



**Expanded Statement by
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On Behalf of
Eldercare Partners
Before the
Joint Economic Committee
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Good morning Chairman Schumer and distinguished members of the Joint Economic Committee. Thank you, Senator Klobuchar, for bringing this critical issue before the committee and inviting testimony from a community-based provider of caregiver services. My name is Leni Wilcox and I am Division Director of the Amherst H. Wilder Foundation's Community Services for the Elderly in St. Paul, Minnesota. Each year, Wilder provides a number of community-based, long-term care services to nearly 2,000 low income, older and disabled adults in the Twin Cities East Metro area. Our goal is to help older adults and their family caregivers so that the older adult can continue to live independently and remain actively involved in the community as long as possible.

One of our most valued partnerships is with three other like-minded, nonprofit social service agencies that serve seniors and their caregivers in the Twin Cities area: DARTS in Dakota County, Human Services, Inc. in Washington County, and Senior Community Services in Hennepin County. We have partnered to offer one-stop access to care coordination and all of our services, including our caregiver coaching service, a national winner of the 2006 Family Caregiving Award for innovation and effectiveness. This partnership, Eldercare Partners, is funded by a National Family Caregiver Support Program grant from our Metropolitan Area Agency on Aging, and provides support to approximately 400 family caregivers each year, giving them the skills they need to do one of life's toughest jobs. Eldercare Partners caregiver coaches provide in-depth assessment of the caregivers and then help them navigate the fragmented service system, provide family mediation if needed, and develop a longitudinal relationship with them to build skills, confidence and resilience. Educating and equipping this generation of caregivers will not only benefit today's seniors, but will foster a new cohort of informed adults better prepared for their own aging.

Caregivers are Affected by Demographic Trends

Many factors, including advances in nutrition, public health, and medicine have increased the U.S. life expectancy by approximately 24 years per century.¹ In addition, our population is aging. Tom Gillaspay, Minnesota State Demographer, reports that over the next two decades, the number of Minnesotans over the age of 65 will double, and by the year 2030 older people will represent over 20% of the state's population. Our aging population, living longer, may acquire more chronic disease and utilize services longer. Increased health care costs, fragmented service systems, and lack of self-identification make the otherwise savvy Baby Boomers ill-prepared for their caregiving roles.

Today's families are smaller, more geographically dispersed, and often require dual incomes to meet basic family needs. Statistically, there are fewer caregivers per elder than in past generations and the caregiver role today can last much longer than it once did. A 2003 study noted caregivers spend an average of 4.3 years providing care. Many are in that role significantly longer than the average.²

Caregivers are Vulnerable, Valuable, and Vital

We know that there are two types of caregivers – (1) those with mastery who have learned how to cope, when to ask for help and where to find it, and (2) those who feel physically overwhelmed, emotionally out of control, and financially stressed. Organizations like ours are critical to helping this second group of caregivers manage not only the lives of the care recipients, but also their own lives. In too many cases, if caregivers do not receive support, they may ultimately no longer be able to fulfill their caregiving role.

Caregiving creates physical, emotional and financial complications for the caregiver. 11% report that caregiving has negative impacts on physical health.³ Multiple studies report that caregivers experience increased physical strain, disturbed sleep and elevated stress levels. Caregivers encounter chronic conditions such as heart attack/heart disease, cancer, diabetes and arthritis at almost twice the normal rate. Caregivers report lower levels of self-care, are more likely to smoke, and have higher alcohol abuse and prescription drug use. They report that their eating and exercise habits have worsened as a result of their role. The ultimate sacrifice of caregiving is earlier death. Spouses, aged 66-96, who experience caregiving related stress, have a 63% higher mortality rate than non-caregivers of the same age.⁴

The emotional toll of caregiving impacts both individual and family structure. Constantly changing needs, priority conflicts and family expectations often create guilt, depression and stress. In addition, a caregiver's identity is continually challenged throughout the journey with lessening of self-esteem, personal value, and life purpose.

¹ Lee, R. 2003. Mortality Forecasts and linear Life Expectancy Trends. University of California, Berkeley.

² National Alliance for Caregiving and AARP. Caregiving in the U.S. Bethesda: National Alliance for Caregiving, and Washington, DC: AARP, 2004.

³ Center on an Aging Society, 2005. How Do Family Caregivers Fare? A Closer Look at Their Experiences. (Data Profile #3). Washington, DC: Georgetown University.

⁴ Schulz, R. and S. R. Beach, Caregiving as a Risk Factor for Mortality: The Caregiver Health Effects Study, JAMA 282 (1999): 2215-2219.

Estimates show that between 40 and 70% of caregivers have clinically significant depression.⁵

Families experience financial burdens because of caregiving. While an estimated 60% of caregivers are employed either full or part-time, they often struggle with balancing family and work. Many must rearrange their work schedules, decrease their hours, and take unpaid leave to meet their caregiving responsibilities. Assuming a caregiving role often leads to workplace absenteeism, reduced job responsibility, lost wages, job termination, and interrupted contributions to Social Security and retirement plans. One study found that women who were caregivers during their working years were 2.5 times more likely to live in poverty as elders than women who had not been caregivers.⁶

Most long-term care is not provided in nursing homes. Families and friends provide approximately 80% of the long term care in the U.S.⁷ and 96% in Minnesota.⁸ In 2000, the U.S. Administration on Aging reported that 50% of the elderly who need long-term care but had no family to care for them, use nursing home care. In contrast, only 7% who have a family caregiver live in an institution. The estimated value of informal caregiving is \$306 billion dollars annually.⁹ Caregiving is a core social value in America regardless of income, cultural background, or geographic region. Families value their elders and want to care for them as they age and need help. Most caregivers are unsung heroes who find great personal satisfaction and growth without asking for recognition or thanks. The caregiver role is not an easy one and services like Eldercare Partners help the caregiver juggle work, raise children, care for their parents, and mitigate stress and burn-out.

Caregivers Benefit from Services and Support

Research continues to show the effectiveness of caregiver support programs. In 2004, Dr. Terry Lum, University of Minnesota, evaluated the Eldercare Partners caregiver coaching service and found that it significantly reduced the level of burden experienced by caregivers and helped them cope and provide care longer. In December 2005, the Partners in Care study¹⁰ demonstrated that caregiver coaching is an effective intervention for empowering caregivers to acquire knowledge and skills, creating improvement in

⁵ Zarit, S., Assessment of Family Caregivers: A Research Perspective. In Family Caregiver Alliance (Eds.), *Caregiver Assessment: Voices and Views from the Field*. Report from a national Consensus Conference (Vol II). San Francisco: Family Caregiver Alliance.

⁶ Wakabayashi, C. and K. M. Donato. 2004. *The Consequences of Caregiving for Economic Well-Being in Women's Later Life*. Presented at the annual meeting of the American Sociological Association, San Francisco.

⁷ Thompson, L., Long-term care: Support for family caregivers (Issue Brief). Washington, DC: Georgetown University, 2004 and Long-Term Care Financing Project, Long-term Care Users Range in Age and Most Do Not Live in Nursing Homes. U.S. Agency for Healthcare Research and Quality, November 8, 2000.

⁸ Status of Long-Term Care in Minnesota 2005. A Report to the Minnesota Legislature. Minnesota Department of Human Services Aging Initiative. June, 2006.

⁹ National Family Caregivers Association and family Caregiver Alliance (2006). *Prevalence, Hours and Economic Value of Family Caregiving, Updated State-by-State Analysis of 2004 National Estimates* (by Peter S. Arno, PhD). Kensington, MD: NFCA and San Francisco, CA: FCA.

¹⁰ McGee, P. and H. Tuokko. 2005. *Partners in Care: Empowering Caregivers Through Coaching*. Centre on Aging, University of Victoria.

attitudes and behaviors related to self and self-care. Multi-intervention programs make a difference. One study showed that patients whose spouses received individual and family counseling, support group participation, and phone support as needed experienced a 28.3% reduction in the rate of nursing home placement and delayed the median time of institutionalization by 557 days.¹¹

The stories of several caregivers served by Eldercare Partners illustrate the effectiveness of caregiver coaching. For example, take Alice. Her father is 80 years old, a polio survivor now living with congestive heart failure, kidney failure, and depression. Alice left her full-time job to provide the considerable assistance and 24-hour supervision he needs. She is paid as a personal care attendant for some of her caregiving hours, but her own income has decreased dramatically. She struggles to find time for the rest of her family and worries about how she is neglecting her own health. The Eldercare Partners coach has helped Alice find useful resources – a mental health consultant for her dad, a rabbi who will visit him at home, a volunteer who provides respite for her. And the coach has been strategizing with her about how to improve her own health. Alice announced proudly to her coach that she had spent one and a half hours with her dog at the dog park – a remarkable achievement for this caregiver.

Another example is Karen. Karen's responsibility is even more daunting. She is the primary caregiver for both her mother, who has Alzheimer's disease, and her brother, who has cerebral palsy and obsessive compulsive disorder. Karen tries to handle her paid job while also meeting their daily needs – finding appropriate adult day programs for each, arranging transportation, accompanying them to medical appointments, learning about the mental health system, keeping bills and insurance matters straight – all the while adjusting to the fact that her mother no longer recognizes her. Karen's mother recently moved from Karen's home to a memory care facility, which adds a new dimension to her caregiver role. And she will be caring for her brother well into the future. Caregiving requires stamina, and the advice and support of an Eldercare Partners coach has helped Karen maintain a healthy perspective throughout her journey. The coach has guided her through complex systems and difficult family conflicts. She's sleeping better now and she says, "at least I'm not stressed over getting stressed."

And finally, John. John, in his mid-50's, lives in Minnesota and cares for his mother who lives in Virginia. John's mother has multiple sclerosis, and he has been a long-distance caregiver for many years. Because she has now developed arthritis as well, both decided the mother should move closer to her son. John has many questions. Would airline staff help her transfer from her wheelchair to the seat in the plane, or must someone accompany her on the trip? Where can she afford to live that has the services she'll need? Will she have to switch Medicare HMOs when she moves? Is a Power of Attorney executed in Virginia valid in Minnesota? The Eldercare Partners coach helped him find the answers and navigate the resources, saving him the frustrating and time-consuming false starts that many caregivers experience. This access assistance is helping John create a smooth transition for him and his mother.

¹¹ Mittelman, M. S., Haley, W. E., Clay, O. J., Roth, D. L. 2006. Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. *Neurology*, 67: 1592-1599.

Caregivers Tap Various Funding Sources

Eldercare Partners receives funds from the Metropolitan Area Agency on Aging via the Minnesota Board on Aging, originating from Title III-E of the Older Americans Act. Our member organizations match these funds with support from municipalities, counties, foundations, United Way, and corporate and individual contributions. Service users pay a share of the cost using a sliding scale based on the care receiver's income, per OAA requirements.

But Older Americans Act funded services comprise only a portion of what caregivers need. Additional supportive services are offered by nonprofit organizations, faith communities, and for-profit companies. Most assistance is purchased directly by consumers at market rates or with sliding fees. Other funding streams Minnesota caregivers can tap include: Alternative Care and Elderly Waiver for financially and functionally eligible individuals, primarily focused on services used by the care receiver; Consumer Directed Care, which is available under the waivers and through Title III-E, giving consumer families funds to purchase services they choose; Long Term Care Insurance, which may cover in-home services for the care receiver that provide relief for the caregiver.

Caregivers Need Our Help

We feel that attention to supporting caregivers is critical for our future. There are three things that are very important to note:

- *The magnitude and challenging circumstances of caregiving today are unprecedented in this country.* As Dr. Johnson described in his testimony, demographic and social trends will exacerbate these problems in the future. With the retirement of the Baby Boomers starting in 2011, our aging population will increase quickly. By 2030, there will be about 71.5 million older persons, or more than twice the number there were in 2000. The 85+ population will grow even more dramatically in that timeframe.¹² While we are living longer, it isn't clear whether disability rates will decline or not. Many Baby Boomers have smaller and non-traditional families. And they are mobile, sometimes living a long distance from their parents and children. To exacerbate the problem, in most parts of the country there are workforce shortages of formal care professionals like nurses and home health aides. Support for informal caregivers will be critical to helping older adults remain at home in more cost-effective, community-based settings.
- *The economic impact of caregiving can span multiple generations.* Most caregivers are women, but we are seeing more and more men in this role. Both men and women are affected by its short-term and long-term consequences. In the short-term, high caregiver stress is associated with premature nursing home admission for the care receiver. In the long run, the caregiving role can have a significant impact on the economic well-being of the caregiver. Negative impacts on job performance and even the ability to retain employment affects many

¹² Department of Health and Human Services. Administration on Aging. A Profile of Older Americans: 2006.

caregivers who sacrifice not only their income, but their future retirement security. Add to that a body of evidence that shows that the mental and physical health of caregivers are at risk, setting them up for disability and future increased health care costs.

- *Service awareness, access, and navigation are our greatest challenges.* Finally, the service and financing “systems” that support community-based long-term care are chaotic, fragmented and, frankly, frightening. The availability of supportive services is not a level playing field with great variation among states and between metropolitan and rural areas. Indeed, there are access barriers for people of all incomes. Although mainstream media coverage about Boomers caring for their parents has certainly increased, there is a great need for more public education to make people who are caring for a loved one aware of services, like those funded under Title III-E, so they can get support and help to navigate our disjointed system.

Caregivers are the heart of the long-term care system and we must do more to address their physical, emotional and financial challenges. Shifting the focus and funding of long-term care to community services is essential. The National Family Caregiver Support Program of the Older Americans Act was a significant first step. It brought needed resources and attention to caregiver needs, but caregiver awareness still remains low, service availability is spotty, and access is difficult. You can help by keeping this issue alive in the public discourse, strengthening access points and navigation assistance, and allowing flexibility in service design so that caregivers have options that suit their unique circumstances. We all need caregivers. They need our help.

Thank you for your attention to this important and growing national issue.