



January 30, 2015

The National Multiple Sclerosis Society supports the full expansion of Medicaid in all states so that more people affected by multiple sclerosis (MS) have access to quality, affordable comprehensive healthcare. The Healthy Utah plan proposed by Governor Herbert would extend coverage to thousands of Utah residents who currently fall within the coverage gap. The Society sincerely appreciates this progress but is concerned about some of the proposal's real world impact on vulnerable Americans—some of whom live with MS.

MS is typically diagnosed between the ages of 20 and 50, when many people are building a career and maximizing their earnings. Due to worsening of MS symptoms such as extreme fatigue, vision problems, bladder and bowel problems, cognitive changes and numbness/paralysis, only 40% of people with MS are in the workforce ten years after their diagnosis. This population ultimately loses not only their wages, but also their access to employer-provided health coverage. For people who fall into a coverage gap, or for those who have spent down their earnings and savings, Medicaid can provide a vital safety net, ensuring access to a wide range of services that people with MS depend on such as rehabilitative services, prescription coverage and home and community based services.

The positive impacts in states that expanded Medicaid are already being felt on numerous fronts—for example, adults experiencing significant reductions in delays accessing healthcare. For those diagnosed with MS, being able to access treatment early and as needed is critical to maintaining optimal health and ideally delay the onset of disability. We applaud Utah for taking steps to insure more residents including people with MS, but are concerned specifically with the work requirement provisions embedded in Utah's Medicaid reform proposal. Work requirements proposed or imposed in some other states have/will serve as impediments to the Society's goal of affordable, comprehensive, quality health coverage and will often result in higher long-term costs to the U.S. healthcare system.

We appreciate, for instance, that Utah is planning to exempt medically frail individuals from the work requirement and automatic referral for job training, but would like more detail around its definition of “medically frail.” We would hope that those living with progressive MS and/or experiencing extreme MS symptoms and exacerbations would fall within the definition. Furthermore, we hope that the definition is flexible—taking into consideration the episodic nature of some diseases such as MS, when individuals can be fairly healthy and able to work one week, followed by sudden and profound symptoms the next (such as paralysis or blindness) that interrupt their ability to work. As Utah continues to shape its work requirement, the Society also urges the State to not withhold or delay other vital benefits in relation to and as a penalty for work requirements. Many vulnerable people with disabilities including MS rely not just on health coverage, but other supports for basic necessities and day-to-day life such as buying groceries or paying utility bills. Withholding life-sustaining benefits could impact not just the person with MS, but caregivers who also may rely on such support.

The Society stands with Utah in its desire to provide quality, affordable, comprehensive health coverage to more of its residents. When doing this, however, we urge Utah to not forget the fundamental purpose of the Medicaid program—to serve as a healthcare safety net for our nation’s most vulnerable. Instituting work requirements that do not recognize or penalize people for the episodic and overall serious nature their disabilities undermines this essential function—in turn, injuring personal health and increasing overall healthcare costs. The Society hopes to work with you to alleviate these concerns and work towards our mutual goal of affordable, quality, comprehensive healthcare for more Utah residents.

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