The National Quality Caregiving Initiative

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Building a Bridge from Science to Practice for America's Caregivers

Rosalynn Carter Institute for Caregiving

The Rosalynn Carter Institute for Caregiving (RCI) was established in 1987 at Georgia Southwestern State University (GSW) in Americus, Georgia. The RCI 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.

Mission and Philosophy

The Rosalynn Carter Institute establishes local, state and national partnerships committed to building quality long-term, home and community- based services. Our focus includes supporting individuals and caregivers coping with chronic illness and disability across the lifespan as well as limitations due to aging.

Four Sections to this Presentation:

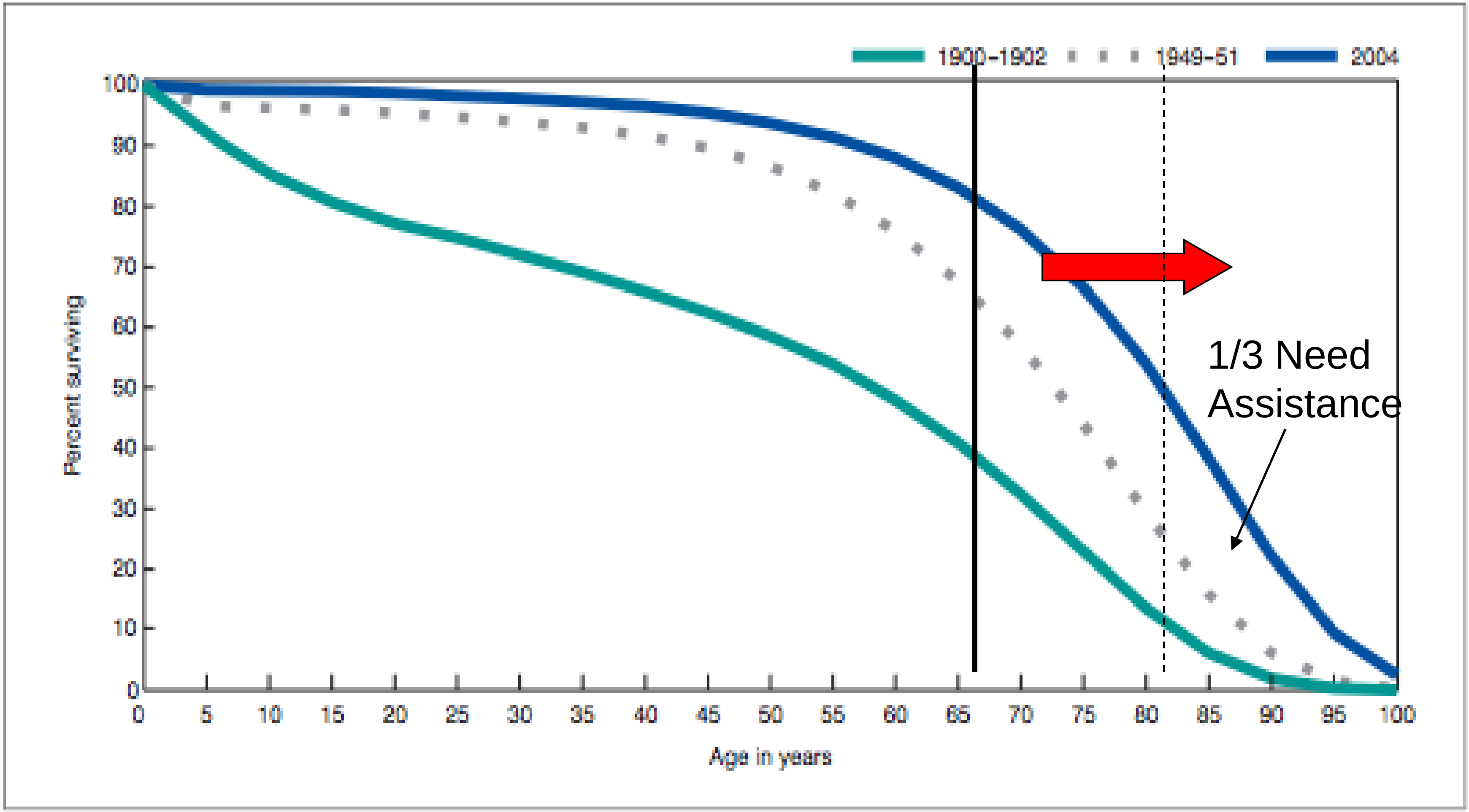
1. The Caregiving Crisis
2. Methods
3. What We Have Learned
4. Proposal for a National Initiative

Part I

The Emerging Caregiving Crisis:

Why We Must Act Now

The Age Wave in the United States



1/3 Need Assistance

Figure 3. Percentage surviving by age: Death-registration states, 1900–1902, United States, 1949–1951, and 2004

Aging Drives the 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 to help with routine activities of daily living because of chronic illness.

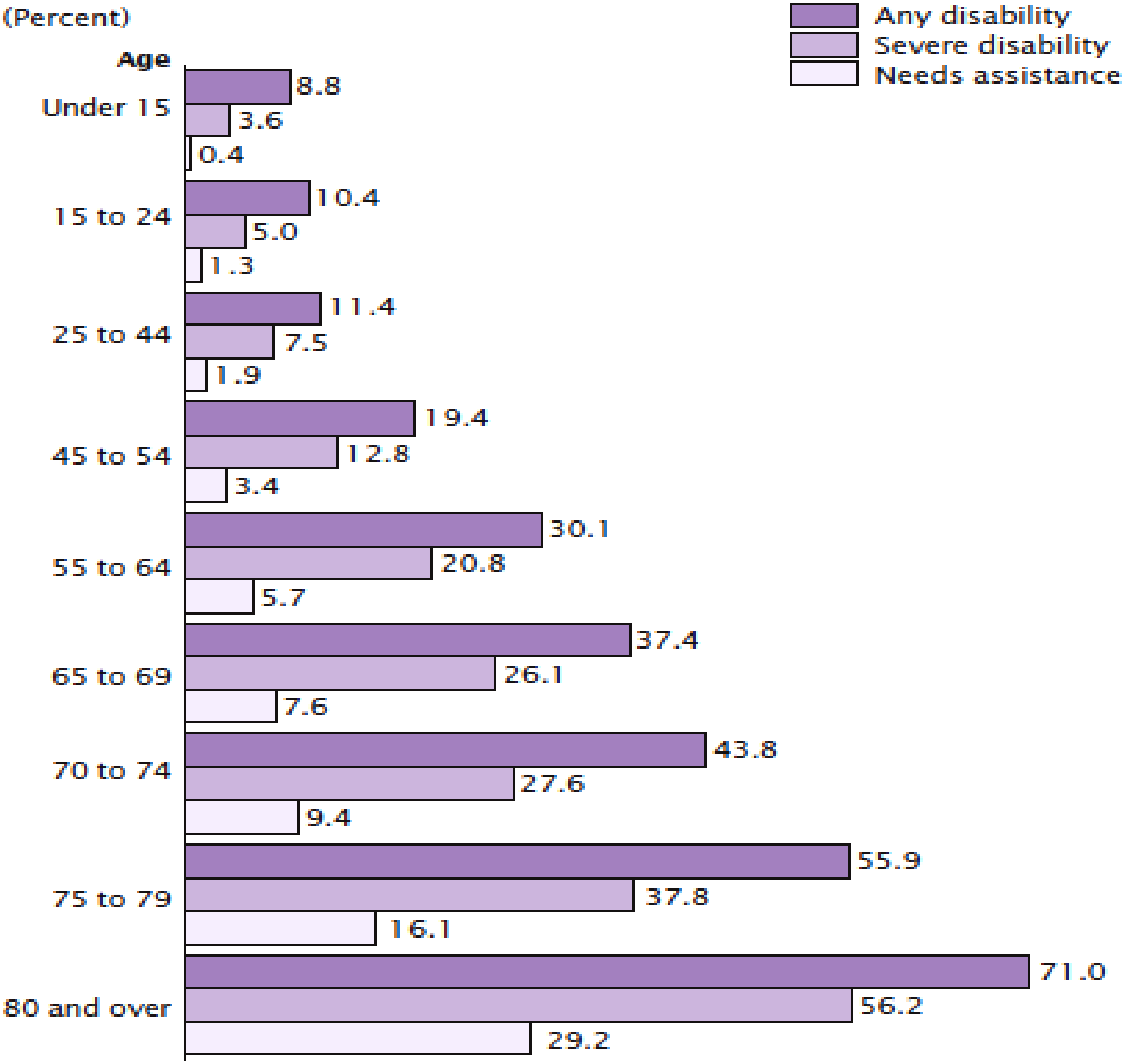


Figure 2.

Disability Prevalence and the Need for Assistance by Age: 2005

(Percent)

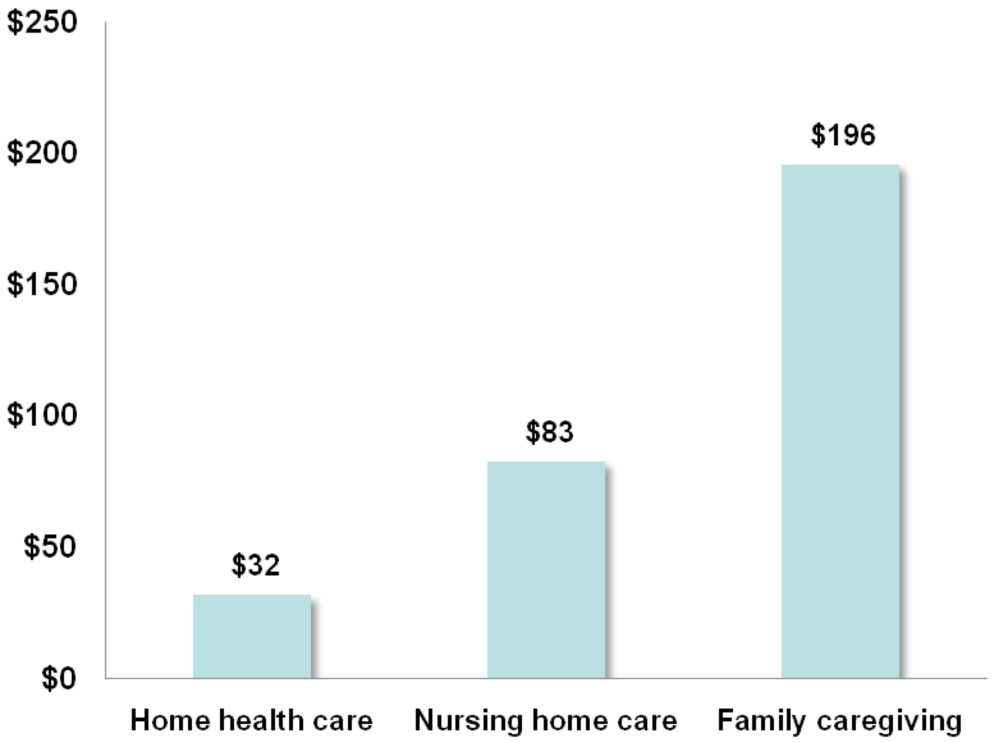
How Many Seniors Require Care?

- 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.
- The family households in which 80% of these individuals will live are truly the backbone of America’s Long-Term Care System**.**

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)



Source: Arno, PS, Levine, C and Memmott, MM, "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:

- Of longer duration, often 5 or more years
- 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.

20% – 30% of Caregivers Fare Poorly

- High levels of stress, frustration, isolation
- 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 and premature mortality.

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.

Our Conclusion…

Unless we move quickly to make interventions that reduce stress and increase knowledge, coping skills and resilience widely available to family caregivers; unfavorable conditions for families, caregivers, care-recipients, professional caregivers and our society will rapidly develop during the next decade, and family commitment to provide care will erode.

Part II: Methods

- RCI has studied caregiving, implemented evidence-based caregiver interventions, served caregivers, and convened caregiving experts and researchers since 1987.
- In 2007, with funding from Johnson & Johnson, we convened 300 leading caregiving researchers and agency leaders from around the United States to examine the evidence-base for caregiver support and the extent to which it was being applied in practice.
- Following that Summit, and based on our finding that effective interventions were <u>not</u> being implemented, we took several steps:

The National Quality Caregiving Network

1. With funding from Johnson & Johnson, we created a national network of community demonstration and university R&D sites to study the process of implementing evidence-based caregiver interventions, identify the challenges, and develop best implementation practices;

2. Since 2008, we have made more than $1M in grants to the NQCN to study how we can speed the dissemination of effective caregiver interventions and make them more widely available to family caregivers.

National Quality Caregiving Network

Community Demonstration Sites

- 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
- Three Area Agencies on Aging, GA

Research & Development Sites

- 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

The National Quality Caregiving Network

3. We have convened six national meetings in the past three years to share our learning with the field and develop consensus about recommendations for change;

4. In the past six months, the RCI Executive Director and a Senior Policy Fellow at RCI have conducted Key Informant Interviews with more than a dozen Senior Administrators in HHS and several caregiving researchers to further refine our understanding of existing challenges and get feedback on draft recommendations.

5. The recommendations that follow are a result of this work.

III. What We Have Learned

- Evidence-based interventions (EBPs) for caregivers have been developed across a range of chronic conditions; the RCI on-line database includes 65 that have shown positive outcomes in random controlled trials.
- These interventions achieve important outcomes including better caregiver health and well being, reduced or delayed nursing home use, and improved quality of care.
- Effective interventions are of longer duration, are individualized to meet caregiver needs, and have multiple components targeting knowledge acquisition, stress management, social support, problem solving and safety.

Characteristics of Evidence-Based Interventions

1. Interventions with heavier “dosage” of treatment that provide more treatment over a longer period of time are more effective than shorter, lower dose interventions.
2. Contact with a helper who has specific intervention protocols to follow that have been evaluated and shown to be effective through rigorous evaluation
3. Interventions and care plans are tailored to the caregiver’s specific needs and risk factors and are flexible enough to be adjusted to meet the changing demands of care,
4. Multi-component interventions that address multiple stressors and risks that affect caregiver health. Multicomponent interventions include a combination of education, skill building, problem solving training, counseling, direct services and altering the physical environment to address priority needs.

However…

<u>None</u> of these Interventions are widely available to caregivers and none have been integrated into:

- The Aging network of services
- The National Family Caregiver Program
- Health and long-term care services (e.g., home care, hospital discharge planning)
- Sustainable funding streams such as health insurance, HMOs, Medicaid, Medicare

Findings, Continued…

- As a result of not receiving proven interventions, caregivers are underserved and subject to excess stress and burden;

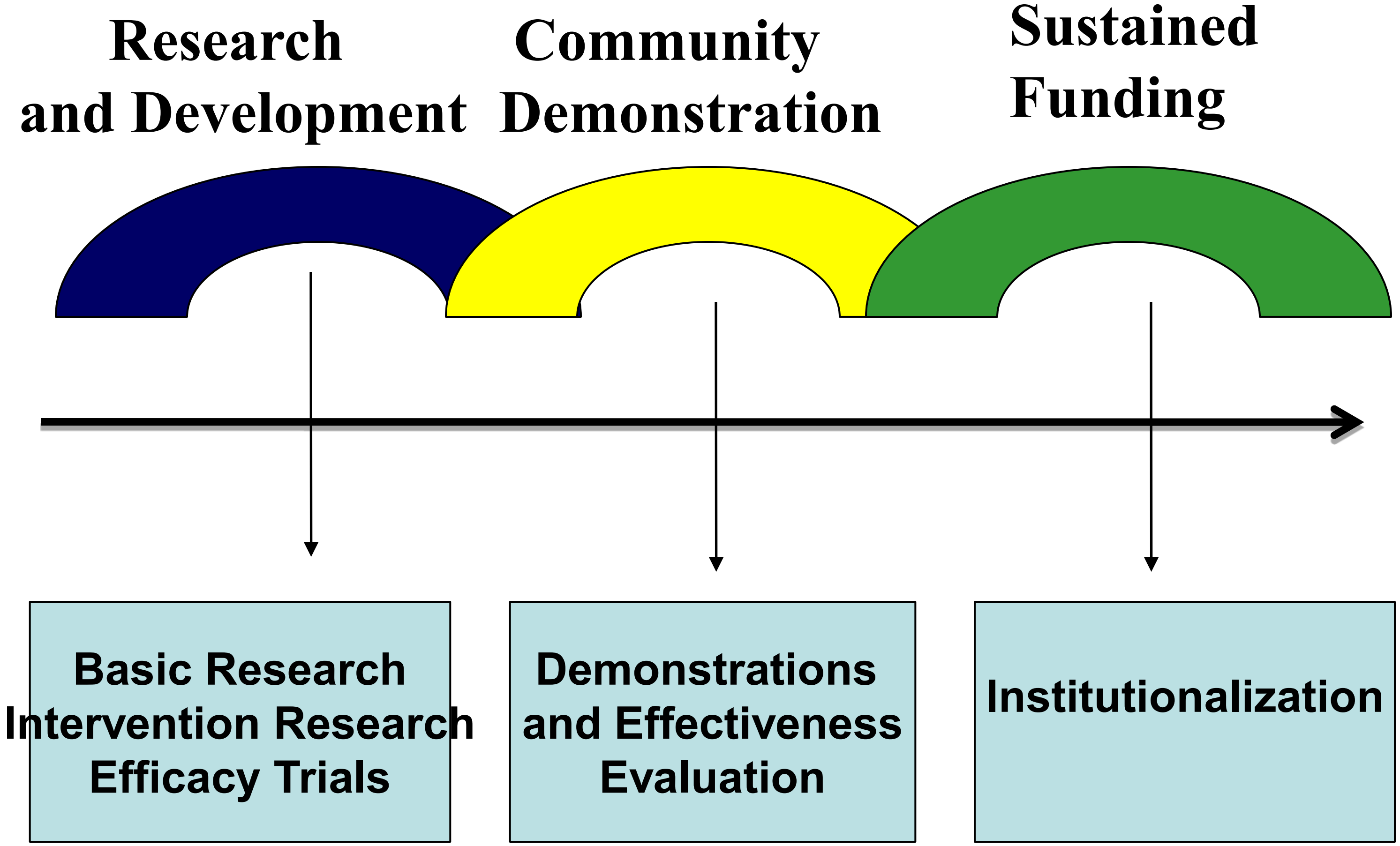
- The excess burden of caregiving results in compromised caregiver health, premature & unnecessary institutionalization, and poor quality care, including elder abuse;

- The widespread adoption of EBPs would significantly lower caregiver stress, extend community living for many seniors and people with disabilities, and improve quality of care.

Why are EBPs not Being Implemented?

1. Lack of awareness/ knowledge that effective interventions exist;
2. Lack of funding to sustain the programs;
3. Training and technical assistance is hard to find and expensive for adopting agencies;
4. The pipeline from research to service for caregivers is broken; NIH, AoA, and CMS do not coordinate their efforts so promising research sits on the shelf;
5. The standard of care for family caregivers is low and does not include use of evidence-based practice.

Ideally, the Process of Creating, Implementing and Sustaining EBPs for Caregivers would be Seamless and Efficient…



Research and Development

Community Demonstration

Sustained Funding

Basic Research
Intervention Research
Efficacy Trials

Demonstrations and Effectiveness Evaluation

Institutionalization

Instead…

- **NIH, AoA and CMS have no collaborative planning process to develop and disseminate caregiver interventions**;
- Effective interventions are developed yet still sit “on the shelf”, while caregivers receive poor quality, ineffective programs;
- While a number of interventions have received AoA demonstration funding in recent years; prospects for their survival after grant funding ends is unclear.

Additional Barriers that Must be Overcome:

1. Absence of state and local data prevents effective planning; national caregiver surveys are overused and do not reflect critical regional, state and local differences;

2. Caregivers in need of assistance are reluctant to ask for help, and do not know where or how to seek it;

3. Surveys show the majority of caregivers have no knowledge of the Area Agency on Aging and do not know where to turn for assistance.

Barriers, continued:

4. Family caregivers rarely receive a professional assessment of their needs or recommendations for support, education and training;
5. Agencies offer one-size-fits-all programs instead of interventions tailored to the unique needs of each family as determined by a professional assessment;
6. When available, caregiver interventions are often unproven, only occasionally available and are the first services cut when budgets tighten;

Barriers, continued:

7. Agencies that try to adopt evidence-based interventions receive little assistance or encouragement to do so making adoption financially and logistically beyond the reach of most providers without outside assistance;

8. Professionals and paraprofessionals likely to work with family caregivers are poorly prepared to do so. Physicians, among others, receive an hour or less of training on the needs of family caregivers and how to assist them;

Barriers, continued:

9. Family caregivers most in need of assistance often have the lowest levels of participation in education, training and stress-management interventions when they are available;
10. The window of opportunity to effectively address the caregiving crisis is closing quickly; “business as usual” is not an option;
11. Traditional research approaches and priorities have failed to support timely translation and implementation of proven interventions; more creative research designs and large scale demonstrations are now necessary.

Barriers, continued:

12. Responsibility for assisting family caregivers is poorly defined and scattered among federal, state and local agencies. The result is ineffective planning and lack of leadership.

IV. Proposal for a National Initiative

The proposed “National Quality Caregiving Initiative” includes twelve recommendations for a comprehensive, multi-faceted effort designed to efficiently build an evidence-based system of support for family caregivers. The plan proposes specific actions designed to overcome key barriers that have hampered efforts in the past. The envisioned system of supports adopts a public health approach including population monitoring, risk-based programming, and a focus on building resilience and preventing illness.

Recommendations for

A National Quality Caregiving Initiative

Why a National Caregiving Initiative?

- To provide an Umbrella for disparate caregiver efforts in Federal, State, and Local Government, the private sector (including voluntary health organizations), private philanthropy, and corporations such as J&J.
- To provide a Blueprint for Building an Evidence-Based System of Support as rapidly and expertly as possible.
- To create Momentum and Focus to address family caregiver issues as part of health care reform.

Twelve Key Actions of the NQC initiative:

1. Monitor Caregiver Health
2. Outreach and Public Education
3. Establish services in “natural” settings for easy access
4. Provide professional assessment and “triage” to all caregivers who want it.
5. Assure caregivers receive Evidence-Based Interventions tailored to their unique needs and level of risk.
6. Expand opportunities for professionals to learn to work with family caregivers

Twelve Key Actions of the NQC initiative:

7. Establish a National Resource Center on Evidence-Based Caregiver Support Programs
8. Provide Technical Assistance to Agencies in adopting and Implementing Effective Programs
9. Accelerate Research and Development
10. Pursue Public and Tax Policy Revisions
11. Target Investments and provide sustainable
12. Provide Strong Federal Leadership and coordination

1. Monitor Caregiver Health

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

1. Monitor Caregiver Health

Recommendation 1a) Establish State-Level Systems to Monitor Caregiver Health by requiring states to adopt the BRFSS caregiver module as part of Older Americans Act funding.

Recommendation 1b) Require a state-level process using BRFSS Data collected every two years to identify sub-populations of caregivers most in need and to allocate Older Americans Act funding and other resources and develop programs in line with identified priorities.

2. Outreach and Public Education

Goal is to reach caregivers who are not currently 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 communities can assist family caregivers in their work.

2. Outreach and Public Education:

<u>Recommendation 2a)</u> Develop and launch a national outreach and public education campaign to reach caregivers most in need. The campaign should be developed and funded by HHS using resources of CMS, CDC, AoA and others to: 1) help family caregivers recognize, locate and accept assistance and, 2) inform the public about the needs of family caregivers and how individuals, communities, employers, and faith communities can best offer help.

3. Establish services in “natural” settings for easy access

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, through their faith community, and while at work.

3. Establish services in “natural” settings for easy access

Recommendation 3:

Provide opportunity grants, training and technical assistance to help diverse agencies and organizations build their capacity to provide evidence-based services to caregivers. These include physician’s offices, hospitals, faith communities, voluntary health organizations, work places, and other locations and agencies that caregivers are likely to access.

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4. Provide professional assessment and “triage” to all caregivers who want it.

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.

4. Provide professional assessment and "triage" to all caregivers who want it

Recommendation 4a)

Offer all family caregivers the opportunity for a professional assessment of their needs.

Assessments should be culturally competent; conducted by someone with the specialized skills to assess caregiver needs and knowledge of caregiver supports, and result in a plan of care outlining services to be provided and measurable outcomes.

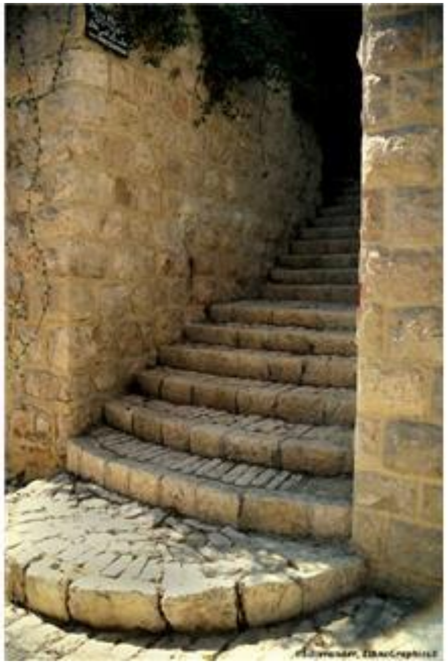
4. Assessment and "Triage"

Recommendation 4b) Assessment programs conducted by health care providers (hospital discharge, home care, outpatient, and rehabilitation specialists) or government-funded entities (such as Area Agencies on Aging) have a caregiver component that is available to anyone who identifies themselves as a family caregiver.

Recommendation 4c) Government and other third-party payers should pay for adequate caregiver assessment as a part of care for older people and children and adults with disabilities.

5. Assure caregivers receive Evidence-Based Interventions tailored to their unique needs and level of risk.

Goal is to provide a menu of services that offers interventions of increasing intensity to meet the needs of caregivers with varying degrees of risk and need.



5. Assure caregivers receive Evidence-Based Interventions

Recommendation 5a) Adopt a standard of care within the Aging Network that requires provision of evidence-based programs to caregivers;

5b) Revamp and Expand the National Family Caregiver Support Program to emphasize provision of evidence-based programs and enable it to provide sustainable funding to successful AoA demonstration projects after grant funding ends.

5. Assure caregivers receive Evidence-Based Interventions

5c) Develop systems of care within states and communities that includes a menu of increasingly intensive, evidence-based interventions at three levels:

(1) “universal interventions” for all caregivers,

(2) “selective interventions” for families at elevated risk for future health and stress-related problems stemming from the demands of caregiving, and

(3) “indicated interventions” to further address heterogeneity in risk factors and severity among the high-risk groups

6. 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.

6. Professional Development

Recommendation 6a) Assure professionals in health care, social work, nursing, occupational and physical therapy, and other fields likely to work with family caregivers have access to training on the needs of family caregivers, how to partner with them, and successful strategies and evidence-based programs to serve them;

6b) Work to assure that professionals in fields likely to support family caregivers require caregiver training and education to achieve licensing and certification.

7. Establish a National Resource Center on Evidence-Based Caregiver Programs

Goal is to centralize information and materials on evidence-based caregiver programs, to work with developers and the field to develop and distribute guidance and training materials and processes, and to take other actions needed to support widespread implementation of effective programs.

7. Establish a National Resource Center on Evidence-Based Caregiver Programs

Recommendation 7: Authorize creation of a National Resource Center for Evidence-Based Caregiver Supports with a role of centralizing all information and materials on evidence-based caregiver programs, tracking successful implementation and translation activities, working with program developers and the field to assure that guidance and training materials and processes are in place, and to take other actions needed to support widespread implementation of effective programs.

8. Technical Assistance for Agencies / Service Providers

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

8. Technical Assistance

Recommendation 8:

Create Technical Assistance Networks to assist with widespread implementation of evidence-based programs within diverse community agencies and organizations. Technical assistance networks could be university- or community-based, tapping into local and national expertise in capacity building, evaluation, and systems design. Technical assistance that is targeted to the particular EBPs should also be available and affordable for community agencies.

9. 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.

9. Accelerated Research and Development

Recommendation 9a) Initiate a multi-site demonstration project to test the effectiveness of different configurations of Evidence-Based Caregiver Interventions within the CMS Center for Innovation. Utilize EBP caregiver interventions that have undergone clinical trials and been found effective since 1990 when MADDE (the last Medicare Demonstration focused on caregivers) was conducted.

9b) Require that all caregiver intervention and demonstration projects funded by AoA, NIH and the VA, examine and publish comparable cost-effectiveness and cost-offset data.

10. 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.

10. Public and Tax Policy

Recommendation 10a)

Design a caregiver credit under the Social Security System as suggested by the GAO. Such a credit would:

1) allow a specified amount of caregiving time, perhaps three or four years, to count as covered employment, and assign a wage to that time;

2) exclude a limited number of caregiving years from the benefit calculation so that earnings are averaged over fewer years; or

3) supplement caregivers' retired worker benefits directly, regardless of whether they took time out of the workforce for caregiving.

10. Public and Tax Policy, cont.

10b) Make Tax credits available to informal caregivers, such as that proposed in the CARE Act in the 110th Congress and considered in several states.

10c) Create incentives for family caregivers to participate in evidence-based programs to increase their skill and knowledge about caregiving; consider tying tax credits to caregiver participation in evidence-based programs.

10d) Governments and other payors provide vouchers for care recipients to pay minimum wage to their informal caregivers upon completion of required training.

11. 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.

11. Targeted Investments and Sustainable Funding

Recommendation 11a) Invest in an expanded, nationwide caregiver support system that makes evidence-based programs for caregivers widely available and easily accessible.

11b) Expand Funding for the Alzheimer’s Disease Supportive Services Program of the AoA, and provide additional funding for the National Family Caregiver Support Program to expand access to evidence-based programs/ interventions;

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11. Targeted Investments and Sustainable Funding, continued

11c) Expand Medicaid home and community-based waiver programs to allow for maximum flexibility to support family caregivers with “wrap-around” services and supports to achieve cost-effectiveness

11d) CMS continue funding successful AoA demonstrations after grant funding ends (three years) through a waiver or other mechanism. CMS should assume responsibility to further refine these demonstration projects for widespread adoption and institutionalization at a state or national level, and to evaluate cost effectiveness.

11. Targeted Investments and Sustainable Funding, continued

11e) Quickly implement the “Class Act” which supports development of a new national LTC insurance program. Assure adequate attention to caregiver support, education and training as part of the plan benefits.

12. 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.

12. Leadership and Coordination

Recommendation 12: Create the “NQC Task Force” to oversee this initiative in the President’s Office with the possibility of shared leadership between the Secretary of HHS and Secretary of Veterans Affairs. The group should include government and private sector leaders and be adequately staffed.

Specific tasks:

1) Develop and communicate a clear vision of the caregiver support system to be created, its components and underlying principles, role in the overall Home and Community Based System, and as a critical part of health care reform. Develop a workplan with priority goals and dates for achievement.

12. Leadership and Coordination, cont.

Recommendation 12: continued.

2) Formalize and define agency-specific roles in the EBP product/service development “pipeline” and create a coordinating body to guide development of EBPs for caregivers from basic research to implementation and sustainability in the community.

3) Define responsibilities of national, state and local entities in carrying out the initiative.

4) Identify all related initiatives and their relevance to the current effort.

5) Develop public communication and liaison strategies to assure public awareness and input, and to facilitate public private partnerships, the involvement of faith communities, corporations and voluntary associations, in the work.

What’s Next

- Professional development for agency staff
- Continuing the dialogue

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

September 29 - The Environmental Skill-Building Program: What is it and how do I implement it in my agency?
Laura Gitlin, PhD, Thomas Jefferson University

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

December 8 - The Importance of Cultural Adaptation in Implementing Evidence-Based Programs for Caregivers
Dolores Gallagher-Thompson, PhD, Stanford University

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

October 20-22, 2010

RCI National Summit & Training Institute

Averting the Caregiver Crisis

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U. S. Dept. of Health &
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Anthony Rodgers
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Center for Strategic Planning
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Washington, DC

Other Presenters Include:

Steven H. Zarit, PhD
Kate Lorig, RN , DrPH
Nancy Whitelaw, PhD
Susan C. Reinhard, RN, PhD
Heather Mahoney-Gleason, LCSW
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