

# AVERTING THE CAREGIVING CRISIS

*Why We Must Act Now*



**ROSALYNN CARTER INSTITUTE FOR CAREGIVING**

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## **TABLE OF CONTENTS**

	<u>Page</u>
<b>I. PROLOGUE</b> .....	4
<b>II. EXECUTIVE SUMMARY</b> .....	5
<b>III. THE EMERGING CAREGIVER CRISIS</b> .....	9
A. Who Are Family Caregivers: An At-A-Glance Look .....	9
B. What Do Family Caregivers Do: An Overview of Activities .....	9
C. Why Are Family Members Invaluable but Neglected Partners in the Healthcare Paradigm.....	10
1. Escalating Need for Family Caregiver Services .....	10
i. Aging Demographic, Increased Longevity and the Growing Burden of Chronic Illnesses.....	10
ii. Overburdened Formal Healthcare System .....	11
2. Recognizing the Unparallel Contributions of Family Caregivers .....	11
3. The Plight of Family Caregivers: Impact of Caregiving on the Caregiver’s Health and Quality of Life .....	12
D. When Should We Act: Averting the Family Caregiver Crisis Now .....	13
<b>IV. RE-ENVISIONING SUPPORT FOR FAMILY CAREGIVERS</b> .....	13
A. The Unmet Needs of Family Caregivers.....	13
B. Strategies for Addressing the Needs of Family Caregivers .....	14
1. Implementing Evidence-Based Programs .....	14
2. Lessons Learned from Evidence-Based Programs .....	15
<b>V. TWELVE RECOMMENDED ACTIONS FOR IMPLEMENTING A NATIONAL CAREGIVING INITIATIVE</b> .....	16
A. Research and Development.....	17
Recommendation 1: Leadership and Coordination.....	17
Recommendation 2: Monitor Caregiver Health.....	17
Recommendation 3: Outreach and Public Education.....	17
Recommendation 4: Professional Development .....	18
Recommendation 5: Accelerate Research and Development .....	18
B. System Design .....	18
Recommendation 6: Establish Services in Natural Settings to Improve Access .....	18
Recommendation 7: Make Professional Assessment and Triage Available to All Caregivers.....	18
Recommendation 8: Assure Caregiver Services are Evidence-Based, Culturally-Sensitive, and Tied to Caregiver Programs.....	18
Recommendation 9: Establish a National Resource Center on Evidence-Based Caregiver Programs.....	19
Recommendation 10: Technical Assistance for Providers.....	19
C. Public and Tax Policy .....	19
Recommendation 11: Tax and Public Policy Changes .....	19
Recommendation 12: Targeted Investments and Sustainable Funding .....	20

**TABLE OF CONTENTS**

	<u>Page</u>
<b>VI. FUTURE DIRECTIONS .....</b>	20
<b>VII. ACKNOWLEDGEMENTS .....</b>	21
<b>VIII. REFERENCES .....</b>	22

## I. PROLOGUE

The Rosalynn Carter Institute for Caregiving (RCI) was established in 1987 at Georgia Southwestern State University (GSW) in Americus, Georgia. 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. At its core, the mission of RCI is to foster local, state and national partnerships committed to building quality long-term, home and community-based services. RCI's focus includes supporting caregivers and their loved ones who are coping with chronic illnesses and disabilities across the lifespan.

This report is based on RCI's more than three years of intensive study of the caregiving process, evidence-based programs to help family caregivers, and current translational strategies for making effective programs widely available to caregivers. Our efforts began in 2007, with funding from one of our corporate partners, Johnson & Johnson. We endeavored to bring together experts in research, program planning, and policy development in support of family caregivers. A national summit was convened with over 300 leading caregiver researchers and agency leaders from around the country to examine the evidence-base for caregiver support interventions and the extent to which it was being applied in practice. One of the summit's key findings was that although many interventions with proven positive outcomes for caregivers have already been developed, most have not been translated into programs at the community level. Without these supports, caregivers will experience significantly increased burden as well as psychological and physical ill health, resulting in an increased likelihood of premature institutionalization of the care recipient and additional disability for the caregivers themselves.

The consensus reached among summit participants was that our nation is in need of a fundamental shift in how it values and recognizes caregivers. Following the summit, RCI convened six national meetings to share findings across key stakeholders and develop consensus about recommendations for change. Additionally, RCI launched several other key initiatives. The first was the development of a network of community coalitions (CARE-NETS) that provides a forum for addressing the needs of caregivers in a concerted and coordinated way. The second was embarking on a new venture called the National Quality Care Network (NQCEN) as a vehicle for innovation, information sharing, and stimulating partnerships for action in our communities. The NQCEN is a learning collaborative comprised of community-based demonstration sites and program developers working to implement, disseminate, and maintain effective translational strategies. Ultimately, the NQCEN aims to create supportive policies and secure long-term, sustainable funding for the integration of caregiver programs within community systems. The third initiative was the distribution of more than \$1 million in grants to the NQCEN to support the timely dissemination and wide accessibility of effective caregiver interventions. The fourth initiative is RCI's CARE Report that will share the translational experiences of providers who have successfully integrated evidence-based programs for caregivers into their respective healthcare settings.

RCI strongly believes that a **National Caregiving Initiative** is necessary to provide an umbrella for disparate caregiving efforts across Federal, state, and local agencies, the private sector, voluntary health organizations, corporations, and private philanthropy. To avert the caregiving crisis, it is critical for us to begin the dialogue that will create momentum and focus to address family caregiver issues as part of overall healthcare reform. The recommendations delineated in this paper represent RCI's effort to launch this national dialogue.

## II. EXECUTIVE SUMMARY

While there is no universally agreed-upon definition, the terms “informal caregiver,” “unpaid caregiver,” and “family caregiver” are often used interchangeably to refer to the estimated 65.7 million Americans who have provided unpaid assistance to an adult or child with functional and/or cognitive limitations. These dedicated caregivers provide between 80 to 90% of the long-term care provided at home to over nine million elderly or disabled individuals.

Today’s caregivers are responsible for providing a wide range of assistance to their loved ones, often involving complex nursing care (e.g., respiratory care, medication management and dispensing, medical monitoring), cognitive support (e.g., management of delirium or agitation, ensuring safety), and care management, both in home (e.g., supervision) and out of home (e.g., arranging medical care appointments). Although the amount of weekly care provided by family caregivers varies greatly, reports have consistently documented that a “typical” caregiver provides an average of 21 hours of care per week. For care recipients who require extensive dependent care, such as persons with Alzheimer’s disease, the estimated 9.8 million caregivers provide 8.4 billion hours of care each year.

Estimates have consistently projected that the need for family caregiving in the United States (U.S.) will escalate significantly in the coming decades. This increase in demand can be attributed to several key trends, including an aging demographic, increased longevity, the growing burden of chronic illnesses, and an overburdened formal healthcare system. Not only are more Americans living longer but the proportion of older adults in the U.S. population (i.e., 65 years or older) is growing rapidly. There are 35 million older adults in the U.S. today. By 2030, when all of the baby boomers have reached age 65, the projected number of older Americans is expected to reach 71 million, or roughly 20 percent (1 in 5) of the U.S. population. Approximately 6,000,000 adults over age 65 need daily assistance to live and that number is expected to double by 2030. About 80 percent of older adults have at least one chronic condition such as arthritis, hypertension, heart disease, diabetes, and respiratory disorders. Over 50 percent of older adults have at least two chronic conditions. Although chronic conditions can often be controlled or alleviated with medications, healthy lifestyle choices (e.g., smoking cessation, physical activity and good nutrition), and other therapies, many chronically ill adults become frail or incapacitated, resulting in an increased need for dependent care.

Experts have estimated that the economic value of services provided by family caregivers is in excess of \$375 billion annually. This figure is (1) as much as the total expenditures for the Medicare program (\$342 billion in 2005); (2) more than total spending for Medicaid, including both federal and state contributions for medical and long-term care (\$300 billion in 2005); (3) far more than the total spending (public and private funds) for nursing home and home healthcare in the U. S. (\$206.6 billion in 2005); and (4) more than four times the total amount spent on formal (paid) home care services (\$76.8 billion in 2005).

Although we know that many caregivers experience no adverse health effects related to caregiving, 20% to 30% fare very poorly. These caregivers are often more prone to depression, grief, fatigue, and physical health problems, all of which may have roots in stress, exhaustion, and self-neglect. Increased use of alcohol, smoking and other drugs are not uncommon, as are poor health behaviors such as inadequate diet, exercise, and sleep. Additional risks are a suppressed immune system leading to frequent infection and an increased risk of heart disease, diabetes, stroke and premature mortality. Caregivers experience chronic conditions at nearly twice the rate of noncaregivers. Although individuals who take on the caregiving role are generally physically healthier than those who do not, evidence suggests that at least one in ten caregivers report caregiving as the cause of their physical health’s deterioration.

It is imperative that we recognize that the confluence of our overburdened healthcare system with an aging population has created both a moral and economic imperative to fix the broken pipeline between caregiving research and practice in this country. Should we fail to act now, the consequences for care recipients will include increased rates of institutionalization, higher risks of abuse and neglect, and decreased quality of life. For family caregivers, the consequences will involve declining health and quality of life as well as reduced financial security. The overall impact on our healthcare system will be to bear an unparalleled cost burden for expensive long-term care management with less capacity due to lack of adequate resources.

We can avert this oncoming caregiving crisis by re-envisioning support for family caregivers. In order to do so, we must address the most pressing unmet needs of family caregivers, including a lack of adequate training, additional respite care, and greater access to support programs. To address these unmet needs, RCI strongly advocates that the following twelve imperative actions across three focus areas, including (a) Research and Development, (b) System Design, and (c) Public and Tax Policy, are adopted through a **National Caregiving Initiative**:

## **A. RESEARCH AND DEVELOPMENT**

**Recommendation 1: Leadership and Coordination.** There must be top-level direction that promotes integrated planning and action in order to increase the efficiency and speed of development of this proposed system, to minimize conflicts and duplication of efforts, and to assure accountability for outcomes. A National Quality Caregiving Task Force should be created to oversee this initiative in the President's Office with the possibility of shared leadership between the Secretary of Health & Human Services and the Secretary of Veterans Affairs. The group 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 the development and subsequent evaluation 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; (5) developing public communication and liaison strategies to assure public awareness and input; and (6) facilitating public-private partnerships, the involvement of faith communities, corporations and voluntary associations, in the work.

**Recommendation 2: Monitor Caregiver Health.** We need to establish state-level systems to monitor caregiver health by requiring states to adopt the Behavioral Risk Factor Surveillance System's (BRFSS) caregiver module as part of Older Americans Act funding. If states are required to collect BRFSS data every two years, they will be able to identify sub-populations of caregivers with unmet needs, provide much needed information on tracking trends in caregiver health, better allocate Older Americans Act funding and other resources, and begin to develop programs that are in line with strategic priorities.

**Recommendation 3: Outreach and Public Education.** We need to reach caregivers at risk of ill health due to high burden. We must educate the public about the critical and often difficult role of caregiving and empower communities to assist caregivers in their work. A national outreach and public education campaign

should be funded by the Department of Health and Human Services using resources of the Centers for Medicare and Medicaid Services, Centers for Disease Control and Prevention, and Administration on Aging.

**Recommendation 4: Professional Development.** It is imperative that persons who actively work with family caregivers (e.g., professionals, paraprofessionals and volunteers), be equipped with the skills necessary to assure an effective and successful working relationship. Skills training should encompass implementation protocols specific to culturally-sensitive, evidence-based programs for family caregivers. The provision of licensing and certification in evidence-based program implementation should be made affordable and widely available.

**Recommendation 5: Accelerate Research and Development.** Knowledge about the effectiveness of different systems of caregiver support should be rapidly generated, and include information about success in serving diverse communities, costs, and cost-effectiveness. Multi-site demonstration projects should be initiated to test the effectiveness of different configurations of evidence-based programs within the Center for Innovation at the Centers for Medicare and Medicaid Services. All future caregiver demonstration projects should be encouraged to examine and publish comparable cost-effectiveness and cost-efficiency data.

## **B. SYSTEM DESIGN**

**Recommendation 6: Establish Services in Natural Settings to Improve Access.** We need to facilitate access to support programs for caregivers. Caregivers are more likely to access needed services in the course of their normal activities and responsibilities, such as while visiting their doctor or taking their loved one to the doctor, upon hospital admission and discharge, through the faith community, and while at work. We recommend providing opportunity grants, training and technical assistance to help diverse agencies and organizations build capacity to provide evidence-based programs for caregivers.

**Recommendation 7: Make Professional Assessment and Triage Available to All Caregivers.** Caregivers should be provided access to skilled professionals who can routinely perform culturally competent caregiver risk and needs assessments. Assessments should result in a care plan specifically related to the level of risk identified and should contain specific and measurable outcomes. Routine assessments already being conducted by healthcare providers (hospital discharge, home care, outpatient rehabilitation) or government-funded (Area Agencies on Aging) should be revised to include a caregiver component. Moreover, government and other third-party payers should reimburse healthcare providers for conducting a caregiver assessment.

**Recommendation 8: Assure Caregiver Services are Evidence-Based, Culturally-Sensitive, and Tied to Caregiver Programs.** A standard of care within the aging network should be adopted that offers a menu of service options and interventions of increasing intensity to address the varying needs of caregivers based on their levels of risk. One approach would be to revamp the National Family Caregiver Support Program to ensure the provision of evidence-based programs.

**Recommendation 9: Establish a National Resource Center on Evidence-Based Caregiver Programs.** Information on implementing and translating evidence-based programs for caregivers should be centralized to support widespread adoption across communities. A National Resource Center should be authorized and funded to track successful implementation and translation activities and assure that guidance and training processes are in place. A special focus at the National Resource Center should be placed on culturally appropriate programming.

**Recommendation 10: Technical Assistance for Providers.** Affordable and culturally-sensitive technical assistance networks should be created to ensure widespread and effective implementation of evidence-based programs for caregivers. These networks could be university or community-based that tap into local and national expertise in capacity building, evaluation, and systems design.

### C. PUBLIC AND TAX POLICY

**Recommendation 11: Tax and Public Policy Changes.** It should be a national goal to preserve family caregiving as a viable option by protecting families from economic hardship associated with caregiving, and to create incentives for family caregivers to increase their skill level to provide sustained higher-quality care. A caregiver credit should be designed under the Social Security System as suggested by the General Accounting Office. Such a credit would: (1) allow a specified amount of caregiving time (3 to 4 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, in proportion to the time they took time out of the workforce for caregiving. Tax credits should be made available to family caregivers, such as those proposed in the CARE Act in the 110th Congress and currently under consideration in several states (Caregiver Assistance and Relief Act, 2007). To combat caregivers leaving the workforce, there should be a policy mandate for flexible work arrangements wherever feasible. Incentives should be created for family caregivers to participate in evidence-based programs that increase their skills and knowledge. Tying tax credits to caregiver participation in such programs also should be strongly considered. Additionally, government entities and other payors should provide vouchers for care recipients to pay minimum wage to family caregivers upon completion of required training.

**Recommendation 12: Targeted Investments and Sustainable Funding.** It should be a national priority to support the development of an essential infrastructure to serve family caregivers, and to promote adoption, implementation, and maintenance of the most effective programs. Investment should be made in an expanded nationwide caregiver support system that makes evidence-based programs for caregivers widely available and easily accessible. Funding for the Alzheimer's Disease Supportive Services Program of the Administration on Aging should be expanded, and additional funding should be provided for the National Family Caregiver Support Program for program expansion. 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. Additionally, after grant funding by the Administration on Aging ends for successful demonstrations, the Centers for Medicare and Medicaid Services should continue funding these programs through a waiver or other mechanism. Moreover, the "CLASS Act" (Community Living Assistance Services and Supports Act), a provision under the enacted Patient Protection and Affordable Care Act, should be quickly implemented to support the development of a new national long-term care insurance program, with inclusion of caregiver support, education and training as components of plan benefits.

As RCI looks to the future, to successfully avert the caregiving crisis facing our nation, it is our position that all sectors of society must come together in new ways to develop effective and timely solutions. The broad and coordinated response outlined in RCI's **National Caregiving Initiative** will require a fundamental shift in how we, as a country, recognize the invaluable contributions of family caregivers as the true backbone of our nation's long-term care system.



### III. THE EMERGING CAREGIVER CRISIS

#### A. Who Are Family Caregivers: An At-A-Glance Look

While there is no universally agreed-upon definition, the terms “informal caregiver,” “unpaid caregiver,” and “family caregiver” are often used interchangeably to refer to adults who provide assistance to relatives, neighbors or family members who are frail, ill or disabled.<sup>1</sup> Today, an estimated 65.7 million Americans serve as unpaid family caregivers<sup>2</sup>, providing approximately 80 to 90% of the long-term care at home to over nine million elderly or disabled individuals.<sup>3-6</sup>

Although the majority of family caregivers are women (66%), the proportion of men serving as caregivers is growing.<sup>2</sup> While most family caregivers are spouses of care recipients<sup>2</sup>, others may be the care recipient’s child, sibling, grandchild, or close friend. Caregivers are culturally diverse, representing a milieu of racial and ethnic backgrounds including non-Hispanic White (72%), African-American (13%), Hispanic (2%) and Asian-American (2%).<sup>2</sup> With regards to education level, four in ten caregivers are college graduates (43%), although three in ten have had a high school level education or less (29%).<sup>2</sup>

A “typical” family caregiver is an average age of 49.2 years and has served as a caregiver for about 4.6 years.<sup>2</sup> An estimated 13% of caregivers caring for older adults are themselves aged 65 or older.<sup>7</sup> Over 73% of caregivers report being employed while providing care to a loved one, 50% of whom have had to make work-related adjustment (e.g., taking frequent time off, reducing to part-time work hours, or taking a leave of absence) in order to be a caregiver.<sup>2,8</sup> Employed caregivers are evenly split between blue- and white-collar workers,<sup>9</sup> with four in ten caregivers reporting a household income of \$50,000 or less.<sup>2</sup>

#### B. What Do Family Caregivers Do: An Overview of Activities

Family caregivers are responsible for providing a wide range of assistance to their loved ones. An estimated 56% of caregivers provide hands-on assistance with one or more activities of daily living (ADLs), such as eating, bathing, dressing, toileting, and transferring.<sup>2</sup> In addition, caregivers often help the care recipient with instrumental activities of daily living (IADLs) including transportation, housework, grocery shopping, meal preparation, managing finances, and performing medical therapies or treatments. On average, family caregivers help with at least two ADLs and four IADLs.<sup>2</sup>

When defining the work of caregiving in the context of ADLs and IADLs, it is important to acknowledge that such tasks are not simple in nature. Rather, they often require complex nursing skills (e.g., respiratory care, medication management and dispensing, medical monitoring), cognitive support (e.g., management of delirium or agitation, ensuring safety), and care management, both in home (e.g., supervision) and out of home (e.g., arranging medical care appointments). In fact, a growing number of researchers and advocates in the field of caregiving have expressed that ADLs and IADLs fail to adequately capture the true work of family caregivers by ignoring the context of caregiving.<sup>10</sup> To address this gap, researchers have proposed that the following additional contextual features of caregiving be considered when assessing a caregiver’s true workload: (1) *frequency of care provision* – whether care is required rarely, frequently but with predictability, or frequently in unpredictable ways; (2) *caregiver’s proximity to the care recipient* – whether the caregiver resides in the same household as the care recipient, or within a close distance, or whether they are distant caregivers; (3) *effort* – how much effort is required to provide care, from

persuading to complete guidance and control; and (4) *participation level of the care recipient* – whether it is active, passive or resistant.<sup>11</sup>

Although the amount of weekly care provided by family caregivers varies greatly, reports have consistently documented that most caregivers provide an average of 21 hours of care per week.<sup>2,12,13</sup> For care recipients who require extensive dependent care, such as persons suffering from Alzheimer’s disease, an estimated 12.5 billion hours of care are delivered each year by approximately 10.9 million caregivers.<sup>14</sup> While most caregivers take on the brunt of caregiving themselves, many require additional hands-on support to meet the daily needs of the care recipient. Reports documenting the prevalence of secondary support sources indicate that 66% of family caregivers say at least one other unpaid caregiver helps their care recipient and another 35% of caregivers rely on paid help from aides, housekeepers, or others to help their care recipient.<sup>2</sup>

Regardless of the approach used to capture the extent and activities of caregiving, it is irrefutable that family caregivers constitute one of the most pervasive sources of support for people who need assistance due to frailty, illness or disability. Simply put, the enormous and valuable contributions of family caregivers is unquestionably helping to sustain our nation’s long-term care system.<sup>15</sup>

## **C. Why Are Family Members Invaluable but Neglected Partners in the Healthcare Paradigm**

### **1. Escalating Need for Family Caregiver Services**

Estimates have consistently projected that the need for family caregiving in the U.S. will escalate significantly in the coming decades.<sup>4,16</sup> This increase in demand can be attributed to several key trends, including an aging demographic, increased longevity, the growing burden of chronic illnesses, and an overburdened formal healthcare system.<sup>2,4,16</sup>

#### **i. Aging Demographic, Increased Longevity and the Growing Burden of Chronic Illnesses**

Not only are more Americans living longer but the proportion of older adults in the U.S. population (i.e., 65 years or older) is growing rapidly.<sup>16</sup> Today, there are 35 million older adults in the U.S.<sup>17</sup> By 2030, when all of the baby boomers have reached age 65, the projected number of older Americans is expected to reach 71 million, or roughly 20 percent (1 in 5) of the U.S. population<sup>4</sup>.

Approximately 6,000,000 adults over age 65 need assistance with activities of daily living, a number expected to double by 2030.<sup>4,16</sup> Among the U.S. population, there has been an increase in the number of individuals with a reported disability from 44.1 million in 1999 to 47.5 million in 2005, comprising 21.8% of all Americans.<sup>16</sup> Over one-third of those reporting a disability are from the aging baby boomers.<sup>16</sup> It has been speculated that these higher rates of disability may be due to the rapid population growth among African-American and Hispanic communities, where higher proportions of conditions such as obesity and diabetes adversely impact functional abilities and health status.<sup>16,18</sup>

About 80% of older Americans have at least one chronic condition such as arthritis, hypertension, heart disease, diabetes, and respiratory disorders.<sup>18,19</sup> Over 50% of older adults have at least two chronic

conditions to manage. While chronic conditions can often be controlled or alleviated with medications, healthy lifestyle choices (e.g., smoking cessation, physical activity and good nutrition), and other therapies, many chronically ill adults become frail or incapacitated, resulting in an increased need for dependent care.<sup>4,16,20</sup>

## ii. Overburdened Formal Healthcare System

With an aging population, an increase in disability rates, and the pressing need to effectively manage care for Americans living longer with chronic illnesses, there are growing concerns about our formal healthcare system's capacity to meet the needs of the public. One of the primary concerns is the lack of sufficient numbers of healthcare professionals needed to render care. By 2030, the U.S. will need an additional 3.5 million formal healthcare providers, a 35% increase from current levels, just to maintain the current ratio of providers to the total population.<sup>4</sup>

Among healthcare professionals, nurses are at the forefront of providing long-term care at both institutional settings and the care recipient's home. Since the late 1990s, our nation has faced a shortage of qualified nurses.<sup>21</sup> Today, there are nearly 20,000 nurse vacancies in long-term care settings.<sup>22</sup> The current nursing shortage is projected to affect healthcare until 2020.<sup>23</sup> Unlike past shortages, this one results from a broad set of factors, including an aging population, fewer young workers entering the healthcare workforce, an aging nursing workforce, increased employment options for women, and increased dissatisfaction with the workplace.<sup>23-25</sup>

Another resource limitation causing concern is institutional capacity. According to national surveys, the overall occupancy rate for the 1.7 million beds across nursing homes is about 86%, with wait lists being common place at many institutions given the average length of stay is 835 days for a typical nursing home resident.<sup>26,27</sup> In addition to nursing home capacity limitations, home health agencies are projected to experience significant challenges in meeting the needs of care recipients. Recent reports from the Visiting Nurse Agencies (VNAs) indicated a 10% vacancy rate for registered nurse positions, and 59% of VNAs report that they are forced to decline patient referrals weekly due to staffing limitations.<sup>28</sup>

## 2. Recognizing the Unparallel Contributions of Family Caregivers

Healthcare expenditures in the U.S. are currently about 18% of the Gross Domestic Product (GDP), and this share is projected to rise sharply.<sup>29</sup> The total amount our nation spends on long-term care services alone is about \$206.6 billion.<sup>30</sup> If healthcare costs continue to grow at historical rates, the share of GDP devoted to healthcare in the U.S. is projected to reach 34% by 2040.<sup>31</sup> At present, the U.S. spends about \$7,400 per person on healthcare each year. Adults aged 65 and older have the highest healthcare spending, averaging \$8,776 per person in 2006. Experts estimate that chronic diseases are responsible for 83% of all healthcare spending.<sup>32</sup> Approximately 96% of Medicare spending and 83% of Medicaid spending is for people with chronic conditions.<sup>32</sup> Healthcare spending for a person with one chronic condition, on average, is two and a half times greater than spending for someone without any chronic conditions. The average annual healthcare coverage cost for people with a chronic condition is \$6,032, five times higher than for people without such a condition.<sup>33</sup> Nationwide, the median nursing home cost is \$74,000 a year, but costs can easily reach \$100,000 a year in some parts of the country. Assisted living facilities average \$36,000 per year, and home health services average \$29 per hour.<sup>34</sup>

Without the unparalleled contributions of family caregivers, our formal healthcare system would be completely bankrupt. The unpaid services provided by family caregivers have a substantial economic value that vastly exceeds the value of paid care. The estimated unpaid contributions of family caregiving was valued at about \$375 billion (2007 dollars), up from an estimated \$350 billion (2006 dollars).<sup>35</sup> A few benchmarks can help put this figure in meaningful context. The estimated \$375 billion is:

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

Although family caregivers are saving our economy billions annually, caregiving can be financially devastating. Caregivers may be forced to dramatically cut their work hours or quit their jobs in order to continue to provide care to their loved ones, resulting in not only lost wages for caregivers but also lost Social Security benefits. Over their lifetime, it is estimated that a family caregiver will experience about \$659,000 in lost wages, pensions, earned interest, employer-matched retirement savings and Social Security benefits.<sup>19,36</sup> In addition, many family caregivers struggle financially as they spend their own money for home modifications, medications, groceries, and other expenses.<sup>2,8</sup> Recent studies have documented that about half of caregivers contribute financially to their loved ones, spending an average of \$200 per month (\$2,400 per year). Caregivers who have the greatest level of caregiving burden report spending approximately \$324 per month (\$3,888 per year) out of pocket.<sup>12</sup>

### **3. The Plight of Family Caregivers: Impact of Caregiving on the Caregiver's Health and Quality of Life**

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. In addition, the type of assistance that caregivers provide has changed considerably. Today's care is of longer duration, often lasting five or more years. Caregiving is more technically and physically demanding, requiring performance of tasks that only skilled nurses performed just a decade ago.<sup>2</sup> Care recipients are often released from hospitals "quicker and sicker", resulting in family members being responsible for skilled nursing care with minimal preparation or training.<sup>37,38</sup> Thus, the "home hospital" has become a reality. These circumstances create additional physical and emotional stress for caregivers, thereby adversely impacting their overall health, well-being and quality of life.

The impact of caregiving on the caregiver has become the subject of heightened concern. Research studies have repeatedly shown that family caregivers have an increased risk of experiencing depression, grief, fatigue, and physical health problems secondary to exhaustion and self-neglect.<sup>2,11,39</sup> In general, women caregivers report more stress and suffer from greater morbidity as a result of caregiving than men caregivers.<sup>40,41</sup> Moreover, the increased use of alcohol, smoking and other drugs are common as coping strategies among caregivers, as is poor health behaviors such as inadequate diet, exercise, and sleep.<sup>42</sup>

Additional health risks associated with caregiving include a suppressed immune system leading to frequent infections, and an increased risk of heart disease, diabetes, stroke and other chronic conditions.<sup>2,16,19,43,44</sup>

The plight of family caregivers has been acknowledged as a critical public health issue because caregiving impacts both the care recipient and the caregiver.<sup>16</sup> To avert caregivers becoming care recipients themselves, the need for supportive action is pressing.<sup>45,46</sup>

## **D. When Should We Act: Averting the Family Caregiver Crisis Now**

It is imperative that we recognize that the confluence of our overburdened healthcare system with an aging population has created both a moral and economic imperative to translate caregiving research into effective community programming in our country. Should we fail to act now, the consequences will be multi-fold for care recipients, family caregivers, and our nation's formal healthcare system.

The inability to successfully support family caregivers will likely have disastrous consequences. The consequences for care recipients will be increased rates of institutionalization, higher risks of abuse and neglect, and decreased quality of life.<sup>38,47-51</sup> The consequences for family caregivers will involve declining health and reduced financial security.<sup>2,16,52</sup> There will also be overall consequences for our healthcare system including an unparalleled cost increases for expensive long-term care management.

With the recent enactment of the Patient Protection and Affordable Care Act (PPACA), our nation has taken a promising step toward recognizing the need for inclusion of family caregivers as valued partners to formal home and community-based service providers.<sup>53</sup> The PPACA emphasizes the importance of care coordination between family and formal caregivers as a means of removing barriers to accessing care. Furthermore, it requires programs to facilitate shared decision-making between patients, their formal health care providers, and their family caregivers. Moreover, the PPACA mandates provisions for family caregiver instruction and training on the management of psychological and behavioral aspects of dementia, communication techniques for working with individuals who have dementia, and proper medication management. Although the impact of the PPACA on addressing the many support needs of family caregivers remains unknown, it is an encouraging component of health care reform legislation.

## **IV. RE-ENVISIONING SUPPORT FOR FAMILY CAREGIVERS**

### **A. The Unmet Needs of Family Caregivers**

As a nation, we must re-envision support for family caregivers if we are to sustain the backbone of our long-term healthcare system. In order to do so, we must address the most pressing unmet needs of family caregivers, including the lack of adequate training, respite, and access to support programs.

Despite home-based medical technologies becoming more widely available, to date little attention has been directed toward identifying, developing, and disseminating the education and training needed to provide care recipients and their caregivers with the skills they need to manage complex technologies and treatment regimens.<sup>52,54-58</sup> Family caregivers often need to perform complex medical tasks such as wound care and coordinate patient care, make decisions and solve problems while they prepare meals, provide assistance with toileting and bathing, and run the household. Difficulties in care provision are frequently compounded if the care recipient has cognitive or neuropsychological symptoms.<sup>37</sup> Today's caregivers not

only face physical and emotional health risks, but many also do not feel prepared with the skills and knowledge they need to provide sustained care for a person with a chronic illness.<sup>37</sup> To be successful in their roles, caregivers require information, access to resources and support to facilitate their role.

Research has consistently shown that family caregivers have concerns in five areas: (1) dealing with change, (2) managing competing responsibilities and stressors, (3) providing a broad spectrum of care, (4) finding and using resources, and (5) addressing emotional and physical responses to care.<sup>59-63</sup> Many studies have documented that these areas of concern remain inadequately addressed.<sup>62,63</sup> Unfortunately, far too often, caregivers report receiving insufficient guidance from their healthcare providers, not knowing how to perform caregiver roles or access and utilize existing resources, and lack of familiarity with the type and amount of care needed.<sup>48,49</sup> As a response, the Institute of Medicine has recommended that family caregivers receive training to improve the care received by older adults and to lessen the strain on these caregivers.<sup>4</sup> Similarly, the American College of Physicians has issued recommendations that physicians develop care plans that are patient- and caregiver-specific and provide information, training, and referrals to support those plans.<sup>61</sup> Office visits and hospitalizations are opportunities for physicians to assess caregiver well-being and listen to their concerns. Physicians may provide appropriate education and social service referrals and identify needs for future patient placement or respite care. When caregivers become skilled in their responsibilities, they are able to acknowledge and accept the changes in their lives and transform their attitudes and experiences into something more positive, even if they do not necessarily like those changes.<sup>48</sup> Although skilled caregivers are still often stressed, they are also able to better balance their personal, family, and caregiving responsibilities.

## **B. Strategies for Addressing the Needs of Family Caregivers**

### **1. Implementing Evidence-Based Programs**

During the past decade, research has led to a better understanding of the processes by which the stresses and demands of caregiving can adversely affect the caregiver's health and lead to nursing home placement for the care recipient. On the basis of this research, substantial headway has been made in developing interventions that result in improved caregiver outcomes. These interventions are multi-dimensional and typically include family and community support groups, respite care, skill training and individual counseling. A growing number of these interventions have undergone rigorous randomized controlled trials to be considered evidence-based programs (EBPs). Collectively, EBPs for family caregivers have been found effective in helping caregivers cope with the demands of caregiving, reducing feelings of burden and stress, improving mental health, increasing satisfaction with social support, enhancing feelings of self-efficacy, successfully managing problem behaviors of care recipients, and in delaying institutionalization of care recipients, and reducing the cost of care.<sup>64-73</sup>

Taken together, the literature highlights the following key attributes as important dimensions of successful EBPs for family caregivers<sup>74</sup>:

1. A heavier “dosage” of treatment over a longer period of time is more effective than shorter, lower dose interventions
2. Periodic caregiver contact with a professional who delivers specific intervention protocols is important in achieving positive outcomes

3. Interventions and care plans must be tailored to the caregiver's specific needs and risk factors with flexibility to meet the changing demands of care
4. The most successful interventions are those that are multi-component including a combination of education, skill building, problem solving training, counseling, direct services and altering the physical environment to address priority needs
5. Rigorous scientific evaluation (i.e., randomized controlled trials) is necessary to test programmatic efficacy
6. Demonstrated results of the intervention (e.g., improved mental health, better quality of life, reduced caregiver burden and strain, delayed nursing home use) have been published in a peer-reviewed scientific journal

Although EBPs have proven effectiveness for family caregivers, little effort has gone into deploying these programs widely in the community. For the most part, EBPs have not been viewed as a vital public health resource to be embedded in the community and made widely available. Instead, they have been viewed as limited efforts offered primarily to those caregivers who seek assistance on their own. To date, none of the EBPs for family caregivers have been integrated into the aging network of services, the National Family Caregiver Program, health and long-term care services, or sustainable funding streams such as health insurance, HMOs, Medicaid and Medicare programs.

RCI's experience indicates many reasons why these EBPs are not being widely implemented. These include a lack of awareness that effective programs exist, inadequate funding to sustain the programs, and a dearth of available and affordable training and technical assistance to implement these programs.

## **2. Lessons Learned from Evidence-Based Programs**

The widespread adoption of EBPs would significantly enhance the overall health and well-being of caregivers, extend community living for many seniors and people with disabilities, and improve the quality of care delivered. Ideally, the process of creating, implementing, and sustaining EBPs for caregivers would be seamless and efficient. However, it is clear that the transition from research to service is very uncoordinated and disenfranchised. As a result, promising research is shelved rather than put into practice at the community level where it could benefit family caregivers and their care recipients.

The collective experiences of RCI's community partners reveal that translational processes involved in successfully implementing, disseminating, and maintaining EBPs for family caregivers are not well understood. We have identified *three key lessons* learned and a series of questions that need to be addressed in order to enhance the timely integration of EBPs across healthcare delivery settings:

1. Interventions that show efficacy in research settings are rarely ready for translation in practice settings without further refinement, modification and development of support materials (e.g., training manuals). Key questions to be answered include:
  - How much "change" is allowable before the integrity of the intervention is compromised?
  - How do we adapt an intervention and maintain its essential programmatic elements?

- How do we develop and design interventions that are more compatible with healthcare delivery systems?
  - Who decides and how?
  - How do we balance program modification and the needs of real-world settings while maintaining treatment fidelity of the program?
2. Agencies, although motivated and in need, are typically not ready to adopt and implement a complex intervention without building additional internal capacity. Key translational tactics that require attention include:
- Changing organizational “culture” to embrace evidence-based programs.
  - Enhancing institutional infrastructure for data collection, fidelity measurement, staff recruitment, supervision and training.
  - Building capacity to deliver a specific intervention by developing expertise; referral, intake and tracking systems; and heightened awareness through public education and outreach campaigns.
  - Developing a common set of programmatic outcomes linked to potential reimbursement streams.
3. Host Systems may not support new service and care provision models without fundamental changes in policies, funding, and thinking. Key translational tactics that require attention include:
- Agency may have capacity to deliver the intervention, but the funding, policies and procedures, hiring restrictions, regulations, etc. of the Host System may be incompatible with integration of new or enhanced service delivery models.
  - Host System and agency goals and priorities may be out of alignment and not permissive of seamless program integration and translation.

A growing body of evidence strongly suggests that the window of opportunity to effectively address the emerging caregiving crisis in our nation is closing quickly. Therefore, business as usual is no longer a viable option.

## **V. TWELVE RECOMMENDED ACTIONS FOR IMPLEMENTING A NATIONAL CAREGIVING INITIATIVE**

To avert the oncoming caregiving crisis, RCI believes that our nation must re-envision support to family caregivers. In order to do so effectively, we must address the most pressing unmet needs of family caregivers, including a lack of adequate training, additional respite care, and greater access to support programs.

RCI strongly advocates for a **National Caregiving Initiative** to provide an umbrella for disparate caregiving efforts within the Federal government level, state agencies, the private sector, voluntary health organizations, corporations, and private philanthropy. As a nation, we must provide a blueprint for building an evidence-based system of support in a timely manner such that focused momentum is created to incorporate family caregiving as a critical component of healthcare reform.



RCI recommends the following twelve imperative actions across three focus areas, including (a) Research and Development, (b) System Design, and (c) Public and Tax Policy, which would collectively serve as the foundation for a **National Caregiving Initiative**:

## **A. Research and Development**

**Recommendation 1: Leadership and Coordination.** There must be top-level direction that promotes integrated planning and action in order to increase the efficiency and speed of development of this proposed system, to minimize conflicts and duplication of efforts, and to assure accountability for outcomes. A National Quality Caregiving Task Force should be created to oversee this initiative in the President’s Office with the possibility of shared leadership between the Secretary of Health & Human Services and the Secretary of Veterans Affairs. The group 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 the development and subsequent evaluation 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; (5) developing public communication and liaison strategies to assure public awareness and input; and (6) facilitating public-private partnerships, the involvement of faith communities, corporations and voluntary associations, in the work.

**Recommendation 2: Monitor Caregiver Health.** We need to establish state-level systems to monitor caregiver health by requiring states 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 states are required to collect BRFSS data every two years, they will be able to identify sub-populations of caregivers with unmet needs, provide much needed information on tracking trends in caregiver health, better allocate Older Americans Act funding and other resources, and begin to develop programs that are in line with strategic priorities. Through monitoring at regular intervals, we can ensure that problems of public health importance related to caregiving are detected in order to identify existing and emerging health concerns and target resources towards their prevention and treatment.

**Recommendation 3: Outreach and Public Education.** We need to reach caregivers at risk of ill health due to high burden. We must educate the public about the critical and often difficult role of caregiving and empower communities to assist caregivers in their work. We recommend developing and launching a national outreach and public education campaign to reach caregivers most in need. The campaign should be funded and led by the Department of Health and Human Services using resources of the Centers for Medicare and Medicaid Services, Centers for Disease Control and Prevention, and Administration on Aging. The goals of the campaign would be 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.

**Recommendation 4: Professional Development.** It is imperative that persons who actively work with family caregivers (e.g., professionals, para-professionals and volunteers), be equipped with the skills necessary to assure an effective and successful working relationship. Professional skills training should encompass education on how to assess the needs of family caregivers in a culturally-sensitive manner, how to effectively partner with them, and how to implement protocols specific to evidence-based programs for family caregivers. The provision of licensing and certification in evidence-based program implementation should be made affordable and widely available.

**Recommendation 5: Accelerate Research and Development.** Knowledge about the effectiveness of different systems of caregiver support should be rapidly generated, and include information about success in serving diverse communities, costs, and cost-effectiveness. Multi-site demonstration projects should be initiated to test the effectiveness of different configurations of evidence-based programs within the Center for Innovation at the Centers for Medicare and Medicaid Services. All future caregiver demonstration projects should be encouraged to examine and publish comparable cost-effectiveness and cost-efficiency data.

## **B. System Design**

**Recommendation 6: Establish Services in Natural Settings to Improve Access.** We need to facilitate access to support programs for caregivers. Caregivers are more likely to successfully access needed services in “natural settings” which they encounter in the course of their normal activities and responsibilities. Such natural settings include the doctor’s office where caregivers often visit with their care recipients, the hospital where caregivers are frequently engaged during admission and discharge of the care recipient, faith-based community settings, and employers. We recommend providing opportunity grants, training and technical assistance to help diverse agencies and organizations build capacity to provide evidence-based programs for caregivers.

**Recommendation 7: Make Professional Assessment and Triage Available to All Caregivers.** Caregivers should be provided access to skilled professionals who can routinely perform culturally competent caregiver risk and needs assessments. Assessments should result in a care plan specifically related to the level of risk identified and should contain specific and measurable outcomes. Routine assessments already being conducted by healthcare providers (hospital discharge, home care, outpatient rehabilitation) or government-funded (Area Agencies on Aging) should be revised to include a caregiver component. Moreover, government and other third-party payers should reimburse healthcare providers for conducting a caregiver assessment.

**Recommendation 8: Assure Caregiver Services are Evidence-Based, Culturally-Sensitive, and Tied to Caregiver Programs.** A standard of care within the aging network should be adopted that offers a menu of

service options and interventions of increasing intensity to address the varying needs of caregivers based on their levels of risk. One approach would be to revamp the National Family Caregiver Support Program to ensure the provision of evidence-based programs.

Following a public health model, systems of care within states and communities can be augmented to assure caregivers receive evidence-based interventions tailored to their unique needs and level of risk. Specifically, intervention intensity should be based on increasing caregiver risk burden at three levels:

1. **Universal** interventions, such as information and education, for all caregivers;
2. **Selective** interventions, such as skills training, for families at elevated risk for future health and stress-related problems stemming from the demands of caregiving; and
3. **Indicated** interventions, such as intensive counseling, to further address heterogeneity in risk factors and severity among the high-risk groups.

**Recommendation 9: Establish a National Resource Center on Evidence-Based Caregiver Programs.**

Information on implementing and translating evidence-based programs for caregivers should be centralized to support widespread adoption across communities. A National Resource Center should be authorized and funded to track successful implementation and translation activities and assure that guidance and training processes are in place. A special focus at the National Resource Center should be placed on culturally appropriate programming.

**Recommendation 10: Technical Assistance for Providers.** Affordable technical assistance networks should be created to ensure widespread and effective implementation of evidence-based programs for caregivers. These networks could be university or community-based that tap into local and national expertise in capacity building, evaluation, and systems design.

## C. Public and Tax Policy

**Recommendation 11: Tax and Public Policy Changes.** It should be a national goal to preserve family caregiving as a viable option by protecting families from economic hardship associated with caregiving, and to create incentives for family caregivers to increase their skill level to provide sustained higher-quality care. A caregiver credit should be designed under the Social Security System as suggested by the General Accounting Office. Such a credit would: (1) allow a specified amount of caregiving time (3 to 4 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, in proportion to the time they took time out of the workforce for caregiving. Tax credits should be made available to family caregivers, such as those proposed in the CARE Act in the 110th Congress and currently under consideration in several states (Caregiver Assistance and Relief Act, 2007). To combat caregivers leaving the workforce, there should be a policy mandate for flexible work arrangements wherever feasible. Incentives should be created for family caregivers to participate in evidence-based programs that increase their skills and knowledge. Tying tax credits to caregiver participation in such programs also should be strongly considered. Additionally, government entities and

other payors should provide vouchers for care recipients to pay minimum wage to family caregivers upon completion of required training.

**Recommendation 12: Targeted Investments and Sustainable Funding.** It should be a national priority to support the development of an essential infrastructure to serve family caregivers, and to promote adoption, implementation, and maintenance of the most effective programs. Investment should be made in an expanded nationwide caregiver support system that makes evidence-based programs for caregivers widely available and easily accessible. Funding for the Alzheimer’s Disease Supportive Services Program of the Administration on Aging should be expanded, and additional funding should be provided for the National Family Caregiver Support Program for program expansion. 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. Additionally, after grant funding by the Administration on Aging ends for successful demonstrations, the Centers for Medicare and Medicaid Services should continue funding these programs through a waiver or other mechanism. Moreover, the “CLASS Act” (Community Living Assistance Services and Supports Act), a provision under the enacted Patient Protection and Affordable Care Act, should be quickly implemented to support the development of a new national long-term care insurance program, with inclusion of caregiver support, education and training as components of plan benefits.<sup>53</sup>

## VI. FUTURE DIRECTIONS

As RCI looks to the future, we envision sustaining our strong commitment to supporting family caregivers. We will continue to foster the development of the network of community coalitions (CARE-NETS) that provide a forum for addressing the needs of caregivers in a concerted and coordinated way. Moreover, we will work toward expanding the National Quality Care Network (NQCEN) as a vehicle for innovation, information sharing, and stimulating partnerships for action in our communities. Our efforts with the NQCEN will focus on working to implement, disseminate, and maintain effective translational strategies of evidence-based programs for family caregivers. Ultimately, through RCI’s partnership with the NQCEN, we will aim to create supportive policies and secure long-term, sustainable funding for the integration of caregiver programs within community systems.

With the launch of a new RCI publication, the CARE Report, we will broadly share the translational experiences of providers in integrating evidence-based programs for caregivers. This bi-annual report will showcase the widespread adoption of evidence-based programs in order to increase awareness about the many positive outcomes of these programs. Among other endeavors, we will continue sponsoring RCI’s annual summit in Americus, GA, as a forum to bring together the diverse groups of health policy leaders, program planners, researchers, and other key stakeholders with vested interests in family caregiving issues. Furthermore, commencing with this year’s annual summit, a summary monograph of the key topics addressed at the sessions will be issued to interested parties at large. It is our hope that the monograph will help broadly disseminate summit activities and facilitate information-sharing.

Other future activities at RCI will include ongoing sponsorship of our Professional Development Webinars that provide technical assistance to agencies wanting to implement evidence-based programs for

family caregivers. And lastly, we will maintain our strong presence as advocates of family caregivers at the Federal, state and local level.

In closing, to successfully avert the caregiving crisis facing our nation, it is RCI's position that all sectors of society must come together in new ways to develop effective and timely solutions. The broad and coordinated response outlined in RCI's **National Caregiving Initiative** will require a fundamental shift in how we, as a country, recognize the invaluable contributions of family caregivers as the true backbone of our nation's long-term care system.

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