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IN OPPOSITION TO

SB 116 AN ACT CONCERNING CAREGIVER AGREEMENT REQUIREMENTS FOR  
MEDICAID APPLICANTS OR RECIPIENTS.

Human Services Committee

Ladies and Gentlemen –

I am writing to you today in a dual capacity of elder lawyer and former family caregiver to express my opposition to Senate Bill 116, as drafted.

I understand the need for rules and regulations and the obligation of the General Assembly to oversee the operation of various state programs as well as the state budget. I also recognize that the cost of care provided to individuals on Medicaid is a significant, and growing, part of the state budget and may be regarded by some as a logical target for budget reduction.

At the same time, it is important for the State of Connecticut to acknowledge that family caregivers are often a crucial component of the health care continuum and recognize that contribution as an irreplaceable resource. For example, a recent study of the monetary costs of dementia in the United States reported that the value of informal care (not including caregivers' out-of-pocket costs) was nearly equal to the costs of ALL direct medical and long-term care of individuals with dementia.<sup>1</sup> The Alzheimer's Association estimates that in Connecticut 177,000 family caregivers provide more than 201,000,000 hours of unpaid care each year valued at more than \$2,450,000,000.

The costs to a family member of providing care for a loved one are psychological, physical and financial. According to data collected by the AARP, seventy-five (75%) percent of the caregivers of people with Alzheimer's disease and other dementias were employed.<sup>2</sup> For many, caregiving responsibilities change both their earning capacity and career options. For example, fifteen (15%) of the dementia caregivers surveyed reported having to take a leave of absence, thirteen (13%) had to go from working full time to part-time, thirteen (13%) had to take a less demanding job and seven (7%) percent had to turn down a promotion. Seventeen (17%) percent of the dementia caregivers surveyed had to give up their jobs before or after assuming caregiving

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<sup>1</sup> . Hurd MD, Martorell P, Delavande A, Mullen KJ, Langa KM. Monetary costs of dementia in the United States. N Engl J Med 2013;368:1326–34

<sup>2</sup> National Alliance for Caregiving and AARP. Caregiving in the U.S. Unpublished data analyzed under contract for the Alzheimer's Association; 2009.



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responsibilities; among those who continued to work, Eight (8%) percent reported losing work benefits. As much as they might like to care for their loved ones without asking for compensation, the hard economic reality for many family caregivers is that they either must try to replace lost income or cut back on their caregiving services. At the same time, it is not unreasonable that the person receiving care wants to try to compensate their family members for their financial sacrifice.

In the best of all possible worlds, family members and the Department of Social Services would work together to ensure that family members who need of long-term care -- whether it be at home or in a health care facility -- receive the best of care and maintain a highest quality of life while keeping costs within some reasonable parameter. Unfortunately, SB 116 serves as evidence that we have not reached the state of Nirvana but rather continue to attempt to function in an adversarial environment in which family members are seen as the enemy rather than as a vital part of the "team". SB 116, like so much of the deficit reduction implementing legislation and accompanying regulations and policy guidelines seem to be based upon a premise that family members will do anything and everything that they can do to qualify a loved one who is in need of long-term care for Medicaid. In actuality, studies show that what motivates most family to become caregivers is not the goal of getting the State of Connecticut to pay the bill for their care but rather the desire to keep their loved ones at home, living as high a quality of life as is possible. Ironically, the very people who will not be hurt by the documentation requirements of SB 116, as drafted, are those people who really are only interested in qualifying their loved one to receive Medicaid benefits while those families are motivated only by the desire to provide the best care for their loved ones may be irreparably damaged.

I have no objection to a desire that all family caregiving be documented and actually always recommend to clients that records be kept, not to satisfy a DSS caseworker but rather to document the evolution of the loved one's illness and care needs. Unfortunately, SB 116, by requiring that documentation be executed before services begin simply does not reflect the reality of how family members fall in to the caregiving role. As was true in my case, family members often assume caregiving responsibilities over time; as needs increase, the list of tasks and services being performed by the family caregiver grows. In my elder law practice, I rarely am approached by a family at the beginning of their caregiving journey. Typically, families who come to see me have already been providing caregiving services for several years and only seek legal counsel when there has been some sort of crisis or potential crisis. They come seeking to questions about how they can continue to care for their loved one at home – not how to get a family member on to Medicaid.

Another provision of SB 116 that is particularly offensive to me is the limitation upon compensation for caregivers who are caring for family members who are residing in a health care facility. Assuming that moving into an assisted living facility or nursing home ends the need for family caregivers reflects a total misunderstanding of the role of the family caregiver. While the family members may



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no longer be responsible for daily physical care, a family member's caregiving responsibilities do not end with placement in a facility. Family caregiver must still monitor the care that is being provided, attend medical appointments and care conferences, advocate on behalf of their loved one and help facility maintain the quality of life that they desire for their loved one. Caregiving responsibilities are no less significant and no less important simply because someone else is bathing and dressing a loved one. The role may change, but it does not disappear.

I urge you to recognize the vital role played by family caregivers, consider the needs and well-being of both caregivers and care recipients and reject this very aggressive approach to a problem that I believe exists more in perception than in reality.