

# RESPITE CARE:

Support for those who care the most

## THE FACTS

**1 out of every 5 Coloradans live with a serious short- or long-term medical condition**

such as autism, chronic illness or mental health conditions.



They depend on help and support from more than



**800,000 caregivers here in Colorado.**

**Respite care provides support and relief for family caregivers so they can:**

- Attend to their own health needs
- Maintain responsibilities and employment
- Provide a meaningful and healthy life for those under their care

Given respite care's critical role to the health care system, its

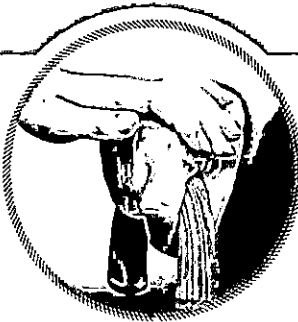


**\$6 billion in economic value!**

and its role in improving Coloradans lives, **it deserves more attention and support.**

<sup>1</sup> "Valuing the Invaluable: 2011 Update, The Economic Value of Family Caregiving in 2009", AARP Public Policy Institute

## A DEEPER DIVE INTO COLORADO'S RESPITE CARE NETWORK:



**Why do we need a strong respite care network?**

- Demonstrates cost savings for health providers, insurers and taxpayers
- Improves quality of life for Colorado's more than 800,000 caregivers
- Reduces emergency medical expenses for caregivers
- Strengthens and preserves family units

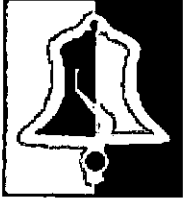
### How we improve respite care in Colorado:

Systematic issues – like funding, access to care and red tape – keep Coloradans from the care they need.

We can improve lives and reduce future burdens to taxpayers by:

- Conducting a return-on-investment study to demonstrate the economic impact of respite care
- Developing a statewide training system for providers
- Expanding the Colorado Respite Coalition's website to serve as a hub for respite care resources
- Developing a centralized community outreach and education program while leveraging existing resources
- Implementing a tax credit to reduce caregivers' out-of-pocket expenses
- Standardizing respite care options across all Medicaid waiver programs
- Streamlining regulatory requirements for facility-based, short-term, overnight respite care





# The Bell Policy Center

**Date:** Apr 15, 2016

**Author:** Natalie O'Donnell Wood

Testimony for the House Public Health Care and Human Services Committee

Madame Chair and members of the committee, thank you for the opportunity to be here today.

I am Natalie O'Donnell Wood, a senior policy analyst with the Bell Policy Center. The Bell is a non-partisan, nonprofit research and advocacy organization founded on progressive values and dedicated to making Colorado a state of opportunity for all.

**The Bell Policy Center supports HB 16-1398, which would direct the Department of Human Services to select a contractor to implement the recommendations of the Respite Care Task Force and sets forth contractor duties. These duties include the development of a respite care training system and ensuring that an economic impact study is conducted. The Bell has been at the forefront of recent state efforts, initiated by the legislature last year, to develop a comprehensive, long-term strategy on aging. Quality respite care is important to achieving that goal. If Colorado creates an infrastructure for and generates good data about caregivers and the support they need, it will benefit our state for generations.**

Colorado is poised to undergo a seismic demographic shift as our state becomes older than it ever has been before. By 2030, the number of Colorado seniors will increase by 150 percent. By 2040, people age 65 or older will make up 19 percent of our population. Approximately 70 percent will have a disability at some point, and half of those over age 85 will need assistance with common home-based tasks.[1]

We will need an adequate infrastructure to support the paid and unpaid caregiver workforce. The Caring Across Generations coalition predicts that by 2020, the state will have roughly 18 people over 65 for every one professional home or personal care aide.[2] The Office of the State Demographer finds that there is currently a low number of and an increased demand for care workers, and that this problem will compound over time. Currently, there are approximately eight to nine potential family members to

provide care to each person over 80 years of age. In 25 years, that ratio will fall to 3.5 to 1.[3] Caregivers themselves will be older, due to the aforementioned demographic shifts. Respite care will be a critical service, and respite training can create a more professionalized, standard approach to offering this support.

We will need better information about what caregivers want and need, and the impact it will have on our state. The AARP offers some insight into economic impact of respite care, estimating that nationally, the value of family caregiving was \$470 billion in 2013. This was more than total Medicaid spending, including the federal and state contributions for health care and long term services and supports, and more than total out-of-pocket spending on health care. In Colorado, AARP estimated that caregivers generated \$7.4 million in economic value to the state per year.[4]

These figures suggest that Colorado could benefit from more comprehensive and diverse information. A study done by Health Management Associates (HMA) for the Respite Services Task Force found that “almost no rigorous data on return on investment in respite services exists, despite overwhelming anecdotal and qualitative evidence” about its benefits.[5] HB 1398 requires the collection of data on respite utilization, the impact on caregivers and cost savings to the health care system, among other categories. The Bell is committed to ensuring that Colorado’s plans for an aging population improve quality of life, protect family integrity and financial security, and reduce costs to the public and private sectors. We thus support the collection of robust data and information such as this to use in shaping those plans.

We thank Representatives Young and Landgraf for bringing this bill to you and thank you for the opportunity to testify.

If you have any questions, or if I can provide further information, please contact me at (303) 297-0456 or wood@bellpolicy.org

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[1]“Colorado’s Care Economy,” Caring Across Generations, August, 2014.

[2]Ibid.

[3]Garner, E. Colorado Population Trends in Aging. Office of the State Demographer, Colorado Department of Local Affairs. 2015.

[4]Reinhard, S., Lynn Friss Feinberg, Rita Choula, and Ari Houser. Valuing the Invaluable, The Economic Value of Family Caregiving: 2015 Update. AARP Public Policy Institute. July 2015.

[5]Respite Care Study Final Report. Health Management Associations, HMA Community Strategies. November 2015.

- See more at: <http://www.bellpolicy.org/research/house-testimony-hb16-1398-implement-respite-care-task-force-recommendations#sthash.JocJnDDY.dpuf>



CHRONIC CARE COLLABORATIVE

*-Advocating for the one in four chronically ill Coloradans*

April 13<sup>th</sup>, 2016

The Honorable Dianne Primavera  
Chair, Public Health Care & Human Services

The Honorable Jonathan Singer  
Vice-Chair, Public Health Care & Human Services

Dear Members of the House Public Health Care & Human Services Committee,

The Chronic Care Collaborative is made up of 34 different voluntary health organizations that advocate for the 1 in 4 Coloradans living with a chronic disease.

There are over 800,000 family caregivers in Colorado and respite care provides a break from the daily responsibilities that caregivers provide. Respite is a necessary service for caregivers to be able to take a 'break' and focus on their own health, personal matters, and general errands.

We ask for your support for HB16-1398 to implement the Respite Care Task Force recommendations to develop an effective infrastructure so that quality respite care can be accessed by Colorado families no matter where they live or what their level of need may be.

The recommendations create effective, efficient ways to provide respite for those Coloradans that may need it. Included in the recommendations are: creating 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 and how to access it, and streamlining respite care regulations with state departments.

HB16-1398 will address the many barriers families face when trying to access respite services and will strengthen Colorado's families and the caregiver resource network that supports these families. Please support implementing the Respite Care Task Force recommendations.

Thank you, on behalf of the Chronic Care Collaborative,

  
Sharon O'Hara  
303-698-5422

Alzheimer's Association, Colorado Chapter  
American Cancer Society Cancer Action Network  
American Council of the Blind  
American Diabetes Association  
American Heart Association  
American Liver Foundation, Rocky Mountain Division  
American Lung Association of Colorado  
Arthritis Foundation Rocky Mountain Chapter  
Brain Injury Alliance of Colorado  
Can Do Multiple Sclerosis  
Colorado AIDS Project  
Colorado Coalition for the Medically Underserved  
Colorado Gerontological Society  
Colorado Ovarian Cancer Alliance  
Crohn's and Colitis Foundation of America, Rocky Mountain Chapter  
Easter Seals Colorado  
Epilepsy Foundation of Colorado  
Hep C Connection  
Huntington's Disease Society of America, Rocky Mountain Chapter  
Komen Colorado  
Leukemia and Lymphoma Society, Rocky Mountain Chapter  
Lupus Foundation of Colorado  
March of Dimes, Colorado Chapter  
Mental Health America of Colorado  
Muscular Dystrophy Association  
NAMI (National Alliance on Mental Illness) Colorado  
National Hemophilia Foundation, Colorado Chapter  
National Kidney Foundation of Colorado, Montana and Wyoming  
National MS Society, Colorado-Wyoming Chapter  
National Stroke Association  
Parkinson Association of the Rockies  
Rocky Mountain MS Center  
Rocky Mountain Stroke Center  
Scleroderma Foundation, Rocky Mountain Chapter  
THRIVE: The Persons Living with HIV/AIDS Initiative of Colorado

## **HB16-1398**

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

Sponsor: Rep. Young, Rep. Landgraf, Sen. Steadman, Sen. Martinez Humenik

### **Testimony HB16-1398**

Good morning, my name is Lynn Robinson. I am President of Easter Seals Colorado, a member of the Colorado Respite Coalition and co-chair of the Respite Care Task Force. I have also been a family caregiver for the past 17 years.

I want to take a moment to talk about what respite care means to a family caregiver. Caring for a family member with a disability can be physically and emotionally exhausting. Respite is a break from continual strain of caregiving. Respite care does not simply impact the caregiver's health and well-being--- there is also a larger benefit. We believe that providing respite care to caregivers is more cost-effective than out of home placement, use of the ER for the care recipient, and may prevent increased incidents of abuse and neglect.

The Respite Care Task Force studied the barriers families face in accessing respite care. The Task Force, represented the lifespan and was statewide. Looking at systems that reduce fragmentation, create a more cost effective process for delivering training, increasing the number of available providers, understanding the value of respite and establishing more consistent rules governing access to respite services are the primary components.

It is crucial that infrastructure for respite care services is built to ensure adequate supports for those with disabilities and chronic health conditions who are unable to live without the supports of a family caregiver. Not only does this tend to keep families together, it results in a reduction of more costly government services. The components in this bill will provide cost savings to Colorado including health care savings and we suspect, reduce the financial impact on employers whose employees are caregivers.

The recommendations for improving the State's respite care infrastructure include:

### **#1 Cost-Benefit Analysis of Respite Care**

Families know how important respite care is, as do many professionals; however, there is limited data on respite nationally, and even less Colorado specific data. We anticipate a comprehensive study will show that respite is cost-effective for the state and that by supporting respite services, out of home placements and hospitalizations are reduced and the quality of life of families facing the challenges of caregiving is greatly improved.

### **#2 Training Component**

We often hear from families that they cannot find a respite provider that is qualified to take care of their loved one. Current trainings are not available statewide and inconsistent. In many parts of Colorado, there are only one or two agencies providing care, and those may focus on a specific age group or condition. We also hear from providers that they must be retrained when they switch agencies. Colorado needs to develop a provider workforce, and the first step is establish consistent, coordinated, high quality training programs. This component will standardize training programs, remove duplicative efforts, increase training access, provide an online inventory of training, and allow providers to effectively serve more families.

### **#3 Statewide Outreach Campaign**

There are more than 843,000 family caregivers in Colorado, but only a small percentage of them know about respite care or how to access it. A statewide outreach campaign is a crucial step to show the many faces of caregivers in Colorado and showcase a centralized hub of respite care and caregiver resources.

### **#4 Respite Systems Standardization**

By working collaboratively with state agencies we expect to simplify difficult funding criteria and establish more consistent respite care regulations, which will benefit family caregivers, professional providers and the agencies themselves. The proposed bill provides the framework for a long-term respite supports for individuals with special needs, their struggling family caregivers, the businesses who employ them and the professional providers.

As an advocate for caregivers across the lifespan, I truly believe these recommendations will greatly impact Colorado's growing number of family caregivers, and will reduce costs to our state in the long run. If we do not provide the appropriate mechanisms to support caregivers, we risk much higher health care costs for those with disabilities as well as for their caregivers.

Forming the Respite Care Task Force was a good start which enable us to identify the barrier, but we should not allow this to be one more task force that makes recommendations that are simply filed away. This is the time to take the next step to implement this plan and work collaboratively to address this fragmented service system today.



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.

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.

## Family Caregiver Testimonials

"I have a 15 year sweet boy with multiple disabilities (from autism to epilepsy and lots more...). The respite program we joined is the most amazing place I have ever encountered! I don't know how they do it, but their staff (every last one of them) is so perfect. They always make my son feel so welcomed and comfortable. He is always happy there! **I would not be able to live without their support!!!** I am able to work and grocery shop (yes, the necessities in life) due to their support!"

- Lisa - Monument, community recreation program

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"When you have a child with a disability, there are so many different challenges to face. School, parenting, health issues, day-to-day care and many other things stack up and can make life overwhelming at times. The respite program became available to my family at a time when the list of challenges seemed overwhelming. They took one item, my daughter's after-school care, and turned it completely around. Instead of being another challenge in our lives – daycare has turned into a helping hand – affecting my daughter's home and school life in a positive way. She is less stressed, has less anxiety, and her needs are being perfectly met. **Respite care has really helped to turn life around** for her, and I cannot speak highly enough of the caring, dedicated staff that work so hard to ensure my daughter is not only cared for, but challenged to be a better person. Thank you for all of your love and support!"

- Daleth - Colorado Springs, community recreation program

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"Our kids adore our respite program! Just today our son was having trouble complying at school. When he was reminded of respite this week, he turned himself around (not easy for an autistic guy), and finished his work! They never want to miss it! As for us, it is a cherished night of "couple time"! Our house all gets excited on the days leading up to Friday! **It is refreshing for the whole family.**"

- Amy - Lakewood, community recreational program

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"I have two daughters with autism. Our oldest daughter is 7 and youngest is 4. My husband and I really appreciate being able to take our children to respite care. **It is nice to get a much needed break from caregiving.** Being parents of two special needs children can leave you hesitant to leave your children anywhere. After one visit we were hooked. Just knowing that our kids are happy and well taken care of makes it easy for us to bring them."

- Meagan - Colorado Springs, community recreation program

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"Respite helped me know my mother wasn't home alone and gave her some **social interaction**. She is mentally able to visit with others, play cards, etc."

- Keri - Grand Junction, day program

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"This respite program has been a godsend for us. We are so grateful that they have taken in our daughter. **She loves it.** The program has been a wonderful break from taking care of her. She used to cry when we dropped her off. Now she doesn't even say goodbye to us! 😊"

- Maria - Denver, community recreational program

"My son Cade lives part time with me, and part time with his mom. Respite allows me to juggle the demands of work and personal time, and without it I'm not sure how I'd manage. **It's impossible to understate the difference respite has made in our lives--Cade included.**"

- *Todd - Colorado Springs, community recreation program*

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"This is the first time I have received respite care services. Our children need a break from us as much as we do from them. **We are happy to see each other and are rejuvenated from having a break.** It's good to have time to miss each other. **The respite we were granted was a lifesaver.** We have no family here and as a result, no support system. If I could afford respite I would use it. It's so nice to know that professionals that know our children are taking care of them so that we don't have to worry. Not just anyone can take care of our kids."

- *Kerry, Colorado Springs, community recreational program*

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"We are so incredibly thankful and would not know what we would do without such a program. It has given my husband and I time to spend together without worrying that she is not in a good environment. **Our daughter comes away so encouraged and happy.** It is an amazing program that allows her to be who she is and to be cared for in such a positive way."

- *Rachel - Littleton, community recreational program*

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"The gentleman running the respite program was awesome and I knew he was super qualified and enjoyed taking care of my son, who was so happy when he came home. **When I was away I didn't need to worry.** I could completely relax and enjoy the time off. It brought my husband and me closer together and **we felt recharged to better care for our son.**"

- *Rebecca - Colorado Springs, community recreational program*

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"My daughter is starting to understand that she is different from other children and that is OK, because there are a lot of "different" children who also have special needs. This respite program is one of the only places where our daughter interacts with other children with disabilities. **Respite brings us all closer.** We can plan for the future and enjoy the present when we have time off from 24/7 caregiving."

- *Michael - Centennial, community recreational program*

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"We are relieved to have someone care for our child that understands his needs. Our provider is doing a fantastic job. We can leave our toddler in her care and not worry. Respite care is such a far-reaching benefit for a family like ours. We knew that having a child would be a challenge since we do not have extended family nearby. When we discovered that our child has special needs, we really didn't know how we were going to make it, but we are making it – one day at a time. And things are improving. **The service has saved our marriage.** We are so thankful."

- *David - Silverthorne, in home respite care*