



**National
Multiple Sclerosis
Society**

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**The Human Services Committee
February 8, 2007**

**Testimony in support of
Proposed SB No. 384, An Act Increasing Funding for the Home-Care Program for the Elderly
and
Increasing Home and Community Based Services for People with Disabilities**

To: The Honorable Jonathan Harris, Senate Co-Chair, Human Services Committee
The Honorable Peter F. Villano, House Co-Chair – Human Services Committee
The Honorable Eric D. Coleman, Senate Vice Chair, Human Services Committee
The Honorable Catherine F. Abercrombie, House Vice Chair – Human Services Committee
The Honorable John A. Kissel - Senate Ranking Member – Human Services Committee
The Honorable Lile R. Gibbons - House Ranking Member – Human Services Committee
and Distinguished Members of the Human Services Committee

Thank you for the opportunity to submit testimony. The National Multiple Sclerosis Society supports Proposed S.B. 384, "An Act Increasing Funding for the Home-Care Program for the Elderly." **We also support broader options for home and community based services for individuals of all ages who have disabilities.**

My name is Susan Raimondo, and I am the Community Programs Director for the Greater Connecticut Chapter of the National Multiple Sclerosis Society. I am also the Family Caregiver Member of the Long Term Care Advisory Council, a member of the Nursing Facility Transition Project Steering Committee, and a spouse of someone with advanced multiple sclerosis.

The Greater Connecticut and Western Connecticut Chapters of the National Multiple Sclerosis Society provide services, education and support to over 6,000 people with MS in Connecticut and the families, friends and professionals who care for them. Our clients with multiple sclerosis are often uninsured or underinsured.

Multiple sclerosis is thought to be autoimmune disease of the brain and spinal cord. The disease can cause blurred vision, loss of balance, poor coordination, slurred speech, tremors, numbness, extreme fatigue, problems with memory and concentration, paralysis, blindness and more. These problems may be permanent or may come and go. MS is diagnosed at the prime of life usually between the ages of 20 - 50.

I have worked at the National Multiple Sclerosis Society for 20 years. Treatments for MS now exist, but in reality, there are still large numbers of individuals who experience disability, loss of independence, employment problems, loss of physical, emotional and cognitive function, and face the need for long-term care services. The National MS Society estimates that approximately 30% of people with MS will need some type of long term care services during their life with MS.

Over the past five years, the National MS Society Connecticut Chapters have been offering Care Management Assessments for individuals with MS who are at risk for institutionalization. These assessments are very similar to those done for the CT Home Care for Elders Program.



The individuals with MS who have been evaluated in our Care Management Program were functionally eligible for the Connecticut Home Care Program for Elders (CHCPE). Their median age was 50, however we have had clients in the program as young as 28. Out of the seven critical needs identified in the CHCPE, the average number of critical needs that the individuals with MS have is 4 and all of our clients had unmet needs. Twenty-five percent were unable to coordinate their own care and 46% of these individuals lived alone.

One of the challenges that we face is that often these individuals end up in a nursing home because they cannot access the support services needed. If there was a state funded pilot home care program for individuals under age 65 that offered ongoing care management and care coordination with additional supports, these individuals would not have to go to a nursing home.

The Nursing Facility Transition Project has transitioned over 130 individuals with disabilities out of nursing homes, but there are many people who have not been able to transition because of our existing service programs are very focused on a person's age and/or diagnosis. The Money Follows the Person Rebalancing Demonstration Project will be an option for some of these individuals.

We are also asking the Human Services Committee to introduce legislation that would require the Department of Social Services to apply for Medicaid state plan amendments and a Medicaid waiver to ensure that all the people who are functionally eligible for the Money Follows the Person Demonstration Program can receive the services offered under that program if they are at risk of being institutionalized or are inappropriately institutionalized.

In my own situation, my husband has progressive multiple sclerosis. He is 42 years old and has resided in a nursing home during 3 different stays over the past 10 years. He is paralyzed from the chest down and only has use of one arm. He requires total care. At times, he loses his voice and his ability to drive his electric wheelchair.

My husband does not qualify for the Medicaid Personal Care Assistance Waiver because like many individuals with MS and other acquired disabilities, his income from Long-term Disability and Social Security Disability Insurance puts him slightly over income for the program. We have not applied for the waiver because he has a small retirement savings and does not want to risk losing it. I work full time and have a somewhat flexible schedule so that I can do his morning personal care and evening personal care. My mother-in-law lives with us and she is home all day with my husband. She is elderly and yet she uses our adaptive equipment to care for him while I am working. Other family is essential for managing and they help us with many things in order to keep my husband at home.

My story is not unique. Many family caregivers are managing but are always living on the edge. Two years ago, my husband was hospitalized for a month and in a nursing home for a month. After staying with him over night, every night in the hospital and going to work during the day, I ended up in the hospital and was diagnosed with a second chronic illness in addition to the other health problems I have.

We need help, especially for individuals under age 65. Individuals who have acquired disabilities that change over time, people not eligible for Medicaid because of a small savings or who have an income only slightly above the allowed amount and people with cognitive impairment, all need support from programs which should not have age restrictions or restrictions based on diagnosis. The best approach is to base eligibility on a person's function and need.

Thank you.

Submitted by,

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