

A V E R T I N G   T H E  
C A R E G I V I N G   C R I S I S

*An Update*



**ROSALYNN CARTER INSTITUTE FOR  
CAREGIVING**

**MARCH 2012**

## **I. PROLOGUE**

The Rosalynn Carter Institute for Caregiving (RCI) was established in 1987 on the campus of Georgia Southwestern State University in Americus, Georgia to honor former First Lady Rosalynn Carter, an alumna of GSW. The RCI fosters local, state, national and international partnerships committed to building quality long-term, home and community-based services. We believe this begins with providing effective supports to caregivers through investments that promote their health, resilience and caregiving skills. We also believe strongly in the need to provide greater recognition for both professional and family caregivers. Our focus work encompasses individuals and caregivers coping with chronic illness and disability across the lifespan, as well as limitations due to aging.

In October of 2010, the RCI released a position paper outlining 12 recommendations for addressing the caregiving crisis that is already upon us. This paper was based on several years of intensive study of the caregiving process, an extensive review of evidence-based programs developed to help family caregivers, and current translational strategies for making effective programs widely available to caregivers. "Averting the Caregiving Crisis: Why We Must Act Now" highlighted the contributing factors to our nation's caregiving crisis and recommended specific strategies for resolving the crisis by re-envisioning support for family caregivers.<sup>1</sup> The original paper can be viewed and downloaded in its entirety at:

[http://www.rosalynncarter.org/RCI\\_Position\\_Paper100310\\_Final.pdf](http://www.rosalynncarter.org/RCI_Position_Paper100310_Final.pdf)

## **II. PROGRESS TO DATE**

Progress has been made at all levels in addressing the unmet needs of family caregivers over the past 16 months. Since October of 2010, the RCI has continued its dialogue with representatives from the Administration on Aging, the Centers for Medicare and Medicaid Services, the Department of Health and Human Services, the Office on Disability, the Department of Labor, the Social Security Administration, and the U. S. Department of Veterans Affairs. In addition, the RCI sought the expertise and feedback of professionals involved in service delivery, caregiving research, and evidence-based implementation and policy. The attached Timeline shares selected milestones that have occurred; yet the need for more concrete action is urgent. To sharpen our focus and advance this agenda, we have restated the twelve original recommendations as six strategic initiatives.

It is critical that we act now to preserve the most important component of our long-term care system. In the words of Assistant Secretary for Aging Kathy Greenlee at our 2010 Summit, "Families are the core of the system. They always have been. They are both the center and the soul of the system. We need family caregivers - we need them because there is no replacement. You can't make this a commodity. But we also need them economically as a nation, because we can't afford to buy this care from strangers."

### III. UPDATED RECOMMENDATIONS

#### **Recommendation 1: Educate the Public.**

We must educate the public about the critical role family caregivers play in our nation's long-term health care system and the risks associated with serving in that role. Messages must be created to help caregivers self-identify and recognize the importance of seeking assistance in order to provide more effective care while protecting their own health and well-being. Our partners at the Department of Health and Human Services, Centers for Medicare and Medicaid Services, Centers for Disease Control and Prevention, Administration on Aging, Department of Veterans Affairs and others have already contributed significantly to caregiver education. We recommend developing and launching a national outreach and public education campaign built upon the existing body of work. This campaign would be jointly developed and funded by these and other agencies who share the goals of helping family caregivers recognize the need for and locate assistance. The campaign would also emphasize how individuals, communities, employers, and faith communities can best offer support to family caregivers.

As part of this outreach, states should be strongly encouraged to adopt the Centers for Disease Control and Prevention's Behavioral Risk Factor Surveillance System's (BRFSS) caregiver module as part of Older Americans Act funding. If caregiver data are routinely collected, problems of public health importance related to caregiving can be detected. Knowledge of existing and emerging health concerns would help craft appropriate messages for caregivers regarding the importance of using effective support services. Additionally, data can be utilized to inform elected officials and government agencies about the financial benefits of providing effective caregiver supports so that individuals can stay in their homes and avoid institutionalization. Data will help make the case for increasing, rather than cutting, funding for caregiver support.

#### **Recommendation 2: Assure Caregivers Receive Evidenced-Based, Effective Support Services that Target Their Identified Needs.**

We believe that evidence-based caregiver programs have the greatest chance of improving the health and well-being of caregivers. National Family Caregiver Support Program funding should ensure that all family caregivers have access to evidence-based caregiver programs that address their specific needs and level of risk. A culturally competent assessment would enable service providers to effectively address individual caregiver's needs. Ideally, a menu of service options based on identified caregiver risk levels would be available through community-based services. Research indicates that caregivers who are supported throughout their caregiving journey are more likely to provide quality, safe care to their loved one, resulting in an improved quality of life for both<sup>2</sup>. Adopting the public health classification system utilized in preventative care<sup>3</sup>, three levels of caregiver support could be offered:

1. **Universal** (available to the entire population of identified caregivers) – All caregivers, upon request, are provided with basic information and skills to assist them in the caregiving role.

2. **Selective** (upon assessment, those caregivers whose risk is determined to be above average for future health and stress-related problems) – Skills training, group support programs, and curriculum based caregiver support programs are made available.

3. **Indicated** (upon assessment, those caregivers determined to be at high levels of risk) – Tailored, multi-component, intensive support programs of longer duration are delivered in the home.

Additionally, professional caregivers working with families must be equipped with the skills necessary to assure an effective and successful collaborative relationship. Skills training for professionals should encompass education on how to assess the needs of family caregivers and effectively partner with them. For those providing specific evidence-based caregiver interventions to families, training in intervention protocols should be mandatory and result in licensing and/or certification in those skills.

### **Recommendation 3: Support the Translation of Evidence-Based Caregiver Programs into Community Settings.**

Millions of dollars have been spent on the development of evidence-based caregiver interventions in clinical settings, yet funding has generally not been available for the critical translation phase. The leap from science to practice cannot occur without funding. Technical assistance is critical to assist community agencies that have varying degrees of expertise in adapting evidence-based caregiver programs with fidelity. Translational funding must include monies for technical assistance through university or community-based networks. These technical assistance networks should tap into local and national expertise in capacity building, evaluation, and systems design. Results from these community-based projects should be rapidly disseminated, and include information about success in serving diverse communities, costs, and cost-effectiveness.

To help facilitate caregiver access to these effective support programs, non-traditional service delivery settings such as hospitals, physician's offices, faith-based community settings and workplaces should be supported with opportunity grants, training and technical assistance to help them build their capacity to provide evidence-based programs to caregivers.

### **Recommendation 4: Advocate for Tax and Public Policy Changes.**

A national goal should target the preservation of family caregiving as a viable option by protecting families from the economic hardship associated with caregiving, and to create incentives for family caregivers to increase their skill level to provide higher-quality care. The Caregiver Assistance and Relief Effort Act of 2007 (S. 2121)<sup>4</sup> and the Social Security Caregiver Credit Act of 2009 (H.R. 769)<sup>5</sup> were both written and introduced; yet neither became law. We recommend that the Internal Revenue Code allow caregivers a tax credit for family members with long-term care needs, provide a tax deduction for long-term care insurance premiums, and apply certain consumer protection provisions to long-term care insurance contracts. Additionally, caregivers should be

allowed to have a specified amount of time (3 to 4 years) count as covered employment, assign a wage to that time, exclude a limited number of caregiving years from the benefit calculation so that earnings are averaged over fewer years, or supplement caregivers' retired worker benefits directly, in proportion to the time taken out of the workforce for caregiving. Advocacy efforts should target supporting these or similar ideas to ensure positive change for family caregivers.

To forestall caregivers leaving the workforce, there should be a policy mandate for flexible work arrangements wherever feasible. Incentives for family caregivers to participate in evidence-based programs that increase their skills and knowledge should be created and tying tax credits to caregiver participation in such programs should be strongly considered.

### **Recommendation 5: Target Investments that Lead To Sustainable Funding.**

As sizeable investments have been made to develop effective caregiver support programs, sustainability of these efforts must be ensured. Mrs. Carter, the U. S. Department of Health & Human Services, and many others, have consistently urged that funding should be continued and indeed increased for the National Family Caregiver Support Program. This would enable expansion of successful evidence based programs, such as the Alzheimer's Disease Supportive Services Program and the Lifespan Respite Care Program. When pilot programs end, those showing positive outcomes for caregivers along with cost effectiveness data should have additional funding streams already identified to ensure their continuance. In addition to National Family Caregiver Support Program funding, Title IIID monies should be considered as a potential funding source. These funds are intended for promoting good health and preventing disease. Supporting family caregivers certainly falls within this objective. Medicaid home and community-based waiver programs should be expanded to allow for maximum flexibility to support family caregivers with "wrap-around" services and supports that achieve cost-effectiveness. The Centers for Medicare and Medicaid Services, as well as private insurance companies, should look at options to include caregiver support services as reimbursable benefits to families. There exists great opportunity for private and public sectors to partner to improve care and reduce the negative effects of caregiving on both families and the workforce.

### **Recommendation 6: Provide Leadership for Coordination of Efforts.**

In order to successfully implement the previous recommendations, there must be top-level direction that promotes integrated planning and action. Creation of a National Quality Caregiving Task Force would increase the efficiency and speed the development of this proposed system, minimize conflicts and duplication of efforts, and assure accountability for outcomes. Ideally initiated in the Office of the President with shared leadership between the Secretary of Health & Human Services, the Secretary of Labor, and the Secretary of Veterans Affairs, the task force should include government and private sector leaders and be adequately staffed. Specific activities to be undertaken by this Task Force should include: (1) developing a work plan with priority goals and target achievement dates that focus on communicating 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 overall healthcare reform; (2) formalizing and defining agency-specific roles in the evidence-based program product/service development “pipeline” and creating a coordinating body to guide development of evidence-based programs for caregivers from basic research to implementation and sustainability in the community; (3) defining responsibilities of national, state, and local entities in carrying out the initiative; (4) identifying all related initiatives and their relevance to the current effort; and (5) developing 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.

#### **IV. CONCLUSION**

Heightened awareness of caregiving issues has occurred and potential solutions have been discussed at both the state and national level, including testimony by Assistant Secretary for Aging Kathy Greenlee and Former First Lady Rosalynn Carter before the Senate Special Committee on Aging<sup>6</sup>. There has also been an increase in collaborative partnerships at Federal, state and local levels to address problems in the system, resulting in procedural changes such as new encouragement to capture cost data for pilot studies of evidence-based caregiving programs.

There remains much work to be done. Without the unparalleled contributions of family caregivers, our formal healthcare system in the United States would be completely bankrupt. Failure to provide effective supports to this often-unacknowledged workforce will result in extremely negative consequences for both caregivers and care recipients. The consequences for family caregivers will include declining health and reduced financial security; for care receivers, the consequences will include increased rates of institutionalization, higher risks of abuse and neglect, and decreased quality of life. In addition, there will be broader consequences for our healthcare system including skyrocketing cost increases for long-term care management. We cannot afford to sit idly by and allow this to happen.

RCI hopes that you will join us in helping move these recommendations forward. Get involved at whatever level you can. Help provide a voice for caregivers who need more effective supports. It is critical for us to create momentum and focus to address family caregiver issues as part of overall healthcare reform in our country.

#### **V. ACKNOWLEDGEMENTS**

Since 2001, RCI has funded supportive programs for family caregivers including multi-state demonstration projects that have focused on the integration and translation of evidence-based programs for family caregivers. We would like to thank Rick Martinez, M.D., Director of Corporate Contributions and Community Relations at Johnson & Johnson, for his many years of support to the RCI. We also thank the RCI Board and Staff Members who willingly dedicated their time, energy, and expertise to this project. Lastly, RCI acknowledges the feedback and contributions of all of its partners in the Federal Government, the State of Georgia, various university-based researchers and community agencies across the country, and all others who have a shared goal of increasing the availability of effective caregiver supports to enhance the quality of care and quality of life for families.

## VI. TIMELINE

10/19/10 - RCI Annual Summit highlighting the release of its position paper “Averting the Caregiving Crisis: Why We Must Act Now” featured Kathy Greenlee, Assistant Secretary for Aging, Administration on Aging, as the keynote presenter.

11/17/10 – RCI Professional Development Webinar: The Care Consultation Program: Our implementation experiences, successes, and challenges - David Bass, PhD, Vice President for Research and Director of the Margaret Blenkner Research Institute of Benjamin Rose Institute.

11/19/10 – RCI held briefings on its recommendations at the Administration on Aging, the Center for Medicaid and Medicare, and the Office on Disability in Washington, DC.

11/23/10 – Huffington Post Blog posting by RCI collaborators Dr. Laura Gitlin, Director, Center for Innovative Care in Aging, John Hopkins University School of Nursing; and Dr. Mary Mittelman, Research Professor, Department of Psychiatry, NYU Langone Medical Center.

12/1/10 – New Public Service Announcement about the importance of caregiving was released featuring former First Lady Rosalynn Carter and Actress Patricia Bethune.

12/5/10 - Mrs. Carter contributed an essay on the caregiving crisis to “The Shriver Report – A Woman’s Nation Takes on Alzheimer’s”, a study by Maria Shriver and the Alzheimer’s Association.

12/8/10 – RCI Professional Development Webinar: The Importance of Cultural Adaptation in Implementing Evidence-Based Programs for Caregivers - Dolores Gallagher-Thompson, PhD, Professor (Research) of Psychiatry and Behavioral Science, Stanford Center on Longevity, Stanford University.

12/15/10 – RCI Professional Development Webinar: Implementing the FOCUS Program for Cancer Caregivers in a Community-Based Setting - Laurel Northouse, PhD, Mary Lou Willard French Professor of Nursing, University of Michigan.

1/21/11 – RCI convened a follow-up meeting held at the Administration on Aging; representatives from Centers for Medicaid and Medicare and the Department of Veterans Affairs also participated.

3/23/11 - Dr. Elena Andresen presented RCI’s recommendations at the Annual Conference of the Behavioral Risk Factor Surveillance System (BFRSS) in Atlanta, Georgia.

4/26/11 - Representatives from the Administration on Aging, Centers for Medicaid and Medicare Services, and the Department of Veterans Affairs provided updates on the work of the National Quality Caregiving Task Force at RCI’s full-day session at the Aging in America Conference sponsored by the American Society on Aging in San Francisco, CA.

5/26/11 – Mrs. Carter and Assistant Secretary for Aging Kathy Greenlee testified before the Senate Special Committee on Aging.

8/5/2011 - RCI conducted a panel presentation at the 2011 Convention of the American Psychological Association in Washington, DC.

9/14/11 – RCI presented on its 12 Recommendations at the 2011 National Conference of the State Units on Aging and Disability (NASUAD) in Washington, DC.

10/5-10/7/11 – RCI hosted its 2011 National Summit & Training Institute at Georgia Southwestern State University in Americus, GA. Hilda Solis, Secretary of Labor; Carolyn Colvin, Deputy Commissioner for Social Security; and Ann Widger, Director, External Affairs for the Department of Health and Human Services addressed the role of their agencies in addressing the caregiver crisis.

2/07/2012 – The Obama Administration makes an additional \$50 million available for cutting-edge Alzheimer’s research and \$26 million available for caregiver support, provider education, public awareness and improvements in data infrastructure.

2/10/12 – RCI invited to participate in “An America Built to Last: White House Community Partnership Summit” in Atlanta, GA.

2/13/12 – Behavioral Risk Factor Surveillance System Update: Additional 10 states commit to conducting cognitive impairment and caregiver surveillance in 2012. Since inception in 2005, 24 states have used the module to capture caregiving data.

Additionally:

RCI implemented three evidence-based, culturally sensitive caregiver programs across the state of Georgia: Georgia REACH, the Georgia Family Support Program (NYUCI) and Care Consultation.

RCI/J&J funded the implementation of 5 evidence-based, culturally sensitive caregiver programs across the U. S.: REACH-OUT in San Diego, CA; NYUCI in Las Vegas, NV; Skills2Care in St. Augustine, FL; FOCUS in Ann Arbor, MI; and Care Consultation in Cleveland, OH. RCI also provided technical assistance to these sites.

## VII. UPDATED REFERENCES

1. Rosalynn Carter Institute for Caregiving. *Averting the Caregiving Crisis: Why We Must Act Now*. Americus, GA, 2010. [http://www.rosalynncarter.org/RCI\\_Position\\_Paper100310\\_Final.pdf](http://www.rosalynncarter.org/RCI_Position_Paper100310_Final.pdf)
2. Patient Safety and Quality: An Evidence-Based Handbook for Nurses, Hughes RG, editor. Rockville (MD): [Agency for Healthcare Research and Quality \(US\)](#); 2008 Apr.
3. Gordon, R. (1987), ‘An operational classification of disease prevention’, in Steinberg, J. A. and Silverman, M. M. (eds.) *Preventing Mental Disorders*, Rockville, MD: U. S. Department of Health and Human Services, 1987.
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6. Carter, R. (2011, May 26). Federal Assistance to Older Americans. Video posted to: <http://www.c-spanvideo.org/program/AmericansR>