

Mental Health and Caregiving: How We Can Best Care for Caregivers





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Nationally, [one in five people](#) are providing care to a loved one with a disability, or an older adult. That means that over one million Coloradans are likely providing care. These caregivers represent an important part of the caregiving ecosystem providing preferred, quality care to a loved one or stepping in to provide care due to a lack of other options or the high cost of paid care. While many caregivers experience [positive emotions](#) due to caregiving, for many, it [increases feelings](#) of stress, anxiety, and sadness/depression. In fact, among Colorado caregivers, a recent Bell survey showed that 80 to 90 percent of caregivers report at least “sometimes” or “always” feeling sad, depressed, anxious, and/or stressed. This is particularly important to consider as mental health is [closely tied](#) to one’s physical health and impacts a person’s ability to cope with life stresses and overall quality of life.

It is crucial that we support these caregivers as they provide an invaluable service to so many Coloradans. As such, the Bell Policy Center embarked on research to better understand and address the challenges faced by caregivers and the impacts on their mental health and possible policy solutions. As a result of this research, Colorado should consider ways to bolster respite care, paid caregiving, reduce systemic barriers to benefits, and provide more immediate financial assistance.

About the Data

In recent years, there has been more attention directed to the importance of mental health of caregivers who care for a loved one, often unpaid, and how caregiving impacts mental health and wellbeing. As information becomes more available as to how many caregivers experience feelings of anxiety and depression, little data exists about the use and access of mental health services among caregivers and what supports are necessary for caregivers to take care of their mental health. As such, in partnership with [Easterseals Colorado](#) and Colorado Department of Human Services (CDHS), the Bell surveyed over 180 caregivers across the state and hosted three focus groups to better understand caregivers’ experiences with mental health. The survey and focus groups were available in English and Spanish. For the purposes of this research, mental health care services referred to professional mental health services such as a licensed therapist, counselor, psychiatrist, doctor, crisis services, or support groups.

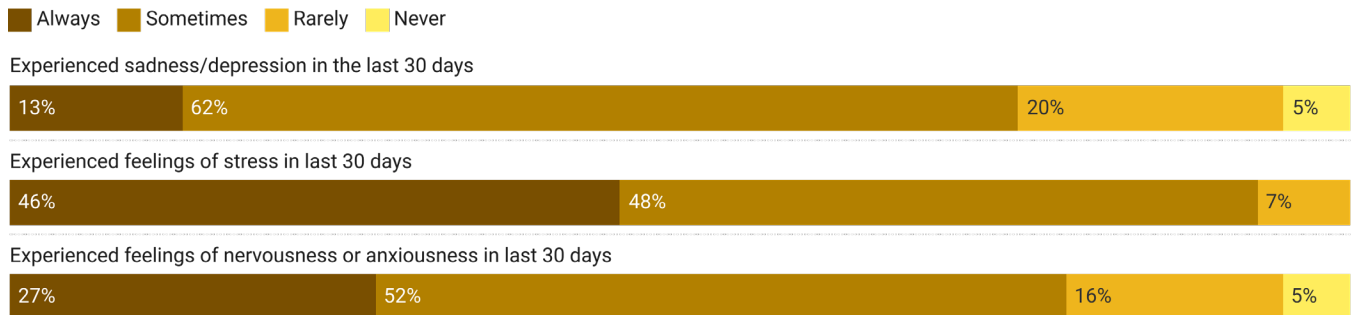


Mental Health and Well-being Among Colorado Caregivers

Feelings of Stress, Anxiety, Sadness, and Depression are Common Among Caregivers

Negative mental health outcomes such as stress, anxiety, sadness, and/or depression are common among Colorado caregivers as over 70 percent of caregivers report experiencing these negative mental health outcomes at least “sometimes.” Importantly, very few to no caregivers “never” experience these feelings, shown in the graph below.

A Majority of Caregivers Express Feeling Anxious, Stressed, Sad/Depressed



Source: Bell Policy Center Mental Health and Caregiving Survey, 2024. *Totals may not add to 100 percent due to rounding.

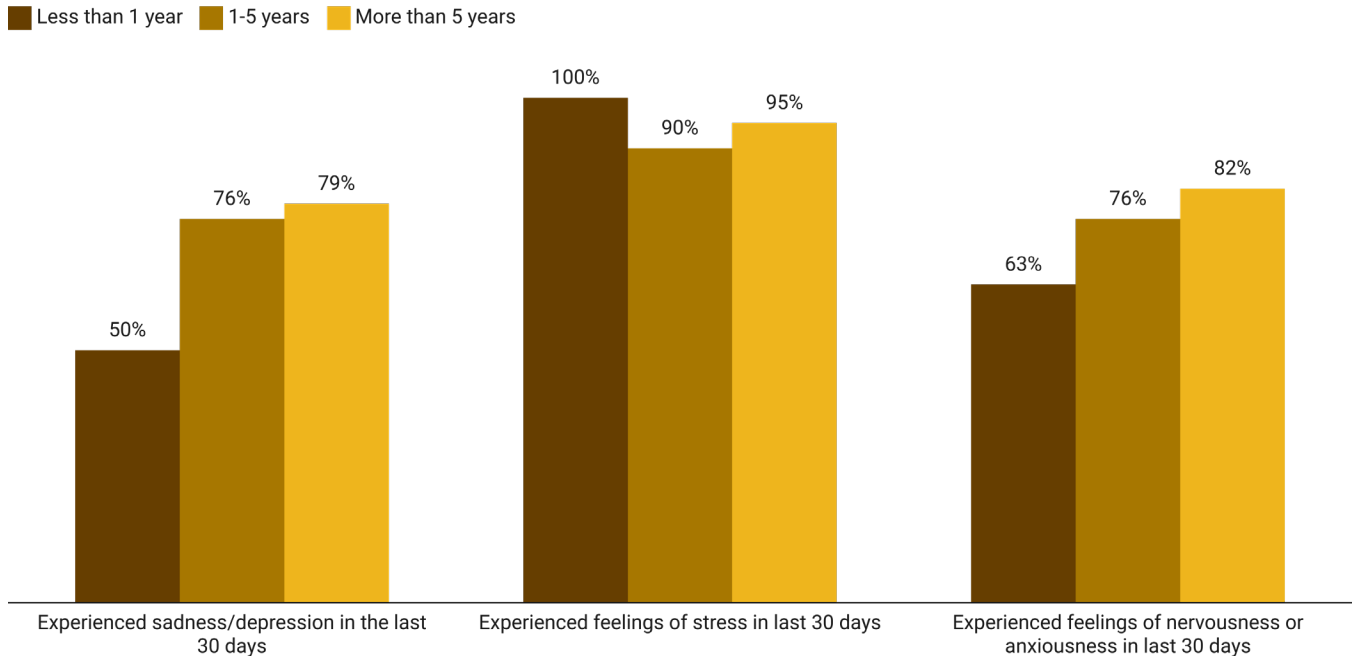
The *persistence* of these feelings, however, varies. For example, a much higher percentage of caregivers, about 46 percent, report “always” feeling stressed compared to only 12 percent of caregivers “always” feeling sad/depressed.

Experiencing anxiety, depression, and stress is not unique to caregivers and many [other factors](#) including [socioeconomic status](#), race, and [physical health](#) affect a person’s mental health. However, [research shows](#) that for many people, caregiving increases the experience of these feelings among other challenging emotions such as loneliness, anger, and worry.

Time Spent Caregiving Impacts Negative Mental Health Outcomes

Among Colorado caregivers surveyed, factors such as the amount of time people have been providing care impacts if or how frequently they experience negative mental health outcomes. The graph below shows that generally, a higher proportion of caregivers experience these negative feelings the longer they have been providing care.

Caregivers' Experience of Feelings Related to Mental Health



Source: Bell Policy Center Mental Health and Caregiving Survey, 2024

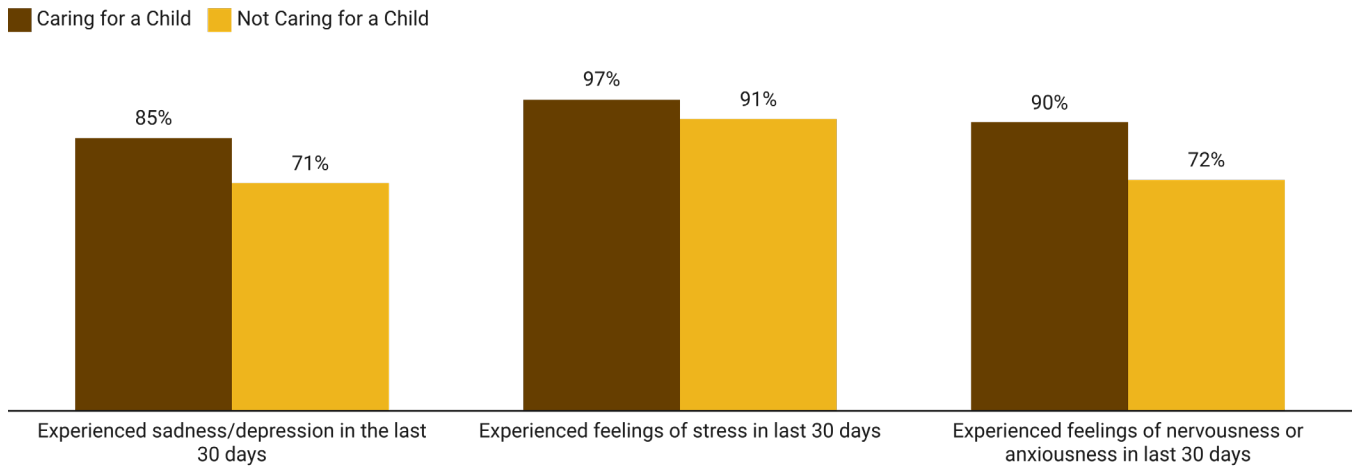
There is a slight departure from this trend as it relates to stress. Overall, rates of stress remain high, regardless of the duration of caregiving. The rate of feeling stressed is highest, at 100 percent, for those who have been providing care for less than one year. One possible reason for this departure is that a new caregiver may experience higher rates of stress than a more “seasoned” caregiver as they navigate a new scenario, find resources, and transition to a new role as a caregiver. The struggle to find resources, particularly around the early stages of caregiving and diagnosis of a loved one, was repeated throughout focus groups.



How the Recipient of Care Impacts Negative Mental Health Outcomes

Some variations in the experience of these negative mental health outcomes also exist depending on who is being cared for. For example, the graph below compares the experiences of negative mental health outcomes for those who care for a child with a disability, to those who are caring for someone who is not a child.

Experience of Feelings Related to Mental Health for Those Caring for a Child



Source: Bell Policy Center Mental Health and Caregiving Survey, 2024. *In addition to caring for a child with a disability, survey respondents could indicate if they were caring for someone with dementia or other cognitive impairment, an older adult, and/or an adult with a disability.

The experience of negative mental health outcomes is notably higher for those caring for a child. It was often cited that there were feelings of anxiety and stress about the future in a way that was not present for other caregivers. For example, sentiments of “who will take care of my child when I am gone” were shared frequently. Still, 70 to 90 percent of caregivers who report caring for someone other than a child report feeling stressed, anxious, and sad or depressed.

Contributors to Feelings of Stress, Anxiety, Sadness, and Depression

Caregiving can impact a person’s life in many ways and has rippling impacts for caregivers, both positive and negative. Caregiving can [strain finances](#), [isolate caregivers](#), and [disrupt their ability to work](#). Therefore, the survey also sought to better understand which aspects of caregiving contributed to their feelings of stress, anxiety, and depression.

The juggling of multiple responsibilities was far ahead of other factors in contributing to feelings of stress, anxiety, and sadness/depression. This was particularly present among focus group participants who shared their experiences in trying to balance work and caregiving. Many caregivers found themselves caught in between needing a full-time job to pay for expenses but not being able to maintain a full-time job due to their caregiving responsibilities. Alternatively, people who did not have a choice in maintaining a full-time job felt like they were unable to tend to other responsibilities, like spending time with their children or other family members.

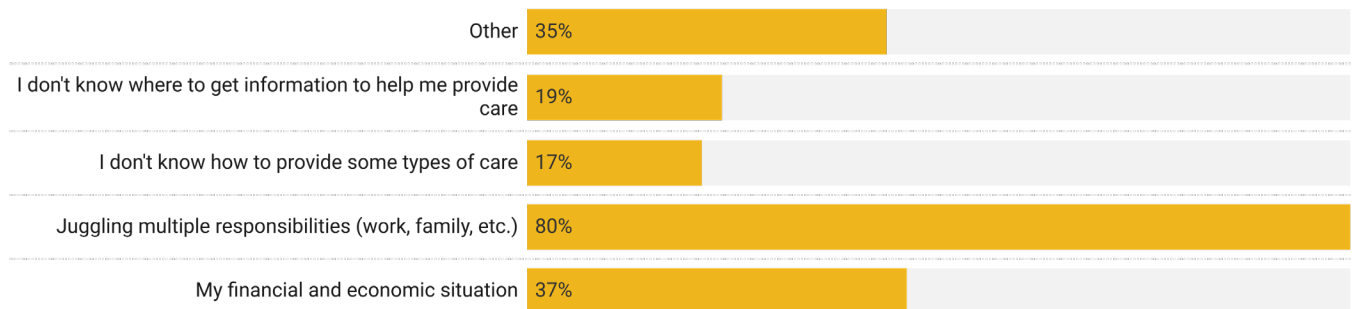
Following multiple responsibilities, the most commonly reported contributors to negative mental health outcomes include:

- Financial and economic situations.
- Not having access to or able to find respite care, day programs, or other resources. [Respite](#) is care that is provided to offer temporary relief or a break to the caregiver. It can be on a one-time basis or ongoing, and allows the caregiver to care for themselves.
- Stress about the future and who would care for their loved one when they no longer can.
- Management of care like documentation, paperwork, and generally navigating the care and benefits system.

The management of care and systemic barriers of Medicaid benefits and the overall care system was a main theme among focus group participants as a stressor with, in some cases, direct impacts on their financial situations. For example, during the reauthorization of benefits, some caregivers noted that their loved ones were denied benefits, in some cases more than once. This not only delayed payments and the necessary financial support, but it could also create additional costs for families. For some families, the delay in receiving benefits meant paying caregivers out of pocket, but some had to go through the court system to appeal the reauthorization decision which is a significant out of pocket cost.



Juggling Multiple Responsibilities is Main Contributor to Feelings of Stress, Anxiety, Sadness/Depression

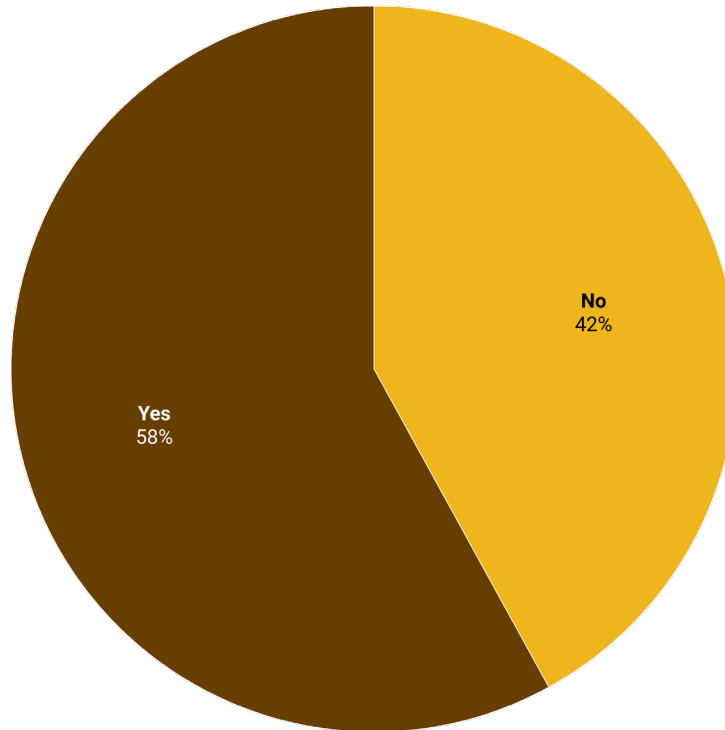


Source: Bell Policy Center Mental Health and Caregiving Survey, 2024.

Current Access and Use of Mental Health Care Services

Encouragingly, 58 percent of caregivers have accessed formal mental health care services, such as speaking with their doctor, a licensed therapist or counselor, or participating in a support group.

More than Half of Caregivers Have Used Mental Health Care Services



Source: Bell Policy Center Mental Health and Caregiving Survey, 2024.

It should be noted, however, that all focus group participants mentioned methods beyond the formal approaches defined in this research. When asked to describe what taking care of their mental health would ideally look like, participants noted informal methods such as meditation, spending time outside, going for walks, and reading. Despite this, for those who were receiving formal mental health care services, the majority (63 percent) said it was meeting their needs.

Regardless of the methods, formal or informal, barriers to taking care of their mental health remain. While caregivers often hear it is important to take care of themselves, the tools and ability for caregivers to do so is often lacking. Forty-seven percent of caregivers who are receiving formal mental health care noted it was not meeting their needs because mental health providers did not understand their caregiving situations or because they did not have the time to receive care frequently enough. Of the 41 percent of caregivers who are not using formal mental health care services at all, only 12 percent cited cost as a barrier, 30 percent reported not needing therapy, but most pointed to not having enough time.

Time was highlighted repeatedly throughout focus groups and is a barrier to caring for one's mental health. In some cases, caregivers identified needing a consistent paid caregiver or respite care to give them more time in the day. Multiple focus group participants noted that despite being able to afford

care, it is inconsistent, and they remain unsure if someone will actually show up to provide care. This results in caregivers being unable to plan ahead and take the time off they need to tend to their mental health. Others preferred to have paid help for domestic tasks in the house – cleaning or having groceries delivered in order to give them time in the day to do their preferred self-care activities to care for their mental health.

Recommendations to Further Support the Mental Health of Caregivers

The stressors and impacts of caregiving that affect mental health and well-being are broad and can be different for every caregiver. While this makes perfect sense as people are in different caregiving situations, it means that there is no one sure-fire way to support all caregivers. Caregivers need more robust support from the state such as investments in respite care, paid caregiving, and support in navigating Medicaid and the state’s benefit system. At the same time, caregivers need immediate support in reducing stressors of caregiving more directly through flexible financial assistance.



Increasing Access to Respite and Paid Care

One of the main findings from this research is that caregivers have very little additional time to complete day-to-day tasks or maintain a job and even less to care for their mental health. Time constraints were stated in combination with the explicit need for respite care. The purpose of respite care is to give the caregiver a break, whether to run errands or just to give them the time to care for themselves. Giving caregivers time in their day allows caregivers to come back recharged and [provide better caregiving, avoid burnout](#), and importantly allow caregivers to engage in the activities they view as positive for their mental health. Despite the benefits, [access to respite care](#) has long been recognized as a challenge. Colorado does [allocate dollars toward respite services](#), though the investment is relatively small and does not meet the needs of caregivers. Increased public investment in respite services would make the support needed more available to families and caregivers allowing them to take the time to care for themselves and their mental health.

Relatedly, increased access to paid care more generally would also allow caregivers to plan and integrate mental health practices into their lives. In Colorado, due to a combination of factors including a workforce shortage and the high cost, there is [not enough paid care](#) to meet the need in the state. This may cause family members to provide more care than they otherwise would have. This also has made it difficult for families to have consistent care. Increased public investment in paid caregiving would, again, allow time for caregivers to take care of their other responsibilities, keep their jobs, and engage in self-care activities that support their mental health.



Improving Resource Navigation Support

Additionally, resource navigation support is needed in two main ways: There is a need for a centralized place to access resources and support, and there is a need for greater support for those who are navigating the Medicaid system.

Many caregivers expressed frustration in knowing where to go and who they might be able to contact to find the resources and support they needed to provide care. Through federal collaboration, a [No Wrong Door System](#) (NWD) was created to simplify access to long term support services and resources. Many states have implemented NWD Systems and [Colorado](#) implemented a pilot NWD System in specific regions in 2015 in partnership with Aging and Disability Resource Centers (ADRC). However, due in part to funding, it was never expanded statewide. Increased funding, outreach, and public education around a NWD System would help address this challenge for caregivers.

For caregivers navigating the benefits system, many noted the documentation of care and necessary paperwork are a major burden. Additionally, the process of reauthorizing their benefits is stressful, they often get denied, and feel that Colorado PEAK, the Program Eligibility and Application Kit where Coloradans can apply for benefits, does not work well with their [Medicaid waivers](#). Medicaid's Home and Community-Based Services waivers are an extra set of benefits for those who qualify to receive long term support services and allows the recipient to remain in their home or community setting. Case managers currently exist to help families and caregivers navigate the benefit system, however many caregivers also explained that their case managers were overwhelmed and often did not provide the support they needed. Having more robust case management can help caregivers understand the paperwork and documentation that is necessary for a smooth application or renewal process for benefits and point them to other available resources.



Direct and Flexible Financial Assistance

Given that the above policy changes will take time, more immediate assistance is needed. Caregivers cited direct financial assistance as the most helpful support in order to care for their mental health. For example, some hoped to create a rainy day fund, cover the cost of nutritious food, pay utility bills, and even to help cover the costs associated with paid care or paid help around the house. Caregiving is expensive and it can be time intensive. This often pulls caregivers out of the workforce, in some cases without the income to cover the costs. Financial assistance that is flexible in its uses would reduce the many related stresses that may come along with caregiving, reduce the need to juggle multiple responsibilities if they can hire help, and provide the opportunity to give time back to the caregiver to care for their mental health. Other states, such as [New Mexico](#), offer a stipend to individuals and their caregivers who do not qualify for support

from Medicaid. Colorado currently has a [Care Worker Tax Credit](#) but it is not available to unpaid, family caregivers. There also exists a [Home Modification Tax Credit](#) in Colorado to help cover some of the out of pocket costs associated with caregiving, but the [allocation remains small](#) and much of it goes unused. Depending on available funds to provide financial assistance, it should be a targeted approach as these stressors disproportionately impact caregivers with lower incomes.

The flexibility of a financial stipend is crucial to its usefulness for caregivers given the responsibilities and tasks that they juggle. While it may seem useful to help pay for therapy or formal mental health care services to address the mental health and well-being of caregivers, it may actually be limiting for many. Until respite care and paid care are widely available to Coloradans, therapy or more traditional mental health services remains, in the words of a caregiver, “another task or another job I need to do” that they simply don’t have the time for.

Additionally, participants from rural areas noted that therapy or other mental health and caregiving resources are generally harder to access in their region. Limiting financial assistance to formal mental health care services, therefore, may exclude many caregivers in more rural areas. If financial assistance were to be directed to formal mental health services specifically, it must still be flexible and broad in the way these services might be used. Caregiving impacts every relationship, whether it is the relationship with their spouse, other children, or other family members. Many caregivers wished they could access mental health support for the sibling of their child they are caring for, or that couples therapy was understood as necessary to their mental health as they undergo what one participant referred to as “extreme parenting” with a spouse.

Flexible Workplace Policies

A majority of caregivers who participated in focus groups noted that they were stuck between needing full-time work to cover general costs of living and the costs of caregiving, but not being able to maintain a full-time job because of the time they needed to commit to caregiving. This puts a unique financial strain on caregivers. Employers should consider flexible workplace policies. Colorado has implemented policies such as paid family leave, known as [FAMLI](#), which is critical to ensuring that family members who are working are able to take paid time off to help care for a loved one. In addition to this, employers should consider [flexible work arrangements](#) such as hybrid or remote workplaces, and job sharing or cross training to ensure flexibility of coverage for caregivers.



Conclusion

[Eighty percent](#) of the care that is provided at home is provided by a family member or friend. These caregivers are a critical pillar of support for families and communities across the state of Colorado. Addressing their mental health is critical not only to their overall quality of life, but ensures they are adequately supported in providing quality care to their loved ones. For caregivers to tend to their mental health and well-being, the state needs to invest in more robust respite services and paid caregiving and help reduce systemic barriers by amplifying existing resource navigation and further exploring a NWD System. There is a simultaneous need for direct and flexible financial assistance so caregivers have the autonomy to decide what is most useful in supporting their mental health whether it be paying for mental health services or paying for grocery delivery while they take a walk.