National
Multiple Sclerosis
Society

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Human Services Committee Public Hearing – March 1, 2012

Testimony in Support of SB 229, An Act Concerning Medicaid Long-Term Care Coverage for Married Couples & SB 230, An Act Concerning Community Choices for Long-Term Care and Disability Services

Good afternoon distinguished members of the Human Services Committee,

My name is Susan Raimondo and I am the Senior Director of Advocacy and Programs for the National Multiple Sclerosis Society, Connecticut Chapter. The National MS Society has offices in Hartford and Norwalk. We serve over 6,000 individuals living with multiple sclerosis and their families in Connecticut.

First we want to thank the General Assembly and the Administration for their ongoing support of the Connecticut Home Care Program for the Disabled as well as other programs that assist individuals with disabilities including those with multiple sclerosis.

The National MS Society urges you to pass SB229, An Act Concerning Medicaid Long-Term Care Coverage for Married Couples and SB 230, An Act Concerning Community Choices for Long-Term Care and Disability Services.

Multiple sclerosis is one of the most disabling illnesses that impacts families that are between the ages of 20 – 50. We know that approximately 30% of people with MS will have a need for Long Term Care at some point during their life. The financial impact of MS is exorbitant; the average annual costs for someone with MS in the U.S., including both direct and indirect costs (i.e. lost wages), is approximately $69,000. Of this, approximately $39,000 consists of health care costs. Total costs for all people with MS in the U.S. are approximately $28 billion annually.

I could quote a number of studies that focus on the economic, physical and emotional aspects of living with multiple sclerosis in a family; instead I come to you today not only as a health professional, but as a family caregiver. I serve on a number of task forces and committees including the Money Follows the Person Steering Committee and i am the family caregiver representative to the CT Long-Term Care Advisory Council.

I have been married for 21 years to my husband who is now paralyzed from the neck down from multiple sclerosis. For the past 12 years, my husband has needed extensive care. His health is very fragile; he is at risk for aspirations and infections. It takes two hours to feed him each meal and I must also assist him with his bowel routine. We use a hoyer type lift, oxygen, hospital bed with a support surface to avoid bed sores, an electric wheelchair and he needs 24/7 care. My mother in law stays with us so I can work during the day; she is 75 and is ignoring her own health problems because of my husband's needs.

My husband has been on the Medicaid Personal Care Assistance Waiver Waiting List for 14 months (his slot just came up a week ago). We have been paying privately for personal care assistance services plus other medical expenses for many years. We have exhausted just about all of our savings and we cashed in his 401k over the summer. Our expenses have been astronomical and in 2011 they exceeded $30,000.

Since we received the good news that my husband's name has come up for the Medicaid Personal Care Assistance Waiver; I now have to apply for full-blown Medicaid for my husband. Even though I work in human services, I am frightened and fearful that I could make a mistake with the Title 19 application.

SB 229 provides a layer of protection so that married couples, like us can have a little hope for the future. For people in my position the only true savings I have is my 403b. If this bill does not pass, I will loose part of the 403b.

We are told to save for the future, but yet families living with disabilities that need to rely on Medicaid to cover long term care expenses must impoverish themselves.

As we work to expand home and community based services for people across the lifespan, we must provide a mechanism to prevent total impoverishment for the "community spouse".

The National MS Society respectfully urges the General Assembly to pass SB229 and SB230.

Thank you.