for Strategic Planning  
 Centers for Medicare & Medicaid  
 Services  
 Washington, DC

**Other Presenters Include:**

Richard Schulz, PhD  
 Steven H. Zarit, PhD  
 Kate Lorig, RN , DrPH  
 Nancy Whitelaw, PhD  
 Susan C. Reinhard, RN, PhD  
 Heather Mahoney-Gleason, LCSW  
 Laurel L. Northouse, RN, PhD, FAAN  
 David M. Bass, PhD  
 Laura N. Gitlin, PhD



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