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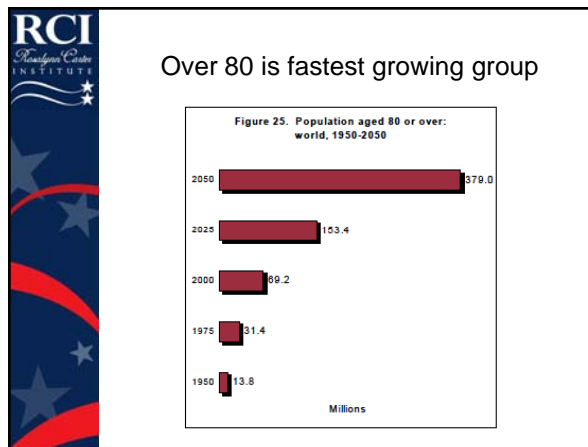
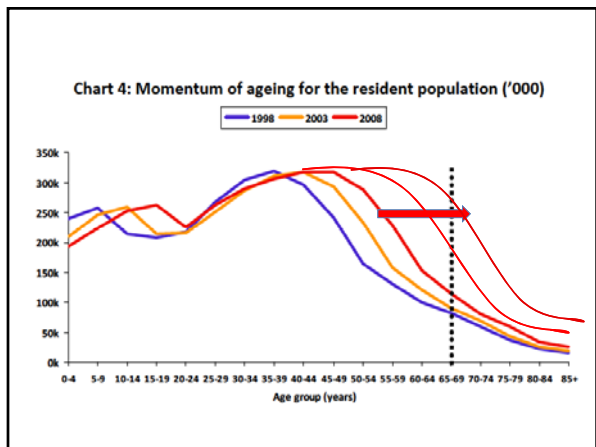
**The National Quality Caregiving Network:
 A Model for Supporting Evidence-Based
 Programs for Caregivers**

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Three Main Sections

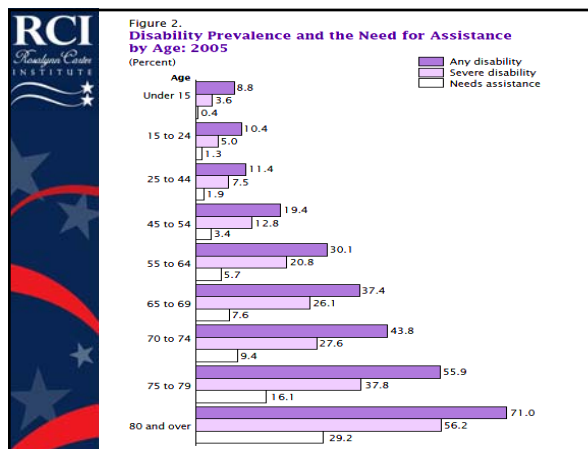
1. The Problem we are Addressing
2. Our experience with NQCN
3. What we propose to do Next




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Ageing 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.





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.

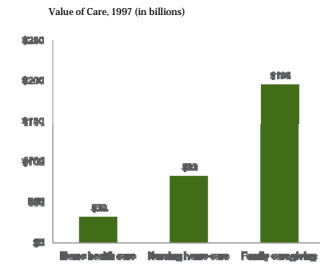
Today, that number is approximately 7,000,000.

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.



Category	Value (in billions)
Home health care	\$52
Nursing home care	\$83
Family caregiving	\$198

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



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)




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.





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.



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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Poor Quality Care and Elder Abuse

- Often associated with Caregiver Stress and Anger
- Growing rates of elder mistreatment are 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/ agencies 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 1st 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:

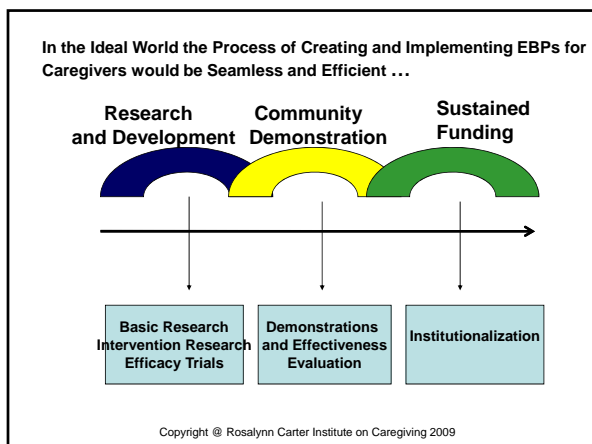
However, NONE of these Interventions have yet been integrated into:

- 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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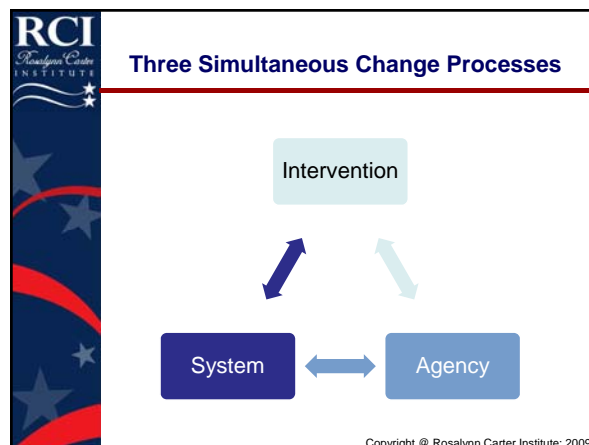
Why are EBPs not Being Implemented?

- 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



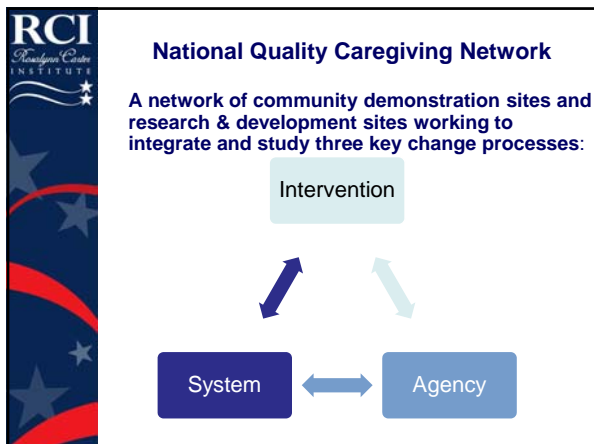
- But... there are three problems
1. **Program/ Interventions** that show efficacy in trials require further refinement, modification and development of support materials.
 2. **Agencies**, although motivated and in need, are typically not ready to adopt and implement a complex intervention without building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

- What we have done...
1. Created a pilot project: "NQCN"
 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, particularly NIRC, National Implementation Research Network.

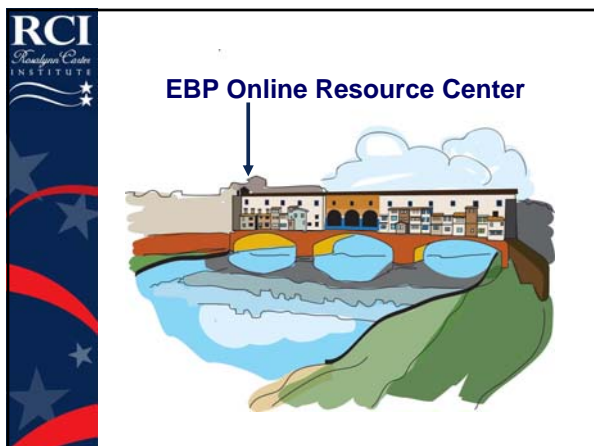


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- National Quality Caregiving Network**
- Researchers and agency leaders and practitioners viewed as equal partners whose work informs and supports one another
 - Serves as a learning community that generates "practice-based evidence"
 - Draws upon 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"> • Fletcher Allen Health Care, NH • Met. Jewish Health System • Cleveland Clinic Lou Ruvo Center for Brain Health • Fox Rehab, PA • St. Johns Council on Aging, FL • Benjamin Rose Institute, OH • Middle Alabama AAA • Scott & White Hospital and Central TX AAA • Southern Caregiver Resource Center, CA • Wellness Community SE Michigan • Middle Flint Council on Aging, GA 	<ul style="list-style-type: none"> • New York U. School of Med. • Center for Applied Research on Aging & Health/ Thomas Jefferson University • Margaret Blenkner Research Institute • U. of Mich/ School of Social Work and School of Nursing • Emory U. School of Nursing • Stanford U. School of Medicine • Veterans Admin. Coordinating Center on Caregiver Research • Rosalynn Carter Institute for Caregiving

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- 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
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- What happens during Exploration?**
- Assessing caregiver & community needs and current performance
 - Studying and assessing "fit" of different programs
 - Assessing capacity, resources, and "buy-in"
 - Interviewing the "purveyor" or program developer
 - Assessing Feasibility
 - Deciding to move ahead/or not
- (Blase and Fixen: NIRN)

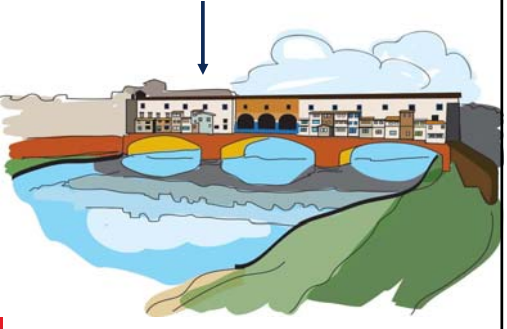
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Objectives of the Online Resource Center for EBP

- 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 practitioners, community agencies, educators, and researchers

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Education & Training



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Assistance at Each Stage of Implementation

April 2009 – Technical Assistance Webinar I: Exploration
Getting Started: Selecting an Evidence-Based Program to fit your Agency and Community's Needs

May 2009 – Technical Assistance Webinar II: Exploration
Getting Started II: Setting up the Implementation Team; Identifying & Addressing System Barriers, Establishing partnerships

June 2009 – Technical Assistance Webinar III: Initial Implementation: Selecting and Supporting Implementation Staff: Best Practices in: 1) Recruitment and Selection, 2) Pre-service and In-service training, 3) Supervision and Coaching and 4) Performance Evaluation

July 2009 – Technical Assistance Webinar IV: Initial Implementation: Establishing Decision Support Data Systems: Strategies for Monitoring Fidelity and Measuring Outcomes.

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Other Products and Services:

- A Series of Reports / Case Studies on Implementing specific EBPs in different systems; challenges, lessons learned, future prospects
- A 2010 Webinar series showcasing the current work of the Research and Development Sites.

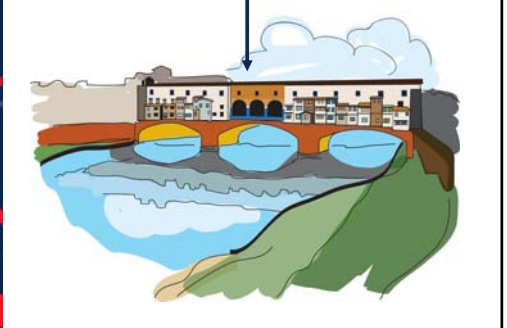
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National Quality Caregiving Network

- 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 Americus Annual Summit.
- www.RosalynnCarter.org

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Implementation Grant Program



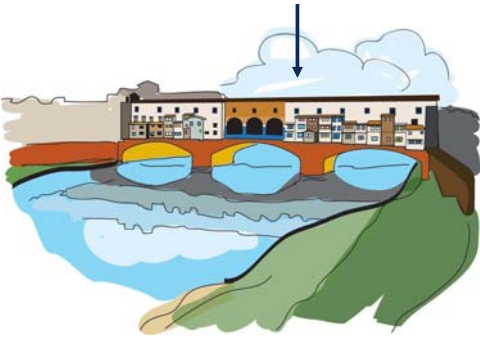
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New Grantees: 2009-2011

- 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

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Targeted Technical Assistance



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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"
- Program Developer delivers both on and off site training & support

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Rosalynn Carter Leadership in Caregiving Award



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What Are Next Steps?

- Issue a Position Paper on Need to Make EBPs Widely Available to Caregivers
- Goal to Initiate a National Initiative to support and coordinate needed efforts.
- "National Quality Caregiving Initiative"
- Quality Caregiving = good for both the care recipient and caregiver.

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NQC Initiative



- Provide an umbrella for disparate efforts in DHHS, NIH, CMS, CDC, VA, Voluntary Health Organizations (e.g. Alzheimer's Association, Cancer Support Community, etc), Private Philanthropy, and Corporations.
- Focus on Building a System of Care constructed from EBPs as rapidly and expertly as possible.

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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/ with more intensive, individualized services for those at greater risk.
4. Focuses on Prevention
5. Recognizes (Caregiver + Receiver) as Irreducible 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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Monitor Caregiver Health

Purpose is to ensure that problems of public health importance related to caregiving are being monitored efficiently and effectively in order to identify existing and emerging health concerns and target resources towards their prevention and treatment.




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Public Education and Outreach

Goal is to reach caregivers who are not seeking services but who are at risk of ill health and/ or of providing poor quality care.

A second goal is to educate the public about the critical and difficult role of family caregiving and how they can assist family caregivers in their community.




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Multiple, "natural" gateways to service

Goal is to enable caregivers to access needed services in the course of their normal activities and responsibilities. For example while visiting their doctor, upon hospital entrance and discharge, in the course of going to church, the pharmacy, or shopping for assistive devices, in calling their AAA, etc.



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Assessment and "Triage"

Goal is to enable families to have a professional, accurate and timely assessment of their resources and needs, to help set goals for care and anticipate future needs, and identify resources to meet current and future needs.



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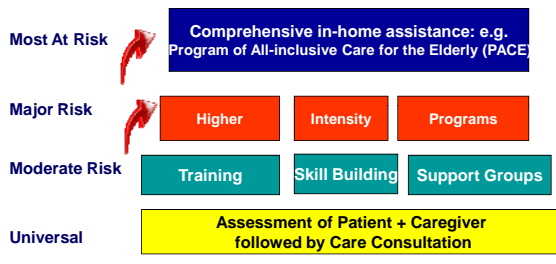
Stepped Menu of Service Options with Increasing Intensity

Goal is to provide a menu of services that targets sub-populations of caregivers effectively and provides the right level of intensity and "dose" to best meet existing needs.



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A Public Health Approach to Serving Caregivers



Most At Risk: Comprehensive in-home assistance: e.g. Program of All-inclusive Care for the Elderly (PACE)

Major Risk: Higher Intensity Programs

Moderate Risk: Training Skill Building Support Groups

Universal: Assessment of Patient + Caregiver followed by Care Consultation

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Professional Development



Goal is to equip professionals and paraprofessionals with skills to assure their success in working with family caregivers.

A second goal is to train professionals and paraprofessionals in evidence-based interventions, and in how to implement those interventions in their practice.

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Technical Assistance to Agencies / Service Providers

Goal is to build capacity of diverse agencies to effectively serve and partner with family caregivers and to adopt the most effective programs and interventions available.



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Accelerated Research and Development

Goal is to rapidly generate knowledge about the effectiveness of different systems of caregiver support, their success in serving diverse communities, and their costs and cost effectiveness.




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Tax and Public Policy Changes

Goal is to preserve family caregiving as a viable option by protecting families from economic harm associated with caregiving, and to create incentives for family caregivers to increase their skills and provide high-quality care.



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Targeted Investments and Sustainable Funding

Goal is to support the development of essential infrastructure to serve family caregivers, and to promote adoption, implementation and maintenance of the most effective programs.



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Leadership and Coordination



Goal is to provide top-level direction and promote integrated planning and action in order to increase the efficiency and speed of development of the envisioned system, to minimize conflicts and duplication of efforts, and to assure accountability for outcomes.

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- We have developed these ideas in the process of working with our agency and research partners in the NQC�.
- With the help of these individuals we have drafted a position paper and recommendations to launch
“The National Quality Caregiving Initiative”
- Invite your participation and assistance.

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Overview of Today’s Sessions

1. Making primary care “caregiver friendly”
2. Assessment as “triage” and as partnering
3. Managing change and organizational transformation that accompanies adoption of EBPs: a Case Study
4. Strategies for building a menu of services
5. Recommendations for NQCI