

HB 1233

Summary: The bill creates the respite care task force to study the dynamics of supply and demand with regard to respite care services in Colorado. The majority and minority leadership of the Senate and House of Representatives shall appoint 9 members to the task force, who shall serve without compensation. The Department of Human Services is directed to provide staff support to the task force. The task force is required to submit a report to the general assembly by December 1, 2015.

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Testimony HB1233

Good afternoon, my name is Lynn Robinson. I am President of Easter Seals Colorado and one of the members of the Colorado Respite Coalition. I am here today to document and help illustrate the need for a task force to study the need and availability of respite in Colorado.

To help describe those impacted by this bill I would like to share a quote by former first lady Rosalynn Carter that may help you and others relate to the issue of caregiving.

**“There are only 4 kinds of people in the world-
Those who have been caregivers,
those who currently are caregivers,
those will be caregivers,
and those who will need caregivers.”**

I believe this bill is a much needed first step in helping to better document the availability and demand for respite services.

We know that at least 843,000 Coloradoans are family caregivers, according to the Family Caregiver Alliance, and that number is considered a low estimate. According to AARP, caregiving in the United States represents an industry valued at \$450 billion a year, which is more than Walmart's yearly profit. As the baby boomers age and diagnosis rates of autism and chronic disease rise, the concern for long-term strategies for addressing the needs of our family caregivers has never been higher. The needs of the caregiving population will impact families, communities, businesses and the government entities. For every \$1,000 spent on respite care, there is an 8% drop in hospitalizations, a significant cost savings to taxpayers, according to the National Respite Coalition. Without a strong, comprehensive plan for caregivers and their loved ones, Coloradoans with special needs can be at risk for increased institutionalization such as nursing home placement, severe financial burden and diminished quality of life.

Chances are each one of you knows or is a family caregiver. Maybe your siblings are helping to care for an aging parent, or your neighbor has a child with autism. Maybe your colleagues have had to face a tough diagnosis for a spouse or partner, or have taken on some of the care responsibilities for their grandchildren. We all see caregivers every day, but may not be aware of the toll it can be taking on them, and ultimately our state.

Respite care provides family caregivers with an opportunity to take a break, knowing their loved one is in good hands. It has many forms – from an adult day program to a week long summer camp to a professional caregiver providing support in the home. Even an hour of respite a week can make a huge difference for families. Respite preserves families, reduces caregiver stress and can help prevent incidents of abuse and neglect, according to the FRIENDS National Resource Center for Community-Based Child Abuse Prevention. As the Colorado Respite Coalition tagline says, respite for caregivers equals better care for their loved one.

Despite the clear need for access to respite care, many families have never been able to utilize the service. Many families have reported to Easter Seals Colorado that the barriers to respite include financial limitations, lack of qualified providers in their area and lack of knowledge regarding the specific condition. In a 2004 study conducted by the ARCH National Respite Network, of 1,245 caregivers, only 5% had ever received respite care. In addition to the families not accessing respite care at all, many families report feeling underserved. Funding may limit families to an hour or two of respite per month, when they really need much more. In our experience through the Colorado Respite Care Program, very few families truly feel their respite needs are met 100%.

A respite care task force will help determine a more accurate picture of the number of caregivers in Colorado and their needs, both short-term and long-term. Ultimately, the task force will help create the strongest possible strategy for addressing caregiver needs, from supports and resources for caregivers themselves to increasing the number of trained respite care providers statewide.

At Easter Seals Colorado and through the Colorado Respite Care Program, we see the effects of special needs on the entire support system. Families feel the impact in many capacities – physically, mentally, emotionally and financially. In many situations, caregivers of older adults are juggling care responsibilities for their parents as well as their children and grandchildren, who often have special needs themselves.

Caregiving has a strong impact on employers as well. According to the 2005-2006 National Survey of Children with Special Healthcare Needs, nearly 24 percent of families with children who have special needs choose to cut back or stop working altogether. On average, each caregiver loses \$659,000 in a lifetime due to lost wages and benefits, and missed promotions as shown in the National Caregiver Library's *Business, Caregiving and the Bottom Line*. On a larger scale, U.S. businesses lose up to \$33 billion annually due to the lost productivity of employees who are also caregivers, according to a 2006 MetLife survey.

Caregiving impacts the entire community, and as the need for family caregivers rises dramatically in the coming years and decades, the impact will be even more widespread.

Caregiver health is also a major concern for long-term caregiver support. According to *Caring Today*, family caregivers are more than twice as likely as non-caregivers to suffer from a chronic condition. Caregiver stress can take up 10 years off a person's life – and often, caregivers pass on before their loved ones, according to a study from the Stanford School of Medicine.

Caregiver health concerns go far beyond physical conditions. The mental and emotional health of a family caregiver is just as important, especially in making the best care decisions for their loved ones. Access to regular respite care is crucial to supporting a caregiver's physical, mental and emotional health. Family caregivers are crucial to keeping individuals with special needs in their homes, living active and meaningful lives in their community. Without caregiver support, people with special needs are more likely to be put in costly long-term care facilities and face incidents of abuse and neglect. The need for a respite care task force to determine next steps in supporting caregivers, and their loved ones, is at an all-time high.

The development of the proposed respite care task force is necessary to begin facing Colorado's caregiving challenges. Public and private sector entities must come together to strategize long-term goals and ideas from the first day of planning through the many years of implementation. As an advocate for caregivers across the lifespan, I support the involvement of diverse representatives to serve on the task force. Easter Seals Colorado and the Colorado Respite Coalition hope to serve on the task force, as a representative of persons with chronic, long-term and disabling conditions across the lifespan.

The proposed bill would not be a luxury for Colorado – it is an absolute necessity. A long-term plan supports all Coloradoans, from the individuals with special needs to their struggling family caregivers and the businesses who employ them to the professional providers giving the caregivers a chance to breathe. We need to take the first step to develop a plan and secure supports and resources today, and that starts with a respite care task force.