

March 19, 2019

Dear Senate Finance Committee,

Easterseals Colorado supports individuals facing disabilities and health challenges, as well as their caregivers. As an agency we strongly believe in supporting the entire family as they face health challenges. Family caregivers provide invaluable support, whether someone needs short-term help recovering from a procedure or lifelong assistance. Family caregivers may provide assistance with dressing and bathing, or take their loved one to the doctor each week, or manage their household. From parents of children with special needs, to individuals caring for their own aging parents, caregiving can happen to any of us. In fact, according to AARP, there are currently more than 584,000 family caregivers in Colorado, a number anticipated to increase in the coming years.

Caregiving is an extremely difficult job, and as a state, we need to be innovative in providing support systems for families facing both short-term and long-term care. According to the Family Caregiver Alliance, 60 percent of family caregivers maintain some level of employment. Juggling work and caregiving is already quite a strain for many, and when a crisis arises, it can be nearly impossible to balance both. The problem is that for many families, taking an extended period of unpaid leave time is not an option. The Family and Medical Leave Act provides some job protection, but is unpaid. In fact, in 2017, only 14 percent of American workers have access to some type of paid leave option, according to the National Compensation Study. Whether it is for a new child or a medical crisis, without an option for paid leave, many families are left to make impossible choices.

Imagine having to decide between being by your terminally ill father's bedside in his last weeks or having enough money to feed your family. Imagine trying to balance 40 hours of work and missing crucial medical and therapy appointments for your daughter who was just diagnosed with autism. Imagine trying to focus on your job responsibilities while knowing your spouse is home alone with limited mobility because you can only afford a nurse for a few hours a day.

These are situations Colorado families find themselves in every single day. Paid family leave provides an opportunity for working Coloradans to take the time they need to care for their own health, and the health of their loved ones. Currently far too many families have to make heartbreaking choices that paid family leave could help ease. Nobody should have to worry about keeping lights on at home because they are not able to work while their loved one is in the hospital.

Easterseals Colorado strongly supports the creation of a family and medical leave insurance program, and asks you to consider the many needed benefits FAMLI can provide to Colorado families. Creating FAMLI can help ensure Colorado remains a wonderful place to live, work and support our families, even in the most difficult times. Thank you for your time and consideration.

Sincerely,

Roman Krafozyk, President & CEO

Easterseals Colorado

Good Afternoon,

My name is Kris Lindsey. I am a single mother with two daughters. I work two jobs, one full-time and one part-time, and for many months, I was a full time caregiver for my mother who was nearing the end of her battle with ALS. Balancing these roles, and balancing them well, was incredibly challenging.

Today, you have an opportunity to make a difference for families like mine, caring through the final days of life. I would like to thank you for this opportunity to testify on behalf of the Family and Medical Leave Insurance Program. I strongly believe that this is an important measure to support Colorado's caregiving families. I will tell you of my family's experience of caring for my mother.

Like many older adults, my mother had a myriad of chronic conditions in her final years, with a team of doctors required to manage her health. Overall, she had 10 "regular" doctors including her primary care physician. My sister took on the responsibility of taking Mom to her doctors' appointments, as mom could not safely do it alone. I was responsible for the more miscellaneous appointments, like for her hearing aids, wound care doctor and visits to the swallowing therapist. These appointments, depending on Mom's health, were weekly, monthly, bi-monthly, quarterly or, if all was well, every six months. Overall, my sister easily spent 20 hours a week supporting my Mom in various ways with personal care, transportation, and health management. This level of care was challenging but manageable, and we adjusted to our new normal that lasted many years.

Despite my Mom's health conditions, she lived independently in her own home and was source of strength and joy to her daughters and granddaughters. Between medical appointments and care, we tried to weave in a normal life and build memories together.

In the fall of 2017, Mom's health began to seriously fail. What started with a relatively straightforward procedure to insert a feeding tube ended up as three months of near constant caregiving. With multiple emergency room visits, hospital stays, and hospice care, managing Mom's care was a 24/7 job. This level of care was not optional or a preference, it was absolutely required. With work, school and family, we made big adjustments to meet her needs to help Mom stay at home.

My sister, my oldest daughter and I rotated shifts. My daughter, a college student, would drive more than an hour from Ft. Collins when she could. We administered medication, managed her oxygen and feeding tube as well as helped with her personal care such as using the commode and bathing. This was around the clock care with very limited sleep while we were caregiving. My sister and I found out that 36 hours was our limit for these shifts. The physical and emotional toll on all three of us was tremendous. The rest of life – caring for other family members, bills, grocery shopping, cleaning, work – somehow continued.

My sister and I went to work when we could. Quitting was not an option, as I am the sole breadwinner with a longstanding career in nonprofit work. Luckily, I was fortunate to have an understanding employer with significant personal, sick and vacation time banked. My sister was also able to use her accumulated paid leave and worked staggered shifts to try and keep up with her work. It was not until after Mom passed in December 2017 that I found out my daughter had dropped all but one of her college classes so that she could help with Mom's care. The impacts of being a caregiver were often bigger than we could see.

During this time, my sister and I often wondered how other families with fewer resources kept going. Even then, the stress was tremendous for us. We were prepared and had been doing this for years before things declined. And even with our skills, love and dedication, things were very hard. We were exhausted physically and emotionally and falling apart from our three month experience. We would have failed without accrued paid time off, options for flexible work schedules, and an extended support network. Without those things, I would not have been able to care for Mom the way she deserved.

We were blessed that we could provide regular support to Mom over the years and dedicated care for Mom in her final months. This is not the case for everybody. We can only imagine what others would need to do - give up their jobs or make difficult choices for their family with no right answer.

Every single person, every family in Colorado, needs to be able to do what we did. My children need to be able to do this for me, and their children will need to do this for them as well. As the population ages, caregiving will impact more and more families who need and deserve to care for their loved ones in their final days. The FAMLI bill you are considering today will enable other families, who do not have the means, to care for their loved ones at such a critical time in life.

Thank you.

Kris Lindsey

7335 S. Bannock Dr. Littleton, CO 80120