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"Family Caregiving Issues and the National Family Caregiver Support Program"

Chairman Kohl and members of the committee,

I am pleased to be here this afternoon and to have this opportunity to speak about caregiving. My interest in the issue goes back to my childhood when I was deeply influenced by how chronic illness affected and shaped my family and by the dedicated and selfless efforts of family caregivers.

Caregiving has been an integral part of my life since I was twelve years old and my father was diagnosed with leukemia at the age of 44. We lived in a very small town – Plains has about 600 residents – and all the neighbors rallied round; but I still vividly remember going to my secret hiding place – the outdoor privy – to cry. I was the oldest child, I felt the burden of needing to help care for my father and my three younger siblings; yet I was scared and didn't always feel like being strong.

Less than a year after my father died, my grandmother passed away unexpectedly, and my grandfather came to live with us. As he grew older, his needs increased. My mother cared for him at home until he died at 95. During the last few years of his life, he was bedridden and totally dependent on her, me and other family members, neighbors and friends for all his needs.

I like to say that there are only four kinds of people in the world- those who have been caregivers, those who are currently caregivers, those who will be caregivers and those who will need caregivers. Valuing caregiving as a critical component of our nation's healthcare system is the impetus behind the work that we do at the Rosalynn Carter Institute for Caregiving (RCI).

The Institute was established in 1987 on the campus of Georgia Southwestern State University in Americus, Georgia. We were really charting new ground when the RCI was formed. Our mission targets supporting caregivers and their loved ones who are coping with chronic illnesses and disabilities across the lifespan as well as limitations due to aging.

In the past 3 years, with the corporate support of Johnson & Johnson, we have convened groups of experts in research, program planning, and policy development to examine the evidence-base for caregiver support interventions and the initial efforts to translate evidence-based clinical research into a community setting. These evidence-based programs have been tested through randomized-controlled clinical trials with the results published in peer-reviewed journals. We as a nation cannot afford for our valuable caregiver support research to sit on a shelf - these programs must be translated into a community setting so that our caregivers can benefit from them. 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. Even with these early beginnings, we have found that evidence-based caregiver support programs are effective and result in helping caregivers cope with the demands upon them, reducing feelings of burden and stress, improving mental health, and delaying institutionalization. [1-12] More efforts are needed to promote evidence-based programs into the communities to support all caregivers.

Our nation is in need of a fundamental shift in how it values and recognizes caregivers especially in view of the rapidly escalating number of older adults, many of whom live with chronic illness and disabilities. There are 39 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 72 million, or roughly 20 percent (1 in 5) of the U.S. population. Approximately 6 million adults over age 65 need daily assistance to live and that number is expected to double by 2030. Approximately 80 percent of older Americans are living with at least one chronic condition, and 50 percent have at least two chronic conditions. [13]

Most frail, elderly and disabled people live at home; and about 90 percent of the care they need is provided by unpaid, informal caregivers. Many of these caregivers are frail and elderly themselves. For many, the burdens of caregiving are enormous. 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. [14-16] Consider these facts:

- Older people caring for spouses have a 63 percent higher mortality rate than those of a similar age without caregiving responsibilities;
- The stress of caring for a person with dementia negatively impacts the caregiver’s immune system for up to three years after caregiving ends, making them much more susceptible to all kinds of illnesses;
- Caregivers report chronic conditions such as heart disease, cancer and diabetes at twice the rates of non-caregivers;
- Up to 50 percent of caregivers report struggling with depression; and the rates are even higher when caring for a loved one with dementia.

Our nation’s family caregivers are enduring both physical and mental problems --- and even dying sooner – because of the responsibilities they have shouldered to care for their loved ones. Yet without them, where would our country be? The demand for institutional care would increase dramatically; and so would the overall costs. Our already over-taxed health care system would be hard pressed to find the work force necessary to deliver high quality institutionalized care. And millions more older people would have to live out their final days deprived of the comfort and security of being in their own homes.

The economic value of family caregivers is substantial. Experts have estimated that the services provided by family caregivers are in excess of $375 billion annually. Benchmarks exist that may help put this value in perspective. This figure is (1) more than total spending for Medicaid, including both federal and state contributions for medical and long-term care ($311 billion in 2007) and (2); approaching the total expenditures for the Medicare program ($432 billion in 2007). 17

The RCI strongly advocates for re-envisioning support for the 65 million family caregivers in our country. We recognize 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. In order to do so, we must address the most pressing unmet needs of family caregivers, including assessment of caregiver health, a lack of adequate training, additional respite care, and greater access to support programs.

Last October the RCI released a very important report, ***Averting the Caregiving Crisis: Why We Must Act Now.*** This report is the result of three years of intensive study which involved hundreds of experts from around the country. I urge each of you to read it carefully, for it contains a blueprint for a new national initiative to support family caregivers. I want to highlight just four recommendations that are relevant to this Committee's work:

1) A National Quality Caregiving Task Force should be created to oversee the caregiving 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.

2) Assess and monitor caregiver health. We need to establish state-level systems to assess and monitor caregiver health. One way to do this may be to utilize the Centers for Disease Control and Prevention's Behavioral Risk Factor Surveillance System's (BRFSS) caregiver module as part of the Older Americans Act funding. If states are required to collect BRFSS data with the caregiver module every two years, they will be able to identify populations of caregivers with unmet needs, provide much needed information on tracking trends in caregiver health, and have data to inform the allocation of resources and the development of programs to support caregivers.

3) Ensure the provision of evidence-based programs for caregivers. There is a need for immersion of evidence-based caregiver support intervention programs into current state and private agencies that provide services to older Americans. Knowledge about the effectiveness of caregiver support programs should be rapidly generated and include information about success in serving diverse communities, costs, and cost-effectiveness. Following a public health model, systems of care within states and communities can be augmented to assure that caregivers receive evidence-based interventions tailored to their unique needs and level of risk. Specifically, a menu of services should be available to support each caregiver at a level that is appropriate for that caregiver – much like one might need a more intense dosage of a medication for a more severe illness.

   My dream is that one day all programs for caregivers will be evidence-based, but I know that this will not be easy to accomplish. At the RCI, we are building the expertise to do so. Our corporate partner, Johnson & Johnson has a long history of working in this field to better understand late life mental disorders. They were the first to conduct clinical trials in nursing homes at a time when there was virtually little or no research being done in these settings where the prevalence of depression and dementia is so significant. Today they are investing to ensure that knowledge gained about dementia through academic research is made easily available to the 15 million caregivers in communities across the country dealing with this problem.

   With Johnson & Johnson's support, the RCI is arming caregivers with information and tools that have proven to improve quality of life. We have introduced evidence-based interventions in ten communities across the country. We also developed a technical assistance program to make sure that participating organizations have the skills and training necessary to ensure successful adoption of the new methods. Today we are expanding this effort in partnership with the Georgia Department of Aging Services and are very grateful for the support provided by AoA for this work. We are eager to share the knowledge we have gained with you.

4) Continue funding for the National Family Caregiving Support program. 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 (that is those demonstrations that are cost effective and achieve the desired outcomes), the Centers for Medicare and Medicaid Services should continue funding these programs through a waiver or other mechanism. One such legislation that may be able to provide the needed support is the "CLASS Act" (Community Living Assistance Services and Supports Act), a provision under the enacted Patient Protection and Affordable Care Act, 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 government work together to develop timely and effective solutions. To that end, the RCI has met with representatives from the Administration on Aging, (AoA), the Centers for Medicare & Medicaid Services (CMS), Department of Health and Human Services, Office of Disabilities (OD), and the Veterans Administration (VA). RCI has upcoming meetings with these key federal agencies and would be delighted to come back before the committee to update you on outcome oriented recommendations that have evolved from these meetings. I applaud the Senate Special Committee on Aging for its efforts to focus on ways to help our health and long-term care system to support and sustain America's family caregivers.

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