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**Testimony
Medical Inefficiency Committee
Informational Forum
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Mr. Kinsella, Ms. Woodsby and distinguished members of the Medical Inefficiency Committee,

Thank you for the opportunity to share our perspective about the proposed changes to the definition of medical necessity in the Connecticut Medicaid program.

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 MS and their families in Connecticut.

For people living with multiple sclerosis and other chronic or progressive diseases, "medical necessity" or "medically necessary" means:

- **Preventing, evaluating, diagnosing, or treating the disease and its symptoms**
Multiple sclerosis is a chronic disease of the central nervous system. The cause is yet unknown, and there is no cure. The symptoms—including fatigue, impaired ambulation, visual disturbances, bowel and bladder problems, cognitive changes, and more—vary from one individual to another and for any given individual over time. Access to a quality, coordinated approach to prevent, evaluate, diagnose, and treat the disease will help assure that the best combination of health care and other services is provided for people with MS, in a way that is **clinically appropriate and considered effective for the disease**.
- **Maintaining an optimal level of health or preventing the *worsening* of conditions**
MS is a progressive disease. To *maintain* a consistent and optimal level of health means you are fighting the progression and the condition is not worsening. An individual might not be getting better, but for an incurable progressive disease like MS, that might never happen. Maintaining health is critical. To treat MS, it is medically necessary to **prevent the worsening of, alleviate, or correct the course of the disease**.

Physical therapy and occupational therapy help maintain an optimal level of health. They also help maintain the person's **capacity for normal activity**. Therapy cannot just be available for restorative purposes. Therapy has been clinically proven to help individuals with MS maintain current mobility and muscular strength.

Over...

Nearly a quarter of individuals living with MS will require **long-term care supports and services** at some point during the course of the disease. Medicare does not cover long-term care services and supports. Long-term care is necessary to keep individuals **independent, in the community, and functioning at the highest possible level**. That includes a continuum of preventative, diagnostic, rehabilitative, therapeutic, supportive, and maintenance services to address the long-term health, social, and personal needs of individuals with a chronic disability or disease such as MS.

- **Ensuring mental health**

Experts and people living with MS agree that there are **many mental symptoms of MS**. In fact, studies have suggested that clinical depression, the severest form of depression, is more frequent among people with MS than it is among the general population or in persons with other chronic, disabling conditions.

- **Preventing interference with capacity for normal life activity**

MS is an often-disabling disease most often diagnosed between the ages of 20 and 50. However, MS is not a fatal disease and a vast majority have a normal life expectancy. When someone lives most of their life with this disease, it makes the **need for normal life activity** even more important. Many people with multiple sclerosis rely on the technology of wheelchairs, scooters, and other devices or medical equipment to get out of the house, go to work, contribute to the community, run errands, and simply enjoy life. That allows for better safety and functionality, supports rehabilitation, improves quality of life, and reduces the burden on caregivers and on the community.

More than half of people with MS require some form of assistance with daily activities. Informal caregivers, usually family members, provide 80 percent of such care. **Home-based care** is important for individuals living with MS because it helps maintain **normal life activity**. It also helps individuals **remain in the community longer**, rather than having to live in an institution or residential facility.

People with more advanced MS are at greater risk for certain kinds of complications. Examples include:

- Osteoporosis (loss of bone density related to reduced mobility and weight-bearing exercise, as well as treatment with corticosteroids);
- Pressure sores (damage to the skin caused by lack of mobility or long hours in a bed or wheelchair);
- Aspiration pneumonia (a problem caused by swallowing problems that allow food particles in to the lungs);
- Severe bladder or kidney infections (resulting from chronic urinary dysfunction).

Our concerns include that if the definition of medical necessity and medical appropriateness is changed by the Department of Social Services it will negatively impact individuals with MS and their families.

It is crucial to include independence and function in a definition of medical necessity. If “independence” is removed or not included in the definition of medical necessity, it will restrict access to many forms of durable medical or assistive technology that are currently covered by Medicaid.

For example, an individual with multiple sclerosis may have significant differences in their ability to function through out the day. In the morning when the person is stronger, he or she may be able to transfer independently to a wheelchair using a sliding board. As the day progresses and the person's fatigue increases, their abilities can drastically change and deteriorate. The same sliding board that worked in the morning can be very unsafe later in the day. Providing a ceiling type patient lift could maximize independence to help the person transfer into bed or use the toilet.

Paralysis, spasticity and immobility are all factors that can lead to skin problems in people with MS. Pressure sores can begin as small reddened areas and it is crucial that a person be able to reposition throughout the day. When they need to reposition, having a rehabilitative type advanced power wheelchair with features like tilt and space is essential for them to avoid pressure sores. These types of wheelchairs are more expensive; however they are a way to prevent further problems. Simply providing a basic wheelchair will not meet their needs and would be wasteful and could cause further damage and be more expensive in the long-run.

Access to assistive technology for people with disabilities makes all the difference between life in a nursing home and living independently. As a member of the Money Follows the Person Steering Committee, we are always reminded that that project looks for ways to create systems change. One of the hallmarks has been work to expand access to assistive technology. The recognition that assistive technology can enhance independence and function is now widely accepted within the disability community.

If DSS changes the definition of medical necessity and removes the independence perspective, this could totally destroy the important work of many disability advocates and independent living activists. It will also be a giant step backward for projects like MFP that are creating positive change and saving money over the long haul.

Access to medications is also crucial for individuals with MS.

For example, currently the preferred drug list under Medicaid includes baclofen as a “skeletal muscle relaxant”. This class of medications is much more complex than what is included on the PDL. Baclofen is an antispasm medication which is much more specific than a general “skeletal muscle relaxant”.

We know that spasticity is a huge factor for people with MS and other central nervous system types of diseases. The other products commonly used for spasticity were not included on the PDL. Each medication works differently, each has a different side effect, and different people respond differently.

Baclofen, for example, can often help attenuate the spasms and tone, but may not be enough as a single agent. Tizanidine can be used in combination with baclofen, or alone, and is an important option for patients with MS to have. Dantrium is unique in that it acts

at the level of the muscle directly- and not centrally, thereby offering advantages for treatment- especially in those people not helped by baclofen and or tizanidine.

There are very few medication options for treatment of spasticity. General muscle relaxants are not specific for true spasticity and are not effective for denervated muscle.

By listing tizanidine and dantrium with a "non-preferred" status", this creates more challenges to obtaining the medication. A provider must jump through huge amounts of paperwork and frustration to get the products authorized. Our members often give up and don't have the energy or resources to complete the process of getting these medications.

Another concern in changing the definition of medical necessity lies in requiring scientific proof or evidence for access to a therapy or medication.

Almost every medication used to treat a symptom of MS is prescribed off label. This means that the U.S. Food and Drug Administration ruled the drug safe and effective for another medical condition, but did not specifically approve it for use with MS. For instance, beta blockers are approved for treatment of high blood pressure and migraines, but they also help to reduce some tremors. Doctors often use these medicines "off label" to treat tremors in MS.

MS is an autoimmune disease and current medications to treat the underlying disease focus on modifying the way the immune system works. Although we have six medications approved for this aspect of MS, not all work for everyone. Some physicians have actively prescribed chemotherapy to suppress the immune system as a way of stopping the immune attacks in MS. Some chemotherapies are being used off label and their effectiveness may not be documented in journals but they can be helpful on an individual basis.

As stated earlier, MS is a disease that impacts individuals differently. Health care providers must be able to tailor their treatments and recommendations on a per patient basis. We must not remove that aspect of medical necessity.

These are just some examples of the types of situations where modifying the definition of medical necessity will negatively impact individuals with MS.

We are asking DSS to work with the Medical Inefficiency Committee as required by the legislation. The committee's recommendations come from many perspectives and bring immense expertise to the table.

Thank you.