

**HB16-1398**

Title: CONCERNING THE RESPITE CARE TASK FORCE RECOMMENDATIONS  
AND THE FUNDING NEEDED FOR IMPLEMENTATION

Sponsor: Rep. Young, Rep. Landgraf

**Testimony HB1-1398**

Good afternoon, my name is Lynn Robinson. I am President of Easter Seals Colorado and a member of the Colorado Respite Coalition. I also served as co-chair of the Respite Care Task Force, which submitted its recommendations to the legislature in January. Additionally over the last 17 years I have been a caregiver for a family member.

I am here today to document and help illustrate the need for implementation of the recommendations made by the Respite Care Task Force and the funding needed to ensure these issues are addressed.

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 caregiving.

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

I believe this bill is the next step in helping to serve Colorado’s family caregivers and ensure that there are quality respite care services and

supports available across our state. The process laid out in this bill potentially will provide cost savings to Colorado with regard to health care expenses and we suspect, that it will also prove beneficial by reducing the financial impact on employers whose employees are caregivers.

There are more than 843,000 Coloradans serving as 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 to address the needs of our family caregivers has never been higher. Respite is not an isolated issue that exclusively benefits the caregiver – respite has a much larger impact on the entire community. The needs of the caregiving population impacts families, communities, businesses and 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 resource network for caregivers and their loved ones, Coloradans 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 you and your siblings are helping to care for an aging parent, or your neighbor has a child with Down Syndrome. Maybe a colleague had to face a tough diagnosis for a spouse or partner, or has assumed 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, our communities, and ultimately, our state.

Respite care provides family caregivers with an opportunity to take a break, knowing their loved one is in good hands. Respite has many forms – from adult day programs, to a week-long camp, to a professional caregiver providing in home support. Respite preserves families, reduces caregiver stress and helps prevent incidents of abuse and neglect, according to the FRIENDS National Resource Center for Community-Based Child Abuse Prevention. As the Colorado Respite Coalition slogan states: *respite for caregivers equals better care for our loved one.*

Despite the clear need for access to respite care, many families have never been able to utilize this necessary service. The Task Force confirmed that the barriers to respite include financial limitations, lack of qualified providers in their area, and lack of knowledge regarding the specific condition(s). In a 2004 study conducted by the ARCH National Respite Network, of 1,245 caregivers, only 5% had ever received respite care. Unfortunately many families are unaware the service exists, though we have seen growth in community awareness over the past several years through collaborative partnerships, of government entities, Colorado Respite Coalition and the Chronic Care Collaborative. **According to the 2011 AARP study, Colorado's family caregivers provide 551 million hours of unpaid care annually, valued at \$6.6 billion.** Many of these family caregivers are forced to reduce their hours at work, turn down promotions, or leave the workforce altogether to continue providing care. They often financially contribute to their loved one's care out of their own pocket, far beyond any fiscal support they may be receiving. If even 10% of Colorado's family caregivers – 84,300 caregivers - suddenly were not able to provide care, imagine the incredible impact it would have on our state. Think of the need for increased out of home placements, the need for new transportation options for people still living at home, and the added influx of clients looking for nutritional services such as Meals on Wheels. According to the United States Department of Health

Human Services, the national average cost for a semi-private room in a skilled nursing facility is \$6,235 per month. At that rate, out of home placement would cost \$74,820 per year, for just one individual!

Even when caregivers are able to remain in their employment and family roles, there can be a severe impact on them which frequently translates to increased health care costs. Family caregivers face chronic conditions such as depression, anxiety and high blood pressure at a higher rate than non-caregivers. According to the Family Caregiver Alliance, spousal/partner caregivers aged 66-96 who experience caregiving-related stress have a 63% higher mortality rate than non-caregivers of the same age. **The economic impact of family caregivers cannot be understated, and it is in our state's economic best interest to provide the supports for them that enables them to keep their loved ones at home.**

The Respite Care Task Force addressed many of these challenges in its recommendations, which includes conducting a cost-benefit analysis of respite care; increasing training opportunities for professionals and family caregivers; conducting a statewide outreach campaign to educate Coloradans about the importance of respite care and how to access it; and lastly, collaborating with state departments to streamline respite care regulations thereby, increasing service, reducing duplication, and simplifying regulations.

There is a need for more data regarding respite care services, both nationally and in Colorado. We understand the barriers faced in accessing respite care, and we know how unbearable the financial impact would be to our state without our family caregivers. A comprehensive study could show the cost savings to the state by providing respite care, and also, how respite care services impact caregivers' health and quality of life. An evidence-based research study will improve the understanding of the importance of caregiving and help formulate more cost effective state policies.

At Easter Seals Colorado, we often hear families say they cannot find a respite care provider with enough training to properly care for their loved one, or they have access to funds for respite care but cannot find a provider located in their community. There is a severe lack of respite care providers in Colorado, and we believe training is the first key to addressing this barrier. By developing an inventory of training opportunities for providers statewide, we can increase access to training for current providers and help encourage growth of the professional care provider industry.

Another barrier many caregivers face is understanding what services and resources are available to them. There are many challenges that caregivers may face: whether they do not have access to a computer and online resources, are facing a cultural or language barrier, or are simply so overwhelmed by their constant caregiving responsibilities, causing many caregivers to report not knowing what supports exist in their community or how to access them. By developing a statewide outreach campaign, we can encourage caregivers to seek support and connect with respite resources to assist them in keeping their loved one at home as long as possible.

Many caregivers report feeling like they have to “jump through hoops” to access services, or receive inconsistent information about what services are available to them. The current respite care system is often seen as overwhelming and confusing for professionals who work in the field every day, and even more so for families trying to navigate through multiple agencies. The Respite Care Task Force recommends collaborative efforts among state departments to streamline respite regulations. Streamlining these regulations will not only help families access resources, but will also help provide more consistent referral information for case managers and professionals.

The implementation of the Respite Care Task Force recommendations 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 truly believe these recommendations will have a great impact on Colorado's growing number of family caregivers. Forming the Respite Care Task Force was a good start to better serving our caregivers, but we cannot allow the recommendations to be lost. Without proper support and resources for our family caregivers, Colorado will be in a very vulnerable position in the coming years.

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 next step to implement a plan and secure supports and resources today, and that starts with the Respite Care Task Force recommendations.

My name is Kandice Kramer. I work for the Northeast Colorado Health Department. We are a rural public health agency that serves the six most northeastern counties in Colorado.

I coordinate a respite program for families of children, ages 3 to 21, who have special needs. The Family Recess Respite program relies heavily on grant funding and the in-kind support of approximately 10 partner entities to provide 7 hours of care on scheduled Saturdays in local schools during the school year.

We provide the only respite program of its kind in the 9,200 square mile region that we serve. By working with the nursing programs at the two community colleges in our region, we are able to offer one-on-one care for children who are medically fragile or behaviorally challenging who might not have access to care elsewhere.

In fact, the program originated out of a need identified more than eight years ago by families whose only option for respite in some cases was to admit their child overnight at a local hospital. This is still the case for some families in our region today who are not able to use our program.

Because we offer one-on-one care, Family Recess is limited by the number of nursing students who are available. Grant funding allows us to provide respite training, typically by someone outside of our region, for the nursing students to help give them the appropriate knowledge and tools needed. The day is scheduled far in advance with the nursing directors and families need to confirm their intention to attend at least two weeks in advance. The nursing students are matched with a child and contact the family in advance so they are familiar with the needs of each child.

We understand that it is difficult for families to plan several weeks in advance because often things come up that prevent them from actually attending the respite day. This is also a challenge for the nursing students who receive needed clinical pediatric hours by helping with the respite day.

One of the goals of Family Recess is to provide affordable and easily accessible respite care for our counties. We ask for a minimal contribution from families for children with special needs and their siblings who are cared for by a licensed child care provider.

Surveys of parents who participate in Family Recess indicate that they believe the time their children spend at the respite day is safe and nurturing. As one family reported, "it gives my husband and I time for just the two of us. It is hard to find a qualified person to come in our home so we can have a date. This time means a lot to us. Thank you!"

If our program stopped, more families would need to go outside of the region to seek private pay agencies, which is financially not possible for most, or not have access to services.

Benefits that have been noted are the ability for our parents and caregivers to take care of their own health needs, have better mental or emotional health, have better relationships with their spouses, be better caregivers and parents, as well as a better balance between the demands of work and family life.

One of the parents from our region served on the Task Force in order to share the issues that rural families face. It is a challenge to provide adequate respite supports to meet ALL of the

various needs of the families across our geographically isolated six counties. Because our providers are only in Logan and Morgan Counties once a month, some families drive more than 160 miles round trip, across one or two counties to access the hours of respite that we can provide. We know that the distance and lack of transportation can be a barrier. We also know that our program may not be ideal to meet the diverse cultural and language needs of our growing immigrant and refugee population.

Living in rural Colorado, our families faces inherent disparities that create stress. Based on health indicator data, we know that compared to the average for the state, our six counties have lower median incomes, higher percentages of individuals enrolled in Medicaid, higher rates of children living in poverty and on free & reduced lunch programs at school. Groceries, especially healthy foods like fresh produce, tend to be more expensive than urban areas, contributing to the food insecurity that many of our residents face. We struggle with an out-migration of our young people and a growing population of aging adults who have greater needs for care. The lack of affordable, quality housing and childcare across the region creates additional barriers. Our region faces shortages in a range of providers – primary care, medical specialists, and mental or behavioral health care to name a few.

Being a care giver for a loved one who has special needs in our rural area increases all these stressors exponentially. In fact, research done at the University of Wisconsin-Madison, published in the Journal of Autism and Developmental Disorders, has shown that mothers of individuals with autism have stress levels similar to those of combat soldiers.

Without increased access to respite care, we know that the risks increase for our families to face greater suffering. We worry about greater breakdown of families, higher divorce rates, parents pushed past a healthy level of frustration, the emotional impact of siblings put into the position of being a caregiver, poor health outcomes, being forced to move outside the area, the double bottom line impact that it can have in our workplaces, or parents giving up their rights to their children with special needs altogether to be placed in a residential setting or with a family member such as a grandparent.

All caregivers need a break now and then, to have time for themselves away from the responsibilities of caring for their loved ones. This is even more true for parents of children with disabilities or chronic illnesses who are providing care or on-call 24 hours a day, 7 days a week, 365 days a year. However, respite care is more difficult to access due to a lack of trained providers and funding support. Increased supports and services for planned respite care is one way we can offer a break for parents of children with special needs.

Thank you.



Coral Cosway  
Director of Public Policy and Advocacy  
Alzheimer's Association of Colorado

### **Testimony on HB16-1398, Respite Care Task Force Implementation**

The Alzheimer's Association supports HB 1398 because quality respite care services are a critical part of caring for a loved one with Alzheimer's in the community. This is why staff from our organization served on the Respite Care Task Force. We want to thank Representatives Landgraf and Young for this effort to move the group's recommendations forward.

Alzheimer's Disease is the most common type of dementia, and 92% of people with dementia rely on informal care providers in some way. That's why this issue is so important to the families we serve.

One critical aspect of quality respite care is training. It's essential that respite care workers be trained to handle the specific needs of populations utilizing their services. For example:

1. The cognitive decline inherent with Alzheimer's means the person being cared for may not understand some or all of what is going on around them and have difficulty expressing their needs to the respite care provider.
2. Additionally, many people living with Alzheimer's experience mental health issues, such as depression or anxiety that may manifest as inappropriate or difficult behavior.
3. Alzheimer's can also cause rapid mood swings and personality changes. When they occur in a negative way, the person can suddenly become confused, suspicious, or fearful.

Colorado's respite care workforce must have sufficient training to be able to handle these and other situations common among people with Alzheimer's and other illnesses impacting cognitive function. We strongly support the training components of this bill so that our families can be assured that Colorado's respite care providers are equipped to care for their loved ones.

On behalf of the 67,000 Coloradans living with Alzheimer's Disease, we thank you for discussing this topic today, and I ask that you vote 'yes' on this bill.