RESPITE COVERAGE & PRIVATE INSURANCE

ANDREA KUWIK

SEPTEMBER 2019 • THE BELL POLICY CENTER

There's a growing imperative to develop robust supports for Colorado's caregivers providing uncompensated care for friends or family who have trouble meeting their own needs. Respite — temporary care provided by an outside individual or organization so caregivers can have a break from their care responsibilities — must be part of any enhanced support system. Already high demand for respite is only expected to grow as demographic changes increase the need for and value of caregiving.

Despite its importance, many Coloradans have difficulty accessing respite. Obstacles stem from a multitude of interconnected factors including inadequate Medicaid reimbursement rates, workforce shortages, and limited state and federal funding. Fortunately, there's growing recognition Colorado can (and should) do more to alleviate these challenges. In 2015, Colorado's legislature created the <u>Colorado Respite Care Task Force</u> to study how the state can increase access to respite. In 2016, the Task Force released its recommendations, several of which were funded through <u>subsequent legislation</u>.

To build on recent momentum, some advocates have begun exploring how private insurance can be used to increase respite access. Though not officially one of the Respite Care Task Force's recommendations, its 2016 report states Colorado should explore ways to "encourage employers to fund respite services directly or include them in their health benefit plans." This brief examines how the state and advocates can advance this suggestion.

Thanks to assistance from the <u>Colorado Consumer Health Initiative</u> (CCHI), this brief offers an analysis of how respite services are currently covered by private insurance in Colorado, information about the limited action other states are taking to advance this work, and concludes with recommendations for advocates interested in increasing private access to respite. Recommendations include:

- Sponsoring a thorough analysis of respite's benefits and costs
- Educating insurers and businesses on the benefits of respite
- Exploring alternative private-sector funding mechanisms

Caregivers are essential to the health and well-being of our communities. Respite is an important support which allows these men and women to look after their own needs as they simultaneously care for their loved ones. By exploring and moving forward with innovative solutions that increase access to respite, we'll be fostering a healthier, more supportive, and robust state.



Background on Respite

Respite is any temporary relief provided to an unpaid caregiver responsible for looking after someone — including older adults who have trouble with activities of daily living and children with special needs — who can't care for themselves. This service can look different depending upon individual needs and available resources. Respite can be provided in a variety of environments, including in a care recipient's home, in an adult day setting, or an overnight facility. Though always temporary, services can last anywhere from an hour or two to several days.

Who Benefits?

An estimated <u>584,000 Coloradans</u> — approximately 10 percent of the state's population — provides unpaid care for a loved one. Care can include help with everything from medication management and transportation to dressing and meal preparation. This support is essential for older adults and people with disabilities who need some level of help to remain in their homes and communities. Collectively, these unpaid efforts in Colorado represent a more than \$7 billion yearly investment of caregiver time.

Research routinely shows caregivers have:

- Higher rates of depression, anxiety, and stress
 - Greater rates of obesity, infection, and an increased risk of cancer
- Lower usage of preventative care and are less likely to fill prescriptions due to cost constraints

Though many willingly take on this work, caregiving has real financial, emotional, and physical costs. The Colorado Health Institute estimates the collective financial impact of caregiving was \$3.7 billion in 2015. This figure accounts for lost wages and benefits, caregiving expenses, and additional health care costs associated with caregiving.

In addition to the impact on individuals, caregiving also effects businesses. <u>Approximately 60 percent</u> of caregivers are employed, and two-thirds of these individuals report making

adjustments to the way they work in order to accommodate care responsibilities. This can include adopting flexible work schedules, working fewer hours, or leaving the workforce entirely. For employers, these changes can result in high turnover costs, increased absenteeism, and decreased productivity.

While more comprehensive research is needed to determine respite's full value, academic and anecdotal evidence suggests temporary breaks for caregivers can defray some of the above-mentioned expenses while simultaneously improving health outcomes for care recipients. Studies show respite can <u>decrease caregiver stress</u> and depression while also reducing their care recipient's rates of <u>hospitalization</u>, <u>Medicaid use</u>, and <u>institutionalization</u>.

Benefits of Respite			
Caregivers	 Decreased stress and depression Decreased <u>marital and inter-personal strain</u> 		
Care Recipients	 Decreased hospitalization Increased ability to remain in the communities of their choice Increased and more <u>diverse social interactions</u> 		
Employers	More engaged, healthy, and present workforce		
State	 Decreased Medicaid spending Stronger communities and workplaces 		
Insurance Companies	Decreased spending on expensive, acute medical care		



Growing Need for Respite

Already a popular and in-demand service, the need for respite is only expected to grow in the coming years. This is the result of several converging factors, including a rapidly aging population and a decline in the number of available caregivers per care recipient.

Caregivers for older adults are one of respite's main beneficiaries. Importantly, these caregivers are <u>responsible for providing the majority of elder care</u> and play a major role in helping older adults remain in their homes and communities. Colorado is one of the <u>fastest aging states</u> in the country, with the number of adults aged 65 and older expected to grow by over 45 percent within the next decade.

Simultaneously, as the need to provide more unpaid care to older adults grows, the <u>number of individuals available to provide this support is decreasing</u>. In 1990, for every Coloradan aged 80 and older — an age where older adults typically need more care — there were eight potential caregivers. With declining fertility rates, this ratio is projected to decrease to fewer than five caregivers for each older Coloradan by 2030. This drop is expected to continue, and by 2050, there will be only one caregiver per older Coloradan. Combined, these two trends will place more care responsibilities on a concentrated group of Coloradans, in turn increasing the need to develop robust supports for these individuals.

Access Challenges

Despite its importance, many Coloradans have difficulty getting the respite they need. While several factors contribute to access challenges, two important issues directly relate to how respite is paid for.

- Limited funding sources: According to the Respite Care Task Force's 2016 report, the two largest funders of respite in Colorado—outside of private pay—are Medicaid and the National Family Caregiver Support program, a federal program which funnels funding to nonprofit community organizations. Combined, these two programs support 3,500 caregivers less than 1 percent of the state's total caregiver population with \$10.8 million of respite. Not only is this current funding inadequate, but reliance on state and federal monies make respite services dependent upon legislators, who often have limited funds to spend on essential government services.
- Expensive out-of-pocket costs: Caregivers who need but can't access respite through either Medicaid or a nonprofit community provider must pay out-of-pocket for services. In 2018, Genworth shows the average hourly cost of a home health aide (a position fairly equivalent to a respite provider) was \$22/hour and \$138/day. On its surface, these costs may seem relatively minimal. However, reports from AARP show family caregivers spend, on average, almost \$7,000/year on out-of-pocket caregiving expenses. These costs, combined with lost wages due to care responsibilities, can put respite out of financial reach for many caregivers.

The way we currently fund respite in Colorado isn't adequately meeting our state's needs. Access is constrained by what the state and federal government can afford and whether individuals have the ability to pay out of pocket. An already overburdened system, these challenges are only expected to grow as the need for respite expands in the coming years.

Private Insurance & Respite in Colorado

One unexplored approach to increasing respite access in Colorado centers on the use of private insurance. While it's widely assumed private insurance doesn't cover these supports, there has been little formal analysis of the topic. To gain a better understanding of this issue, CCHI conducted an analysis of how private insurance is currently used to pay for respite in Colorado.

Analysis

To conduct their analysis, CCHI used information from Colorado's Division of Insurance (DOI) and the National Association of Insurance Commissioners (NAIC) to assess which insurers — including those offering long-term care, life, and individual/small/large group health plans — in Colorado offer respite benefits. The Center for Improving Value in Health Care (CIVHC) — a nonprofit that, among other things, collects claims data from health care payers throughout the state — provided information on how many respite claims were filed in Colorado throughout the past several years.



Note on Data

While DOI, NAIC, and CIVHC provide a significant amount of information, it's important to note what's not included in these, and any other reliable public data systems. This includes information about:

- Insurance plans: Approximately 30 percent of insured lives in Colorado are covered by an employer-based self-insured health plan. Information about these plans and offerings are not tracked by DOI or NAIC, and as a result, aren't included in CCHI's analysis.
- Respite claims: It's openly acknowledged respite can be difficult to categorize and takes many forms. Simultaneously, a service like home health or overnight care may be prescribed because it benefits the care recipient, while at the same time providing time off for the caregiver. As a result of these two factors, claims data may not capture all instances where a service provided respite. To mitigate some of these concerns, representatives from both CIVHC and Easterseals Colorado provided feedback on which claim codes should be used in CCHI's analysis.

Self-insured health plans, also known as self-funded health plans, are insurance plans that the employer takes responsibility for the cost of employees' medical claims instead of an insurance company.

These plans are typically offered by larger employers, are less regulated, and often have more benefit flexibility.

Since 1999, there has been a gradual rise in the share of employees covered by self-insured plans.

Additionally, information about long-term care and life insurance claims isn't tracked. However, as only <u>11 percent of people over the age of 65</u> have long-term care insurance, the share of respite claims filed through long-term care insurance is likely minimal.

Findings

CCHI's analysis reveals several key findings about how respite is covered by private health insurance in Colorado.

- Health insurance plans offer limited respite: CCHI examined 18 health insurance plans for their analysis. Of
 these plans, 16 offer respite for hospice patients—or those receiving end of life care. However, no plans offer
 non-hospice respite. This exclusion of non-hospice respite significantly curtails the number of Coloradans able to
 take advantage of respite through private insurance.
- Most long-term care insurance plans offer respite: CCHI examined 19 of the most popular long-term care/life insurance plans with accelerated benefit riders (optional life insurance policies which let participants draw down a portion of their life insurance benefits to pay for long-term care). Of these plans, only 4 of 19 explicitly exclude respite coverage.
- Respite claims are minimal: As seen below, there are relatively few respite claims filed through private health insurance, especially when compared with those filed through Medicaid:

Colorado Respite Claims (Cumulative for 2013, 2015, & 2016)				
	Covered Population	Total Claims	Total Expenditures	
Private Health Insurance	<u>1,025,526</u>	151	\$10,306	
Medicaid Waivers	<u>49,775</u>	78,865	\$33 million	

Claims data for both private health insurance and Medicaid from 2014, 2017, and 2018 is not included in the above table because the number of private claims was too small to be captured by CIVHC.

CCHI's research shows many Coloradans can't currently access respite through private health insurance. Instead, to obtain respite, individuals must either meet restrictive Medicaid qualifications, have access to vouchers, benefit from services offered by nonprofits, or be able to pay out-of-pocket. These funding limitations prevent Coloradans who need these services from being able to access them. By broadening how we finance respite, we'll be taking a positive step forward in creating a more robust caregiving support system that benefits Coloradans.



Efforts in Other States

Limited access and funding for respite is a nationwide problem. As a result, it's useful to examine how states across the country are addressing this issue. To ensure a thorough examination of other states' work to expand private access to respite, several actions were taken. This includes examining the work of state-based respite and caregiving task forces; working with Easterseals Colorado to survey members of the <u>ARCH National Respite Network</u>, a national organization dedicated to increasing access to respite services; and exploring recent legislative efforts throughout the country.

Collectively, this research reveals little is being done to holistically grow access to respite through private insurance. Most is piecemeal and aimed at increasing services for specific populations of caregivers. For caregivers of older adults, these efforts center on bolstering access to long-term care insurance, a product which often offers respite benefits. This includes work in:

- Minnesota: Legislators and state agencies have been influential in creating a <u>tax credit</u> for those who purchase long-term care insurance, creating public information campaigns about long-term care insurance, and <u>proposing</u> new long-term care products, which would likely cover respite.
- Michigan and Illinois: Both Michigan and Illinois have commissioned studies to examine the current and future needs of their older adult and caregiver populations. Michigan's study will specifically examine what it can do to increase residents' ability to pay for long-term care. Though they haven't been completed, these studies will likely include information about how private sector support can be better leveraged to finance long-term care.

Parallel efforts to increase supports for caregivers of people with disabilities includes work in:

- Kentucky: Most states require private insurers to cover at least some services for people with autism. While specific requirements vary from state-to-state, Kentucky's mandate is unique in that insurers must cover respite. Autism benefits are limited to \$500 per month per child and the mandate only applies to children between 2 and 21.
- Missouri: In 2019, Missouri became the third state in the country to require private insurers cover medically necessary services—including physical, occupational, and speech therapy—for children with developmental disabilities. Though respite isn't a required benefit, this effort is a step forward in recognizing the unique health needs of different populations and offers a structure which can be built upon in coming years.

Many state-based efforts to expand private access to respite have yet to merge the interests of two primary, but often distinct, groups of caregivers: those caring for older adults and those caring for people with disabilities. However, initiatives are beginning to form that may allow both communities' resources and interests to be leveraged, including:

- Caregiver Task Forces: In recognition of the important role caregivers play in fostering community well-being
 and health, states are creating task forces charged with recommending ways to better support these individuals.
 In the past year alone, task forces to study family caregiving were established in New Jersey and Wisconsin.
 These efforts offer an opportunity to bring together different constituencies to collectively advocate for more
 holistic caregiving solutions.
- Federal RAISE Act: Though not a state initiative, the U.S. Congress passed the federal RAISE Family Caregivers Act in 2018. This act requires the Department of Health and Human Services to develop a comprehensive strategy to support family caregivers of older adults and people with disabilities. One of the plan's required focus areas is respite. When released, this strategy may be able to inform state efforts to increase respite.

In addition to efforts meant to increase respite access through private insurance, there have been corresponding work to create new public financing mechanisms that pay for respite and other long-term care services in:

- Washington: In 2019, Washington became the first state in the country to develop a publicly run <u>long-term</u> care social insurance program. Open to all residents, this program covers a variety of long-term care services, including respite. California is currently considering whether and how to create a similar program.
- Hawaii: Created in 2017, the <u>Kupuna Caregivers program</u> is specifically designed to help Hawaii's working caregivers. Participants can receive up to \$70/day to cover a range of supportive services, including respite, transportation, and adult day services.
- Maine: Though it failed, in 2018, Maine ran a first of its kind ballot measure to create a <u>universal long-term care program</u>. Funded through a tax on high-income earners, residents in need of assistance with at least one activity of daily living would have been able to receive a range of long-term services and supports such as respite, home repair, and transportation assistance.

Throughout the country, efforts to increase private access to respite haven't coalesced into a sustained and cohesive movement. Instead, work is scattered and often exists as part of larger movements to expand services for either older adults or people with disabilities. However, new structures and initiatives offer a foundation upon which to build in the coming years.

Obstacles to Increasing Respite Access Through Private Insurance

In order to increase access to respite through private insurance, Colorado advocates will need to overcome several hurdles, including:

- Lack of awareness about the value and cost of caregiving: Though beginning to change, public awareness about
 the value and costs of caregiving both to individuals and businesses is lacking. For example, research from
 the <u>Harvard Business Review</u> shows employers rarely track, and often underestimate, caregiving's impact on
 their workforce. Without broader awareness of caregiver issues, efforts to develop more comprehensive
 supports will remain challenging.
- o **Insufficient research on respite's value:** While some analysis has been done to quantify respite's value including recent work in Colorado and continuing efforts by the <u>National Respite Network</u> a comprehensive assessment of the service's costs and benefits doesn't currently exist. To expand respite offerings through the private sector, more in-depth research must be conducted.
- Benefit ambiguity: Finally, even for those who recognize and value the service, there are questions about how
 respite, if covered by private insurance, should be structured. For example, in talking with private insurers for
 this report, many had questions about whether the service would be attached to the caregiver's or care
 recipient's insurance policy. Without additional information, these uncertainties will continue to make it difficult
 for insurers to offer respite benefits.

Recommended Actions to Increase Private Access to Respite

Though obstacles exist, there are several actions stakeholders can take to expand access to respite through private insurance. These recommended actions are laid out in more detail below. Notably, none of these recommendations requires support from the governor's office or state agencies. However, efforts will be more effective if the state is involved. As a result, information about what actions state agencies can take is included in each of the following recommendations.



Educate Health Insurers

One of the major obstacles to increasing private access to respite centers on insurers' lack of awareness about respite, its value, and how to create systems which cover the service. Information gaps can be addressed by:

- Conducting thorough assessments on respite's impact and value: It's difficult to convince insurers they should include respite in benefit packages without solid information about how the service impacts their bottom line. As a result, supporters should sponsor holistic and comprehensive research on the value of respite. Insurers should be consulted as these studies are developed so results provide the information companies need to make decisions about whether to include respite in benefit packages.
 - State's role: Colorado's Department of Human Services (CDHS) recently funded an evaluation to study respite's value. This study provided important information, but it can and should be built upon in coming years. CDHS should continue to fund this work, or at the very least, provide technical assistance to help advocates think through how to obtain necessary information.
- Educating insurance companies: As comprehensive evaluations on respite are being conducted, stakeholders should continue to engage with insurers. In conversations with insurance company representatives for this project, it's apparent many in the industry aren't aware of what respite is and how it functions. Industry outreach will build insurers' base understanding of respite, the growing need for these services, how benefits can be structured, and the impact offering respite will have on their bottom lines.
 - State's role: DOI has relationships with insurance companies and an in-depth understanding of the insurance industry. To leverage this knowledge and these connections, DOI should convene stakeholder groups with both insurers and advocates to discuss how respite coverage can be expanded within the private market. However, it should be noted for DOI to play this role, advocates may first need to educate the agency about the value and importance of respite.
- Connecting respite to prevention efforts: In the insurance industry, there's growing awareness of the value in funding preventative care. This interest can be leveraged to increase access to respite. In Colorado, some insurers like Kaiser Permanente, have already embraced a health care model that's meant to be more preventative, holistic, and integrated. Prioritizing outreach to these insurers may be an effective way to build momentum for continuing work.
 - and Financing (HCPF) runs the state Medicaid program, and is one of the largest funders of respite in Colorado. As a result, HCPF can play an important role in furthering the larger conversation about the preventative value of respite and other supportive services for caregivers. Additionally, HCPF and DOI are in the process of developing a new public health care option for Colorado. As these two agencies develop their plan, they should examine and learn from Los Angeles' public health care option. With an emphasis on preventative care, Los Angeles' plan coordinates with social service providers to ensure the provision of several wrap-around services, including respite for caregivers of children with disabilities.

Colorado's legislature approved

<u>HB19-1004</u> in 2019. This bill
requires DOI and HCPF to develop a
new public health care option that
utilizes existing state infrastructure.

Throughout the summer of 2019, DOI and HCPF solicited public feedback and will propose a new public health care option to the legislature in early 2020.

Educate Businesses

Insurers can play a larger role in expanding respite access, but so can private businesses. As a result, stakeholders can:

Educate and inform businesses: Similar to insurers' knowledge gaps, many business leaders don't understand what respite is or its value. As a result, stakeholders should educate businesses about respite and the costs of caregiving—with a special focus on employers that self-fund their employees' health benefits. Feedback from businesses about what type of data would be useful as they're deciding whether and how to support caregivers should be incorporated into ongoing respite research.



- State's role: Colorado's Department of Labor and Employment (CDLE) has deep relationships with businesses throughout the state. To leverage these connections, CDLE should convene employers to share best practices and information on the economic importance of supporting caregivers. However, it should be noted for CDLE to play this role, advocates may first need to educate the agency about the impacts of respite and caregiving.
- Encourage employers' use of other benefit programs: As increasing the provision of respite through private health insurance is pursued, there should be similar efforts around growing access through other employee benefit programs. Specifically, this should include work to increase access to respite through Employee
 Assistance Programs (EAPs). EAPs vary but they generally provide a range of wrap-around benefits to support workers' personal and family needs. Benefits often include helping workers find and access legal and financial counseling, mental health counseling, and child and older adult care. While EAPs aren't overwhelming abundant, they can still be an important mechanism through which to expand respite. To leverage this opportunity, business outreach should include information about which EAPs offer respite and caregiving supports.
 - State's role: As CDLE convenes businesses and advocates, the agency should distribute information and resources about EAPs and other benefit programs which can support caregivers.

Partner with Existent Initiatives

As a final way to expand private access to respite, stakeholders should explore collaboration with ongoing efforts to grow caregiver and care recipient services. Fortunately, there are several such efforts in Colorado, including:

- Area Agencies on Aging: Collectively, Colorado's AAAs represent a state-wide network of service providers responsible for meeting the holistic needs of older adults and their caregivers. Limited state and federal funds combined with a growing demand for their services often require Colorado's AAAs to develop new and innovative financing streams. This includes recent work in 2018 by the Boulder County Area Agency on Aging (BCAA). Partnering with Boulder Community Health, BCAA provided in-home services to older adults at-risk of nursing home placement. This partnership created a new funding stream from fees and payments that came from health care payers and providers. By finding ways to build upon these innovative initiatives, respite advocates can expand their own efforts.
 - partnerships are initiated at the local level. Certain state officials and programs are in opportune positions to recognize these opportunities and facilitate relationships to expand and strengthen this work. This includes officials like Colorado's Senior Advisor on Aging, programs like the <u>Lifelong Colorado Initiative</u>, and bodies like the Strategic Action Planning Group on Aging (SAPGA). As part of their larger work, each of these stakeholders are already helping to coordinate existing initiatives and have an interest in developing supports for caregivers. By continuing to strengthen the capacity and reach of these stakeholders, the state can grow access to respite.

Lifelong Colorado is an initiative created in 2018 by Governor Hickenlooper. This initiative is working to bring together stakeholders from across Colorado to learn from and share locally formed best practices that support healthy aging.

Formed in 2015, SAPGA exists to develop a comprehensive strategic plan to meet the needs and leverage the opportunities associated with an aging demographic. SAPGA's first state-wide strategic plan was released in 2016 and updated in 2018.

What's Not Recommended

Though a mandate requiring insurers cover respite would be a simple way to increase private access to this service, it isn't included in the above recommendations. Currently, there's simply too little comprehensive information about the need for and value of respite. If a mandate is considered in the future, this type of information will be essential for those making decisions about cost, value, and benefit structure.



Moving Forward

Respite for caregivers is already a popular and in-demand service. As Colorado's population ages, and as the number of caregivers per individual in need of support diminishes, the importance and value of respite will only grow. Yet, the current way we fund respite — primarily through state and federal funding — prevents too many Colorado caregivers from accessing the supports they need.

Currently, private health insurance is an underutilized funder of respite. As found by CCHI, no Colorado health insurer covers non-hospice respite care. Fortunately, those interested in expanding access to respite through private insurance have actionable ways to move this work forward by:

- Conducting thorough cost-benefit studies on the value and growing need for respite
- o Educating insurers and private companies about the need to and benefits of supporting caregivers
- o Partnering with ongoing efforts to increase supportive services for caregivers and care recipients

Though advocates can pursue this work on their own, the state of Colorado can, and should, play a role in lending their support to these efforts. Specifically, the state can:

- Convene stakeholders including businesses, insurers, and local innovators to discuss the value of supporting caregivers and best practices in this ongoing work
- Sponsor, or at least support, efforts to evaluate the costs, benefits, and need for respite

By working collaboratively and leveraging collective strengths, Colorado can move forward in creating an environment where every caregiver has the support and resources to look after their own needs as they care for others.

Thank you to CCHI for its comprehensive analysis of how respite is currently covered by Colorado's private insurance companies.



Key Next Steps

Increasing access to respite through private insurance will require interconnected actions from advocates, researchers, and the state.

Advocates: With the most information, knowledge, and interest in expanding access to respite, advocates' involvement in this work is key, and should include:

- Building relationships with state agencies, including DOI, HCPF, CDLE, and the Governor's Office to solicit their help in funding and supporting expanded access to respite
- o Supporting comprehensive evaluations of the need for respite and its benefits and costs
- Educating private insurers and businesses about how respite can be offered and its benefit to their employees and bottom-lines
- o Partnering with existing initiatives that are building support for enhanced caregiver and care recipient services

Researchers: There will likely be little substantial movement on this issue without quality research that speaks to respite's value and costs. As a result, researchers can play an important role in this work by:

o Conducting thorough and comprehensive research that builds upon existing analysis of respite's value

State government: Though their involvement isn't essential for this work to advance, the support of state agencies, officials, and initiatives can bolster efforts to expand the use of private insurance to cover respite. To support this work, the state can:

- o Fund, or at least support with technical assistance, comprehensive evaluations of respite
- Convene private insurers, businesses, and advocates to share best practices and raise awareness about the value of offering benefits which support caregivers
- Consider including respite benefits in the new public health care option
- Encourage collaboration across different sectors and communities to share innovative work and best practices

