

SUPPORTING COLORADO CAREGIVERS THROUGH RESPITE SERVICES

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Executive Summary

Respite care is an increasingly important service, both nationally and in Colorado. An [estimated 584,000 Coloradans](#) are informal caregivers, and provide unpaid care for a loved one over the age of 18. This number is expected to grow in the coming years as our state's population of older adults rises. Both informal caregivers and their loved ones reap multiple benefits from respite care. Despite its importance, Colorado families, through interviews and surveys, cite cost, availability, and their lack of knowledge about options as barriers to accessing respite services.

HB15-1233 created the Respite Care Task Force to study the dynamics of supply and demand with regard to respite care services in Colorado. Among other recommendations in its final report, Colorado's Respite Care Task Force recommended policy changes related to accessing respite care in two specific areas: respite through Health First Colorado, the state's Medicaid program; and respite in a facility-based, short-term, overnight setting. HB16-1398 required the Colorado Department of Human Services (CDHS) to contract with a vendor to implement the recommendations of the Respite Care Task Force. In February 2017, CDHS contracted with Easter Seals Colorado (ESC), which in turn subcontracted with the Bell Policy Center (the Bell) to conduct work on policy recommendations. The Bell's partnership with ESC is focused on reshaping Colorado's lifespan respite care policy accordingly.

[Over 40,000 Coloradans](#) benefit from the state Medicaid program's Home and Community Based Services (HCBS) waiver programs. Respite care is a service offered through all Medicaid HCBS waivers (waivers). Enrolling into a waiver can be complicated and confusing. Challenges may continue for some once they become eligible for services. The Colorado Department of Health Care Policy and Financing (HCPF) has undertaken initiatives to update policies related to respite care. These initiatives seek to simplify and improve Colorado's HCBS system, including creating a clearer, more flexible definition of respite, improving pay for those who provide it, and increasing attention on family caregivers, who are often a key support for someone receiving services at home or in community. The Bell participates in these initiatives and promotes the policy interests identified by the Respite Care Task Force, as shown in Appendix B. However, change through these processes has been slow and is often subject to state budgetary constraints.

Stakeholders consulted by the Bell note families have difficulty finding qualified respite care workers. This challenge will be exacerbated in the future as shifting demographics increase demand for paid and unpaid caregiving. Colorado's health care and social assistance industry, which includes jobs such as home health and personal care aides, [is projected](#) to see rapid growth through 2026. Unfortunately, despite this growth, the state is facing a gap between those needing services and those who provide them. Respite care providers keep care recipients safe and cared for, performing tasks for their care recipient similar to the aid given by these workers. However, [these positions](#) often pay low wages, have unpredictable schedules, and offer few benefits, contributing to high employee turnover rates. Low retention rates concern families who value stability and consistency from the respite workers who are providing care for their loved ones. Colorado's state policymakers can improve pay and job quality for the respite care workforce because they have the ability, among other things, to increase Medicaid provider reimbursement rates and require those increases be passed on to direct care workers.

Families also [report](#) difficulty accessing overnight, facility-based respite care. A 2018 survey of Colorado caregivers revealed over 30 percent of surveyed families would like to use this type of service more. According to interviews with state agency personnel and respite providers, complex licensing requirements from state departments and local zoning regulations are partially to blame for the lack of quality facility-based overnight care. These regulations constrain the ability of providers, especially those serving young children, who want to offer overnight respite in a facility. The cost of meeting regulatory requirements dissuades them from trying to offer it in the first place.

Respite is a vital service for families who are taking care of a loved one at home. This brief offers important background information that can help policymakers better understand the structural needs, challenges and opportunities to providing higher quality and increased access to respite care.

This brief also provides actionable recommendations for Colorado policymakers, including state department staff, legislators, local decision makers, and advocates:

- 1. In concert with stakeholders, HCPF should continue progress towards developing a clear and flexible definition of respite that can be used across Colorado's waivers. The definition should meet the needs of families instead of the program.**
- 2. HCPF should monitor and report on how informal caregivers are impacted by new service definitions in their proposed combined waiver for adults with disabilities. If effective, HCPF should replicate these new service definitions across other waivers and solicit stakeholder feedback in the process.**
- 3. HCPF should ensure a tracking tool is available for all families to help them better and more closely gauge how much respite care they have accessed or used. The tracking tool should measure availability and utilization.**
- 4. Waiver case managers and HCPF should collaborate to develop a system that clearly identifies when a service provides respite for an informal caregiver. For example, personal care is a very popular program in the Elderly, Blind and Disabled (EBD) waiver, however current documentation does not identify if this care could be considered respite for a caregiver.**
- 5. HCPF should evaluate outcomes from 2018 legislation, [HB18-1407](#), that authorizes a direct service provider wage increase for services in three of the waivers, paying close attention to how respite care is impacted. Stakeholders should support and implement an increase in direct service provider pay rates across the remaining waivers.**
- 6. Colorado's health system should recognize and measure the needs of family caregivers. A better understanding of these needs will enable more families to keep their loved one at home rather than seek outside placement. Potential strategies to achieve this goal include assessing caregiver needs through the health system and collecting data through existing health surveys.**
- 7. In consultation with the Colorado Department of Public Health and the Environment (CDPHE), HCPF and the Office of Early Childhood (OEC) should explore the creation of a clear but flexible state respite care license definition in the child care licensing statute (C.R.S. 26-6-100) through the legislative process, with corresponding rule formation and approval by the State Human Services Board.**
- 8. State and local governments should coordinate the development of zoning regulations with child care licensure to ensure safety while allowing for small respite providers to operate in a cost-effective and child-centered manner.**
- 9. HCPF, CDPHE and OEC should study newly launched overnight respite programs in Colorado, such as ESC's latest facility-based program, as a model. They should share best practices from the development of this facility with other providers. Proposed regulatory changes can flow from this model as well.**

Introduction

Caregivers who assist those with special health care needs comprise a large — and growing — constituency in Colorado. Estimates by [AARP](#) show 584,000 Coloradans are acting as an informal caregiver, who are often unpaid and/or a family member of the individual receiving care.¹ This number will rise as Colorado's demographic picture continues to shift and a greater percentage of our population — about [20 percent](#), by 2030 — is comprised of those over age 65.² Additionally, medical advances, new technologies, and an increased focus on serving people in their homes and communities mean both older people and adults and children with disabilities can live longer, healthier lives, in the setting of their choice. Colorado's informal caregivers are more valuable than ever, as their care enables their loved ones to remain in those settings.

These trends point to a growing need in Colorado for respite, or a break from caregiving. Respite, as [defined](#) by the Colorado Respite Care Task Force, is temporary relief for families of children or adults of any age with special needs who are unable or need assistance to care for themselves.³ Respite care can range from a few hours of care provided on a one-time basis to regular care, or even overnight or extended care sessions. It can be provided at home by a friend, family member, volunteer or paid service, or in a community-based care setting, such as adult day care or a respite facility. It can be a planned break from caregiving or occur in an emergency.

Many family caregivers must be available 24 hours per day, seven days per week to ensure their loved ones have the support and tools they need to live their best lives. AARP's "Valuing the Invaluable" [finds](#) "caregiving today is more complex, costly, stressful, and demanding than at any time in human history."⁴ Respite helps caregivers get a break from this important work, which can benefit their health, economic mobility, and their overall well-being.⁵

"If not for respite care, we would have had to look for alternatives for my husband and I want him to stay home. If I had to do this all by myself I don't think we could stay here." -Spousal caregiver in Park County

"For any caregiver who doesn't have a break or respite, they become health challenged and then the person they provide care to ends up in the nursing home. Even if something were to happen to me down the line, I have a plan so my daughter doesn't end up in a nursing home." -Parent caregiver in Arapahoe County

Respite also helps those receiving care. Respite providers enable their care recipients to expand their social networks. Respite providers sometimes have medical training or paid caregiving experience, which helps them identify needs of the care recipient that might have otherwise gone unnoticed. Access to quality respite and qualified providers is also crucial, as it directly impacts an individual's safety and well-being. Caregivers must be able to trust and depend on the individuals providing respite care to their loved ones.

"It's good for my son to be exposed to new people on a consistent basis. [Respite providers] help him develop communication and problem-solving skills and build his confidence." -Parent caregiver in Boulder

"When you're overloaded as a caregiver it's hard to be completely aware of what's going on. One nurse helped us discover our son had broken his arm. It was so important to have another perspective with medical training. It takes the stress off us, knowing our provider is tuned into my son's needs." -Parent caregiver in Boulder

“When our respite provider comes in, he brings a whole new perspective. He is cheerful, uplifting, encouraging. He brings laughter, when maybe we aren’t laughing so much otherwise.”

-Spousal caregiver in Park County

“It’s great for my husband to have someone focused on him. Sometimes I don’t have the energy. One guy used to take him to fish. I would never do that.” -Spousal caregiver in Park County

Thanks to the efforts of policymakers and advocates, Colorado is making strides in increasing awareness of the need for respite care, leveraging funding to provide it, and increasing access to it. [The Colorado Respite Coalition](#), housed within ESC, is a community group formed in 2007 to support families who are caring for individuals of all ages with special needs.⁶ It serves as a resource, reference, and champion for respite care. State and federal funding support families who need respite care. Health First Colorado, through the [Office of Community Living](#) (OCL) within HCPF, and the Lifespan Respite Grant, through the [State Unit on Aging](#) within CDHS and ESC, pay for respite services for some family caregivers in Colorado.⁷

The General Assembly created the [Respite Care Task Force](#) via [HB15-1233](#), which studied the state of respite care in Colorado and issued research-based [recommendations](#) on projects that could be implemented to strengthen the respite care network in Colorado. These recommendations were intended to address some of the commonly perceived barriers that restrict respite care availability and quality for families in Colorado. [HB16-1398](#) required CDHS to contract with a vendor to implement the recommendations of the Respite Care Task Force.⁸ ESC, through a contract with CDHS, is charged with implementing the recommendations. ESC also created an advisory committee comprised of eight community stakeholders and partners, many of whom served on the Respite Care Task Force, to gain feedback on updates regarding each of the four recommendations.

The Bell, through a sub-contract with ESC, is examining ongoing state challenges related to respite care and advancing systemic policy change based on two of the Respite Care Task Force’s recommendations: respite through the state’s waiver system, and respite provided in a facility-based, overnight setting. This research report highlights Colorado’s progress on these goals and offers further suggestions for policy change.

Improving Access to Respite Through Colorado’s Medicaid Waivers

Goal

Work with HCPF to standardize the full continuum of respite care options across Colorado’s Medicaid waiver programs.

Background

Colorado’s waiver programs, which are part of the state Medicaid program, are a critical respite access point for Coloradans. This is largely due to the financial assistance they provide. Colorado families pay for respite care in different ways. Many pay out-of-pocket for respite care. In 2016, family caregivers spent an annual average of nearly \$7,000 on out of pocket caregiving expenses, of which \$550 was attributed to outside care and respite services.⁹

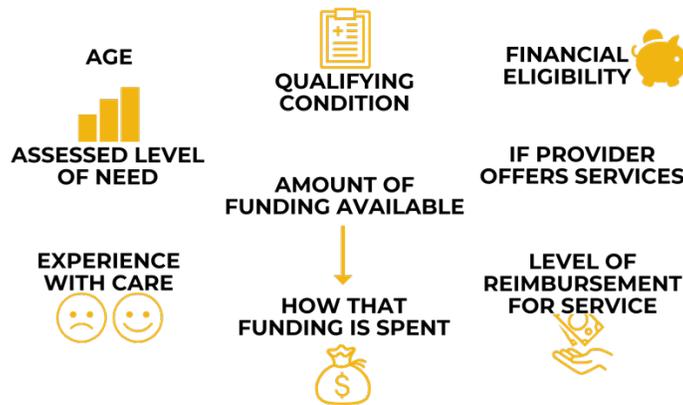
Families pay for other services that can provide them with a break from caregiving but are accounted for separately, such as homemaker services and adult day care or nursing home care. [Genworth’s 2017 Cost of Care Survey](#) showed that the average monthly cost of home maker services in Colorado was \$4,572 and the average monthly cost of adult day health care was \$1,495. Importantly, [research](#) finds many caregivers don’t utilize respite because of issues like cost, limited accessibility, a lack of information, feelings related to lack of trust of outside providers, guilt, or non-identification as a family caregiver. Cost was listed as a barrier to respite care by nearly 50 percent of respondents in a 2018 survey of Colorado caregivers.¹⁰ Additionally, 23 percent of respondents said program and financial assistance qualifications precluded them from accessing respite.¹¹

The federal Older Americans Act allocates some funding to cover respite services for older adult caregivers, or those caring for older adults. Medicare doesn't provide a robust respite care benefit, nor do most private health insurance plans. Most [long-term care insurance policies](#) do cover respite.¹² Unfortunately, only [11 percent](#) of adults over age 65 — about 5 million people nationally — have these policies, and long-term care insurance coverage has been in decline.¹³ According to [state by state long-term services and supports scorecards](#) released by AARP, the SCAN Foundation and the Commonwealth Fund, only 61 of every 1,000 Coloradans over age 40 have these policies.^{14,15} Waivers are the largest source of financial support for respite in Colorado, as they are in most states.

“Respite care is only affordable if provided by Medicaid.” -Caregiver in Elbert County

Waivers allow the state, with the federal government's approval, to provide additional long-term services and supports (LTSS) to eligible Coloradans — services that help someone receive care for his or her condition at home or in the community, instead of in an institution like a nursing home. Waivers aim to keep the care recipient, and his or her needs, as the driver and center of the services, rather than letting the system direct the care. They give vital assistance to the over 44,000 Coloradans who are served by them.¹⁶ And they [provide economic value](#) to the state.¹⁷ Over the past few years, Colorado [spent](#) just over \$16,000 per year on each enrollee receiving waiver services compared to nearly \$60,000 for each person receiving care in a nursing facility.¹⁸ Nearly 40 studies published from 2005 to 2012 [found](#) providing services through an waiver is less costly than institutional care.¹⁹ Other research points to the health and social benefits of care in a community setting.²⁰

Colorado has 10 different waivers (more than most states) and each contains a set of services that are available to waiver enrollees. Respite care is one such service — others include personal care, non-medical transportation, home modifications, day programs, and behavioral therapies. Eight of the 10 waivers allow for a respite care service allocation. The waiver system is complex, and a person's experience in that system can vary greatly depending upon many factors, including:



Colorado has been a leader in providing LTSS, in part because of our efforts to help people access quality care in a community setting. According to the latest [LTSS scorecard](#), Colorado's system ranks eighth best in the country, and ninth best for the share of Medicaid and other state funding going toward HCBS for older Coloradans and those with physical disabilities, with 47.1 percent going toward these systems versus institutional-based care.²¹

Unfortunately, there continues to be complexities and barriers to accessing respite care through the waivers. As detailed in the Respite Care Task Force's 2015 report, these barriers include cost, geographic accessibility, provider shortages, lack of culturally competent providers and those who can care for individuals with high needs, and restrictions on the types and amounts of respite covered under each waiver.²²

HCPF has tried to address these barriers with several different initiatives, the most notable being the formation of the [Community Living Advisory Group](#) (CLAG) and subsequent creation of OCL. The CLAG made many [recommendations](#) to improve LTSS in the state.²³ Several of those recommendations that relate to streamlining waivers were supported by

policymakers and have been implemented, or are in the process of being implemented, by OCL. Waitlists have been eliminated or reduced, two adult waivers are being consolidated, and all waivers are now administered by HCPF.

In addition, HCPF facilitates and directs other processes and initiatives that impact the waivers, the services they provide, the providers of those services and the clients that receive them. They are detailed in Appendix A, along with the Bell's involvement. Changes to Colorado's waivers require approval from the federal Centers for Medicare and Medicaid Services (CMS) and the Colorado General Assembly, and public feedback and participation. They can also be multi-year efforts. For example, the [Waiver Implementation Council](#) was formed in 2013. It is in the final stages of creating a combined waiver for adults with disabilities with the goal of submitting a new waiver application in 2019.

Strategies to Assess Community Need

The Bell concentrated on three strategies to assess community needs that will standardize access to respite through the waiver system. First, the Bell interviewed nearly 25 stakeholders, including Colorado caregivers, respite providers, organizations that manage services, and advocates. Other partners working with ESC collected results from a state-wide caregiver survey, which provided additional qualitative data. Second, the Bell interviewed and engaged with HCPF staff, including the state Medicaid Director and leadership with OCL, and participated in several ongoing HCPF initiatives that impact, or have the potential to impact, respite care. Finally, the Bell reviewed statutes, state regulations, Medicaid waiver language, and state and federal materials.

Stakeholder interviews provided crucial institutional knowledge, history and context about the evolution of waivers in Colorado and the impact on access to respite care. The interviews gave further insight into the scope of barriers to accessing respite. Some interviewees offered specific suggestions of how to create systemic improvements.

Definitions and Limits

An oft-mentioned challenge is the definition and provision of respite care differs across waivers, departments and among families. Each waiver must be approved by CMS, and each defines respite. There is a shared, basic definition of respite across waivers, but caveats may apply. For example, respite in the waiver for those with spinal cord injuries specifies "respite" can include help with "unskilled personal care" duties, which includes bathing, dressing, and toileting, but this isn't noted in all waiver definitions. *(See Appendix Three for waiver service definitions for respite care.)*

Differences in authorized providers, authorized settings, and licensure and certification requirements for each waiver can complicate access or prevent uniform access to respite care. So, too, does the timeframe that directs what providers can bill and what direct care workers are paid. When these waivers were created, their differential qualities may have been purposeful; however, as noted by the [Respite Care Task Force](#), consumers cite these differences as a barrier to accessing adequate respite services.

In addition to respite, there are variety of services and providers for those services in waiver programs, with corresponding reimbursement rates and qualification criteria. When someone enters onto a Medicaid waiver, their needs are assessed. Based on the assessment results, the care recipient is then given a unit allocation and case management assistance to help determine and prioritize authorized services, and connect with the providers of those services, who, in some cases, bid on serving the care recipient. Each service is capped based on the recipient's assessed need. This process complicates a family's overall suite of benefits.

Unfortunately, this leads to confusion and consternation. For instance, one caregiver reported not knowing how much respite they use or how much of their allotment has been put toward the service. The Bell's review of state resources didn't reveal an apparent, self-directed way for families to access that information. Families also say the type of respite they can access through the waiver doesn't always align with their needs. If their loved one needs help with certain medical tasks as a part of respite and none of the respite providers who bid for or offer the services can perform those tasks, the family cannot access respite. Some families prefer their loved one be cared for at home, and facility-based care is not a viable option for them.

Some stakeholders interviewed by the Bell also speculated that families may use some waiver services, such as personal care, to get respite but the system does not track their usage as such. This further complicates the picture of who needs respite and who is receiving it.

“The respite [allocation] isn’t enough. I don’t want to complain, but it’s just the bare minimum. We don’t have family in town or grandparents to split the load.” -Parent caregiver in Boulder County

“The challenge is we need to make sure we don’t use up our allocation too soon. There’s no access to data on how much respite we have used. I try to keep track myself, but it’s hard. I’m not trying to get information I shouldn’t have access to, but I want to be more efficient with our time.” -Parent caregiver in Mesa County

“Sometimes the respite funding is so narrow. It doesn’t give me the flexibility I need. The rules for reimbursement — you must use it in a certain way and by a certain time. These are taxpayer dollars and you need to be responsible, but simplicity should be considered.” -Parent caregiver in Arapahoe County

Due to recommendations made by CLAG, Colorado is in the process of combining two waivers (the Supportive Living Services (SLS) and Developmental Disabilities (DD) waivers which are defined in Appendix A, along with other definitions). A group of stakeholders has been meeting for some time to help the state prepare and apply for the change. In 2017 and 2018, the Bell participated in public meetings to monitor progress and offer input into how the new waiver will define respite. The proposed new definition takes a broader view of respite, creating a category of HCBS service called “caregiver supports,” which encompasses planned respite, unplanned respite, and respite as part of a behavioral intervention strategy, in addition to providing training for informal caregivers. This waiver integration process will hopefully serve as a model for future efforts to streamline services.

“For a long time, everything was really siloed, but we’re finding those silos need to break down. Definitions should be melded.” -State department official

[Studies](#) find caregivers are financially, emotionally and physically stressed.²⁴ Integrating other types of caregiver supports at a system level would enable more families to keep their loved ones at home rather than outside placement. Policymakers can affect changes that would better recognize, measure and meet their needs.

Incremental progress is being made nationally. In 2018, Congress passed the [Recognize, Assist, Support, Include and Engage \(RAISE\) Act](#), which requires the Secretary of Health and Human Services to develop, maintain and update a strategy to recognize and support family caregivers. Colorado has taken an additional step to recognize the role caregivers play in the health system by adopting the [Caregiver, Advice, Record, Enable \(CARE\) Act](#). The CARE Act integrates caregivers into the medical care plans of their loved ones by requiring hospitals inform family caregivers about their loved one’s discharge plans and give them instructions on needed medical tasks. Additionally, HCPF is in the process of redesigning their LTSS assessment tool to better capture and understand caregiver needs. HCPF expects to begin using this new tool by 2020.

[Research](#) conducted by the Colorado Health Institute on behalf of SAPGA highlights 33 specific actions state policymakers could take to create a system of support for Colorado’s informal caregivers. Many of these involve engaging the health system, building awareness, and data collection about caregivers. For example, Colorado could adopt proven assessment tools like the [Tailored Caregiver Assessment and Referral](#) tool (TCARE). Colorado could include ongoing questions on its Behavioral Risk Factor Surveillance System (BRFSS), a state-level health behavior survey.

Staff from HCPF note the department is updating the state’s assessment tool for waiver enrollment so that it includes caregiver perspective. According to one official, “the tool will assess the level of support provided by informal caregiver(s) and is designed to be used to 1) identify situations in which relief or support is critical to the continuation of informal caregiving and 2) identify situations in which paid supports should be initiated.” HCPF plans to implement the new tool in 2020.

Provider Rates, Qualifications, and Retention

Nearly every stakeholder consulted by the Bell claims Medicaid’s respite care provider rates are too low and act as a barrier to access respite, particularly high quality and consistent care. The mix of required oversight, qualifications, and training for respite care providers compounds the problem of low pay. Respite work is reimbursed at a similar level as other direct care services, as shown in Appendix E. Service agencies say the insufficient rates mean they can’t afford to meet training requirements for direct service workers, let alone pay them well. Finally, workforce turnover and the resulting inconsistency in care are of high concern for surveyed families. National and Colorado-specific research supports these concerns.

Respite providers offer social engagement, independence, health care and other supports to those needing care. Like other direct care workers (a term encompassing personal care attendants and home health aides), they often assist with a variety of needs including eating, dressing, personal hygiene, household maintenance, supervision, administering medication, and assisting with breathing or feeding tubes. A care recipient’s friends and family members sometimes become certified to perform some of these duties to help with respite, though it isn’t an easy process.

By 2020, the U.S. workforce is projected to have more than 1.6 million new direct care workers and an additional 828,500 direct care jobs will be needed over the next decade.²⁵

In addition to shifting demographics, the U.S. Bureau of Labor Statistics [attributes](#) some of this occupational growth to changes in patient preferences and shifts in federal funding toward in-home or community-based care. Unfortunately, Colorado is facing a large gap between those needing these services and those who can provide them. According to projections from the Colorado Department of Labor and Employment and the State Demography Office, by 2026, the state will have 37,654 personal care aides and 20,264 home health aides to care for over 1.1 million older adults.²⁶ Given a third of Coloradans age 65 and older are living with a disability, and not including the demand driven by younger adults and children with special health needs, this 19:1 ratio is insufficient.

Direct care jobs are mostly low-wage jobs that often lack benefits like a predictable schedule (and consistent hours and pay as a result), paid sick time, or other paid leave. [Analysis](#) by the Bell in 2013 quantified how little Colorado direct care workers earn. While more recent economic gains in Colorado have resulted in wage growth, increases in the cost of living [have generally outpaced](#) wage gains. Twenty-five percent of workers report a total personal income of \$9,999 or less. Another 34 percent report income between \$10,000 and \$21,000. Approximately 90 percent of all home health care workers fall into the bottom two income quintiles, while just 4 percent are in the top two.²⁷

[Data](#) analyzed by the Paraprofessional Health Institute (PHI) shows median hourly wages in Colorado for personal care aides have only grown by six percent from 2006-2016, and declined by five percent for home health aides in the same time period.²⁸ PHI also [finds](#) over one-third of home care and nursing home staff in Colorado receive some form of public assistance, such as Medicaid or food stamps.²⁹ Twelve percent of our state’s direct care workers [lack](#) health insurance.³⁰

Several statewide groups and commissions urge Colorado to improve and cultivate its paid caregiver workforce. Colorado’s Strategic Action Plan on Aging (SAPGA) [recommends](#) we act on strategies that create “enough skilled, educated and trained workers, paid commensurate to their abilities and training, to meet the needs of employers and industries serving Colorado’s growing senior population.”³¹ This recommendation builds on [suggestions](#) made by CLAG, which called for Colorado to “grow and strengthen the paid and unpaid LTSS workforce” and the [Colorado Commission on Aging](#), which set forth a goal of “promoting fiscal security for caregivers.”^{32,33}

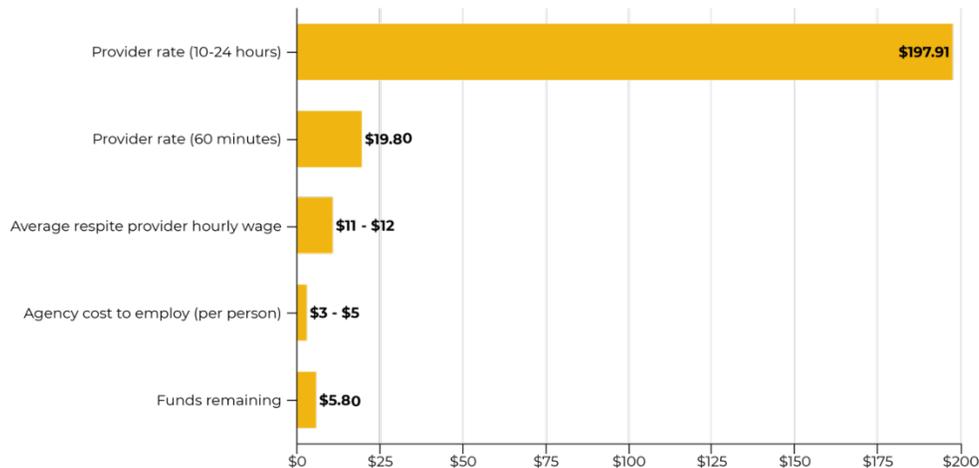
Nationally, “direct care has long been undervalued, as evidenced by persistently poor job quality” according to [research](#) conducted for the Working Poor Families Project (WFPF) , of which the Bell is a member.³⁴ Importantly, public funding streams exacerbate economic challenges for the direct care workforce. At the heart of many of these challenges are the

Medicaid reimbursement rates paid to long-term care providers, which the WFPF report finds “insufficient.” Other problems attributed to poor public investment are low wages, lack of training for direct care workers, limited career advancement opportunities, high turnover (whereby many leave caregiving work for the retail or food services professions because the pay is better), and the growing worker shortage.

“My wages as a respite care worker in Colorado were pretty crummy, and the income and hours were rarely steady. At one point, I found I could make more money working as a cashier for the zoo. That took away incentive to stay with the agency.” -Respite care provider in Denver County

Feedback from respite agencies reimbursed by Medicaid argue reimbursement rates aren’t enough to pay for their costs. As one example, PASCO, a large Colorado respite care agency, [states](#) the rate paid by the state Medicaid program is insufficient to cover its provider wages (which are just above the state minimum wage) and other related expenses such as training, workers compensation, and health insurance.³⁵ PASCO’s calculations demonstrate that the reimbursement does not cover various training-related requirements for respite providers, such as CPR, safety care, feedings through a gastronomy tube, and administering medication. This, it argues, leaves service agencies with a choice between subsidizing these costs through other programs or discontinuing respite care services. Even if rates rose by 25 percent, it found it would only generate an additional \$40 in additional revenue per care recipient.

RESPITE RATES & REIMBURSEMENT CHALLENGES FOR PROVIDERS



Source: 2017 data from HCPF HCBS waiver service reimbursement rates and provider agency information from PASCO and Easterseals Colorado

WFPF’s [analysis](#) provides support for this argument and suggests “adequate reimbursement rates in Medicaid would allow long-term care providers to invest in the workforce through enhanced training opportunities, higher wages, and expanded benefits.” It also could reduce the need for direct care workers to rely on Medicaid for their own health coverage, “potentially reducing net Medicaid expenditures.”³⁶

Some provider agencies are concerned about the impact of Colorado’s minimum wage increase. The increase is constitutionally required and was approved by Colorado voters in 2016. The minimum wage, which is currently \$10.20 an hour, will incrementally rise to \$12.00 in 2020. This means when fully implemented, a minimum wage earner will be making \$24,960 per year — barely above the 2017 federal poverty level for a family of four (FPL).³⁷ The Bell [argues](#) this increase benefits local economies, leads to positive workplace outcomes, and is vital to the economic mobility of the nearly 500,000 workers who will benefit from it.³⁸ Still, employers of direct care workers publicly have expressed worry before HCPF staff. They argue they must increase pay for all workers as the lowest paid earn more. They claim without a corresponding increase in state funding they will be unable to continue to serve Medicaid clients.

Families surveyed and consulted for this project are also worried and frustrated about the lack of continuity of care due to provider turnover and care that is available but inconvenient. Caregivers spoke about the importance of stability, consistency and trust in offering appropriate respite care for their loved ones, and a lack of steady providers erodes a family's ability to fill that need. They expressed concern about the low rates paid to many of their care providers and that it's not a problem exclusive to respite.

“In the SLS waiver, the rates are all so low. People prioritize day services and don’t have money left over for respite.” -Parent caregiver and advocate in Arapahoe and Douglas County

“We have a nursing company that comes to the home, but sometimes they can’t find us nurses. We waited months to find nurses, then they come and go. Initially, respite was only on weekends for us — it wasn’t like we got a choice. Then the only respite available to us was nine hours each week at a care facility in Wheat Ridge, and we live in Erie. We don’t have stability.” -Parent caregiver in Boulder County

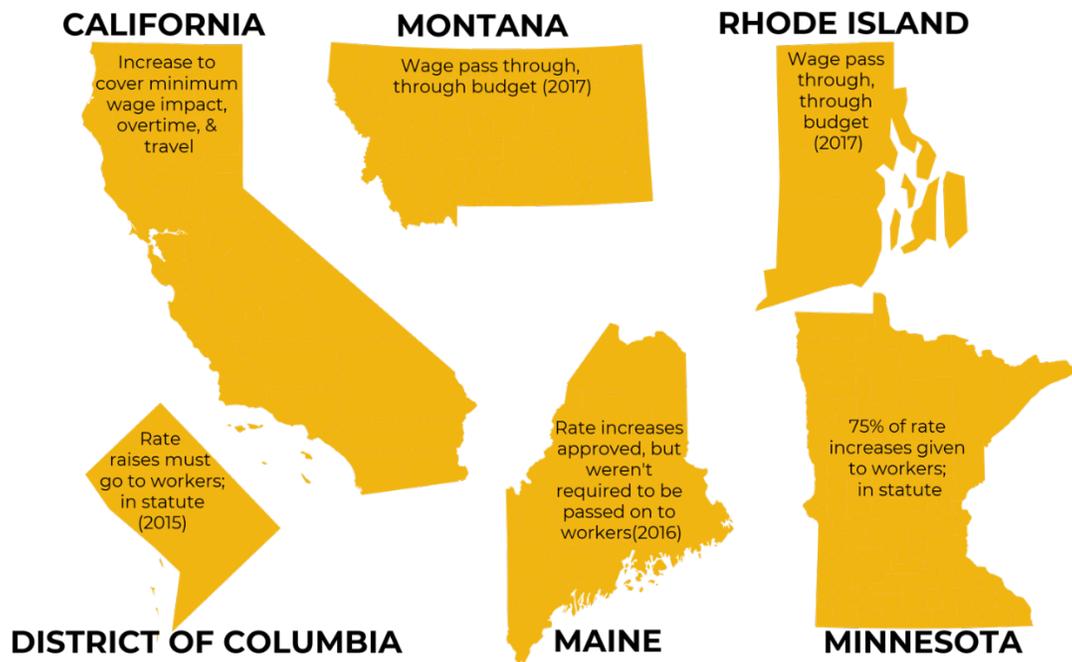
***“My mother needs consistency, or she refuses to comply with simple requests like eating.”
-Family caregiver in Delta County***

Fortunately, state policymakers are well-positioned to improve job pay and job quality for the respite care workforce and direct care workers more broadly. This is largely because states [have wide latitude](#) over the structure and policies of their Medicaid programs.³⁹ Colorado uses several processes to determine Medicaid reimbursement rates, including respite care through the waivers, which are then approved by the federal government. For waiver services, the rate setting and rate review processes are separate but related aspects of determining reimbursement rates (see Appendix B for more information). Ultimately, the General Assembly is the final authority on the rates paid to providers, as it appropriates the funding.

Medicaid reimbursement rates for all waivers were [reviewed](#) in 2017.⁴⁰ To aid in the waiver rate review process, HCPF [analyzed and reported](#) on Colorado claims data to make inferences about the amount of respite care accessed and respite provider retention rates.⁴¹ Analysts also benchmarked Colorado's rates to other states. The Medicaid Provider Rate Review Advisory Committee (MPRRAC) heard testimony and feedback from a variety of stakeholders, including [the Bell](#).⁴² The combination of this information revealed “rate-related access barriers for certain services” within the waiver, including respite. Through the budget process, the General Assembly approved limited rate increases for HCBS providers and combined with a rate-setting process newly launched by HCPF in 2017, this helped to raise rates by at least 2.4 percent, effective in 2018.

In December 2018, pending federal approval, Colorado will join the list of states implementing a wage pass-through for direct care workers. [House Bill 18-1407](#), which passed with bipartisan support, allocates additional state funding for a 6.5 percent direct care worker pay bump and eliminates a waiver wait list. The changes will impact respite workers and others providing services under the three waivers that support adults and children with intellectual and developmental disabilities — DD, SLS, and Children's Extensive Support (CES). The bill requires HCPF to monitor compliance to ensure funds are spent on worker compensation.

Policymakers in these states have supported the direct care workforce via targeted wage increases through Medicaid:



Source: Working Poor Families Project, 2017

The legislative declaration in HB18-1407 acknowledges a “workforce crisis” within the state’s direct caregiver workforce, naming low wages, limited benefits, lack of career advancement, challenges with worker recruitment and retention, and the resulting disruption in continuity of care as key problems and characterizes the steps taken in the legislation as an “initial investment” to allow for compensation that better reflects Colorado’s job market and the high level of responsibility required in these jobs.

Many respite care advocates supported the measure because of consensus around these challenges. This is an important step forward for Colorado, and the increase should serve as an initial investment. Furthermore, service providers under all waivers would benefit from the same wage increase. As wage parity across the waivers helps streamline respite access, policymakers should monitor the implementation of HB18-1407 and look to its usefulness as a model to push for improvements in the waivers not addressed in the legislation.

Families report another barrier related to providers: the difficulty in finding providers who meet their needs. For example, care recipients who are medically fragile require highly skilled respite providers. Though agencies are required to identify the level of skilled care they provide, some families can’t discern between skilled and unskilled providers, who are not authorized to perform certain medical tasks. Even if a provider is authorized, it does not ensure he or she is trained well enough to perform certain tasks (cleaning G-tubes and repositioning were most-mentioned during stakeholder interviews). Because some of these tasks must be performed frequently, family members report returning home to the care recipient during their break to help. Skilled providers also must be supervised, which means an RN must periodically oversee the task being performed. This is challenging in rural areas where both provider and supervisor must travel long distances, often without mileage reimbursement, to provide the care. Lastly, some stakeholders are dissatisfied with a lack of culturally competent providers.

One interviewee faults agencies, saying they “will not hire, train and supervise anyone that will have to perform high-skilled care.” Others think new state licensing requirements are the main problem.

The Bell will turn greater attention toward provider qualifications, competencies and training concerns in state fiscal year 2019. With respect to this issue, along with wages, research finds there are similar challenges between those caring for adults and children with special health needs and early care and education (ECE) workers. Colorado is currently

implementing a workforce development plan for ECE, called [Colorado's Early Childhood Workforce 2020 Plan](#).⁴³ The strategies and objectives of this plan may offer examples and insights for the direct care workforce.

Wage pass through policies, broader service definitions in waivers and other changes to improve access to respite care may necessitate increased public investment. Implementation of HB18-1407 will require a state appropriation of nearly \$43.4 million in fiscal year 2019-2020 (in addition to federal matching funds) to pay for the wage increase in just three waivers. One goal in streamlining the Medicaid program's definitions of respite is to have more people use respite, which could mean Medicaid will increase costs to pay for more care. Colorado's changing demographics will also continue to impact costs of and demand for waivers and other Medicaid services. A recent [study](#) commissioned by SAPGA in 2016 found one of every five Colorado Medicaid dollars will be spent on the older adult population by 2030.⁴⁴

Policymakers need information about the potential fiscal impact of such changes as well as more insight into how increased availability of respite and changing demographics will affect demand for waiver enrollment statewide. Additionally, research [supports](#) the notion that any attempt to streamline waiver services requires exploration of financing, enrollment and evaluation of changes.⁴⁵ In the coming fiscal year, the ESC and the Bell will work with HCPF, state fiscal analysts and stakeholders with the goal of better identifying and projecting these factors.

Other important policy implications for respite care may result as the state learns from its No Wrong Door pilot sites, which began implementation last year. (For more information on the No Wrong Door program, please see Appendix B.)

Recommendations for Policymakers, Including State Department Staff, Legislators, Local Decision Makers, & Advocates:

- 1. In concert with stakeholders, HCPF should continue progress towards developing a clear and flexible definition of respite that can be used across Colorado's waivers. The definition should meet the needs of families instead of the program.** This is consistent with CLAG's recommendations for all services in the new combined waiver for adults with disabilities. The CLAG also recommended all waivers include options for respite care, with flexibility in definition(s). The state is required to keep the person receiving care as the center point of all services, but that person's informal caregiver(s) is a crucial part of his or her support network and quality of life and should be at the near-center.
- 2. The HCPF should monitor and report on how informal caregivers are impacted by new service definitions in their proposed combined waiver for adults with disabilities. If effective, HCPF should replicate these new service definitions across other waivers and solicit stakeholder feedback in the process.**
- 3. HCPF should ensure a tracking tool is available for all families to help them better and more closely gauge how much respite care they have accessed or used. The tracking tool should measure availability and utilization.** State agencies need to create or use a tracking tool that provides data measuring not only access but utilization.
- 4. Waiver case managers and HCPF should collaborate to develop a system that clearly identifies when a service provides respite for an informal caregiver. For example, personal care is a very popular program in the EBD waiver, however current documentation does not identify if this care could be considered respite for a caregiver.**
- 5. HCPF should evaluate outcomes from 2018 legislation, [HB18-1407](#), that authorizes a direct service provider wage increase for services in three of the waivers, paying close attention to how respite care is impacted. Stakeholders should support and implement an increase in direct service provider pay rates across the remaining waivers.** The need for improved direct service provider retention, quality of care, and pay will become more pronounced as Colorado's 65+ population grows and older adults and their families rely more on HCBS services.
- 6. Colorado's health system should recognize and measure the needs of family caregivers. A better understanding of these needs will enable more families to keep their loved one at home rather than seek outside placement.** Potential strategies to achieve this goal include: conducting caregiver assessments as part of waiver enrollments; adopting proven assessment tools for caregivers like the Tailored Caregiver Assessment and Referral tool; or adding additional questions to the state's Behavioral Risk Factor Surveillance System.

Improving Access to Facility-Based Respite

Goal

Work with various state departments, including CDHS, HCPF, and CDPHE, to streamline the regulatory requirements for facility-based, short-term, overnight respite care.

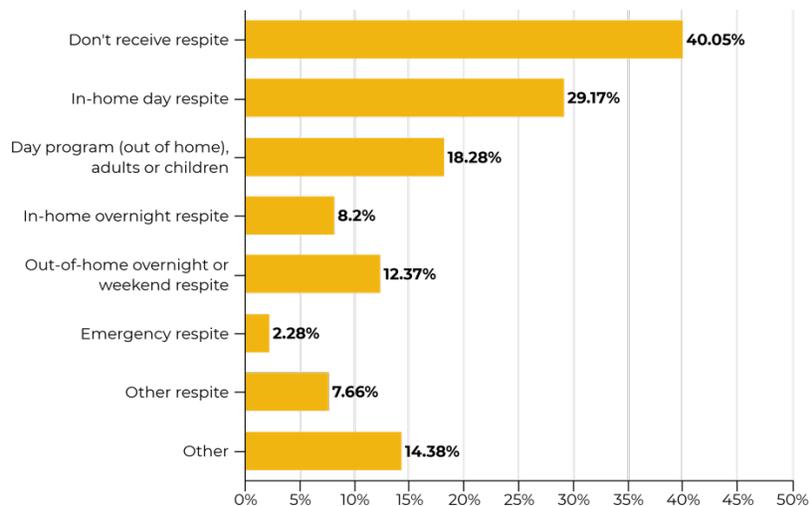
Background

The Respite Care Task Force’s work identified a specific respite need that is not well-met by Colorado’s current system. Families who want overnight respite care for their loved one for a brief time-period, in a setting aside from their own home, don’t have many options, regardless of how they pay for care. The Bell identified few resources for families to turn to in Colorado. Only three options exist, and those that do are along the Front Range.

“There is a dire need for out-of-home weekend or week-long respite so families can take a vacation or get a true break. A few hours to get to the store is vital, but it doesn’t provide the rest and restoration a week of rest can provide. I think without this option available to families, long-term support of individuals is in critical condition. I have even looked into starting something similar, but the regulations would be extremely difficult for an average person to overcome.” -Parent caregiver in El Paso County

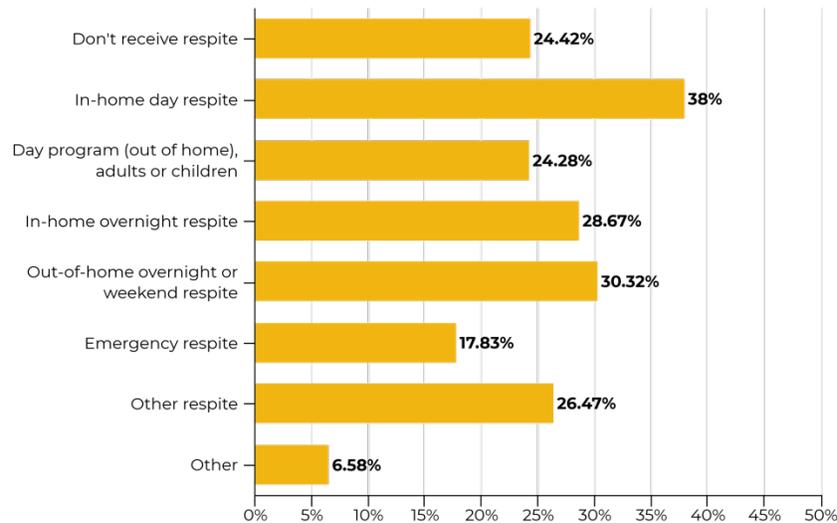
Providers interested in establishing this type of respite care have encountered barriers, including various state regulations that set out requirements and parameters for providing care. A 2018 survey of caregivers finds low rates of overnight or weekend respite use. Thirty percent of caregivers who have used respite want more overnight care or weekend care.

WHAT TYPE(S) OF RESPITE CARE SERVICES HAVE YOU USED?



Source: 2018 Colorado Caregiver Survey, Health Management Associates The Bell

WHAT TYPE(S) OF RESPITE CARE SERVICES WOULD YOU WANT TO USE MORE?



Source: 2018 Colorado Caregiver Survey, Health Management Associates, the Bell

A variety of state statutes and regulations determine and affect the settings in which respite occurs. CDPHE licenses and surveys programs that provide respite in the home or community, such as home health, home care, and hospice, as well as facilities that provide respite, such as nursing homes or assisted living facilities. CDPHE also can certify these programs, services, and facilities on behalf of HCPF which enables them to provide services (and receive reimbursement for them) through the Medicaid program. The definitions and requirements outlined in the waivers impact that certification. Not all licensed providers are certified. CDPHE is charged with the oversight of services and settings where respite can occur — in the home or in adult-day settings, in assisted living facilities, or in skilled nursing facilities.

State child care licensing statutes and rules promulgated by OEC also impact respite care, as those serving children with special health needs must be licensed to care for children. As with CDPHE, OEC has different departments with oversight and regulation duties — one with oversight of child care that occurs over a 24-hour period and another with oversight of less than 24 hours of care.

“This respite center is both child care and respite for my daughter and I.”

-Parent caregiver in Adams County

Neither department oversees respite care as a standalone service in a facility-based setting. No such standalone facility exists for purposes of CDPHE licensure and certification, nor does CDPHE license respite as an individual service. CDPHE licenses, regulates, and makes recommendations for certification in facilities where respite occurs, such as assisted living and skilled nursing facilities. Similarly, licenses are often needed for Home Care Agencies that provide personal care or respite in a person’s home. Most adults who receive facility-based respite overnight receive it in these an assisted living or skilled nursing facility. OEC also lacks a “facility-based respite” definition in child care licensure regulations.

Currently children who are receiving overnight respite receive it in a home setting. Families caring for both adults and children want more overnight, out-of-home respite. However, the Bell focused on barriers related to caring for children for the first fiscal year of the project.

Respite care has the potential to be an effective two-generation strategy to support Colorado families. A two-generation approach to policymaking involves an intentional commitment to serving children and adults simultaneously, thus helping the entire family advance economically. When parents of children with special health needs have access to quality respite care, it has multiple benefits for families and state programs. Effectively serving Colorado’s children with quality care during their earliest years not only yields downstream societal savings in the future but provides immediate support to working parents. Governor Hickenlooper and CDHS have been strong supporters of the two-generation approach. Their support, which has included financial commitments, have made Colorado a national leader in the field.

Strategies to Assess Community Needs

The Bell set out to better understand the systems and processes creating these barriers to offer reasonable and family-friendly solutions. This was accomplished by: interviews with state department personnel charged with the oversight of and authority over licensure and facility regulations; interviews with respite care providers who have offered overnight care as well as those who are trying to create a new type of facility to offer this service; asking caregiver survey respondents were asked to indicate whether they used this type of respite and if they needed it; and reviewing relevant rules and statutes.

Respite providers who are also serving children in a licensed childcare setting describe challenges related to complying with many regulations. They voice concerns over the fact that child care provider requirements for licensure differ from Medicaid provider requirements for certification. For instance, child care licensure requires different staffing levels while Medicaid requires service providers know CPR, first aid and how to administer medications. Child care licensing visits occur annually and are described as more focused on staff records and child immunizations. CDPHE visits usually occur once every three years and last between one to three-days. Inspectors look at the care environment itself and compliance to confidentiality expectations. Providers must be ready to address concerns raised by inspections from both departments.

One provider interviewee expressed frustration with the need to adhere to all the various requirements:

“We are a square peg in a round hole as it is. We are not a typical place, we are not an early learning child care center. We are caring for children with medical and behavior needs.” -Respite care provider

Providers who want to offer facility-based overnight respite to children can be licensed under an existing definition in statute, but it can involve asking for requirements to be waived or may result only because of another aspect of the facility or program making it permissible. State administrators provided two examples of how this works in practice.

In one example, overnight camps in two metro locations which provide respite can be licensed under a "children's resident camp" designation, if the camp is serving children over age six and is providing “education and recreational activities in an outdoor environment.” In the other example, overnight short-term respite for young children will be permissible in a [newly-created](#) “crisis nursery” in Mesa County.

“We have so many asks about respite care right now. The best foot forward would be to statutorily define a respite care license that could incorporate these different asks, especially one for young children.” -Licensing official

Local zoning requirements also constrain the ability of providers to offer overnight respite in a facility, particularly if they'd like to serve many young children. Family child care homes, in which four or fewer children are cared for, are exempt from health and fire inspections, but facilities caring for more children must comply with these requirements. Compounding the challenge, many municipalities adopted international building codes which require sprinkler system installation for fire safety compliance. One provider estimated it would cost her \$80,000 to install this kind of safety measure, which was financially unviable given her business model.

Home-based child care providers who serve non-special needs children across Colorado are being affected by these requirements as well. Policymakers are concerned with this problem as it could further limit the state's supply of child care providers, particularly in areas of the state that rely heavily on in-home child care, at a time when they are needed more than ever. According to one department interviewee: "The international building code thing is a big deal. It's a problem right now."

Lastly, as discussed in the Respite Care Task Force's 2015 report, organizations such as ESC and Hayley House have been working to establish a program similar to an Arizona facility called [Ryan House](#). Ryan House provides respite and palliative care for children with life-limiting conditions for up to seven consecutive days and a total of 28 days in a year. The facility can also accommodate pediatric hospice and families who wish to remain in the facility. ESC has made progress in this endeavor by working with state partners to overcome the barriers the current regulations create without requiring rules changes.

In the coming fiscal year, the Bell will focus on regulatory strategies that could improve access to short-term overnight respite for adults, particularly the older adult population.

Recommendations for Policymakers, Including State Department Staff, Legislators, Local Decision Makers, & Advocates:

- 1. In consultation with CDPHE, HCPF and OEC should explore the creation of a clear but flexible state respite care license definition in the child care licensing statute (C.R.S. 26-6-100) through the legislative process, with corresponding rule formation and approval by the State Human Services Board.** This definition could incorporate lessons learned through the overnight facility currently being developed by ESC, through the implementation of the crisis nursery approved in spring 2018 in Mesa County, and other exemptions that have been granted from the current child care licensing regulations. Implementing this recommendation will require a multidisciplinary team-based approach with the creation of a regulatory body to oversee the work as it does not fit within the expertise of either the Office of Early childhood Licensing Unit or Child Welfare Placement Services.
- 2. State and local governments should coordinate the development of zoning regulations with child care licensure to ensure safety while allowing for small respite providers to operate in a cost-effective and child-centered manner.**
- 3. HCPF, CDPHE, and OEC should study newly launched overnight respite programs in Colorado, such as ESC's latest facility-based program, as a model. They should share best practices from the development of this facility with other providers.** Proposed regulatory changes can flow from this model as well.

Respite care is a critical support to Colorado caregivers and their loved ones. Strategies to improve Colorado's respite care infrastructure, including standardizing the service across waivers and easing regulatory barriers that make providing overnight care difficult will increase family access to this important service. The Bell has uncovered concrete steps policymakers can take to help achieve these goals. The Project will share these recommendations with state leaders and continue to pursue current strategies, such as advising and working with WIC, the Medicaid provider rate setting processes, and the child care licensure system to affect change. It will place future focus on other identified priorities, including increased access to overnight care for adults, the fiscal implications of standardizing respite across waivers, and respite provider qualifications, competencies, and training concerns.

Appendix A: Key Acronyms

AAA: Area Agencies on Aging. AAAs help older adults receive services in their homes and communities. AAAs receive funding from the federal and state government (via CDHS). Caregivers for older adults can access respite care through some AAAs. Unlike respite provided through the state's home and community-based service (HCBS) waivers, this funding is not means-tested.

CCT: Colorado Choice Transitions. Colorado Choice Transitions (CCT) is designed to assist Colorado Medicaid members transition out of long-term care facilities back into home and community-based settings. CCT provides members access to Medicaid benefits and home and community-based (HCBS) waiver services in addition to CCT-enhanced services and supports aimed at promoting independence for 365 days of enrollment.

CCB: Community Centered Board. CCBs are organizations that help people access long term services and supports (LTSS) through some of the state home and community-based waiver (HCBS) waivers. Specific waivers require CCBs to coordinate services to clients in the least restrictive setting possible with the goal of keeping them in their homes and communities as an alternative to institutional care.

CDASS: Consumer-Directed Attendant Support Services. CDASS lets the person being cared for direct and manage the attendants who provide personal care and homemaker and health maintenance services, rather than working through an agency. Through CDASS, people hire, train, and manage attendants to best fit their unique needs or they can delegate these responsibilities to someone else. Respite is not offered under CDASS, however, some families use self-directed services to help a caregiver receive "coverage" or "supervision" of their loved one.

CHCBS: Children's Home and Community Based Services Waiver. CHCBS is available for disabled children with significant medical needs and who are at risk for institutional care in an acute hospital or skilled nursing facility.

CDHS: Colorado Department of Human Services. The Colorado Department of Human Services (CDHS) oversees state human services programs, which includes services for older adults, those with disabilities and children. Colorado has a state-supervised and county-administered human services system. Under this system, county departments are the main provider of direct services to Colorado's families, children, and adults.

CDPHE: Colorado Department of Public Health and Environment. The Colorado Department of Public Health and Environment is responsible for public health and environmental regulation. CDPHE personnel regulate facilities that provide respite care.

CLAG: Community Living Advisory Group. CLAG was a study and advisory body created in 2012 and over several years considered and recommended changes to Colorado's long-term services and supports (LTSS) system.

CMS: Centers for Medicare and Medicaid Services. The Centers for Medicare & Medicaid Services is part of the Department of Health and Human Services (HHS) and is the federal authority through which state Medicaid funding flows. CMS also approves elements of each state's Medicaid programs, including home and community-based service (HCBS) waivers.

DIDD: Division of Intellectual and Developmental Disability. The Colorado Division for Developmental Disabilities provides leadership for the direction, funding, and operation of services to persons with developmental disabilities. It is part of the Colorado Department of Health Care, Policy and Financing (HCPF). DI/DD provides leadership for the state, however, on the website, information about services are integrated by the role of the person searching.

HCBS: Home- and Community-Based Services Waiver. A waiver is an extra set of Health First Colorado (Colorado's Medicaid Program) benefits. Home and Community Based Services (HCBS) waiver benefits help people remain in their homes and communities. Respite care is one such benefit; others include personal care, non-medical transportation, home modifications, day programs, and behavioral therapies. Each waiver has its own set of benefits. Colorado has 11 HCBS waivers, more than most states. Each waiver has its own program rules and eligibility requirements.

HCBS-BI: Brain Injury Waiver. Provides services to persons over age 16 with a brain injury who need extra support to live in their communities.

HCBS-CES: Children's Extensive Support Waiver. Provides children with developmental disabilities or delays and their families with services and supports that will help children establish a long-term foundation for community inclusion as they grow into adulthood.

HCBS-CHRP: Children's Habilitation Residential Program Waiver. Provides home-based services for children and youth in foster care who have a developmental disability and very high needs. Their needs for support put them at risk for institutional care.

HCBS-CLLI: Children with a Life Limiting Illness Waiver. Provides benefits in the home for children with a life limiting illness and allows parents or caregivers to seek curative treatment while their child is receiving palliative or hospice care.

HCBS-CMHS: Community Mental Health Supports Waiver. Provides a home- or community-based alternative to nursing facility care for adults with major mental illness (as defined in Colorado regulations).

HCBS-EBD: Elderly, Blind and Disabled Waiver. Provides assistance to adults age 65 and older who have a functional impairment or are blind, and to people aged 18-64 who are physically disabled or have a diagnosis of HIV or AIDS and who require long-term services and supports (LTSS) to remain in the community.

HCBS-DD: Developmental Disabilities Waiver. Provides adults with access to a variety of living arrangements that give them 24-hour supervision and support to live safely and participate in their community. Respite is not provided in this waiver.

HCBS-SCI: Spinal Cord Injury Waiver. Provides a home- or community-based alternative to nursing care for adults in the Denver Metro Area with a spinal cord injury.

HCBS-SLS: Supportive Living Services Waiver. Provides services and supports for adults with intellectual or developmental disabilities who can either live independently with limited supports or who, if they need extensive supports, are already receiving that high level of support from other sources, such as family.

HCPF: Colorado Department of Healthcare Policy and Financing. The Colorado Department of Health Care Policy and Financing (HCPF) is the principal department of the Colorado state government responsible for administering Medicaid, Child Health Plan Plus and HCBS waiver programs as well as a variety of other programs for Colorado's low-income families, older adults and persons with disabilities.

HIPPA: Health Insurance Portability and Accountability Act. Passed in 1996, the Health Insurance Portability and Accountability Act (HIPPA) requires the United States Department of Health and Human Services to create regulations which protect certain pieces of health information. This Act led to two rules, the HIPAA Privacy rule and the HIPAA Security rule.

JBC: Joint Budget Committee. Comprised of six state legislators, Colorado's Joint Budget Committee (JBC) is charged with studying the management, operations, programs, and fiscal needs of the agencies and institutions of state government. Throughout the year, the JBC holds meetings and considers a range of documents to help prepare budget recommendations for the full General Assembly.

LTSS: Long-Term Services and Supports. A range of supportive services for people with physical, cognitive or mental disabilities or conditions that limit their ability to care for themselves. Services range from personal and homemaker services to skilled nursing care. Older Coloradans are at higher risk of needing LTSS, and as the number of older Coloradans grows, the demand for LTSS will grow.

MRRAC: Medicaid Provider Rate Review Advisory Committee. The Medicaid Provider Rate Review Advisory Committee (MRRAC) was created in 2015 and advises Colorado's Department of Healthcare Policy and Financing (HCPF) on setting the rates paid to Medicaid providers, including providers of HCBS waiver services.

NWD: No Wrong Door. A federally-funded program designed to experiment with approaches to better serving consumers who use long-term services and supports (LTSS). Four regional pilot sites are testing and refining various tools and approaches through 2019.

OEC: Office of Early Childhood. The OEC resides within the Department of Human Services and is charged with child care licensing responsibilities, among other duties, which impact respite care for children.

OCL: Office of Community Living. The Office of Community Living was created by Governor Hickenlooper through an Executive Order in July 2012 and is housed within Colorado's Department of Healthcare Policy and Financing (HCPF). The Office helps meet the growing need for long-term services and supports (LTSS) by people with disabilities and aging adults.

SEP: Single Entry Point. Single Entry Point (SEP) Agencies provide case management, care planning, and make referrals to other resources for Medicaid members with the following qualifying needs: elderly, blind and disabled, persons living with HIV/AIDS, mental health, brain injury, spinal cord injury, children with a life-limiting illness, and medically fragile children.

WIC: Waiver Implementation Council. The Waiver Implementation Council provides advice and consultation for DIDD's efforts to redesign its home and community-based services (HCBS) waivers serving adults with intellectual and developmental disabilities.

Appendix B: Current Initiatives Affecting HCBS Waiver Services; Respite Care

Method	Entity	Timing	Considerations	Respite Care Project Involvement
Rate review	HCPF/Medicaid Provider Rate Review Advisory Committee/General Assembly	Occurred in 2017 and JBC heard considerations for FY 18-19 budget. Next review for waivers in 2022.	MPPRAC is comprised of advocates and stakeholders and the process is required by statute. HCPF helps provide MPPRAC with data and reports to aid in recommendations, some of which detail provider retention, service usage and comparison rates from other states for similar services to inform recommendations. MPPRAC's then makes recommendations to HCPF. HCPF considers MPPRAC's recommendations and then submits both a report and the recommendations to the GA (JBC). The GA takes this information into account but can ultimately appropriate whatever it wishes for rates. In 2016, 2017 and 2018, it adhered to some of HCPF's recommendations but not all. Waiver services were studied in 2017 and ultimately the MPPRAC decided to rely on HCPF's rate setting (see below) process to help determine rate adequacy.	The Bell attended MPPRAC meetings and provided testimony during the stakeholder feedback process (March 2017) highlighting concerns with low provider rates, as did ESC. Respite care was highlighted in the MPPRAC report as one of the waiver services that drew the most stakeholder concern and attention. It is more difficult to find perfect comparisons for waiver services, because unlike health care, Medicare rates cannot be used as a benchmark.
Rate setting	HCPF/CMS	<p>Each waiver is on a separate rate schedule, as required by CMS. This process occurred through spring-fall of 2017</p> <p>Spring-summer 2017: HCPF processed and solicited feedback</p> <p>Fall: CMS approved 1.4% across the board increase for 5 waivers (four mentioned here and CLLI). Began same process for SLS, DD, CES.</p> <p>Winter: New rates announced; difficult to tell if 1.4% increase also applied to these waivers or no change through June 30, 2018. Respite through CCT also saw minimal increases.</p>	<p>HCPF began a new process in 2017 to set waiver service rates, a process that is distinct from but influences the MPPRAC process. HCPF surveyed service providers to collect information about the factors that impact rate setting, held a webinar about the process and accepted feedback in July 2017 for 4 waivers – EBD, SCI, CMHS, BI, CHCBS. In October, HCPF accepted feedback for the remaining waivers. To change rates HCPF must get approval from the federal government (CMS).</p> <p>The rate setting process does not apply to services with a negotiated price methodology (nursing facility, for example)</p>	The Bell provided feedback both verbally and in writing in August 2018, suggesting HCPF include a geographic factor, a client acuity factor, use more recent wage data, and include rate setting info for in-home respite, as it was missing from the proposed rates. Colorado Respite Coalition members were also encouraged to provide feedback. The Respite Care Project was suspended in October 2018, so no feedback was provided for that process.

Waiver Renewal	HCPF/CMS	Every 5 years; each waiver is on a different cycle		
Waiver Implementation Council (WIC)	HCPF/CMS/General Assembly (GA)	Legislature passed a bill to require this work in 2015 (HB15-1318). Stakeholder work ongoing since spring 2016. Next iteration began in July 2018.	WIC grew out of CLAG work and recommendations. Goal is to create a consolidated IDD waiver by merging with SLS. GA needed to approve budget request so HCPF could have funding needed to continue administrative work of consolidating the waivers, including actuarial analysis.	The Bell participated in WIC stakeholder meetings, but ongoing information about the WIC's work was hampered because 1. The Bell is not a member and 2. The WIC suspended work for a long duration of time. As of spring 2018, a process plan was being developed, which will help non-WIC stakeholders give input into the Service Coverage Standards that are being developed. The Council is accepting applications for new members in summer 2018.
Final Settings Rule		2016-2021	Goal is to be more client-centered, more personal.	The rule has potential to impact some adult day settings and the Bell will be tracking its implementation as a result.
No Wrong Door (NWD)	HCPF/CMS (ACL)	2015-2019	Colorado received funding from ACL in 2015 to pilot NWD program, whereby those receiving LTSS could more easily enter into and access the LTSS system. Implementation in four pilot sites started in fall 2017-winter 2018. Pilot will run through fall 2019.	ESC and the Bell met with HCPF and Colorado Access to discuss the work as the pilot sites were selected and gearing up for implementation. The Bell will reconnect with both organizations in the coming Fiscal Year.
New Assessment Tool	HCPF	2018-2019; fully implemented by 2020	Will create a single state-wide assessment tool for LTSS. Will have 19 modules with algorithms that pertain to what you want and what you need (currently up to 50 different assessments).	
2018 Legislative Session	General Assembly/HCPF/CMS	2018	HB18-1407 eliminates DD waiting list and includes 6.5% funding increase for direct service providers in 3 waivers. Bill requires a system be developed to ensure funding is being used by service agencies to increase wages. HB18-1328 moves administration of the CHRP waiver from CDHS to HCPF. It removes a requirement that families relinquish custodial rights of the child so he or she can qualify for CHRP, so it's no longer only available to those in foster care. Adds in-home services to assist the child and his or her family to avoid an out-of-home placement.	This is an important step forward for Colorado direct care workers but the state should ensure wage parity among services so as not to exacerbate access problems. The Bell will monitor implementation. Access issues could result because the changes theoretically will increase a family's ability to gain in-home services, which include respite.
LTSS Regulatory Review	HCPF	Summer 2018	All LTSS regulation requires that State agencies are required to review, on a continuing basis, all existing rules to ensure they use the best, most innovative and least burdensome tools for achieving their goals. They are also required to provide an opportunity for public comment. All LTSS regulations are eligible for public comment through August 15, 2018.	The Bell may provide input during the public comment process or with HCPF leadership.

Appendix C: Colorado Definitions of and Limitations on Respite Care through HCBS Waivers*

HCBS Waiver	Colorado Regulation 10 CCR 2505-10	Definition of respite	Limitations
Brain Injury (BI)	Sec. 8.515; 8.516	<p>Respite care means services provided to an eligible client on a short-term basis because of the absence or need for relief of those persons normally providing the care.</p> <p>Respite care providers: Class I nursing facility, an alternative care facility or an employee of a certified personal care agency which meets the certification standards for respite care specified.</p>	<p>An individual client shall be authorized for no more than a cumulative total of 30 days of respite care in each certification period unless otherwise authorized by the Department. This total shall include respite care provided in both the home or in a nursing facility.</p> <p>A mix of delivery options is allowable as long as the aggregate amount of services is below 30 days, or 720 hours, of respite care. In home respite is limited to no more than 8 hours a day.</p> <p>Nursing facility respite billed on a per diem. Only those portions of the facility that are Medicaid certified for nursing facility services may be utilized for respite clients.</p>
Children’s Extensive Support (CES)	Sec. 8.503	<p>Respite is provided to clients on a short-term basis, because of the absence or need for relief of the primary caregivers of the client.</p> <p>a. Respite may be provided:</p> <p>i.) In the client’s home, private residence,</p> <p>ii.) The private residence of a respite care provider, or</p> <p>iii.) In the community.</p> <p>b. Respite is to be provided in an age appropriate manner.</p> <p>i.) The eligible client age twelve (12) or older may receive respite during the time the caregiver works because same age typical peers don’t need ongoing supervision at that age and the need for the respite is based on the client’s disability.</p> <p>ii.) A client eleven (11) years of age and younger, won’t receive respite during the time the parent works, pursues continuing education or volunteers, because this is a typical expense for all parents of young children.</p> <p>c. When the cost of care during the time the parents works is more for an eligible client, eleven (11) years of age or younger, than it is for same age peers, then respite may be used to pay the additional cost. Parents shall be responsible for the basic and typical cost of child care.</p> <p>d. Respite may be provided for siblings, age eleven (11) and younger, who reside in the same home of an eligible client when supervision is needed so the primary caretaker can take the client to receive a state plan benefit or a HCBS-CES waiver service.</p> <p>e. Respite shall be provided according to an individual or group rates as defined below:</p> <p>i) Individual: the client receives respite in a one-on-one situation. There are no other clients in the setting also receiving respite services. Individual respite occurs for ten (10)</p>	<p>Sibling care is not allowed for care needed due to parent’s work, volunteer, or education schedule or for parental relief from care of the sibling.</p> <p>Federal financial participation shall not be claimed for the cost of room and board except when provided, as part of respite care furnished in a facility approved pursuant to 2 CCR 503-1 Section 16.221 by the state that is not a private residence.</p> <p>The total amount of respite provided in one service plan year may not exceed an amount equal to 30 day units and 1,880 individual units. The Operating Agency may approve a higher amount based on a need due to the client’s age, disability or unique family circumstances.</p> <p>Overnight group respite may not substitute for other services provided by the provider such as Personal Care, Behavioral Services or services not covered by the HCBS-CES waiver.</p> <p>Respite shall be reimbursed according to a unit rate or daily rate whichever is less. The daily overnight or group respite rate shall not exceed the respite daily rate.</p> <p>The purpose of respite is to provide the primary caregiver a break from the ongoing daily care of a client. Therefore, additional respite units beyond the service limit won’t be approved for clients who receive skilled nursing, certified nurse aid services, or home care allowance from the primary caregiver.</p>

		<p>hours or less in a twenty-four (24)-hour period.</p> <p>ii) Individual day: the client receives respite in a one-on-one situation for cumulatively more than 10 hours in a 24-hour period. A full day is 10 hours or greater within a 24-hour period.</p> <p>iii) Overnight group: the client receives respite in a setting which is defined as a facility that offers 24-hour supervision through supervised overnight group accommodations. The total cost of overnight group within a 24-hour period shall not exceed the respite daily rate.</p> <p>iv) Group: the client receives care along with other individuals, who may or may not have a disability. The total cost of group within a 24-hour period shall not exceed the respite daily rate. The following limitations to respite service shall apply:</p>	
Children’s Habilitation Residential Program (CHRP)	Sec. 8.508	Respite care means services provided to an eligible client on a short-term basis because of the absence or need for relief of those persons normally providing the care.	Respite may be approved for up to 30 days a calendar year for each eligible client.
Children with a Life Limiting Illness (CLLI)	Sec. 8.504	<p>Respite Care means services provided to an eligible client who is unable to care for himself or herself on a short-term basis because of the absence or the need for relief of those persons normally providing care. Respite Care is provided in the client’s residence and may be provided by different levels of providers depending upon the needs of the client.</p> <p>Respite includes any of the following in any combination necessary according to the Support Planning service plan: Skilled nursing, Home health aide, Personal care</p>	Respite shall be provided in home on a short-term basis, not to exceed 30 days per annual certification as determined by the Department-approved assessment. Respite shall not be provided at the same time as state plan Home Health or Palliative/Supportive Care services.
Community Mental Health Supports (CMHS)	Sec. 8.492; 8.509	<p>Respite care means services provided to an eligible client on a short-term basis because of the absence or need for relief of those persons normally providing the care. Respite care providers: Class I nursing facility, an alternative care facility, or respite care provided in a residence by an employee of a certified personal care agency which meets the certification standards for respite care specified.</p> <p>The nursing facility does not have to maintain or hold open separately designated beds for respite clients but may accept respite clients on a bed available basis.</p> <p>(Nursing facilities must adhere to certain respite care standards and procedures outlined in the regulation.)</p>	<p>Respite may be approved for up to 30 days a calendar year for each eligible client unless otherwise authorized by the Department. Alternative care facilities shall not admit individuals for respite care who are not appropriate for alternative care facility placement, as specified at 10 CCR 2505-10 section 8.495.</p> <p>Only those portions of the facility that are Medicaid certified for nursing facility or alternative care facility services may be utilized for respite clients.</p>
Elderly, Blind, Disabled (EBD)	Sec. 8.485; 8.492	<p>Respite care means services provided to an eligible client on a short-term basis because of the absence or need for relief of those persons normally providing the care. Respite care providers: Class I nursing facility, an alternative care facility, or respite care provided in a residence by an employee of a certified personal care agency which meets the certification standards for respite care specified.</p>	<p>Respite may be approved for up to 30 days a calendar year for each eligible client unless otherwise authorized by the Department. Alternative care facilities shall not admit individuals for respite care who are not appropriate for alternative care facility placement, as specified at 10 CCR 2505-10 section 8.495.</p> <p>Only those portions of the facility that are Medicaid certified for nursing facility or</p>

		<p>The nursing facility does not have to maintain or hold open separately designated beds for respite clients but may accept respite clients on a bed available basis.</p> <p>For each respite client, the nursing facility must provide an initial nursing assessment, which will serve as the plan of care, must obtain physician treatment orders and diet orders; and must have a chart for the client. The chart must identify the client as a respite client. If the respite stay is for 14 days or longer, the MDS must be completed. (Nursing facilities must adhere to certain respite care standards and procedures outlined in the regulation.)</p> <p>* Respite for the EBD HCBS waiver is also defined in the Colorado Revised Statutes 25.5-6-303 (19) (20): Services of a short-term nature provided to a client, in the home or in a facility approved by the state department, in order to temporarily relieve the family or other home providers from the care and maintenance of such client, including room and board, maintenance, personal care, and other related services. Respite providers are defined as: Facilities or agencies that meet all applicable state and federal requirements and are state-certified to provide respite services.</p>	<p>alternative care facility services may be utilized for respite clients.</p>
<p>Spinal Cord Injury (SCI) (This waiver is only available to those living in the Denver metro area.)</p>	<p>Sec.8.492; 8.517</p>	<p>Respite care means services provided to an eligible client on a short-term basis because of the absence or need for relief of those persons normally providing the care. Respite care providers: Class I nursing facility, an alternative care facility, or respite care provided in a residence by an employee of a certified personal care agency which meets the certification standards for respite care specified.</p> <p>The nursing facility does not have to maintain or hold open separately designated beds for respite clients but may accept respite clients on a bed available basis. (Nursing facilities must adhere to certain respite care standards and procedures outlined in the regulation.)</p>	<p>Respite may be approved for up to 30 days in each certification period unless otherwise authorized by the Department. Alternative care facilities shall not admit individuals for respite care who are not appropriate for alternative care facility placement, as specified at 10 CCR 2505-10 section 8.495. Only those portions of the facility that are Medicaid certified for nursing facility or alternative care facility services may be utilized for respite clients.</p>
<p>Supportive Living Services (SLS)</p>	<p>Sec. 8.500.90</p>	<p>Respite service is provided to clients on a short-term basis, because of the absence or need for relief of the primary caregivers of the client.</p> <p>a. Respite may be provided:</p> <p>i) In the client's home and private place of residence,</p> <p>ii) The private residence of a respite care provider, or</p> <p>iii) In the community.</p> <p>b. Respite shall be provided according to individual or group rates as defined below:</p> <p>i) Individual: the client receives respite in a one-on-one situation. There are no other clients in the setting also receiving respite services. Individual respite occurs for 10 hours or less in a 24-hour period.</p>	<p>i) Federal financial participation shall not be claimed for the cost of room and board except when provided, as part of respite care furnished in a facility approved pursuant to 2 CCR 503-1, Section 16.221. by the state that is not a private residence.</p> <p>ii) Overnight group respite may not substitute for other services provided by the provider such as personal care, behavioral services or services not covered by the HCBS-SLS Waiver.</p> <p>iii) Respite shall be reimbursed according to a unit rate or daily rate whichever is less. The daily overnight group respite rate shall not exceed the respite daily rate.</p>

		<p>ii) Individual Day: the client receives respite in a one-on-one situation for cumulatively more than 10 hours in a 24-hour period. A full day is 10 hours or greater within a 24-hour period.</p> <p>iii) Overnight Group: the client receives respite in a setting which is defined as a facility that offers 24-hour supervision through supervised overnight group accommodations. The total cost of overnight group within a 24-hour period shall not exceed the respite daily rate.</p> <p>iv) Group: the client receives care along with other individuals, who may or may not have a disability. The total cost of group within a 24-hour period shall not exceed the respite daily rate.</p>	
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*The HCBS waivers themselves, which are approved by CMS and are available online, are where Colorado’s respite definitions and limitations originate, with the exception of the EBD waiver. The language comprising definitions and limitations mostly aligns with language in Colorado’s Code of Regulations. HCBS waivers are overseen by HCPF. As a result, when ‘Department’ is used above, it refers to HCPF.

Appendix D: Income Eligibility for Colorado HCBS Waivers*

HCBS Waiver	Financial Requirements
Brain Injury (BI)	Income must be less than three times the current Federal Supplemental Security Income (SSI) limit per month.** If single, your countable resources must be less than \$2,000. If you are married, your countable resources must be less than \$3,000. Those who don’t meet financial requirements may be eligible through the Health First Colorado Buy-In Program for Working Adults with Disabilities .
Children’s Extensive Support (CES)	Children must meet the Health First Colorado financial determination for long-term services and supports (LTSS) eligibility. Financial determination requirements are outlined in the Colorado Code of Regulations 10 CCR 2505-10, Section 8.100 . (Household income cannot exceed 300% FPL after income disregards.)***
Children’s Habilitation Residential Program (CHRP)	The child’s eligibility for Supplementary Security Income (SSI) benefits is established. The income of the child does not exceed 300% of the current maximum SSI standard maintenance allowance. The resources of the child don’t exceed the maximum SSI allowance.
Children with a Life Limiting Illness (CLLI)	Your child’s income must be less than three times the current Federal Supplemental Security Income (SSI) limit per month (See SSI website for current information) and their countable resources must be less than \$2,000. Parent income is not considered for the child’s eligibility.
Community Mental Health Supports (CMHS)	Income must be less than three times the current Federal Supplemental Security Income (SSI) limit per month. (See SSI website for current information) If single, your countable resources must be less than \$2,000. If you are married, your countable resources must be less than \$3,000. Those who don’t meet financial requirements may be eligible through the Health First Colorado Buy-In Program for Working Adults with Disabilities .
Elderly, Blind, Disabled (EBD)	Income must be less than three times the current Federal Supplemental Security Income (SSI) limit per month. (See SSI website for current information) If single, your countable resources must be less than \$2,000. If you are married, your countable resources must be less than \$3,000. Those who don’t meet financial requirements may be eligible through the Health First Colorado Buy-In Program for Working Adults with Disabilities .
Spinal Cord Injury (SCI)	Unclear; likely similar to EBD waiver as some SCI enrollees transfer from EBD.
Supportive Living Services (SLS)	Income must be less than three times the current Federal Supplemental Security Income (SSI) limit per month. (See SSI website for current information) If single, your countable resources must be less than \$2,000. If you are married, your countable resources must be less than \$3,000. Those who don’t meet financial requirements may be eligible through the Health First Colorado Buy-In Program for Working Adults with Disabilities .

*Three Colorado HCBS waivers don’t offer a respite benefit and are not reflected here.

**In 2018, the [Federal SSI](#) monthly limit is \$750 for an individual and \$1,125 for a couple.

***In 2018, 300% Federal Poverty Level for a family of four is \$73,800 annually.

Appendix E Respite & Personal Care Rates

Rates effective as of 7/1/2018

	In-Home Respite Rates	In-Home Respite Notes	Personal Care Rates	Personal Care Notes
Brain Injury (BI)	\$4.99/15 Mins or \$19.96/Hr	Not to exceed 8hrs/day	\$4.38/15 Mins or \$17.52/Hr	
Children’s Extensive Supports (CES)	\$5.07/15 Mins or \$20.28/Hr or \$202.69/Day	Day rate is used when respite services exceed 40 units (10 hrs) in a 24 hour period		
Children’s Habilitation Residential Program (CHRP)	Level 1 \$56.11/Day to Level 6 \$194.75/Day		N/A	
Children with Life Limiting Illnesses (CLLI)	Unskilled 4 hrs or less: \$5.50/15 Minutes or Unskilled 4 hrs or more: \$98.96/Day CNA 4 hrs or less: \$7.21/15 Minutes or CNA 4 hrs or more: \$128.12/Day Skilled RN/LPN 4 hrs or less: \$15.68/15 Minutes or Skilled RN/LPN 4 hrs or more: \$282.09/Day	Combined max of 30 calendar days/service plan year for all respite care services	N/A	
Community Mental Health Supports (CMHS)	N/A		\$4.38/15 Mins or \$17.52/Hr	
Elderly, Blind & Disabled (EBD)	\$4.99/15 Mins or \$19.96/Hr	Not to exceed Nursing Facility per diem (6.5 hrs/day)	\$4.38/15 Mins or \$17.52/Hr	
Spinal Cord Injury (SCI)	\$4.99/15 Mins or \$19.96/Hr	Not to exceed Nursing Facility per diem (6.5 hrs/day)	\$4.38/15 Mins or \$17.52/Hr	
Supportive Living Services (SLS)	\$5.07/15 Mins or \$20.28/Hr or \$202.69/Day	Day rate is used when respite services exceed 40 units (10 hrs) in a 24-hour period	\$5.07/15 Mins or \$20.28/Hr	

Appendix F: Recommendation Impacts on Waiver Utilization & State Finances

Appendix Summary

An analysis was conducted to quantify how, if enacted, this report’s recommendations will impact the total number of Coloradans using Medicaid respite services, the amount of respite used by beneficiaries, and the resulting effects on the state budget. The chart below summarizes the range of impacts the Bell believes are likely on each of these fronts:

	Low-End Projections	Mid-Level Projections	High-End Projections
Net Beneficiary Increase	125	250	400
Net Service Utilization Increase	5%	10%	15%
Additional Cost to State Per Year	\$4.25 Million	\$5.75 Million	\$7.25 Million

Based upon best estimates, we believe the mid-level projections noted above are most likely. However, because there is relatively little historical information or evidence-based research to project with greater certainty, both the low and high-end projections listed above are possible.

The nine recommendations in this report are designed to work in tandem. As a result, their impact is collectively assessed, and is only differentiated based upon whether the recommendation is designed to standardize the full continuum of respite care options or streamline regulatory requirements for facility-based, short-term, overnight respite.

Though collectively assessed, the relative impact of each recommendation is considered in this analysis. Assessments were conducted regarding each recommendation's effect on enrollment, service utilization, and overall impact. Values — low, medium, high, and unknown — are assigned for each of these categories. A summary of each recommendation's impacts is below:

	Impact on Number of Beneficiaries	Impact on Service Utilization	Overall Impact
Recommendation One	High	High	High
Recommendation Two	Unknown	Unknown	Unknown
Recommendation Three	Low	Low	Low
Recommendation Four	High	High	High
Recommendation Five	Low	Low	Low
Recommendation Six	Low	Low	Low
Recommendation Seven	Low	High	High
Recommendation Eight	Low	High	High
Recommendation Nine	Unknown	Unknown	Unknown

The remainder of this appendix examines the process and findings from this analysis in greater depth.

Data Used in Analysis

For this analysis, data was taken from multiple sources, including:

- Documents created by Health Managements Associates (HMA) for the Respite Care Task Force, including the “Colorado Respite Care Impact Study,” and [“Colorado Caregiver Survey and Caregiver Interviews Report”](#)
- Usage and cost data from HCPF’s [“2017 Medicaid Provider Rate Review Analysis Report”](#)

Fiscal year 2015-2016 utilization and cost data are used in this analysis. Though these numbers have grown in the intermediary, it’s not believed they have changed significantly enough to impact this analysis.

Recommendations on Standardizing Full Continuum of Respite Care Options

Recommendations one through six are designed to standardize the full continuum of respite care options. The impact each of these recommendations will have on how many people utilize respite and how much respite they utilize are discussed below:

- **Recommendation One:** Develop a clear and flexible definition of respite that can be used across waivers. A flexible and clear definition of respite will allow beneficiaries to tailor services to their specific needs. With fewer service restrictions, recipients will likely use more short-term, long-term, in-home, and/or alternative facility-based respite. Importantly, at least one-third of HMA’s caregiver survey respondents indicate they’d like to use additional types of respite. In addition to impacting how much respite people use, this recommendation will likely increase the number of people eligible for respite services. HCPF staff mention the difficulty some case managers have in determining whether to include respite as part of a client’s benefit package. A clearer, better understood definition of respite will help case managers better assess when the service is needed. For these reasons, it’s projected this recommendation will have a *high overall impact*.
- **Recommendation Two:** Monitor and report on how informal caregivers are impacted by new service definitions in the proposed combined waivers for adults and people with disabilities. New service definitions from the combined waivers for adults and people with disabilities are still being developed. As a result, this recommendation’s impact is *unknown*.
- **Recommendation Three:** Ensure a tracking tool is available for all families to help them better and more closely gauge how much respite care they have used. This recommendation stems from interviews with existent beneficiaries who say they don’t know how much respite they’ve utilized. Implementing this recommendation will improve caregivers’ experience with the Medicaid system, but other factors likely present obstacles to accessing respite. As a result, this recommendation is projected to have a *low overall impact*.
- **Recommendation Four:** Develop a system that clearly identifies when a service provides respite for an informal caregiver. HCPF staff mention their case managers often have different ideas about what respite is, which can result in the assignment of varying amounts of respite. Clearer definitions and assignment systems will allow for more uniformity in how respite is used and assigned. Similar to recommendation one, this is projected to have a *high overall impact*.
- **Recommendation Five:** Evaluate outcomes from 2018 legislation, HB18-1407, which authorizes a direct service provider wage increase for services in three waivers. As noted in both this report and in the Respite Care Task Force’s [initial](#) recommendations, the lack of qualified respite providers is a major obstacle that prevents recipients from accessing needed services. Increasing wages has been shown to help with the recruitment and retention of direct care workers. However, to meaningfully impact the supply of workers, additional changes, including increased training and career advancement opportunities as well as more significant wage increases, are needed. As a result, this recommendation is projected to have a *low overall impact*.
- **Recommendation Six:** Recognize and measure the needs of family caregivers. Assessment tools like TCARE have been shown to reduce state Medicaid expenditures and positively benefit both caregivers and their care recipients. However, it has also been [shown](#) when programs like TCARE are implemented, services other than respite (which are better suited to a caregiver’s specific needs) may be recommended instead. As a result, this recommendation is projected to have a *low overall impact*.

Collective Impact

By increasing beneficiaries' access to needed respite options, properly identifying caregiver needs, and ensuring case managers have a comprehensive understanding of what respite is, these recommendations will collectively increase waiver utilization. If adopted, it's estimated the total number of people utilizing Medicaid respite services will increase between 5 percent and 15 percent. Simultaneously, it's expected the amount of respite beneficiaries use will increase between 10 percent and 20 percent. Combined, these changes are expected to increase state spending on Medicaid waiver services by approximately \$1 million to \$5 million.

Information about how these specific recommendations will impact waiver enrollment and utilization is scarce. To estimate impact, research was conducted on how other states look to increase enrollment and access to Medicaid services. Research shows efforts in [California](#) aimed at increasing education and awareness about available Medicaid services grew enrollment by between 10 percent and 12 percent. While specific actions taken in California are different than those recommended in this report, these results speak to possible enrollment impacts when individuals better understand the breadth of available Medicaid services. In this analysis, California's experiences are extrapolated to project an increase in enrollment of between 5 percent to 15 percent.

Estimates regarding service utilization increases are based upon multiple HMA resources, including reports showing approximately 75 percent of authorized respite services were unused in fiscal year 2014-2015, and at least 35 percent of HMA caregiver survey respondents indicate they would like to use additional respite services. Based upon this information, it's assumed respite utilization will increase with better access. The specific 10 percent to 20 percent estimation is based upon the assumption that though available options will increase, allocated services will continue to be underutilized due to a mix of factors, including provider shortages.

Projections

Net Projected Impact on Enrollment			
FY15-16 Waiver Beneficiaries (baseline)	5% Increase	10% Increase	15% Increase
2,625	131	263	394

Net Projected Impact on State Funding for Medicaid Respite Services				
Beneficiaries	No Change to Utilization	10% Increase in Utilization	15% Increase in Utilization	20% Increase in Utilization
2,625 <i>FY15-16 Baseline Enrollees</i>	0*	\$1,299,252	\$1,948,878	\$2,598,504
2,756 <i>5% Enrollment Increase</i>	\$649,626	\$2,013,841	\$2,695,949	\$3,378,056
2,888 <i>10% Enrollment Increase</i>	\$1,299,252	\$2,728,430	\$3,443,019	\$4,157,608
3,019 <i>15% Enrollment Increase</i>	\$1,948,878	\$3,443,019	\$4,190,089	\$4,937,159

*Baseline spending is \$12,992,524, the amount spent in FY15-16

Impact on Streamlining Regulatory Requirements for Facility-Based, Short-Term, Overnight Respite

Recommendations seven through nine are collectively designed to increase utilization of facility-based, short-term, overnight respite. Their impacts are detailed below:

Recommendation Seven and Eight: Explore the creation of a clear but flexible state respite care license definition in the child licensing statute & Coordinate the development of zoning regulations with child care licensure to ensure safety while allowing small respite providers to operate in a cost-effective and child-centered manner. As identified in HMA's caregiver survey, there is a need for additional overnight respite. However, as noted in the Respite Care Task Force's initial report, there are gaps in the availability of these services, due in part to a lack of providers. Streamlining regulatory requirements, as proposed in recommendations seven and eight, will increase the number of providers offering these services, in-turn allowing more individuals to take advantage of overnight respite. As a result, it's projected these recommendations will have a *high overall impact*.

Recommendation Nine: Study newly launched overnight respite programs in Colorado. While this recommendation could prove helpful in increasing access to overnight respite in the future, it is still too early to determine its impact. As a result, the impact of this recommendation is *unknown*.

Collective Impact

Collectively, it's projected recommendations seven through nine will impact individuals who already have access to overnight respite, but due to a lack of providers, don't use as much as they would like or are qualified for. It's assumed regulatory streamlining will benefit the approximately 30 percent of enrollees who already have access to applicable waivers and would increase this group's total utilization by about 10 percent. This equates to approximately two additional overnight stays. In total, this will increase waiver costs by approximately \$2 million.

These projections use information from HMA's caregiver survey, which shows approximately 30 percent of those surveyed would like to use more facility-based, short-term, overnight respite. There is little information about how many providers will be interested in and able to offer overnight respite services if regulations are streamlined. However, it's assumed because reimbursement rates for these services will remain relatively low, there won't be a large influx of new providers coming into the market initially, even with the adoption of these recommendations. As a result, it's projected that though these recommendations will lead to an increase in the utilization of overnight respite, growth will be limited to approximately 10 percent.

Projections

Beneficiaries Currently Using Applicable Waivers	Projected Number of Impacted Beneficiaries	FY 15-16 Base Funding for All Applicable Waiver Beneficiaries	Net Change to State Funding with 10% Increase in Facility-Based, Short-Term, Overnight Respite
988	296	\$5,734,451	\$2,154,552

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- ² Initial Strategic Action Plan on Aging for Colorado. Strategic Action Planning Group on Aging. November 2016.
- ³ 2016 Report to: Members of the Senate Health and Human Services Committee, Colorado General Assembly & Members of the House Public Health Care and Human Services Committee, Colorado General Assembly. January 2016.
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- ⁵ Respite Care Study: Final Report Health Management Associates. November 30, 2015.
- ⁶ History. Colorado Respite Coalition. Accessed June 2018.
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- ⁹ Rainville, C., Skufca, L., and Mehegan, L. Family Caregiving and Out-of-Pocket Costs: 2016 Report. AARP. November 2016.
- ¹⁰ In spring 2018, the Bell and ESC conducted an online survey of Colorado caregivers. Over 1000 people participated, but not all answered each question. When asked “do you or have you faced barriers in getting respite care?” 518 responses were given.
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- ²⁴ Putting a Price on Informal Caregiving in Colorado. Colorado Health Institute. 2016.
- ²⁵ Colorado’s Care Economy: Changing Demographics Highlight the Need for Statewide Research and Reform. Jobs with Justice. 2014.
- ²⁶ Calculated using CDLE CMI Gateway future occupational employment data and SDO statewide population data by single year of age.
- ²⁷ Ibid.
- ²⁸ Workforce Data Center. Colorado Wage Trends. Paraprofessional Health Institute. Accessed June 2018.
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- ³³ Colorado Aging Framework: A Guide for Policymakers, Providers, and Others for Aging Well in Colorado. Colorado Department of Human Services and Colorado Commission on Aging. July 2015.
- ³⁴ Cook, A. Improving Job Quality for the Direct Care Workforce: A Review of State Policy Strategies. The Working Poor Families Project. 2017.
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- ³⁸ Colorado Minimum Wage Facts. Coloradans Families for a Fair Wage. June 2016.
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- ⁴⁰ In 2017, HCPF approved a 1.4 percent increase for services provided through the Colorado Choice Transitions program and HCBS waivers, and an additional 50 cent/hour increase for agency-based personal care and homemaker services through the BI, EBD and SCI waivers. In 2018, the General Assembly approved a 1 percent increase for community services, including those through the HCBS waivers.
- ⁴¹ 2017 Medicaid provider Rate Review Recommendation Report. Colorado Department of Health Care Policy & Financing. November 1, 2017.
- ⁴² Wood, N. Testimony to the Medicaid Provider Rate Review Advisory Committee. Bell Policy Center. March 17, 2017.
- ⁴³ Colorado’s Early Childhood Workforce 2020 Plan. Colorado Department of Education.
- ⁴⁴ The Effects of Aging on Colorado’s Revenues and Expenditures: A View to 2030. Colorado Futures Center. December 2016.
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