The Colorado Respite Care Impact Study

Conducted for
Easterseals Colorado and the
Colorado Department of Human Services

In response to requirements per
HB16-1398 of the
Colorado State Legislature

Research Team
Health Management Associates
Preface
The purpose of this report is to present the results of the Colorado Respite Care Impact Study, a four-part examination of respite care in Colorado conducted for Easterseals Colorado and the Colorado Department of Human Services (CDHS) by Health Management Associates (HMA), a national health and social care research and consulting firm. This study is intended to enhance understanding of how the state can improve access to respite care services to those who need them and improve the quality of respite care services across Colorado, across the lifespan of care recipients, and across the needs of both caregivers and care recipients. This study is in response to the recommendations of the Respite Care Task Force created by House Bill 15-1233 and the subsequent legislative mandate through House Bill 16-1398 to “implement recommendations of the Respite Care Task Force,” which included, “Ensure that a study is conducted to demonstrate the economic impact of respite care and its benefits for those served.” The findings from this study are intended to help guide Colorado policy makers and program administrators in making long-term plans for respite care services and delivery.

The Colorado Respite Care Impact Study combines qualitative and quantitative research methods to assess the impact of respite care services on the health of caregivers, the quality of life for caregivers and care recipients, and spending both inside and outside of the healthcare system. Generally, it is believed that respite care provides an opportunity for caregivers to get a welcome and much-needed pause from the ongoing responsibility of caregiving, and that respite allows caregivers to “re-charge” so that they can resume their dedicated caregiving and avoid “burn-out.” The findings of this study reaffirm this belief and provide some insights into the nuances related to how respite care services impact Coloradans.

Across the United States, the economic value of caregiving ranges from $10.53 per hour in Louisiana to $15.05 per hour in Alaska.\(^1\) In Colorado, approximately one in 10 individuals (11% of the population, or 584,000 people) are caregivers, providing 543 million hours of care per year. The value of this care is

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\(^1\) AARP. (2015, July). *Valuing the Invaluable, The Economic Value of Family Caregiving*
estimated to be $13.68 per hour for a total economic value to the state of $7.4 billion per year. These are individuals providing full- or near full-time care, typically for a family member or loved one such as a child/youth with special needs, an elderly parent, or a sibling who is elderly and/or has special needs. While estimates of the economic value of informal caregiving vary, it is generally recognized that the market value of this unpaid labor is greater than the cost of paid home care assistance.

Many of these individuals provide caregiving on a year-round basis. Some have had to leave the workforce, with detrimental effects on their long-term career paths. Others try to balance caregiving with employment, but may experience frequent absences from work or lower productivity and fewer opportunities for promotion. For caregivers who are both working and taking care of an older adult, the financial cost to them and their employers is significant. For example, a 2010 national study by MetLife found that employees who were also caregiving for an older adult had 8 percent higher healthcare costs compared to employees who were not caregiving. These additional costs were extrapolated to assess an extra $13.4 billion per year in expenditures for employers and an estimated average lifetime loss of $303,880 for caregivers who are working and care for an older adult. It is important to note that because this study only includes estimates of informal caregiving by adult children 50+ and only for aging parents, the estimates are very conservative in terms of national estimates reporting the impact of caregiving on work.

In addition to work and other economic impacts, caregiving is known as one cause of many negative health impacts, including physical, mental, behavioral, and emotional health effects, on caregivers. The MetLife study found that caregivers are more likely to report fair or poor health relative to non-caregivers. In another national study, three-fifths of caregivers reported fair or poor health status, one or more chronic conditions, or a disability, compared with one-third of non-caregivers. Caregivers reported having a chronic condition such as heart attack/heart disease, cancer, diabetes, and arthritis at nearly twice the rate of non-caregivers (45% vs. 24%).

The Colorado Respite Care Impact Study seeks to define the role of respite care services in alleviating negative impacts of caregiving on the caregiver and bringing about positive benefits for the care recipients, as well as impacts on the Colorado economy and healthcare system. It also seeks to begin to define the value of respite care services in offsetting or reducing these other costs or the return on investment (ROI) of respite care services across public and private sectors. Almost no rigorous data on ROI of respite care services currently exists despite overwhelming anecdotal and qualitative evidence that: they are valued by caregivers and care recipients, they improve quality of life for both caregivers and care recipients, and they may help to allow individuals to remain in their homes and communities longer.

Understanding and measuring the cost effectiveness of respite care services is challenging. However, some previous research has been conducted to provide a glimpse at potential ROI, including that undertaken by several national organizations to explore whether respite care reduces hospitalizations

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2 Ibid.
3 Ibid.
5 Ibid.
and nursing home admissions, thus saving the cost of that formal care. For instance, one such study revealed cost reductions using Medicaid records of children with autism, finding that $1,000 of services that may offer caregiving relief to families (including respite care and home health aides/personal care assistances) reduced the risk of hospitalization by 8 percent. \(^7\) Another study found that monthly hospital inpatient days and outpatient days significantly decreased after a child’s first involvement in palliative hospice respite care. \(^8\) Lastly, informal basic personal care was found to reduce nursing home use by about 60 percent for Americans aged 70 and older who have a disability; but that study also found no significant reduction in admissions when help was measured more broadly to include assistance with chores and errands. \(^9\)

One reason why understanding the impact of respite care services on caregiver and care recipient outcomes is so challenging is the lack of a common definition for respite care services within the long-term services and supports (LTSS) system. Respite care is one of the most commonly requested caregiver support services; however, definitions of respite care services vary among programs and states making comparisons difficult. Additionally, the amount of respite care services accessed by caregivers varies from state to state and within states from zip code to zip code. The most recent publicly-available data related to respite care services spending per person in Colorado is from a 2007 study by the American Association of Retired Persons (AARP). That study found that Colorado spent $2.72 per caregiver in 2007 on respite services, compared to a national rate of spending per caregiver of $5.43 the same year. That same study found respite spending per caregiver in 2007 ranged from a low of $0.48 in Massachusetts to a high of $43.02 in Alaska. \(^10\)

A 2014 review of outcomes research on respite care services showed that differences in methodologies, respite definitions, and targeted populations have resulted in a divergence of conclusions about the benefits of respite care services for certain population groups. \(^11\) Many of the articles included in the review describe research that concludes that reductions in family caregiver stress and burden, improved quality of life and well-being for both caregivers and care recipients, reduced need for out-of-home placements, and reduced risk for abuse and neglect may be associated with use of a variety of models and modes of delivery of respite care services and/or crisis care programming. Conversely, other articles did not find similar positive associations related to respite care services. Some of the articles concluded with no real clear and compelling evidence that respite care services and/or crisis care programs achieve certain outcomes.

**Colorado Respite Care Impact Study Limitations**

All research has limitations. Throughout this report, the limitations of this study are identified, as well as potential areas for future study. The questions being asked in the Colorado Respite Care Impact Study are particularly complex and there is scant research available from which to gather the information.

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\(^10\) Houser, A & Ujvari, K. (2012). Measurement of Respite Care. AARP Public Policy Institute. Note: Due to definitional differences about what services are defined as “respite” between sources, as well as between states, data may not be comparable across states and should not be used for comparative purposes.

needed to explore the answers. There are many challenges with various research that is available and was cited to support this analysis. For example, the definition of respite care services is unclear or undefined in many cases; service provision is often unmeasured or, again, not well defined; and outcomes and impacts cross life domains and are associated with different individuals (e.g., the caregiver vs. the care recipient). These other reports also use different “units of analysis” such as individuals, families, communities, states, the system of funding, and systems of care. Because of these types of complexities and, as a way to lay a foundation for further exploration of the issues, this study used various research methodologies and attempts to collect diverse data elements to ensure that factors are examined from a variety of perspectives. It attempts to clearly identify research parameters and limitations and use caution in interpretation of the findings. There are many factors that may be at play in impacting the changes observed in this research and these should be investigated, to the degree possible, to continuously enhance the collective understanding about the benefits – and costs – of respite care services in Colorado.

Components of the Study
With the above caveats related to existing information about respite care services, this study includes the compilation of research findings from an array of surveys that are available, which were conducted by AARP and other organizations, data from Colorado state agencies, U.S. government reports, academic research, and Colorado Medicaid claims. It also incorporates primary research generated through a survey and interviews with caregivers and care recipients in Colorado. The combination of quantitative methods and qualitative research is designed to help tell a broader story about the potential impact of access to respite care services than just one approach alone could do. Thus, the study includes four key components that synthesize data from several sources:

1. **Respite Care Services and Medicaid Costs in Colorado**: This component used claims data for individuals enrolled in a Colorado Medicaid Home and Community Based Services (HCBS) waiver that included respite care services benefits, which were defined as both the *respite care benefit* plus the *adult day services benefit* as classified by Colorado Medicaid. The analysis compared the costs of providing respite care services with the costs of utilization of other healthcare services for the *care recipients* (the individual enrolled in Medicaid) to assess any potential return on investment.

2. **An Economic Model**: In addition to the research using the Medicaid claims data, the study includes an Economic Model component that was designed to estimate potential benefits and cost savings of providing respite care services beyond what could be found in the claims data. It focuses primarily on impacts to *caregivers* (those with responsibility for caring for someone). The model incorporates available information from published national and state research and data on respite care services. It is designed so that additional factors can be added and analyzed over time, as the body of information about respite care services grows.

3. **Colorado Caregiver Survey**: For this component, a survey was created and distributed broadly across the state to *caregivers*, to gather qualitative information about the impacts of receiving respite care services on both their and their care recipients’ lives. More than 1,000 surveys from caregivers representing a diverse cross-section of individuals from across Colorado were completed.

4. **Interviews with Caregivers**: The final component of the Colorado Respite Care Impact Study includes interviews with a subset of the individuals who took the Colorado Caregiver Survey. The interviews afforded the opportunity to delve further into some of the issues identified through
the survey, but also from the Medicaid claims analysis and the Economic Model. It also provided opportunity for individuals to share their particular stories about the value of respite care services to them and to their care recipients.

The organization of the full report is intentional to allow for understanding of the key findings from each component, as well as to transparently link those findings with any limitations of the specific methodology and approach used. Each component is designed to “stand alone” as its own report as well as be incorporated into the overall study report.

The Colorado Respite Care Impact Study and its components do not and cannot alone answer all the important questions about the value of respite care services. Rather, the overall goal of this multipronged approach and results is to help create a path toward a fuller understanding of the benefit and cost impacts of respite care services and to generate further work by researchers and evaluators to continue to examine the important questions investigated here.
Executive Summary

The Colorado Respite Care Impact Study is a four-part examination of respite care in Colorado. This study is intended to enhance understanding of how the State can improve access to and the quality of respite care services. This study was conducted per HB16-1398, which required the Colorado Department of Human Services to contract for the implementation of the recommendations of the Respite Care Task Force created by House Bill 15-1233. Per HB16-1398, the study must include:

(I) “Provide an analysis of the populations that are caregivers and the differences between those who do and do not use respite care services, including impact on caregivers;

(II) Identify existing data and areas where additional data could be collected from the Department of Health Care Policy and Financing and other respite care sources to examine respite care utilization and the need for support;

(III) Show the impact of funds spent on respite care versus funds saved in health care;

(IV) Use a consistent evaluation tool to assess the waiver respite care programs and all Colorado respite care programs;

(V) Identify data points that the Colorado Respite Coalition can use to collect additional complementary data from caregivers using respite care services and improve evaluation for agencies to show the effect of respite on caregivers, identify varied needs across programs and geographic areas, and demonstrate cost savings of respite care versus institutionalization and hospitalization.”

The findings in this report are intended to help guide Colorado policy makers and program administrators in making long-term plans for respite care services and delivery across Colorado, across the lifespan of care recipients, and across the needs of both caregivers and care recipients. The study defines “caregiving” as regular paid or unpaid care or assistance to a family member or friend who has a health condition, long-term illness or disability; and it defines “respite care” as temporary or short-term care of an individual that is provided by someone other than the person’s normal caregiver.

The Colorado Respite Care Impact Study combines qualitative and quantitative research methods to assess the impact of respite care services on the health of caregivers, the quality of life for caregivers and care recipients, and spending both within the healthcare system and larger society context. There is a general belief in healthcare that respite care services give caregivers a chance to have a break from their responsibilities of caregiving, “re-charge” and avoid “burn-out” that can occur when caring for someone full or near-full time. The findings from the various components of this study reaffirm this belief and offer insights into the many nuanced ways in which respite care services impact Coloradans.

In Colorado it is estimated that nearly one in 10 individuals (584,000 people) are caregivers providing some 543 million hours of care per year. The estimated economic value of this care is $7.4 billion per year.12 Many of these individuals are providing full- or near full-time care, typically for a family member or loved one such as a child/youth with special needs, an elderly parent, or a sibling who is elderly and/or has special needs. Estimates of the economic value of this informal caregiving vary, but generally it is recognized that the market value of this unpaid labor is greater than the cost of paid home care assistance.13

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13 Ibid.
Components of the Study
A compilation of research findings from an array of national surveys, data from Colorado state agencies, U.S. government reports, and academic research was used to support the research in this study. Additionally, the study gathered primary research through a survey and interviews with caregivers and care recipients in Colorado. Because of the complex nature of respite care and the limited existing research about it, this study purposefully combines quantitative and qualitative methods that are designed to paint a more complete picture about respite care services than one approach alone could do. For this reason, the study incorporates four key components:

1. **Respite Care Services and Medicaid Costs in Colorado** for individuals enrolled in a Home and Community Based Services (HCBS) waiver (e.g., care recipients) that included respite care services benefits, which were defined as both the *respite care benefit* plus the *adult day services benefit*, as classified by Colorado Medicaid.

2. **An Economic Model** designed to allow the estimation of potential benefits and cost savings of providing respite care services primarily on impacts to caregivers. It incorporates data from validated national and state research on respite care services and is structured so that additional factors can be added and analyzed over time.

3. **The Colorado Caregiver Survey** was distributed to caregivers across Colorado to collect qualitative data about the impacts of receiving respite care services for both caregivers and care recipients. More than 1,000 individuals representing a diverse cross-section from across the state completed the survey.

4. **Interviews with Caregivers** were conducted with a subset of the individuals who took the Colorado Caregiver Survey and provided a deeper look into issues identified through the survey as well as from the Medicaid claims analysis and the Economic Model.

Importantly, the Colorado Respite Care Impact Study and its components do not and cannot alone answer all the important questions about the value of respite care services. However, it is hoped that this multipronged approach, one of the first of its kind, will inspire more and deeper examination of the important questions not answered here about the benefit and cost impacts of respite care services in Colorado.

Summary of Study Results
**Respite Care Services and Medicaid Costs in Colorado**

This analysis found that for Medicaid beneficiaries (considered care recipients) enrolled in one of the seven HCBS waivers which includes respite care services (respite care plus adult day services benefits), and who met a minimum threshold of receiving at least 90 days of at least one unit of respite care services, the average cost per claim for their other healthcare services (all non-respite care healthcare claims) dropped by $76 after the start of respite care services. Applying these savings to all the beneficiaries analyzed (4,326), translates into a potential savings of as much as $5.7 million per year. It is important to note that this savings does not include the cost for respite services, which for all the beneficiaries analyzed was about $9.8 million per year.

Thus, the results indicate that while respite care services do help to reduce other healthcare costs, they do not “pay for themselves.” Yet the costs of adding respite care services can be mitigated, at least partially, by avoiding costs for other healthcare services. Essentially, this analysis suggests that for every $1 spent on respite care services, the state potentially could avoid spending up to an additional $0.42 on...
other healthcare costs. It is critically important to understand what these findings mean, particularly the distinction between *cost avoidance* (avoids incurring future or additional costs) and *cost savings* (lower current spending or investment). The findings do provide a strong case for the potential value of respite care services in helping to improve the health and costs of healthcare for Medicaid beneficiaries, and calls for additional research to further understand that potential more fully.

**Economic Model**

The model was designed to test the proposition that providing paid respite care for unpaid caregivers will generate savings both within and outside of the health care system that will exceed the cost of that paid respite care. The key findings from calculations in the model include:

- The potential annual costs of providing the equivalent of two weeks of paid respite care to all Colorado caregivers (regardless of the age of their care recipient) is $5.2 billion. The primary driver of these potential savings is the opportunity to delay or reduce a care recipient’s need for institutional care (about 90% of the total benefits estimated in the model). Keeping just 9 percent of care recipients out of a nursing facility can create *savings that equal costs*. Any delays in nursing facility admissions *above* 9 percent can generate *savings in excess of costs*.
- Other sources of potential savings do not, by themselves, exceed the cost of paid respite care; however, they can offset as much as two thirds of such costs.
- Benefits of paid respite care also accrue outside of the health care system. National estimates show that 35 percent of caregivers leave employment as a result of their caregiving responsibilities, and 37 percent reduce their work from full-time to part-time status. In Colorado, if 7.5 percent of caregivers who left work due to caregiving burdens returned to work in part due to access to respite care services, it could generate additional tax revenue to the state of as much as $845 million. If 10 percent of those who went from full-time to part-time work returned to full-time work in part due to access to respite care services, it could result in potentially $297.9 million in revenue to the state.

A key takeaway from analysis in the economic model is that it takes spending money on respite care to save money or avoid additional spending in other areas. Additionally, a critical finding from the model is that it identifies a “social rate of return,” which does not attribute savings to individual payers. As with the Medicaid claims analysis, the economic model is not intended to provide a “final set of answers” to important questions related to the impact of respite care. It does offer a way to explore order-of-magnitude estimates of the benefits and costs of respite care.

**The Colorado Caregiver Survey and Caregiver Interviews**

The Colorado Caregiver Survey and Caregiver Interviews begin to tell a collective story of caregiving and respite care services in Colorado for both caregivers and care recipients, primarily from the perspective of caregivers. For both caregivers and care recipients, the analysis explored impacts of access to respite care services on mental and physical health, and on quality of life (e.g., improved social supports and family relationships). Specifically for care recipients, there also were questions to explore reductions in/avoidance of institutionalization as a result of respite care services. Specifically for caregivers, several questions asked about the impacts of caregiving on employment and income stability, and the role of respite care in alleviating those impacts. The key findings from the survey and interviews, include:

1. Fully 40 percent of respondents indicated they received no respite care services in the past 12 months, suggesting a significant unmet need. However, it was found that in part, respondents living
in an urban setting or with a care recipient enrolled in a Medicaid HCBS waiver had greater access to respite care services.

2. Caregivers are using a much broader range of HCBS waiver services beyond just the “respite” benefit as their “respite care.” This exemplifies one of the many nuances about “respite care services,” in particular, how they are defined, and how difficult that makes them to measure.

3. Younger and middle-aged groups of caregivers (those ages 44 to 64 years) experience the largest financial impacts of caregiving – including employment impacts and reduced savings. This is occurring right at the time when it is most important for them to be saving for retirement and their own future long-term care needs. These findings imply that this age group of caregivers may be at higher risk for significant negative financial impacts as a result of their caregiving responsibilities.

4. Respite care services have a larger impact on improving caregivers’ and care recipients’ quality of life than their mental health and physical health. Specifically, 42 percent of all caregivers who use respite care services reported that respite care “very much” impacted their quality of life, compared to their mental health (29%) and their physical health (21%). However, the mental health benefits of respite care services are much higher among caregivers ages 28 to 44 years old – where 42 percent said respite “very much” helps their mental health.

5. Overall, respite care was found to have an impact on reducing or avoiding institutionalization with little more than one in four caregivers reporting that it “very much” had an impact. Specifically, 26 percent of caregivers of care recipients 24 years and younger and 31 percent of caregivers of care recipients 65 years and older reported that respite care “very much” helped avoid an institutional stay for their care recipient.

Some of the key takeaways from the surveys and interviews are that, on average, caregivers reported that respite care services “somewhat” have an impact on their quality of life, mental health, and physical health. Further analysis of the responses suggests that one reason for the limited impact may be related to barriers to accessing respite care services - such as finding appropriate, affordable, and reliable care - that prevents a full realization of the benefits of respite care services. Additionally, understanding how respite care services can impact a caregiver’s ability to work also is important, so benefits can be designed in ways that maximize financial strength for both caregivers and care recipients. Finally, the findings regarding quality of life and health (mental and physical) impacts suggest the need for much more understanding of these issues and highlighting some of the challenges in trying to quantify the benefits of respite care.

Recommendations for Further Research

There are numerous findings in this report that deserve further analysis to better understand the impacts of current and future respite care service policies and programs across multiple stakeholders. It is hoped that the Colorado Respite Care Impact Study will provide a platform for those stakeholders to continue this critical research. Based on some of the findings and limitations of this study and its components, areas the state should consider for additional research and evaluation include:

1. **Further Explore the Urban/Rural Dynamic of Caregiving in Colorado** and the extent to which respite care service impacts vary and why they vary across geographic location.

2. **Expand the Economic Model** to include additional relevant scenarios, such as the differences in impact between the caregiver for a young care recipient versus a caregiver for an older adult care recipient.
3. **Additional Medicaid claims data analysis** should be conducted to disaggregate the data further into subpopulations and how the subpopulations vary in their use of different types of respite care services and health care utilization outcomes.

4. **Additional Medicaid claims data analysis** should be conducted to include more types of respite care service benefits offered through the HCBS waivers and their role in health care utilization of waiver beneficiaries.

5. **Exploration of respite care services through private payers** and for individuals who do not have access to publicly-funded respite care services.

**Conclusion**

The Colorado Respite Care Impact Study is designed to provide useful information for policymakers, providers, patients, and payers, and to stimulate further research to extend and refine the collective knowledge about the benefits of respite care. This becomes particularly compelling vis-à-vis demographic and labor force trend projections for 2010 to 2040. During this time, the proportion of Colorado’s population age 65 and older is expected to grow from 11 to 19 percent. The population of older people in Colorado is growing faster than the employed population, which will put an increasing strain on middle-age and older caregivers. Respite care is a vital part of a package of support services that can help those who are caring for family members and friends across the age spectrum. To provide such support, Colorado also will need a sufficient supply of paid caregivers, which in turn, will require adequate compensation to attract and retain them.

The study shows that by spending carefully targeted dollars to support informal caregivers, the state would be taking important steps to helping sustain a critical, yet largely unpaid and hidden, labor force. The findings from this study validate the need for Colorado to develop a package of services and supports that includes paid respite care designed to keep individuals in the community - such as the Home and Community Based Services (HCBS) programs in Medicaid – and to ensure those programs are effectively implemented. Doing so has the potential to yield large savings for the state as well as improve overall health outcomes for caregivers and care receivers.

The hope is that the Colorado Respite Care Impact Study and its key components will help the state to start the journey toward a better understanding of the potential of respite care to yield long-term benefits to the overall system.
Introduction and Purpose

The purpose of this report is to present the results of a four-part study of respite care services in Colorado – the Colorado Respite Care Impact Study – conducted for Easterseals Colorado and the Colorado Department of Human Services (CDHS) by Health Management Associates (HMA), a national health and social care research and consulting firm. This study combines qualitative and quantitative research methods to assess the impact of respite care services on the health of caregivers, the quality of life for caregivers and care recipients, and spending both inside and outside of the healthcare system. There is evidence that respite care services can provide caregivers important breaks from the ongoing responsibility of caring to rest, take care of work and personal needs, spend time with other family and friends, and avoid “burning-out.” Due to the complexity of the subject matter and the myriad ways to explore the questions asked in this study, it is important to view it for what it is - a starting point for encouraging a continued discussion of the questions and issues that this analysis does not and cannot answer, but that nevertheless are critical to helping further the collective understanding of the value of respite care services and to quantify that value.

Caregiving: The Hidden Workforce of Colorado

Colorado, like the rest of the U.S., has a precious asset that frequently goes unnoticed to the general public. This asset is a huge “unpaid workforce” that cares for family members and friends with serious health problems and limitations that require continuous attention. The U.S. Bureau of Labor Statistics publishes monthly reports on the country’s formal employment situation—the number of people working, looking for work, and those out of the labor force for various reasons. For example, as of April 2018, an estimated 155.2 million Americans were working, while another 6.3 million had actively looked for work in the past month.14 Each month when such figures are reported, they get widespread attention and frequently influence financial markets. Even as the “visible workforce” gets regular and popular attention, an important yet more “invisible workforce” is toiling mainly in the shadows; they receive no wages or benefits, but are highly valued by the family members and friends to whom they extend a lifeline.

More than 43 million people in the U.S. are providing unpaid care, and the economic value of this caregiving has been estimated at $470 billion.15 Many of these caregivers are also in the workforce. Some 60 percent of family caregivers caring for an adult are working full-time or part-time.16 Thus, millions of Americans are, in effect, working two jobs—one they get paid for and one they do not.

Caregiving is usually very time-intensive. An AARP survey found that on average, caregivers spend 24.4 hours a week providing care. Nearly one-quarter (23%) provide 41 or more hours of care a week, exceeding the time commitment of an average work week for full-time employees. For those caring for a spouse/partner, caregiving averages 44.6 hours a week.17

The largely hidden labor force of unpaid caregivers is providing much needed support and comfort to the most vulnerable members of our society. Their work is supplemented and complemented by a much

16 Ibid.
smaller, but vital paid workforce of home health aides and personal care aides. The number of such aides, however, falls far short of the amount of care needed.

**Aging Demographic Impact**

The challenge of providing effective and affordable respite care can best be viewed against the backdrop of an aging population and a slowly growing labor force. The population age 65 and older is expected to nearly double by 2050 – from 43.1 million in 2012 to 83.7 million. In fact, between 2010 and 2030, the proportion of people in the U.S. age 65 and older is projected to jump from 13 percent to more than 20 percent. An important subset of the elderly is those age 85 and older. This is the fastest growing part of the U.S. population. In 2012, 5.9 million people were age 85 and older, and this number is estimated to grow to 8.9 million in 2030, and to 18.0 million in 2050.\(^{18}\)

Colorado is experiencing similar trends. According to the Colorado State Demography Office:

> “Colorado has begun to experience rapid increases in the population over age 65 with the movement of the baby boom generation into older age groups. The number of persons over age 65 in 2040 will be nearly 3 times as many as today [2010], growing twice as fast as the total population.”

Based on data from the Colorado State Demography Office, in 1970 people age 65 and older made up approximately 9 percent of the population. Forty years later in 2010, people age 65 and older make up 11 percent of the total population of the state. In another 30 years (2040), people age 65 and older are projected to make up 19 percent of the state’s population. The same office issued a report showing that in the 1970s, the Colorado labor force grew by more than the state’s population—4 percent versus 2.8 percent, respectively. But for the 2020 to 2030 period, the labor force is projected to grow only by 1.2 percent, less than the estimated population growth of 1.5 percent over that same time period.\(^{19}\)

This projected increase in the population age 65 and older suggests that there will be more people who require services from a caregiver, which in turn will drive an increase in the demand for respite care services, roughly proportional to the increase in the population. Additionally, the increase in the number of people age 65 and over means that more caregivers will be age 65 and older. This will drive additional increases in the demand for respite services as older caregivers will need more respite care services to attend to their own care needs. This suggests that the growth in demand for respite care services will increase by more than the increase in the population age 65 and older.

In addition to those caring for older people and adults with disabilities, there are a growing number of parents caring for children with disabilities. These individuals are frequently holding down three jobs—the job of physically caring for their children, including in many cases lifting them out of bed, in and out of a wheelchair, and helping them with meals; the job of advocating for special accommodations for them in school and customized equipment, etc.; and a paid job to provide the earnings needed to maintain their household and continue some degree of career development. Respite care services are absolutely vital for these parents who are heavily multi-tasking around the clock.

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\(^{19}\) Colorado State Demography Office, Department of Local Affairs. January 2014.
An Insufficient Workforce for Caring

Nationally, the growth of U.S. employment is not on par to support the rapid aging of the population. Life expectancy continues to increase, while the tax base and the workforce to support this older population is not keeping pace. As the number of jobs continues to grow, labor force participation remains near a low not seen in the U.S. since 1978. In April 2018, labor force participation was 62.8 percent, a level that has hardly risen at all right through the nine-year economic recovery from the 2008-2009 recession. Part of this low participation is related to the retirement of the baby boomers, but several other factors are at work. Many people are under-employed, while others are out of the labor force for reasons such as believing that no work is available for which they qualify (discouraged workers). Some 1.4 million people are designated as “marginally attached” to the U.S. labor force—they are not currently looking for work, but have done so in the last year. Reasons they are not currently working or searching for work include family responsibilities and school attendance. The former category includes many caregivers.\(^\text{20}\)

Economist Paul Osterman projects a shortfall of unpaid family and friend caregivers of 3.8 million in 2030 and 11.1 million in 2040. He also projects a shortfall in paid caregivers of about 151,000 in 2030 and about 355,000 in 2040; but Osterman notes that the shortfall of paid caregivers will be rendered higher by the dramatic shortfall in unpaid caregivers. The clear message is that in the U.S. there is a need for many more of both types of caregivers.\(^\text{21}\) Related, the burnout and pressures on caregivers are accompanied by a limited supply of paid home health aides and personal care aides, those most likely to offer respite to caregivers, as well as formal respite care services providers. This is due in no small part to the fact that the system literally and figuratively undervalues respite care services as a vital long-term service and support (LTSS) for both care recipients and caregivers.

Overview of the Colorado Respite Care Impact Study

In response to the recommendations of the Respite Care Task Force created by House Bill 15-1233, including one to conduct a return on investment analysis of respite care services, CDHS and Easterseals Colorado contracted with Health Management Associates (HMA) on a multi-year project to better understand how the state can improve access to respite care services to those who need them, and to improve the quality of respite care services across Colorado, the lifespan, and needs. One result of these efforts is this report - the Colorado Respite Care Impact Study. The findings from this study are intended to help provide both a guide and a pathway to additional research to support Colorado’s long-term policies and plans for respite care services and delivery.

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**Caregiving:** Regular paid or unpaid care or assistance to a family member or friend who has a health condition, long-term illness, or disability.

For the purpose of the study, *caregiving* is defined as regular paid or unpaid care or assistance to a family member or friend who has a health condition, long-term illness, or disability. They provide this care so that their family member or friend can maintain an independent lifestyle. This family member or friend could be an adult or a child. Caregiving assistance can range from a few hours of shopping and cleaning to

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\(^{20}\) In April 2018 there were also 5 million people working part-time who prefer to work full-time. This likely includes people working part-time due to caregiving responsibilities. [https://www.bls.gov/news.release/empsit.nr0.htm](https://www.bls.gov/news.release/empsit.nr0.htm)

intensive medical or personal care. Tasks can include shopping, house cleaning, cooking, giving medications, toileting assistance, and so forth.

*Respite care services* are defined as temporary or short-term care of an individual that is provided by someone other than the person’s normal caregiver. They are designed to give the caregiver brief personal time away from the daily tasks of caregiving. Respite care services are provided either in-home or out-of-home. They are offered by community organizations such as mental health centers, nursing homes, churches, or private agencies. These organizations provide either a paid worker or a trained volunteer to provide respite care services.

**Methodology**

This study has compiled research findings from a wide array of surveys conducted by many national organizations, data from Colorado state agencies, U.S. government reports, academic research, Colorado Medicaid claims, and a survey and interviews with caregivers and recipients. Together the combination of quantitative methods and qualitative research tells a story about the potential impact of access to respite care services that incorporates more perspectives than one approach alone would include. Thus, the study includes a synthesis of data from four different components:

1. **Respite Care Services and Medicaid Costs in Colorado:** This component used Medicaid claims data for individuals on Home and Community Based Services (HCBS) waivers with respite care benefits (these were care recipients). For purposes of this specific analysis, *respite services* were defined as both the *respite care benefit* and the *adult day services benefit* provided in seven of the HCBS waivers. The analysis also compared the costs of providing these respite care services with the costs of beneficiaries’ utilization of other healthcare services to assess any potential return on investment.

2. **An Economic Model:** The Economic Model component was designed to help start to quantify the potential benefits and cost savings of providing respite care services beyond what could be demonstrated in Medicaid claims data. The model used existing data identified in other research studies on respite care services (e.g., number of caregivers in Colorado), as well as local and national economic data. While the current version of the model focused primarily on caregivers in Colorado, it is designed so that additional factors can be added and analyzed. For example, as more data about rural caregivers or those caring for children with special needs becomes available that data can be added to the model and explore the potential benefits and costs of providing respite care given those new factors.

3. **Colorado Caregiver Survey:** For this component, a statewide online survey was conducted with caregivers (those with responsibility for caring for someone) to measure changes in their quality of life as well as their care recipients’ quality of life as a result of receiving respite care services. More than 1,000 surveys were completed by a broad spectrum of caregivers representing urban and rural areas of the state, those whose primary language was English or Spanish, those with incomes from less than $25,000 to more than $200,000, and those caring for older persons, youth, and children.

4. **Interviews with Caregivers:** The final component includes the analysis of interviews that were conducted with a cross-section of 20 individuals who had completed the Colorado Caregiver Survey to further enhance understanding of the impacts identified through the claims analysis, economic model, and the survey, as well as identify any additional important outcomes and benefits.
Each of the components of the Colorado Respite Care Impact Study includes an introduction with an overview of the findings and limitations of that component, and then a more in-depth discussion of the findings and implications.
Component #1: Respite Care Services and Medicaid Costs in Colorado

Introduction
The Respite Care Services and Medicaid Costs Analysis is one component of the four-part Colorado Respite Care Impact Study, conducted for Easterseals Colorado and the Colorado Department of Human Services (CDHS) by Health Management Associates (HMA). Respite care services are designed to provide temporary relief to caregivers who have the responsibility of taking care of an individual of any age with special needs, who may be at risk for abuse or neglect, or who may not be able to care for themselves any longer. Many caregivers are family members who are unpaid for their work. Respite care services offer them a break to take care of themselves and their other responsibilities. Having this “time off” from caregiving also can help to improve the health of these individuals providing care (caregivers), as well as the health of those receiving care (care recipients). For example, one important goal of improving health is reducing utilization of high-cost healthcare, such as emergency department (ED) visits and inpatient hospitalizations.

This study examines claims data from the Colorado Medicaid program to explore one aspect of the potential impact of respite care services on other healthcare costs. The analysis focuses specifically on beneficiaries who were enrolled in Medicaid Home and Community Benefit Services (HCBS) waivers and are defined in this analysis to represent “care recipients.”

Study Questions
This study analyzed claims data for beneficiaries enrolled in Colorado Medicaid from January 1, 2010, through December 31, 2016. The analysis was designed to help answer the following study questions about respite care services:

1. Does the provision and increased utilization of respite care services result in reduced costs for healthcare provided to Medicaid beneficiaries who are care recipients?
   a. What are the demographic characteristics of care recipients who show the largest cost reductions in other healthcare services when they utilized respite care services?

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22 These beneficiaries are the care recipients in this analysis, and all received some type of respite care services through Medicaid. Therefore, they are assumed to have some type of caregiver supporting them.
b. Does utilization of respite care services result in reductions in Emergency Department (ED) and inpatient hospitalization expenditures – both of which are high-cost and can be inefficient forms of care – for care recipients?

c. Are there differences in cost reductions among the HCBS waivers that provide respite care services?

2. Are respite care services cost-effective, when measurable healthcare costs for care recipients are taken into account?

Methodology

Description of Claims Data Set

Colorado Medicaid claims data were examined for Medicaid beneficiaries with service dates between January 1, 2010, and December 31, 2016.

The subset of the full data that was used for analysis included only those beneficiaries enrolled in HCBS waivers that offer respite care services. For purposes of this study, “respite care services” were defined as both the “Respite Care” and the “Adult Day Services” benefits. Beneficiaries receiving these respite care services through one of the HCBS waivers were identified using procedural codes documented on each Medicaid claim. Beneficiaries who did not have any of these respite care services claims were excluded from further analysis.

There are seven HCBS waivers (out of the total 12 HCBS waivers) that offer these respite care services, as shown in Table 1. Some waivers include respite care only, while others include both respite care and adult day services. Additional description of the exact procedural codes used for the analysis is provided in Appendix A.

Table 1: Colorado Medicaid HCBS Waiver Programs with Respite Care and Adult Day Services Benefits

<table>
<thead>
<tr>
<th>HCBS Waiver Program</th>
<th>Types of Respite Provided</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Waiver for Persons with Brain Injury</td>
<td>• Adult Day Services</td>
</tr>
<tr>
<td></td>
<td>• Respite Care</td>
</tr>
<tr>
<td>2. Waiver for Children with Life Limiting Illness</td>
<td>• Respite Care</td>
</tr>
<tr>
<td>3. Waiver for Persons with Spinal Cord Injury</td>
<td>• Adult Day Services</td>
</tr>
<tr>
<td></td>
<td>• Respite Care</td>
</tr>
<tr>
<td>4. Children’s Extensive Support Waiver</td>
<td>• Respite Care</td>
</tr>
<tr>
<td>5. Supported Living Services Waiver</td>
<td>• Respite Care</td>
</tr>
<tr>
<td>6. Waiver for Community Mental Health Supports</td>
<td>• Adult Day Services</td>
</tr>
<tr>
<td></td>
<td>• Respite Care</td>
</tr>
<tr>
<td>7. Waiver for Persons Who are Elderly, Blind, and Disabled</td>
<td>• Adult Day Services</td>
</tr>
<tr>
<td></td>
<td>• Respite Care</td>
</tr>
</tbody>
</table>

23 As noted in the Study Limitations below, for purposes of this study, Day Habilitation and Day Treatment benefits were not included in the definition of “respite care services.”

24 The procedural codes for the Respite Care and Adult Day Services benefits come from HCBS Waiver Billing Manuals published by Colorado Health First.
**Table 2** shows how many of the beneficiaries (10,500)\(^{25}\) were enrolled in one or more of the seven HCBS waivers that offer either the respite care benefit, the adult day services benefit, or both.\(^{26}\)

**Table 2: Number and Percentage of Beneficiaries in the Claims Dataset Enrolled in One or More of the 7 HCBS Waivers with Respite Care and Adult Day Services Benefits**

<table>
<thead>
<tr>
<th>HCBS Waiver Program</th>
<th># of Beneficiaries per Waiver (including multiple waivers)</th>
<th>% of Beneficiaries per Waiver (for total of 14,908 including multiple waivers)</th>
<th>% of Beneficiaries per Waiver (for total of 10,500 not including multiple waivers)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Waiver for Persons with Brain Injury</td>
<td>90</td>
<td>0.6</td>
<td>0.9</td>
</tr>
<tr>
<td>Waiver for Children with Life Limiting Illness</td>
<td>153</td>
<td>1.0</td>
<td>1.5</td>
</tr>
<tr>
<td>Waiver for Persons with Spinal Cord Injury</td>
<td>2163</td>
<td>14.5</td>
<td>20.6</td>
</tr>
<tr>
<td>Children’s Extensive Support Waiver</td>
<td>1798</td>
<td>12.1</td>
<td>17.1</td>
</tr>
<tr>
<td>Supported Living Services Waiver</td>
<td>2704</td>
<td>18.1</td>
<td>25.8</td>
</tr>
<tr>
<td>Waiver for Community Mental Health Supports</td>
<td>1813</td>
<td>12.1</td>
<td>17.3</td>
</tr>
<tr>
<td>Waiver for Persons Who are Elderly, Blind, and Disabled</td>
<td>6187</td>
<td>41.5</td>
<td>58.9</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>14,908</strong></td>
<td><strong>100.0%</strong></td>
<td><strong>142.1%</strong></td>
</tr>
</tbody>
</table>

\(^{25}\) An unduplicated count of all beneficiaries in the data set was derived by using the unique Medicaid ID numbers that are assigned to each beneficiary.

\(^{26}\) Note that many of the 10,500 beneficiaries are enrolled in more than one waiver over the seven-year period and are thus counted more than once. The second column divides the number of waiver beneficiaries by the total of 14,908 that counts the multiple waivers for the same beneficiary. The third column divides by the 10,560 individual beneficiaries and does not count beneficiaries enrolled in multiple waivers over the course of the seven-year period.
Identification of the Waiver Beneficiary Subset for Analysis

To capture the impact of respite care services, the analysis focused on beneficiaries who received a “meaningful amount” of respite care services. Beneficiaries who were just beginning respite care services or leaving after only a brief period of respite care services cannot be expected yet to show the full benefits of utilizing those respite care services. Exploration of the data suggested that beneficiaries who received at least 90 days of respite care services over the course of the seven-year period would best reflect a minimum threshold of respite care service utilization and its benefits. For this reason, the remaining analysis conducted used the receipt of at least the minimum amount of respite care services per day on at least 90 different days over the course of the seven-year period as the threshold for inclusion. Thus, this analysis counted a “day” of respite care as a date with a minimum of at least one unit of respite care or one unit of adult day services. Those beneficiaries who received a unit of respite care services on fewer than 90 different dates were excluded from the rest of the analysis. Thus, the second subset for analysis included only Medicaid beneficiaries who received at least some respite care services for 90 days over the seven-year period. One consideration for future analysis would be to determine a minimum number of days of respite used per year, to get a more comprehensive understanding of utilization patterns and potential impacts. Another would be to measure the amount of time for each day in calculating a minimum duration.

Additionally, and of special importance, the analysis measured the first date for use of respite care services for those beneficiaries who received at least 90 days of services. For each beneficiary, the measure divided the period of study into two parts: before and after the start of any respite care service. In other words, the “Before” period is the time before which a beneficiary who had used at least 90 days of respite care services first began receiving any respite care services, and the “After” period is the time after which they first began receiving any respite care services. Once this was established, then costs received in the Before period could be compared to costs in the After period.

The comparison across periods requires additional refinement of the beneficiaries used in the analysis. To ensure an appropriate comparison, each beneficiary had to have at least six months in the Before period and six months in the After period. Beneficiaries who had less than six months of time in either the Before or After periods lacked sufficient time for a valid comparison, so they were excluded from the final analysis. In practice, the beneficiaries included in the analysis began their respite care service after June 30, 2010, and before July 1, 2016. The logic is illustrated in Figure 1.

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27 As noted in Limitations #6 and 7 below, the respite care and adult day services benefits have different units of service. For simplification, this study considered the receipt of at least one unit of either respite care or adult day services on a single day as a “day” on which the beneficiary received a respite care service. Beneficiaries who had at least 90 days out of the 7-year timeframe on which they received respite care services have likely received a sufficient amount of respite care services to evaluate the services.
In summary, to make the comparison as precise as possible, the final analysis examined a subset of Medicaid beneficiaries on the seven HCBS waivers that offered respite care services and who met the following restrictions:

- They received at least one unit of respite care services on at least 90 different days during the seven-year study period.
- They began receiving respite care services at least six months after the start of the seven-year study period and no more than six months before the end of the study period.

After excluding beneficiaries who did not meet the above restrictions, the final analysis subset included 4,326 Medicaid beneficiaries who were enrolled in at least one of the seven HCBS waivers that include respite care services benefits as defined in this study. These 4,326 beneficiaries had a total of 1,871,989 claims that were used in the final analysis of costs. This is the subset of Medicaid waiver beneficiaries and claims is used in all the analyses going forward for this component.
Figure 2: Exclusions and Number of Beneficiaries Used in Analysis

Beneficiaries that Received Respite Care Services from one of the 7 HCBS Waivers\textsuperscript{28}  
\[ N = 10,500 \]

Beneficiaries who received Respite Care Services on 90 Different Days with a Minimum of at Least One Unit of Respite Care or Adult Day Services  
\[ N = 6,946 \]

Beneficiaries with a Before Period and After Period of at Least 6 Months  
\[ N = 4,326 \]

Beneficiaries Used in the Final Analysis  
\[ N = 4,326 \]

Study Measures
The analysis used several measures available from the Medicaid claims data file, which are defined below:

- \textit{Respite care services}: Any Medicaid claim that includes a procedure code referencing the respite care or adult day services benefits, as defined by Colorado Health Services procedure codes. See Appendix A for a list of all procedural codes used in the analysis.

- \textit{Beneficiary}: A person enrolled in Medicaid with a unique Medicaid ID. For this study, a beneficiary is also receiving respite care service(s).

- \textit{Days of respite care services}: A date on which at least one unit, regardless of length (could be as little as 15 minutes), of respite care services (inclusive of both \textit{respite care} and \textit{adult day services} waiver benefits) is received.

- \textit{Claim cost}: The total amount paid for services with a unique Member ID and unique claim ID.

- \textit{Cost for respite care services}: The total amount paid for claims with a procedure code indicating \textit{respite care} or \textit{adult day services} benefits.

- \textit{Cost for other healthcare services}: The total amount paid for claims for all services that are not either respite care or adult day services (referred to as “respite care services”), as defined by procedural codes. This includes services that beneficiaries received as part of their traditional Medicaid benefits, as well as non-respite care services they received through the waiver(s) in which they were enrolled.

- \textit{Inpatient}: Medicaid claims with a place of service code that indicates “Inpatient-Hospital.”

\textsuperscript{28} Again, as defined for purposes of this study, \textit{respite care services} means the respite care benefit and the adult day services benefit.
- **Emergency department**: Medicaid claims with a place of service code that indicates “Emergency Room-Hospital.”

- **Before period**: The service dates (with costs for those service dates) before any respite care services are utilized by a beneficiary; the length of the before period varies across individual beneficiaries.

- **After period**: The service dates (with costs for those service dates) on or after the start of any respite care for a beneficiary; the start date and length of the after period varies across individual beneficiaries.

**Analytic Strategy**

The analytic strategy for this study was to examine how costs changed from the period Before to the period After the start of respite care services. Reduction in costs from the Before period to the After period may be seen as costs avoided or as savings, with some caveats. A key point of differentiation between cost avoidance and cost savings is that cost savings lower current spending or investment; cost avoidance is a way to avoid incurring future or additional costs.

By examining the same beneficiaries both Before and After the start of respite care services, the analysis controlled for many extraneous sources of differences that can distort comparisons with beneficiaries who never used respite care services. Other factors beyond the receipt of respite care services can affect the differences between costs in the Before and After periods of respite care services utilization; for example, that beneficiaries started to receive respite care services at different dates and some were on waivers longer than others. Additional strategies were employed to control for these factors and limit this potential bias. While the Before and After comparison of beneficiaries on HCBS waivers that include respite care service benefits provides valuable insights, it is important to note that it does not bring the same level of confidence as a randomized control trial.

Using this strategy, the primary goal of the Medicaid claims analysis was to understand if there was a reduction in other healthcare costs for beneficiaries as a result of the use of respite care services. Thus, the analysis first examined Medicaid claims costs for healthcare services other than respite care services. This allowed for examination of respite care services in terms of reductions in other healthcare costs. It then examined total costs combined, or the expenditures for respite care services plus the expenditures for other healthcare services, which reflects the balance of program costs and benefits. A potential future analysis could include examination of acute care services that are included in traditional Medicaid benefits versus waiver-only benefits to determine if there are differences.

Note that the Before and After period varies across beneficiaries: some started respite care relatively early in the seven-year period and some started later. Averaged across all beneficiaries, however, the

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29 As noted in Limitation #6, “all other healthcare costs” are services that are not either respite care or adult day services (referred to as “respite care services”) and include services that beneficiaries received as part of their traditional Medicaid benefits, as well as non-respite care services they received through the waiver(s) in which they were enrolled.
Before period is shorter than the After period for most beneficiaries. In other words, most beneficiaries started early in the seven-year period. The average amount of time before the start of respite care services was 2.48 years (about 30 months), and the average amount of time after the start of respite care services was 4.90 years (about 59 months). It was important to consider these differences in the analysis.

**Statistical Models**

Two specific statistical strategies were used to control for extraneous factors besides respite care services that may affect costs in the Before and After periods. First, in comparing waiver beneficiaries Before and After the start of respite care services it is necessary to adjust for a general upward trend in costs. Otherwise, the costs in the After period would be generally higher in the later years due to inflation. This adjustment is done using multiple regression models that control for a linear trend based on the date of service. The models treat other healthcare costs as the outcome and the Before/After period as the key predictor or driver of this outcome, with date of service as a control variable. Date of service controls for the trend toward higher costs over the seven-year period.

Second, the average claim cost may be affected by the characteristics of individual beneficiaries in the Before and After periods. Some beneficiaries received respite care services early and some received respite care services later. Those starting early in the seven-year period who therefore may have longer periods of potential respite care service utilization, may differ from beneficiaries who received respite care services later within the seven-year period and have shorter periods or opportunity for respite care service utilization. Such differences could affect the results, suggesting the need to control for individual healthcare and respite care service utilization differences between beneficiaries. The data lack a full set of control variables, but a fixed-effects model was used to create a control variable unique to each beneficiary in the analysis subset. The result was an estimate of the change across the Before/After periods that adjusts for each beneficiary’s characteristics that are related to costs and stable over time.

**Study Assumptions and Limitations**

1. This impacts analysis is limited to Medicaid beneficiaries, who are the care recipients. While it is not possible to know for certain if all the beneficiaries in the data sample had caregivers because they used respite care services, the analysis assumes that they had some type of caregiver. See Limitation #4 below for additional information about respite care services assumptions.

2. This study did not include analysis of the cost impacts on caregivers. Other components of the larger Respite Care Program Study include analysis focused primarily on caregivers.

3. This study results cannot be projected directly into the future. It is limited to the beneficiaries in 2010 to 2016. As the Medicaid population ages, it is likely that regardless of respite there will be an increasing number of claims because older individuals in particular tend to have a more complicated health/medical needs, regardless of whether they access respite care services or not.

4. This analysis defined “respite care services” as the respite care benefit plus the adult day services benefit available through several of the HCBS waiver programs in Colorado Medicaid. It is recognized that not all Medicaid beneficiaries use the adult day services benefit for “respite” for a caregiver. It also is recognized that there are other waiver services that beneficiaries sometimes use for “respite.” These include Day Habilitation Services and Day Treatment Services. Future studies
may consider incorporating the other waiver services, given the challenges of defining what “respite care services” can mean.

5. The respite care and adult day services benefits have different billable units of service. For respite care, one unit equals 15-minutes, whereas for adult day services, one unit equals three-to-five hours. This analysis counted a “day” of respite care as a date with a minimum of at least one unit of respite care or of adult day services. It did not distinguish amounts, or number of units, of service per day.

6. This analysis examined the costs for all healthcare services used by the beneficiaries during the study period of seven years – both those services they received through traditional Medicaid, and those services they receive through the HCBS waiver(s) in which they were also enrolled. There may be value in examining the services available through traditional Medicaid and those available through the waivers separately in another analysis to determine if there are any differences.

7. It is important to understand the difference between cost avoidance and cost savings, as used in this study. Cost savings lower current spending or investment; cost avoidance avoids incurring future or additional costs.

8. While this comparison of Medicaid beneficiaries on HCBS waivers with respite care services benefits provides valuable insights, it is important to note that this study design does not have all the strengths of a rigorous randomized control trial. As in most research, findings related to cost savings or cost avoidance should be interpreted and used with caution.

Analysis Results

Waiver Types

Table 3 below shows the number of beneficiaries who are in each waiver of the analysis (column 1). Note that many beneficiaries are enrolled in more than one waiver over the seven-year period. Since beneficiaries enrolled in two or more waivers over the seven-year period are counted more than once, the total number of beneficiaries is 6,065 – considerably more than the 4,326 individual beneficiaries identified for the subset analysis. The most common overlap of waivers was for 1,014 individual beneficiaries who were enrolled in both a Persons Who Are Elderly, Blind, and Disabled waiver and a Community Mental Health Supports waiver. The second column divides the number of waiver beneficiaries by the total of 6,065 that counts the multiple waivers for the same beneficiary. The third column divides by the 4,326 individual beneficiaries and does not count beneficiaries enrolled in multiple waivers over the course of the seven-year period.

Within this subset of beneficiaries, respite care services for beneficiaries on the Persons Who Are Elderly, Blind, and Disabled waiver was most common (2,543, 41.9%, 58.8%).\(^{30}\) The beneficiaries on the Children’s Extensive Support, Supported Living Services, and Community Mental Health Supports waivers each made up 15.6-18.1 percent or 21.9-25.4 percent.

Column 5 shows the average number of days of respite care service on each waiver for those beneficiaries who received the waiver during the study period. Thus, over the full seven-year analysis

\(^{30}\) Additional analyses not presented in the table indicate that adult day services make up the vast majority of respite care services for the Persons Who Are Elderly, Blind, and Disabled waiver.
period for all beneficiaries in the subset, the average days of respite care service on a waiver range from 46 days for beneficiaries on the Persons with Spinal Cord Injury waiver (which had a small number of enrollees), to 653 days for those on the Persons Who Are Elderly, Blind, and Disabled waiver (which had the majority of enrollees). Findings from the analysis suggest that the beneficiaries enrolled on the Persons with Spinal Cord Injury waiver experience short enrollment periods as nearly all beneficiaries on that waiver also indicated enrollment in the Persons Who Are Elderly, Blind, and Disabled waiver, which lasts for a longer period of time.

Table 3: Prevalence of Beneficiaries by Type of Waiver

<table>
<thead>
<tr>
<th>Waiver Type</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td># of Beneficiaries per Waiver (including multiple waivers)</td>
<td>% of Beneficiaries per Waiver (for total of 6,065 including multiple waivers)</td>
<td>% of Beneficiaries per Waiver (for total of 4,326 not including multiple waivers)</td>
<td>Average # of Respite Care Service Days per Waiver (including multiple waivers)</td>
<td></td>
</tr>
<tr>
<td>Persons Who Are Elderly, Blind, and Disabled</td>
<td>2,543</td>
<td>41.9</td>
<td>58.8</td>
<td>653</td>
<td></td>
</tr>
<tr>
<td>Children’s Extensive Support</td>
<td>946</td>
<td>15.6</td>
<td>21.9</td>
<td>530</td>
<td></td>
</tr>
<tr>
<td>Supported Living Services</td>
<td>1,099</td>
<td>18.1</td>
<td>25.4</td>
<td>511</td>
<td></td>
</tr>
<tr>
<td>Community Mental Health Supports</td>
<td>1,066</td>
<td>17.6</td>
<td>24.6</td>
<td>435</td>
<td></td>
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<tr>
<td>Persons with Spinal Cord Injury</td>
<td>307</td>
<td>5.1</td>
<td>7.1</td>
<td>46</td>
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<tr>
<td>Children with Life-Limiting Illness</td>
<td>66</td>
<td>1.0</td>
<td>1.5</td>
<td>184</td>
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<tr>
<td>Persons with Brain Injury</td>
<td>38</td>
<td>0.6</td>
<td>0.9</td>
<td>339</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>6,065</td>
<td>100%</td>
<td>140%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Average Medicaid Claim Costs

Table 4 below lists the average Medicaid claim costs for the full seven-year period of analysis. The first column includes costs for all non-respite care services or “other healthcare services,” where the average

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As noted in the Limitations Section below, costs were determined using Medicaid claims data. Each “claim” was defined as one data point with a unique claim number and Medicaid ID number.
across the sample is $378 per claim. When this average is multiplied by the 1,675,943 claims, the total cost for the subset over the seven-year period equals $633.5 million. The second column lists the average for only the respite care services claims, where the average is $385 per claim. The total cost for the 196,046 respite care services claims is $75.5 million (10.6% of the total cost of all claims). The last column shows the average cost of $379 for all claims from the subset, including both respite-care services plus other healthcare services. The total cost for all claims is $709.5 million.

Table 4 also presents figures for each beneficiary in the subset. The numbers divide the total cost of all claims by the 4,326 beneficiaries. Across all seven years, the average total cost of claims for other healthcare claims for each beneficiary was $146,440 and the average total for all respite care services claims was $17,453 per beneficiary. The average total cost for all healthcare services, including respite care services, was $164,008.

Table 4: Average and Total Claim Costs Over the Full Study Period

<table>
<thead>
<tr>
<th>Per Claim</th>
<th>Other Healthcare Services</th>
<th>Respite Care Services</th>
<th>Respite Care + Other Healthcare Services</th>
</tr>
</thead>
<tbody>
<tr>
<td># of Claims</td>
<td>1,675,943</td>
<td>196,046</td>
<td>1,871,989</td>
</tr>
<tr>
<td>Average Cost per Claim</td>
<td>$378</td>
<td>$385</td>
<td>$379</td>
</tr>
<tr>
<td>Total Cost (millions)</td>
<td>$633.50</td>
<td>$75.50</td>
<td>$709.50</td>
</tr>
<tr>
<td>(over full 7-year period)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Per Beneficiary</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td># of Beneficiaries</td>
<td>4,326</td>
<td>4,326</td>
<td>4,326</td>
</tr>
<tr>
<td>Average Cost per Beneficiary</td>
<td>$146,440</td>
<td>$17,453</td>
<td>$164,008</td>
</tr>
</tbody>
</table>

Figure 3 shows that for this analysis, respite care services are 12 percent of the total costs of all services (respite care services plus other healthcare services).
Changes in Average and Total Other Healthcare Costs from Before and After Respite Care Services

When analyzing the costs from the Before and After periods of when beneficiaries began receiving respite care services, Table 5 below shows the average cost of $385 for any other healthcare services claim (not including costs for respite care services) in the Before period.32 It also shows the average cost for these same services is $309 for the After period (adjusted for the general upward trend in Medicaid claim costs).33 The average cost per healthcare services claim thus declines by $76, or nearly 20 percent (19.7%) from the Before period to the After period. Note that the number of claims during the After period more than doubles from the Before period because the time span is twice as long. This is discussed more fully below.

Table 5: Average and Total Other Healthcare Services Claims Costs for Before and After Periods

<table>
<thead>
<tr>
<th>Only Healthcare Services</th>
<th>Before Receipt of Respite Care Services</th>
<th>After the Receipt of Respite Care Services</th>
<th>Difference (After – Before)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td># of Other Healthcare Services Claims</td>
<td>567,305</td>
<td>1,304,684</td>
</tr>
<tr>
<td></td>
<td>Average Cost per Other Healthcare Services Claim</td>
<td>$385</td>
<td>$309</td>
</tr>
<tr>
<td></td>
<td>Total Costs (millions)</td>
<td>$218</td>
<td>$403</td>
</tr>
<tr>
<td></td>
<td>Average Length of Period (years)</td>
<td>2.48</td>
<td>4.90</td>
</tr>
<tr>
<td></td>
<td>Total Cost per Year (millions)</td>
<td>$87.9</td>
<td>$82.2</td>
</tr>
</tbody>
</table>

32 Respite care services costs are treated as 0 in these calculations.
33 This figure and the others to follow come from multiple regression models, described in the Methodology Section of this report, that control for a trend based on the date of service.
Figure 4 below demonstrates graphically the drop in average claim costs for other healthcare services once respite care services are introduced.

Figure 4: Change in Other Healthcare Costs After Beneficiary Receives Respite Care Services

![Figure 4: Change in Other Healthcare Costs After Beneficiary Receives Respite Care Services](image)

It also is important to note that the Before period is on average shorter (2.48 years) than the After period (4.90 years); however, some simple calculations to compute the savings per year were used to normalize the change in costs when adjusting for the different time period spans. Table 5 above presents these calculations in the bottom rows. The total cost equals the number of claims multiplied by the average claim; the total cost per year equals the total cost divided by the average length of the period. The total costs per year are more comparable, given they are standardized for the length of the period.

Thus, as Table 5 shows overall, the total cost per year in the Before period was $87.9 million, compared to the total cost per year in the After period of $82.2 million. The difference is the estimated costs avoided because of the use of respite care services – or $5.7 million. While not the same as direct cost savings (planned expenditures that are not spent, and therefore available for other purposes), costs avoided are nevertheless important because they may be seen, with due qualification, as an estimate of avoidance of additional expenditures that otherwise would have been made had it not been for the intervention – in this case, respite care services. While this measure is hypothetical rather than actual, it still illustrates well the potential benefits of respite care services.

Changes in All Services (respite care services and other healthcare services) from Before to After Respite Care Services

The analysis of the averages for total Medicaid claim costs in Table 6 found that the average cost in the Before period was $384 (nearly identical to the total cost for other healthcare services, because respite care services are not used in the Before period). The average in the After period was $367. The difference of $17 equals a decline of 4.4 percent.

34 The small difference between $385 in Table 4 and the $384 in Table 5 comes from minor differences in the trend in other and total costs in the multiple regression equations.
Table 6: Average and Total Medicaid Claim Costs for Other Healthcare Services Plus Respite Care Services in the Before and After Periods

<table>
<thead>
<tr>
<th></th>
<th>Before</th>
<th>After</th>
<th>Difference (After - Before)</th>
</tr>
</thead>
<tbody>
<tr>
<td># Claims</td>
<td>567,305</td>
<td>1,304,684</td>
<td></td>
</tr>
<tr>
<td>Average Cost per Claim</td>
<td>$384</td>
<td>$367</td>
<td>-$17</td>
</tr>
<tr>
<td>Total Costs (millions)</td>
<td>$218</td>
<td>$479</td>
<td></td>
</tr>
<tr>
<td>Average Length of Period (years)</td>
<td>2.48</td>
<td>4.90</td>
<td></td>
</tr>
<tr>
<td>Total Cost Per Year (millions)</td>
<td>$87.9</td>
<td>$97.7</td>
<td>$9.8</td>
</tr>
</tbody>
</table>

The total costs based on the number of claims and average cost per claim are also shown in Table 6. Dividing total costs by the average length of each period gives comparable numbers for total cost per year. Total costs, adjusting for the differences in period length, were $87.9 million per year in the Before period, and $97.7 million per year in the After period. The average cost per claim declined; however, there are more claims (e.g., inclusion of respite care services claims and the longer average After period compared to Before period) in the After period. Therefore, the estimated total cost for all healthcare services, including respite care services, increased by $9.8 million per year. This increase can be assumed to represent the cost of the respite care service investment, as illustrated in Figure 5.

Figure 5: Potential to Avoid Other Healthcare Services Costs as a Result of Respite Care Services

To what extent is there a reduction in healthcare costs as a result of the investment in respite care services?
Taken together, the findings indicate that $9.8 million per year, on average, was spent on respite care services. The cost avoided in other healthcare services because of the investment in the respite care services was $5.7 million. Therefore, there was a total potential cost of $4.1 million per year that might have been spent without the respite care intervention. Using the calculation provided below, the avoidance in cost indicates that for every $1 spent on respite care, Medicaid can potentially avoid spending as much $0.42 in other healthcare costs. Therefore, while respite care services do not “pay for themselves,” they do generate a benefit in avoided costs.

\[
\text{Cost Avoidance} = \frac{\text{Costs Avoided as a Result of the Intervention}}{\text{Cost of Respite Care Services}}
\]

\[
\text{Cost Avoidance} = \frac{\$4.1 \text{ Million Per Year}}{\$9.8 \text{ Million Per Year}}
\]

\[
\text{Cost Avoidance} = \$0.42 \text{ cost avoided in other healthcare costs per } \$1.00 \text{ spent on respite care services}
\]

Controlling for Individual Differences

As described above in the Methodology Section, the average claim cost may be affected by the characteristics of the sample in the Before and After periods. Beneficiaries who received respite care services early and have a longer After period may differ from beneficiaries who received respite care later and have a shorter After period. Controlling for individual differences can help to better identify the real impact of respite care services.

The averages in the After period obtained from the fixed-effects model are shown in the last columns of Table 7 below. The estimated change in average benefit with this type of control is $56 lower for other healthcare costs, but $54 higher for total costs. These results show that the reduction in other healthcare costs persists, even with the controls. However, the findings of this claims analysis also demonstrated a slightly higher cost for respite care services than the costs avoided for other healthcare services.
Table 7: Average and Total Medicaid Claim Costs for Before and After Periods - Fixed Effects Controls

<table>
<thead>
<tr>
<th></th>
<th>Before</th>
<th>After</th>
<th>Difference (After – Before)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Only Other Healthcare Services</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td># of Other Healthcare Services Claims</td>
<td>567,305</td>
<td>1,304,684</td>
<td></td>
</tr>
<tr>
<td>Average Cost per Other Healthcare Services claim</td>
<td>$384</td>
<td>$329</td>
<td>-$56</td>
</tr>
<tr>
<td>Total Costs (millions)</td>
<td>$218</td>
<td>$429</td>
<td></td>
</tr>
<tr>
<td>Average Length of Period (years)</td>
<td>2.48</td>
<td>4.90</td>
<td></td>
</tr>
<tr>
<td>Total Cost Per Year (millions)</td>
<td>$87.9</td>
<td>$87.6</td>
<td>$0.30</td>
</tr>
</tbody>
</table>

| Other Healthcare Services Plus Respite Care Services |        |       |                             |
| # Claims                                            | 567,305 | 1,304,684 |                             |
| Average Cost per Claim                              | $384   | $438  | $54                         |
| Total Costs (millions)                              | $218   | $571  |                             |
| Average Length of Period (years)                    | 2.48   | 4.90  |                             |
| Total Cost Per Year (millions)                      | $87.9  | $116.5 | $28.6                       |

Who Benefits the Most from Respite Care Services

The analysis also examined the change from the Before period to the After period for several subgroups among the 4,326 Medicaid beneficiaries. These figures are listed in Table 8 and show the change in the average claim from the Before to the After period. For the change in costs, a negative value indicates declining, or avoided costs, and a positive value indicates increasing, or added costs.

Declining costs appeared greater for:

- Males than females
- Younger and middle-aged beneficiaries than older beneficiaries
- The years 2010-2013 than the years 2014-2016
Table 8: Average and Total Medicaid Claim Costs for Before and After Periods – by Subgroups of Beneficiaries

<table>
<thead>
<tr>
<th>Subgroup</th>
<th>Before Period Average Cost per Claim for Other Healthcare Costs</th>
<th>After Period Average Cost per Claim for Other Healthcare Costs</th>
<th>Change in Other Healthcare Costs</th>
<th>Change in Respite Care Services Plus Other Healthcare Costs</th>
<th>Change in Respite Care Services + Other Healthcare Costs (After - Before)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>$391</td>
<td>$298</td>
<td>$93</td>
<td>$360</td>
<td>-$31</td>
</tr>
<tr>
<td>Female</td>
<td>$321</td>
<td>$268</td>
<td>-$53</td>
<td>$323</td>
<td>$2</td>
</tr>
<tr>
<td>Age &lt; 18</td>
<td>$437</td>
<td>$423</td>
<td>-$14</td>
<td>$480</td>
<td>$43</td>
</tr>
<tr>
<td>Age 19-64</td>
<td>$338</td>
<td>$282</td>
<td>-$56</td>
<td>$344</td>
<td>$6</td>
</tr>
<tr>
<td>Age &gt;65</td>
<td>$214</td>
<td>$216</td>
<td>$2</td>
<td>$272</td>
<td>$58</td>
</tr>
<tr>
<td>2010-2013</td>
<td>$356</td>
<td>$260</td>
<td>-$96</td>
<td>$320</td>
<td>-$36</td>
</tr>
<tr>
<td>2011-2014</td>
<td>$365</td>
<td>$332</td>
<td>-$33</td>
<td>$391</td>
<td>$26</td>
</tr>
<tr>
<td>Inpatient</td>
<td>$115</td>
<td>$66</td>
<td>-$49</td>
<td>$66</td>
<td>-$49</td>
</tr>
<tr>
<td>Emergency</td>
<td>$49</td>
<td>$40</td>
<td>-$9</td>
<td>$40</td>
<td>-$9</td>
</tr>
<tr>
<td>Other Healthcare Services</td>
<td>$373</td>
<td>$289</td>
<td>-$84</td>
<td>$350</td>
<td>-$23</td>
</tr>
</tbody>
</table>

Inpatient and Emergency Department (ED) Costs
The change from Before to After respite care services for costs for other healthcare services also was examined, with a focus on two high-cost services: inpatient hospital stays and ED visits. The results listed in Table 8 above show few savings for ED services, but more substantial savings for in-patient services. As Table 8 also shows, the largest cost reduction occurs for “Other” services, which include more routine services that take place outside of the ED and/or hospital.

Wavier Type
Table 9 below shows the change in costs for subgroups of beneficiaries enrolled in each of the seven HCBS waivers included in the final subset analysis. The table first lists the Before period average cost, which is the same for both other healthcare costs and for other healthcare costs plus respite care services. The table next lists the After period average cost for both other healthcare costs and for other healthcare costs plus respite care services. Finally, it lists the change from the Before period to the After period for both other healthcare costs and for other healthcare costs plus respite care services. As in
Table 9, negative numbers for the change show avoided costs avoided, while positive numbers show added costs.

The most expensive waiver in terms of costs added was Persons with Spinal Cord Injury, followed by the waiver for Children with Life-Limiting Illnesses. These waivers have relatively fewer participants. The other waivers have lower costs for other healthcare services.

Table 9: Average and Total Medicaid Claim Costs for Before and After Periods, by Waiver Types

<table>
<thead>
<tr>
<th>Waiver Type</th>
<th>Before Period Average Cost per Claim for Other Healthcare Costs</th>
<th>Change in Other Healthcare Costs</th>
<th>Change in Respite Care Services and Other Health Care Costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Persons with Brain Injury</td>
<td>$500</td>
<td>-$268</td>
<td>$289</td>
</tr>
<tr>
<td>Children with Life-Limited Illness</td>
<td>$435</td>
<td>$1</td>
<td>$449</td>
</tr>
<tr>
<td>Persons with Spinal Cord Injury</td>
<td>$272</td>
<td>$48</td>
<td>$382</td>
</tr>
<tr>
<td>Community Mental Health Supports</td>
<td>$324</td>
<td>-$110</td>
<td>$299</td>
</tr>
<tr>
<td>Supported Living Services</td>
<td>$383</td>
<td>-$37</td>
<td>$402</td>
</tr>
<tr>
<td>Children's Extensive Support</td>
<td>$431</td>
<td>-$18</td>
<td>$470</td>
</tr>
<tr>
<td>Waiver for Persons Who are Elderly, Blind, and Disabled</td>
<td>$275</td>
<td>-$50</td>
<td>$286</td>
</tr>
</tbody>
</table>

The Children’s Extensive Support waiver had a modest reduction in other healthcare costs (-$18 per claim), while the other waivers appear to have greater reductions in other healthcare costs. The Community Mental Health Supports waiver (-$110) and the Persons with Brain Injury waiver (-$268) appear to have the largest reductions; however, the Persons with Brain Injury waiver has the fewest
number of enrolled beneficiaries, which limits its overall impact. The beneficiaries on Supported Living Services (-$37) waiver and the Waiver for Persons Who are Elderly, Blind, and Disabled (-$50) who use respite care services also appear to reduce other healthcare costs. When including both other healthcare costs and respite care costs, only the Persons with Brain Injury and the Community Mental Health Supports waivers appear to reduce overall costs.

Summary of Key Findings
This initial data analysis of Medicaid claims indicated that for Medicaid beneficiaries (e.g., the care recipients) enrolled in one of seven HCBS waiver that offered respite care and/or adult day services, and who met a minimum threshold of respite care services, the average cost per claim for their other healthcare services dropped by $76 (19.7%) after the start of respite care services. If these savings were applied to all the beneficiaries in the analyzed subset (4,326), it would translate into an estimated costs avoided of as much as $5.7 million per year with the use of respite care services. Even when taking a more conservative approach, the analysis still showed that the average cost per claim for other healthcare services declined, albeit less, when respite care services were utilized. These results suggest that spending for respite care services can be mitigated, at least partially, by avoiding costs for other healthcare services. Stated in another way, the findings from this analysis suggest that for every $1 spent on respite care services, the state potentially could avoid spending up to an additional $0.42 on other healthcare costs. It is important again to note here the difference between cost avoidance and cost savings. Cost savings lower current spending or investment; cost avoidance avoids incurring future or additional costs.

In this analysis, the estimated cost reductions from respite care services were greatest for male beneficiaries, younger beneficiaries, and during the early years of the study period (the first 3 of the 7 years). The most substantial cost avoidance was for beneficiaries in the Persons with Brain Injury and Community Mental Health Supports waivers; however, there also were cost reductions noted for beneficiaries in the Supported Living Services waiver and the Waiver for Persons Who are Elderly, Blind, and Disabled. Finally, the analysis found that respite care services did reduce inpatient hospitalization costs, but had only a small positive impact (reduction) on ED costs.

Conclusion
Respite care services are an important benefit in many of Colorado Medicaid’s HCBS waiver programs and provide recipients and their caregivers critical supports. While this brief analysis did not find evidence that respite care services completely “pay for themselves,” it did find that providing respite care services has the potential to reduce total costs by helping beneficiaries to avoid other, more expensive healthcare services such as hospital inpatient admissions. As with the other components that were part of the larger Colorado Respite Care Impact Study, it is important to continue research like this to help move toward a better understanding of these findings, and whether other kinds of benefits of respite care can help to close the gap between the current costs of respite and the savings they can create.

Note that the calculations for total costs accounted for the number of beneficiaries in each of the waivers. For example, although the Persons with Brain Injury waiver has a small number of beneficiaries compared to the other waivers, it therefore contributes less overall than the other waivers to the averages for all beneficiaries.
Component #2: The Economic Model

Introduction

The Economic Model is one component of the four-part Colorado Respite Care Impact Study, conducted for Easterseals Colorado and the Colorado Department of Human Services (CDHS) by Health Management Associates (HMA). This model is intended to help determine the economic value of the benefits of respite care services in Colorado, and the extent to which these benefits justify the costs of providing such services to caregivers. Specific questions the model seeks to answer include:

- How much of a reduction in the use of health care in high-cost settings (e.g. Emergency Departments (EDs), hospitals, nursing homes) among caregivers would it take to justify the cost of respite care, and yield savings that exceed such costs?
- What is the “cross-over point” at which respite benefits justify their costs?

The logic of the economic model is that the timely and effective provision of respite care services for those in need across the life cycle will generate savings, both within the medical system and outside of that system. Benefits include delays in or avoidance of admissions to long-term care facilities for those receiving unpaid care from a family member or friend and inpatient hospital admissions for the caregivers whose health can deteriorate without respite care. Even small reductions in such use of the most highly expensive components of our health care system will yield significant savings.

In addition to reduced medical and long-term care spending, respite care services may lead to fewer days of missed work and higher productivity for caregivers who get relief through respite care, along with reductions in sick days and family medical leave. Beyond these quantifiable benefits, respite also provides value in that it can improve quality of life – both for caregivers and care recipients. These benefits, while less tangible than some of those identified in this economic model, are covered in more detail in a separate component of the overall study that includes a survey and interviews with caregivers.

Supporting the Unpaid Workforce of Caregivers is a Good Investment

The analysis of this economic model explores the proposition that informal, unpaid caregiving is in many cases the best option for the care recipient and will be less expensive than paid home care assistance, as

Study Purpose: To begin to identify and quantify the value of respite care services. The component parts of the Colorado Respite Care Impact Study underscore just how complex respite care services are, and that there are numerous ways of looking at questions about respite care services. Therefore, it is important to view this study for what it is – a starting point for encouraging a continued discussion of the questions and issues that this analysis does not and cannot answer, but that nevertheless are critical to helping further the collective understanding of the value of respite care services and to quantify that value.
referenced in the 2015 AARP study *Valuing the Invaluable, The Economic Value of Family Caregiving.* 36 Smart investments in respite care will protect the health and well-being of caregivers, which in turn will help improve or maintain the health and functional status of care recipients. *Meeting both these policy goals can yield “double victories”—first, improving quality of life, and second, yielding substantial savings.* With effective and timely respite care, care recipients from children through disabled adults and the frail elderly, as well as their caregivers, can have a higher quality of life. At the same time, caregivers will make fewer trips to the ED, experience fewer inpatient hospital admissions and readmissions, and, critically important, care recipients may delay or avoid entering institutional long-term care facilities such as nursing homes.

This is not to disregard the importance of paid caregiving. Many care recipients will need both types of care over their lifetimes, and it is also important that the state has an adequate paid workforce comprised mainly of home health aides and personal care aides. These are the workers who will most likely provide the respite care that will strengthen the unpaid caregivers and help avoid their “burnout.” In this sense, caregiving provided by family and friends, and care provided by paid workers are complementary.

Respite care is an important component of a cluster of services, such as those typically offered under Home and Community Based Services programs in Medicaid, that provide a range of supports allowing people to remain in their homes and in the community. This is not only good health and social policy—it also makes good business sense. One purpose of the economic model is to test the hypothesis that there will be a positive return on investment (ROI) from respite care. Analysis of the model’s inputs presents the potential of respite care to generate savings both inside and outside the health care system. The model delivers a “best case” scenario and quantifies the savings if respite care were to achieve its anticipated potential.

**Description of the Economic Model Elements**

To make the economic model comprehensive, yet not too complex, a set of factors, or elements, for which data could be gathered from state and federal sources, private foundations, surveys, and academic research. These data sources were assembled and translated into findings showing various types of impacts of respite care on caregivers, care recipients, and payers for health care services (e.g., Medicaid, private insurers, and private and public employers and employees). Each of the model elements is described below, with information about how data were derived, research used to substantiate data, and assumptions and caveats about the data. This iteration of the model is designed to account for the value of respite care to caregivers; however, there is opportunity to refine the model to evaluate specific elements and populations, such as caregivers supporting children with special needs or caregivers living in rural Colorado versus urban Colorado. The model is not set up as a controlled experiment or quasi-experimental research design with treatment and control groups. That approach is beyond the scope of this study’s design. However, it does identify and draw upon several studies that used such designs, along with numerous surveys of caregivers and in-depth analyses published by the AARP and other similar organizations. The model and the data are valid and robust enough to draw general conclusions that can provide policy and program leaders solid information from which to make informed decisions about respite care services.

36 AARP. (2015, July). *Valuing the Invaluable, The Economic Value of Family Caregiving*
Limitations of the Model

Understanding the above, there are several limitations of the model that are noted here.

1. The foundation of the model is the number of caregivers living in Colorado. This is an unknown number for many reasons, including insufficient and timely data collection methods to accurately capture number of caregivers, as well as that many times a caregiver does not self-identify as caregiver. The model may be under-estimating or over-estimating the potential benefits since the actual number of caregivers is unknown.

2. The model analysis did not include the scope and available time and resources to employ a quasi-experimental design with “treatment“ and “control” groups. The model does not incorporate individual level data by which techniques such as a multiple regression analysis could be used to control for certain factors other than respite care that might have contributed to desirable outcomes. Therefore, this analysis does not definitively establish cause-and-effect relationships between respite care and such outcomes as reduced ED use and inpatient care and reduced or delayed nursing home admissions, but rather leverages other studies suggesting that such outcomes do occur.

3. The model presents data on certain prevalent medical conditions affecting caregivers, such as depression, but it does not include data on other diseases that may be afflicting caregivers. Related, the model assumes a diagnosis leads to treatment, and thus costs of that treatment. It is unclear to what extent caregivers diagnosed with a medical condition then go on to pay for and receive treatment.

4. The parties that make the up-front investments in respite care may not be the ones who capture the savings. This model calculates both the costs and the benefits of respite care but stops short of being able to attribute the savings to particular payers. In that sense, it determines a kind of “social rate of return” rather than a return to Medicaid alone or to a private insurer, employer, etc.

5. The model does not take into consideration the level of care the caregiver is providing to the care recipient. These costs will be impacted by whether the caregiver is providing complex care 24/7 to their care recipient versus a caregiver who cares for someone with less complex needs.

There are four key set of inputs to this version of the model. However, the model itself is designed so that over time it can be updated with new information and/or additional inputs determined to be of interest to the state.

Model Input #1: Estimate the number of people who are likely to be providing respite services in Colorado for an older adult, using existing data sources and existing definitions.
   • Data point: Number of caregivers and care recipients (assume a 1:1 relationship).

Model Input #2: Estimate the expenses associated with providing respite care services.
   • Data point: Annual cost of respite care services provided by a Personal Aide/Home Health Aide.

Model Input #3: Estimate the costs of health care impacts from caregiving and the mitigation of these costs as a result of respite care services.
   • Data point: The cost of chronic care (e.g. depression or insomnia) resulting from caregiving.
   • Data point: The cost of acute care resulting from caregiving including caregiver injuries or short-term medical conditions.
• Data point: Both chronic and acute care conditions can lead to repeated physician office visits, new medications, ED visits, and inpatient hospital admissions.

**Model Input #4:** Estimate the economic effects from caregiving, beyond added health care spending, that relate to the labor force and the economy.

• Data point: Colorado average income
• Data point: Unemployment/underemployment rates among caregivers
• Data point: Tax revenue to the state from employed caregivers

**Methodology**

An extensive literature review was conducted to identify studies that provide data on each of these four key elements in the economic model. This review included research studies conducted at universities, government agencies, research institutes, and a wide range of surveys of caregivers conducted in recent years. No one article or study presents the answer and/or all the data points required to inform the model. Some literature points primarily to the Medicaid and Medicare populations, while other studies focus on caregiving, regardless of any specific population. Taken together, however, the studies, reports, and articles we reviewed provide a solid base of information and inform a model that identifies the order of magnitude of savings that result from funding and supporting respite care services. The amount of savings is substantial.

For example, some of the literature cited includes national studies of caregivers and care recipients by the AARP as well as by leaders in the insurance field such as Transamerica, Genworth, and the National Association of Insurance Commissioners (NAIC). Other literature included state reports of Medicaid home and community based (HCBS) waivers and several academic studies investigating more specific health and/or economic impacts of caregiving and access to respite care services.

**Model Assumptions**

All data below has been estimated specifically for Colorado caregivers. These categories tie to the model inputs noted above. An important additional note about the assumptions of this analysis is that they estimate the best-case potential for cost avoidance and/or savings for Colorado.

**Demographic Assumptions**

Based on a combination of national surveys and studies, AARP (2015) estimates that there are as many as 584,000 unpaid caregivers in the state.\(^{37}\) These are individuals providing full- or near full-time care for a family member or loved one such as a child/youth with special needs, an elderly parent, or a sibling who is elderly and/or has special needs. The model assumes a one-to-one relationship between a caregiver and a care recipient (the individual for whom care is being provided).\(^ {38}\) Thus, there also are an estimated 584,000 care recipients in Colorado.

- Number of unpaid caregivers providing full- or near full-time care: 584,000
- Percent of caregivers who receive no respite care services: 85%\(^ {39}\)

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\(^ {37}\) AARP Study valuing the invaluable 2015. The estimate is calculated from combination of weighted averages from a number of studies/surveys from 2009-2014

\(^ {38}\) The majority of caregivers (82%) care for one other adult, while 15% care for 2 adults, and 3% for 3 or more adults, as found in the National Alliance for Caregiving and AARP 2015 study *Caregiving in the U.S.* The model can be revised to reflect this.

\(^ {39}\) 2015, NAIC and AARP Public Policy Institute
Respite Care Cost Assumptions

Data on wages and salaries for full-time paid respite care workers are from the U.S. Bureau of Labor Statistics state-by-state estimates. These Colorado-specific wage estimates were increased to reflect the common overhead factors used for companies that provide these services. This provides an hourly cost of respite care that is provided by a paid professional Personal Care Aide or Home Health Aide. Additionally, the model establishes a threshold of respite care services that is the equivalent of respite care provided 24-hours a day, seven days a week, for two weeks.

- Total cost, including wages paid to workers and overhead costs for home health aides/personal care aide agency (i.e., cost to caregiver) $26.40/hour
- Total amount of respite care per year per caregiver 24/7 care for 2 weeks

Health Impacts

HMA gathered from national studies prevalence data among caregivers of chronic conditions and health care utilization. One study presented an opportunity to quantify the burden of caregiving for working caregivers by providing prevalence of depression and insomnia rates among working caregivers and working non-caregivers.40

Depression41

- Rates among caregivers 53.0%
- Rates among non-caregivers 31.7%

Insomnia42

- Rates among caregivers 17.9%
  Rates among non-caregivers 9.9%

Health care utilization rates were identified for ED utilization and in-patient hospitalization among working and non-working caregivers.

ED Utilization (# of visits in past 12 months)43

- Rate for working caregivers 1.2
- Rate for working non-caregivers 0.4

Inpatient Hospitalization (# of visits in past 12 months)44

- Rate for working caregivers 1.2
- Rate for working non-caregivers 0.2

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41 Ibid.
42 Ibid.
43 Ibid.
44 Ibid.
Health Care Costs

HMA gathered information from national sources, as well as from Colorado Medicaid, Colorado hospitals, and other providers to establish averages for costs for nursing facility care, ED visits, inpatient hospitalization, care for someone with a diagnosis of depression, and treatment for insomnia. A caveat to this data is that the information did not include the numbers of individuals who received these treatments.

- Average annual cost for private room nursing facility care in 2018\(^\text{45}\) $102,565
- Average cost per ED visit (for ED serving +8,000 patients, in 2013)\(^\text{46}\) $2,168
- Level One Care cost per ED visit (St Joe’s Hospital, in 2018)\(^\text{47}\) $143
- Level Five Care cost per ED visit (St Joe’s Hospital, 2018)\(^\text{48}\) $1,752
- Average cost per inpatient day across all hospital types\(^\text{49}\) $2,639
- Costs of depression (all costs are per person per year, 2014 dollars)\(^\text{50}\) $8,187
- Costs of treating insomnia (ranges from about $200 a year for a generic sleeping pill to up to $1,200 for behavioral therapy, in 2011 dollars)\(^\text{51}\) $700

Economic Impacts

To derive data related to the economic impacts of providing respite care services, analysis focused on several key data points: 1) the number of caregivers who are working at least part time; 2) average hourly wages of those working caregivers and the average annual income based on that hourly rate; 3) the Colorado individual income tax rate; 4) estimates of the number of caregivers who are not working at all because of their caregiving responsibilities and the number who are working only part-time; 5) the number of caregivers who would go back to work either full- or part-time if they had access to adequate respite care services; and 6) a “multiplier effect” of increased wages where the extra income leads to more spending, and this overall economic improvement for caregivers going back to work. A variety of national and Colorado sources of information were used to determine these data, and specific studies and research are cited. The model includes reasonable assumptions about the percent of caregivers who return to the workforce, which are clearly defined below.

- Percent of working caregivers\(^\text{52}\) 60.0%
- Average hourly wage\(^\text{53}\) $25.34
- Average annual income (based on average hourly wage)\(^\text{54}\) $52,707

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\(^{45}\) Genworth Cost of Care Survey, 2017, State Median


\(^{47}\) https://www.sclhealth.org/locations/saint-joseph-hospital/patients-visitors/understanding-medical-costs-fr/

\(^{48}\) Ibid.

\(^{49}\) The Henry J. Kaiser Family Foundation. 2015. Available at https://www.kff.org/health-costs/state-indicator/expenses-per-inpatient-day-by-ownership/?currentTimeframe=0&sortModel=%7B%22collId%22:%22Location%22%22sort%22:%22asc%22%7D


\(^{52}\) National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.


\(^{54}\) Ibid.
• State Flat Income Tax Rate\textsuperscript{55} 4.63%
• Percent of caregivers who give up work entirely as a result of caregiving responsibilities\textsuperscript{56} 35.0%
• Percent of caregivers who reduce work from full-to part-time status\textsuperscript{57} 37.0%
• Assumption: Percent of caregivers who return to the workforce due (in part) to receiving respite care services 7.5%
• Assumption: Percent of caregivers who return to the workforce full time from part time due (in part) to receiving respite care services 10.0%
• Assumption: Additional spending due to the multiplier effect of economic improvement of caregivers, generating income for others 80.0%

Cost/Benefit Calculations
Using the assumptions noted above for: 1) demographics of caregivers and care recipients; 2) average costs of respite care services; 3) average costs of other medical and health care services; and 4) economic information such as average wages/income, the state flat income tax rate, and percentages of caregivers working part-or full-time, the model calculates the following estimates of the costs and benefits of access to respite care. Importantly, these costs and benefits do not necessarily accrue in a direct relationship. For example, while Medicaid may cover the cost of respite care for many individuals, the benefits to a caregiver receiving that respite may not be realized by Medicaid if the caregiver is not a Medicaid beneficiary. Similarly, increased tax revenues for the state from a caregiver who is able to go back to work may not directly benefit the entity paying for that respite care. This is why it is important to consider the costs and benefits as a whole, and to understand the complexities of respite care services, who they impact and how they impact those individuals and entities.

Cost of Providing Respite Care in Colorado
Annual cost of respite care services provided by a Personal Aide/Home Health Aide at the equivalent of two weeks of 24/7 care per year, at an hourly rate of $26.40 (includes hourly wage plus overhead costs).

• Cost of two weeks of paid caregiving per year\textsuperscript{58} $8,870/person
• Cost of two weeks of paid caregiving per year for every caregiver in Colorado $5.2 billion/year
• Cost of two weeks of paid caregiving per year for the estimated number of caregivers in Colorado who currently receive no respite care services (Assumes 85% of caregivers do not receive respite care services)\textsuperscript{59} $4.4 billion/year

Cost of Nursing Home Care in Colorado
The Colorado average annual cost of nursing home (NH) care in 2018 is $102,565/year.

\textsuperscript{55} Colorado Revised Statutes and Legislative Council Staff, available at https://leg.colorado.gov/agencies/legislative-council-staff/individual-income-tax
\textsuperscript{56} National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.
\textsuperscript{57} Ibid.
\textsuperscript{58} For reference, the analysis estimates the average cost of respite care services (defined as respite care and adult day service benefits) for individuals on a Medicaid HCBS waiver to be $17,466. The assumption is lower for all care recipients, since only 23% of care recipients are on Medicaid waiver.
\textsuperscript{59} 2015, NAC and AARP Public Policy Institute
• Cost if 25 percent caregivers in Colorado chose to place their care recipient in a NH with no access to respite care\(^60\) (2018) $14.8 billion/year

• The ROI for two weeks of 24/7 respite care for all caregivers that prevents/delays NH care for one year for 24 percent of care recipients $1 in respite care: saves $2.89 in NH care

• The ROI for two weeks of 24/7 respite care for all caregivers versus NH care for all care recipients (2018) (Assumes that respite care prevents or delays for one year institutional care) $1 in respite care: saves $10.56 in NH care

Figure 8 below shows the calculated breakeven point for the investment in respite care services and reduction in nursing home care costs. Breakeven measures risk of investment rather than a return on investment. The analysis reveals that if respite care services can delay NH admissions by a year for just 9 percent of Colorado’s care recipients, the savings realized equals the costs associated with providing that respite care. Any portion of care recipients above that 9 percent who can be kept in the community creates potential savings that exceed the cost of that respite care service investment.

Figure 8: Break Even Point for Nursing Home Care

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\(^60\) This represents an extreme outer limit; in reality, a good number of people who are needy enough to require caregiving in the home may not actually qualify for nursing home care.
Costs of Other Health Care Services in Colorado

Caregiving has all the features of a chronic stress experience: it creates physical and psychological strain over extended periods of time; is accompanied by high levels of unpredictability and uncontrollability; has the capacity to create secondary stress in multiple life domains such as work and family relationships; and frequently requires high levels of vigilance. Chronic stress puts caregivers at increased risk for numerous health problems including: anxiety, depression, digestive problems, headaches, heart disease, sleep problems, weight gain, and memory impairment, among others.

Health Costs for Caregivers

To estimate the impact of providing respite care services on the health of caregivers in Colorado, the economic model incorporates research that assessed lifestyle characteristics among working caregivers and working non-caregivers to determine the burden of caregiving on health care resource utilization and mental health among employed adults. Specifically, the model identified costs for ED visits, hospital inpatient stays, and treatment for a diagnosis of depression and insomnia.

ED Utilization

Average costs of ED visits for 350,400 working Colorado caregivers assuming that these caregivers require 1.2 visits per year compared to those same individuals if they were not caregiving. Working non-caregivers require 0.4 visits per year.

- Annual costs of ED visits (national ED rate) for working Colorado caregivers: $911.6 million
  - Annual cost of Level 1 visit at Joseph’s Hospital (Denver): $60.0 million
  - Annual cost of Level 5 visit at St Joseph’s Hospital (Denver): $736.7 million

- Annual costs of ED visits (national ED rate) for those same individuals if they were not caregiving: $303.9 million
  - Annual cost of Level 1 visit at Joseph’s Hospital: $20.0 million
  - Annual cost of Level 5 visit at St Joseph’s Hospital: $245.6 million

Potential savings (cost difference) in ED costs that respite care services could realize if respite care services reduced ED utilization among working caregivers down to non-caregiving rates (national ED rate; 33% difference): $607.7 million

- Potential annual savings of Level 1 visit at Joseph’s Hospital: $40.0 million
- Potential annual savings of Level 5 visit at St Joseph’s Hospital: $491.1 million

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63 Ibid.
65 The cost of an emergency visit is determined by the level of care required including the amount of resources utilized for assessing, testing, treating, and monitoring the patient. Usually, more complex or severe problems will cost more and reflected in Level 5 visit, with higher number of tests, examinations, and coordination needed to determine a patient diagnosis, stabilization, and treatment.
Inpatient Hospitalization

HMA used the following average cost per inpatient day in Colorado, based on information from the 1999 - 2015 American Hospital Association Annual Survey (as provided via the Henry J. Kaiser Family Foundation).66

- State/local government hospital $2,248
- Nonprofit hospital $2,922
- For-profit hospital $2,746

For simplicity, the model uses a calculated average inpatient day cost of $2,639. Again, the model assumed 350,400 working Colorado caregivers requiring on average 1.2 inpatient days per year (which happens to be the same rate as ED visits per year), compared to those same individuals if they were not caregiving. Working non-caregivers require on average 0.2 inpatient days per year.67

- Annual costs for 1.2 inpatient hospital days for working caregivers $1.1 billion
- Annual costs for 0.2 inpatient hospital days for working non-caregivers $184.9 million

➤ Potential savings (cost difference) in cost of inpatient stays that respite care services could realize if services reduced inpatient stays among working caregivers down to non-caregiving rates (83% decrease) $924.5 million

Depression Rates and Cost of Treatment

- Annual costs for treating depression among working caregivers $1.5 billion
- Annual costs for treating depression among working non-caregivers $909.4 million

➤ Potential savings (cost difference) for reduced rates of depression among working Colorado caregivers compared to those same working individuals if they were not caregiving (40% decrease) $611.0 million

Insomnia Rates and Cost of Treatment

- Annual costs for treating insomnia among working caregivers $43.9 million
- Annual costs for treating insomnia among working non-caregivers $24.3 million

➤ Potential savings (cost difference) for reduced rates of insomnia among working Colorado caregivers compared to those same working individuals if they were not caregiving (45% difference) $19.6 million

66 The Henry J. Kaiser Family Foundation. 2015.
Economic Costs – Impacts on the Workforce

Another important input examined in the model is the impact of caregivers re-entering the workforce or working more when they use respite care services. The analysis used the following data and assumptions to derive the results for this element of the model.

- Number of caregivers who gave up work as a result of caregiving responsibilities (assumes 35% of caregivers give up work entirely)\(^{68}\) 204,400
- Number of caregivers who reduced work from full- to part-time status as result of caregiving responsibilities (assumes 37% of caregivers reduce to part-time)\(^{69}\) 216,080
- Annual taxable income (in dollars) lost by caregivers who reduce their hours or give up work entirely as a result of caregiving responsibilities (assumes annual earnings of $52,707)\(^{70}\) $8.1 to $10.8 billion

Using the above, the following state tax revenue impacts were calculated for providing respite care for Colorado caregivers.

Estimated Benefits

- 7.5 percent of caregivers returning to the workforce full time (as a result of receiving respite care services) would generate additional state tax revenue. (Assumes annual wage of $52,707, caregiver returns full time, and the flat Colorado income tax rate of 4.63%) $37.4 million
- Additional spending due to the multiplier effect (generation of income for others) from 7.5 percent of caregivers returning to the workforce full time. (Assumes multiplier effect of 80%) This additional spending also could generate some new revenue for the state in sales taxes and personal and business income taxes. $646.4 million
- 10 percent of caregivers returning to the workforce full time from part-time status (increase of 10 hours per week) would generate additional state tax revenue. (Assumes annual earnings of $52,707 and the flat Colorado income tax rate of 4.63%) $13.2 million
- Additional spending due to the multiplier effect (generation of income for others) for caregivers returning to the workforce from part-time to full-time status. (Assumes multiplier effect of 80%) This additional spending also could generate some new revenue for the state, as noted above. $227.8 million

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\(^{68}\) Based on findings from the study: National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.

\(^{69}\) Based on findings from the study: National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.

\(^{70}\) While in a very small proportion of cases, the job a caregiver left would be filled by someone not working and therefore newly paying state income taxes, the model assumes that this would be more or less offset by the fact that also a small proportion of people who fill those jobs would be moving to Colorado from another state, and therefore would be a new taxpayer for the state. Thus, with these two forces "cancelling each other out," it is valid to assume the full revenue loss would be realized by the state.
Estimated Costs

- Annual cost of providing respite care services to all caregivers who left the workforce or reduced their hours in the workforce so they could be caregivers: $1.8 billion to 1.9 billion

Balance of Respite Care Costs versus Benefits

Figure 9 below provides an overview of the costs and benefits of providing respite care services to Colorado’s caregivers that were analyzed in this economic model. The figure reveals that no single benefit, per se, other than the potential savings from delayed institutional care, can bring a noticeable return on investment for costs associated with delivering respite care services. However, the timely and effective provision of respite care for those in need across the life cycle enables savings to be realized, when considering benefits both within the health system and outside of that system.

In summary, the model recognized benefits and costs associated with:

- Avoided healthcare costs for caregivers receiving respite care services (total of ED, inpatient, depression, and insomnia health care utilization costs)
- Increased earnings for caregivers receiving respite care services
- Increased state tax revenues and multiplier effect for caregivers re-entering the workforce or working more hours

Based on the economic model’s inputs and analysis, the overall annual cost of delivering two weeks of 24/7 respite care to all Colorado Caregivers could potentially be as much as $5.2 billion. The benefits realized could amount to $17.5 billion, as summarized below in Figure 9. This adds up to a possible return on investment (ROI) of $2.37 for every $1 spent on respite care.

Return on Investment is calculated as:

\[ \text{ROI} = \frac{\text{Benefit} - \text{Investment in Respite Care}}{\text{Investment in Respite Care}} \]
When looking across the benefits, the vast majority of the return on investment for respite care services is found by delaying institutional care for the caregivers’ care recipients, as shown in Figure 9. As discussed in the Colorado Caregiver Survey and Interview component of the study, caregivers were asked to assess to what degree they believe that respite services have helped their care recipient avoid a nursing home stay or other institutional stay. 24 percent of caregivers who received respite care services felt that respite care services “very much” or close to “very much” helped their care recipient avoid a nursing home stay, suggesting that delayed institutional care occurs. Pictured in Figure 10, as a portion of the benefits and savings assessed in the economic model, delayed institutional care makes up 83 percent of those savings, and is the largest portion.
Summary of Key Findings

The model was designed to test the proposition that providing paid respite care for unpaid caregivers will generate savings both within and outside of the health care system that will exceed the cost of that paid respite care. The key findings from calculations in the model include:

- The potential annual costs of providing the equivalent of two weeks of paid respite care to all Colorado caregivers (regardless of the age of their care recipient) is $5.2 billion. The primary driver of these potential savings is the opportunity to delay or reduce a care recipient’s need for institutional care (83% of the total benefits estimated in the model). Keeping just 9 percent of care recipients out of a nursing facility can create savings that equal costs. Any delays in nursing facility admissions above 9 percent can generate savings in excess of costs.

- Other sources of potential savings do not, by themselves, exceed the cost of paid respite care; however, they can offset as much as two thirds of such costs. For example, reduction in hospital stays or ED visits.
Benefits of paid respite care also accrue outside of the health care system. National estimates show that 35 percent of caregivers leave employment as a result of their caregiving responsibilities, and 37 percent reduce their work from full-time to part-time status. In Colorado, if 7.5 percent of caregivers who left work due to caregiving burdens returned to work in part due to access to respite care services, it could generate additional tax revenue to the state of as much as $845 million. If 10 percent of those who went from full-time to part-time work returned to full-time work in part due to access to respite care services, it could result in potentially $297.9 million in revenue to the state.

Conclusion

A key takeaway from analysis in the economic model is that it takes spending money on respite care to save money or avoid additional spending in other areas. Additionally, a critical finding from the model is that it identifies a “social rate of return,” which does not attribute savings to individual payers. Findings should reveal to policy makers and program administrators the importance of look at caregiving and the role of respite care in a holistic way, not just pieces here and there, to understand the full impact (positive and negative) of respite care.

As with the Medicaid claims analysis, the economic model is not intended to provide a final set of answers to important questions related to the impact of respite care. It does offer a way to explore order-of-magnitude estimates of the benefits and costs of respite care, during a critical time to really understand and begin to address these issues as the number of people needing care will continue to grow and the people available to care for them decrease. If caregivers were replaced by paid care, the economic model begins to reveal impacts it would have on state, local, and family budgets.
Components 3 & 4: Colorado Caregiver Survey and Caregiver Interviews

Introduction
The Caregiver Survey and Interviews are two components of the four-part Colorado Respite Care Impact Study, conducted for Easterseals Colorado and the Colorado Department of Human Services (CDHS) by Health Management Associates (HMA). Respite care services offer a significant opportunity for individuals who are providing care to someone full or near-full-time to have a break from caregiving and be able to take care of themselves and their other life responsibilities, including family, employment, and friends. The Colorado Caregiver Survey and Caregiver Interviews research seeks to explore to what extent caregivers and care recipients can achieve certain outcomes when they have access to respite care services. The survey and interviews were designed to gather qualitative information to help to quantify the impacts of receipt of respite care services among Coloradans, as well as explore more in-depth the experiences and outcomes for caregivers and their care recipients. This information can further understanding of the nuances in respite care services benefits and why certain caregivers and care recipient achieve different outcomes.

Study Purpose: To begin to identify and quantify the value of respite care services. The component parts of the Colorado Respite Care Impact Study underscore just how complex respite care services are, and that there are numerous ways of looking at questions about respite care services. Therefore, it is important to view this study for what it is - a starting point for encouraging a continued discussion of the questions and issues that this analysis does not and cannot answer, but that nevertheless are critical to helping further the collective understanding of the value of respite care services and to quantify that value.

Taken together, the Colorado Caregiver Survey and Caregiver Interviews begin to tell a collective story of respite care services in Colorado, primarily from the perspective of caregivers. Specifically, the information included in this survey and interview analysis focused on understanding several factors that impact both caregivers (individuals responsible for providing care to someone) and care recipients (individuals receiving/requiring care).

For caregivers, the analysis explored -

1. Employment and income stability
2. Continued improved mental and physical health
3. Improved quality of life (e.g., improved social supports and family relationships)

For care recipients, the analysis explored -

1. Continued improved mental and physical health
2. Improved quality of life (e.g., stabilization of living situation, improved social supports and family relationships)
3. Reduction in/avoidance of institutionalization
Survey Methodology and Limitations

There is not a lot of existing research that examines the impact of respite care on caregivers, care recipients, and society in general. While it represents just one picture in time, the survey and interviews do offer an important glimpse into these impacts for caregivers and care recipients in Colorado. The two key components of this research include the following:

1. **The Colorado Caregiver Survey**: A statewide online survey conducted with caregivers (those with responsibility for caring for someone) to measure changes in their quality of life, health, and employment, as a result of receiving respite care services. The survey also asked questions related to these factors for care recipients.

2. **Interviews with Caregivers**: Interviews conducted with individuals who had taken the survey and agreed to talk with researchers. Interviews were designed to further enhance understanding of the impacts identified through the survey as well as identify any additional important outcomes and benefits. Interviews also added qualitative information to issues identified in another component of the larger Colorado Respite Care Impact Study, an analysis of Medicaid claims data for Home and Community Based Services (HCBS) waiver beneficiaries receiving respite care services.

The methodology and key findings from the survey and interviews are presented here as complimentary to one another. The survey provides additional qualitative data points on Colorado caregivers, while the interviews provide an opportunity for context and in-depth understanding of the survey results.

### Survey Respondent Snapshot

**Survey dates**
April 2 – 25, 2018

**Demographic Information**

- Total number of respondents: 1,008 of which 890 provide paid or unpaid care
- 19 percent use Medicaid to fund respite care services
- 11 percent are non-white race and ethnicity
- 82 percent live along Front Range Urban Corridor
- 50 percent care for a child
- 18 percent care for partner or spouse
- 19 percent care for a parent
- 13 percent care for someone else (other)

(additional details on the distribution tactics can be found in Appendix C). The survey was open for three weeks in April 2018, and respondents were offered an opportunity to enter their name into a raffle for a $100 VISA gift card as an incentive for participation.

**Survey Methodology**

The 2018 Colorado Caregiver Survey was designed in partnership with Easterseals Colorado, the Colorado Department of Human Services, and the study’s Advisory Committee (see Appendix B for Survey Questionnaire). Additionally, the survey incorporated questions that were intended to gather qualitative data to further expand on quantitative data gathered through the other two major components of the larger Colorado Respite Care Impact Study - an analysis of Medicaid claims data and an Economic Model designed to explore costs and benefits of respite care services in Colorado. Researchers used Survey Monkey, an online survey tool, to create and disseminate the survey. It was distributed principally electronically through direct emails, e-newsletters, Twitter and Facebook advertising, with information explaining the survey’s intended audience and purpose.
Survey Limitations
There are some limitations to this component’s data - primarily that the information is self-reported caregiver data. Therefore, it is also limited in the extent to which the care recipient’s voice is heard. Care recipients’ experiences are told largely through their caregivers; however, the findings do include some specific, albeit limited, care recipient data.

Caregiver Interviews
Interviews were conducted to further enhance understanding of the impacts identified through the survey as well as identify any nuances and additional important outcomes and benefits related to respite care services that might not have been observed through the survey results (see Appendix D for Interview Questionnaire). A total of 315 caregivers who responded to the survey identified themselves as willing to participate in an interview. This group of respondents was further analyzed to identify a subset who could provide an in-depth qualitative understanding of experiences of caregivers who may have been underrepresented in the survey, e.g., caregivers from rural communities and those of a non-White races and ethnicities. Caregivers also were selected for an interview if they indicated their care recipient used a HCBS waiver to fund respite care services. There were 20 interviews conducted, each lasting approximately 45 minutes to one hour. Interviewees were sent a $25 VISA gift card and an appreciation for them taking the additional time to talk with researchers.

Statewide Distribution of Survey and Interview Respondents
The map below (Figure 11) presents a picture of the statewide distribution of the survey and the interviews. While the majority were concentrated in more urban areas, there was representation from many rural areas of Colorado.
About Colorado’s Caregivers

Approximately three in four (76.5%) of Colorado’s caregivers became a caregiver voluntarily, and did so because they had a close relationship to the care recipient. There are various duties caregivers perform for their care recipients. Most common among them is accompanying them to medical appointments (91%), followed by meal preparation (88%), running errands (86%), companionship (86%), and healthcare coordination (85%). Many caregivers are providing services that otherwise likely would have to be done by a costlier professional such as a Certified Nursing Assistant (CNA) at $14.95 median hourly wage, a Licensed Practical Nurse (LPN) at $23.91 median hourly wage, or even a Registered Nurse (RN) at $33.77 median hourly wage.\(^7\) These services include medication management (79%), personal care (75%), and medical treatment administration (54%).

The Time Caregivers Spend Providing Care

Time caregiving can mean many things, but generally implies time not working in a professional career setting, time not spent taking care of oneself, as well as time not spent on relationships with others (other family members, friends, etc.). Figure 12 demonstrates that just over one third (35%) of caregivers reported caregiving full-time (24 hours a day, 7 days a week, or 24/7), while slightly more

\(^7\) Median hourly wages provided by Bureau of Labor Statistics, May 2017.
(37%) reported providing 24/7 care “except while my child is in school.” The remaining respondents, on average, reported 38.5 hours per week of caregiving. Figure 12 below also shows the number of hours spent each week in caregiving by the age of the caregiver. Younger caregivers whose care recipients are in school are receiving the benefit of having that time as “respite,” even though otherwise they are providing care 24/7. However, more than half (56%) of caregivers providing 24/7 care with no breaks for a care recipient being in school are age 44 to 64. Both of these findings have implications for how respite care services should be structured to leverage existing supports such as school for those supporting younger care recipients and finding additional respite care sources for older caregivers supporting care recipients who do not have access to services such as school.

Figure 12: Hours Caregivers Spent Caregiving Per Week, by Age of Caregiver

Table 10 shows the average and median, or most typical, responses across all survey respondents regarding the amount of time they spend caregiving by the age of the caregiver. Across all ages of caregivers, the average number of caregiving hours per week was 38.5 hours, while the median was 21 hours per week. Interestingly, caregivers who are age 65 years and older reported more hours on average caregiving per week than any other age group. As described above, the fact that some younger caregivers are supporting younger care recipients who are in school, may be reflected here in the number of hours these caregivers reported spending in caregiving. Again, both of these findings have implications that should be further explored.

Table 10: Average and Median Hours Per Week of Caregiving Among Survey Respondents

<table>
<thead>
<tr>
<th>Age of Caregiver</th>
<th>Average Hours Caregiving per Week</th>
<th>Median Hours Caregiving per Week</th>
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</thead>
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<tr>
<td>18 to 44 years</td>
<td>34.1</td>
<td>20.0</td>
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<tr>
<td>44 to 64 years</td>
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<td>65 years and older</td>
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<td>All ages</td>
<td>38.5</td>
<td>21.0</td>
</tr>
</tbody>
</table>
Respite Care Utilization
This section of the report describes the findings related to respite care utilization, such as use of respite based on the age of care recipients, “formal” and “informal” respite care use, types of respite care services used, and those that respondents would like to be able to use more often or use at all.

Of particular note is the fact that 40 percent of survey respondents indicated they receive no respite care services in the past 12 months. Of these caregivers who identified as living in a county not along the Front Range Urban Corridor, 51 percent reported having no respite in the past 12 months. This is compared to 34 percent of caregivers living along the Urban Corridor. Of caregivers who identified their care recipient as a beneficiary of a Medicaid HCBS waiver, 36 percent reported having no respite in the past 12 months, compared to 40 percent of caregivers who reported not having access to a waiver. These findings suggest a significant unmet need among Colorado caregivers, which is in part relieved when living in an urban setting and by being a beneficiary enrolled in a Medicaid HCBS waiver. The interviews, discussed in detail below, offer some additional insights into the reasons why at least some caregivers may not be accessing respite care services.

Utilization of Respite Care Services
Among the caregivers responding to the survey, 61 percent said they received some level of respite care services, as shown in Figure 13 below. Specifically, 37 percent of caregivers received respite care services “a few times” and one in four caregivers (25%) reported they “regularly receive respite.” Those supporting care recipients age 24 years or younger were slightly more likely to report receiving some level of respite care services (69%) compared to 59 percent of those caregivers supporting someone age 55 years and older. Caregivers of older care recipients were more likely to have received no respite care services (40%) compared to those with younger care recipients (30%).

Figure 13: Caregiver Respite Care Utilization, by Age of Care Recipient

The survey asked caregivers “What agency or organization most recently provided respite services,” including whether it was a family member or friend. For this study, family or friend was defined as “informal” respite, whereas an agency or organization was considered “formal” respite. Among all caregivers, 34 percent reported having last received respite care services from a formal provider or agency.
a formal provider of respite as their most recent service rather than an informal provider (18%). Meanwhile, caregivers with younger care recipients were just as likely to have received their last form of respite from a formal (36%) or an informal provider (34%). These findings are shown in Figure 14 below.

Figure 14: Caregivers’ Use of Formal and Informal Respite Care Services, by Age of Recipient

Taken together with the regularity of respite care and the formality of the type of respite care, these findings suggest that caregivers of younger care recipients may be more likely to receive regular respite care because they are able to depend more on informal respite care from a friend or family member. Whereas caregivers of older care recipients, who overall use less respite care, rely more on formal care when then do need it. Quantifying the impact of this informal respite care for caregivers and their care recipients is very challenging because there is no way to track how much of is occurring.

Types of Respite Care Used
Again, some 40 percent of caregivers responded that they do not receive any type of respite care services. For those that did receive services, the most commonly reported type of respite care service is “in home day” respite, at 29 percent of caregivers, followed by “day program” (18%) and “out of home overnight or weekend” (12%) respite care service. These figures are shown below in Figure 15.
A review of “other responses” indicated an additional set of respite care services. Responses were analyzed and grouped again into one of two types – formal or informal – respite care services. The most common type of respite care that individuals use is from family members, whether from grandparents, parents, or siblings. Caregivers stated that they relied on family members to provide brief breaks to run errands, go out with friends or loved ones, and just take a pause from providing caregiving duties. Similar to family members providing respite care services, friends are also frequently relied upon to provide caregiving services. In some cases, these friends come from the caregiver’s social group, community members, church members, or unpaid volunteers. Although caregivers indicated using these kinds of informal respite services, they also mentioned wanting to utilize more professional respite services but said they were unable to do so because of issues such as affordability or not being able to find skilled providers they can rely upon.

Regarding formal respite services, caregivers mentioned using services such as nursing homes for longer-term breaks, hiring private nurses, utilizing host homes and even using the hospital. It is important to mention that these are all costly alternatives to more traditional respite care. Finally, caregivers mentioned a wide variety of local community organizations that they rely upon to provide respite services, primarily out of home day and evening care.

There is similar utilization of the various types of respite care by both caregivers of younger care recipients and those supporting older care recipients, with one exception – as shown in Figure 16 below. Caregivers of younger care recipients reported they are six times more like to use community-based respite care or recreational programs (15%) than those supporting older care recipients (only 2%).
Across the board, caregivers who responded said they would like to use more of each type of respite care when compared to the type of respite care they currently are accessing. As Figure 17 shows, on average, 15 percent of caregivers would prefer to use more of each type of respite, with the greatest demand being for community-based respite care services: 8 percent of caregivers access this type of respite, while 24 percent would like to use more of it. Similarly, for day programs, 18 percent of caregivers access this type of respite, while 30 percent would like to use more of it.
Figure 17: Types of Respite Care Services Caregivers Use and Would Like to Use More

![Bar chart showing types of respite care services used versus those wanted more.](chart.png)

Figure 18 shows that when looking at what types of respite care services caregivers would like to use more of by the age of those they are caring for, in-home day care was by far the top choice of both those supporting younger care recipients (44%), as well as those caring for older care recipients (40%). Similarly, regardless of the age of their care recipient, caregivers reported their second top choice of the type of respite care services they would like more of as out-of-home overnight/weekend care (38% for those supporting younger care recipients, 24% for those supporting older care recipients). One difference between the two groups is that those caring for younger care recipients also indicated a high preference for community-based respite services (also 38%) versus only 12 percent of caregivers supporting older care recipients who wanted more of that type of respite care.
From many of the interviews, and as discussed later, it was clear that these kinds of programs – community-based services and day or overnight programs – offer a real benefit to the care recipient and may be one reason why both caregivers of older adults and young children are seeking more of these types of respite. For example, caregivers reported that community-based respite care services help their care recipient achieve social and developmental milestones as it exposes them to new people and experiences. These types of respite care programs also help their care recipient maintain important physical exercises to keep them healthy.

_Utility of Medicaid Waiver Benefits as Respite Care_

Approximately 20 percent of caregivers who have a care recipient on a Medicaid HCBS waiver were asked to report how frequently they use the care recipient’s waiver benefit as a form of respite care. Among the types of Medicaid HCBS waiver benefits, personal care was reported as the most frequently used form of respite (41%), followed by specialized habitation (32%), homemaker services (22%) and adult day services (20%). Day treatment (14%) and alternative care (3%) were least likely to be used as a form of respite. This is shown below in Figure 19 below. It is important to note however, that overall utilization of these waiver services varies (based on specific benefits available in each type of HCBS waiver) and this may drive to what extent a waiver service is used as “respite” by the caregiver. For example, more than half of caregivers said they do not use alternative care (56%) or day treatment (51%) services for any reason, and therefore, do not use it as respite.

One interesting note regarding this information is tied to the analysis of claims data for Medicaid beneficiaries on HCBS waivers, which was conducted as another component of the Colorado Respite Care Impact Study.

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72 Medicaid waiver benefits were defined as follows in the survey: Day treatment (mental health treatment along with special education); Adult day services (day-time supervision of individuals in a group environment in a center or location); Homemaker services (assistance with general household activities needed to maintain a healthy and safe living environment, such as housekeeping, meal preparation and laundry); Personal care services (bathing, grooming, dressing, feeding, etc.); Specialized habilitation services (self-feeding, toileting, self-care, sensory stimulation and integration, self-sufficiency, maintenance skills, and supervision); Alternative care facility or assisted living residence.
Care Impact Study. For purposes of that Medicaid claims analysis, which was done prior to the survey and interviews, “respite care services” were defined as the *respite care* benefit and the *adult day services* benefit. The thinking at the time was that these two benefits represented the services that would be most widely used as respite care services. However, what the survey has shown is that in addition to the actual respite care benefit, caregivers are using a much broader range of HCBS waiver services as “respite care,” even if they may not be using as much of those other services as they are using adult day services. This is a good example of how and where there are many more nuances about respite care that can and should be further explored.

**Figure 19: Caregivers’ Use of Medicaid Waiver Benefits as Respite Care Services**

As shown in **Figure 20**, among those caregivers who said they do use Medicaid HCBS waiver benefits as a form of respite care, 80 percent use *alternative care services* 50 to 100 percent of the time as their type of respite care, whereas only 31 percent of caregivers said they use *day treatment* 50 to 100 percent of the time as their type of respite care.
Impacts of Caregiving and Respite Care Services on Caregivers

On a scale of one to 10 (1 being a small impact, 10 being a large impact), when asked to rate the impact of respite care on their health and well-being as a caregiver, caregivers responded on average that they felt the impact was 9.5, or very high.

The remaining findings for both the survey responses and the interviews explore the impacts of being a caregiver and the role that respite care services has in alleviating those impacts related to both the caregiver and the care recipient. Specifically, the findings explore the following:

- **Caregiver impacts** – economic effects such as employment, income stability, and finances; continued improved mental and physical health; improved quality of life
- **Care recipient impacts** - continued improvement of mental and physical health, improved quality of life, and reduction in/avoidance of institutionalization

The findings also explore the financial cost of caregiving to caregivers, why caregivers seek respite care services, and how they fund or afford those services. For certain measures, the experiences of a

---

*Figure 20: Caregivers Using Medicaid HCBS Waiver Benefits as Respite Care*

<table>
<thead>
<tr>
<th>Service</th>
<th>Up to 50% of the time</th>
<th>50 to 100% of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alternative care (n=5)</td>
<td>20%</td>
<td>80%</td>
</tr>
<tr>
<td>Specialized habilitation</td>
<td>38%</td>
<td>62%</td>
</tr>
<tr>
<td>services (n=47)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal care services</td>
<td>33%</td>
<td>67%</td>
</tr>
<tr>
<td>(n=61)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Homemaker services (n=32)</td>
<td>44%</td>
<td>56%</td>
</tr>
<tr>
<td>Adult day (n=30)</td>
<td>67%</td>
<td>33%</td>
</tr>
<tr>
<td>Day treatment (n=16)</td>
<td>69%</td>
<td>31%</td>
</tr>
</tbody>
</table>
caregiver for a child versus an older adult are compared and for others, experiences by age of the caregiver were explored.

The Financial Cost of Caregiving for Caregivers: Paying for Respite Care

Nearly 80 percent, or approximately three in four caregivers, reported they experience various types of financial impacts as a result of their caregiving. Just about half of caregivers reported facing “financial strain” by providing care (48%) and 67 percent said they do not receive any payments for their caregiving. To cover the costs of the respite care services they use, 29 percent of caregivers responded that they pay with their own funds, as shown in Figure 21. Nineteen percent of caregivers responded they use fund from their care recipients Medicaid waiver.

Figure 21: Funding Respite Care Services

Q: How do you pay for respite care services? Select all that apply (n=738)

- I use my own funds: 29%
- I use funds from Medicaid waiver: 19%
- Other (please specify): 11%
- I use funds from the care recipient: 8%
- I am a paid CNA Providing care to my care recipient: 7%
- I use funds from a CBO or nonprofit agency: 5%
- I use funds from my local AAA or ADRC: 4%
- I use funds from family members: 3%
- I use funds/benefits from my private health insurance: 2%

Figure 22 shows that the burden of self-pay for respite care appears higher among the caregivers supporting younger care recipients compared to those supporting older care recipients. Specifically, 37 percent of caregivers for younger care recipients pay for their own respite care compared to 17 percent of caregivers for older care recipients who pay for their own respite care. These findings suggest that caregivers are burdened financially to access respite to help alleviate the other economic, health, and quality of life impacts described below.

“The [Easterseals] voucher program supports 12 to 18 hours every four to six weeks. All other respite care is out of pocket.”

– Caregiver for parent with dementia

73 39 percent of the respondents do not receive services and are not represented in this chart.
Meanwhile, approximately, one in five caregivers (19%) reported that they receive payment for respite care services through their care recipient’s Medicaid HCBS waiver. Figure 23 shows that caregivers with access to Medicaid HCBS waiver are more likely to care for younger care recipients (27%) compared to those caring for older care recipients (4%).

Figure 23: Payment for Respite Care Services Through a Medicaid HCBS Waiver, by Age of Care Recipient

The Financial Cost of Caregiving for Caregivers: Out-of-Pocket Costs for Care Recipient
Respondents were asked to provide approximately how much money out-of-pocket, they spend each month to cover expenses for their care recipient (e.g., groceries, over-the-counter medications, gas, parking, etc.). Figure 24 shows that approximately half of all caregivers said they spend less than $500 per month on their care recipient. However, caregivers of younger care recipients are 87 percent more likely to report spending $500 to $1000 per month than those who care for recipients age 65 years and older. This may be a function of being parents, who would generally spend money on these types of expenses for their children versus what they are spending specifically as a result of special caregiving they provide. Again, this type of question would be worth further examination to better understand the nuances and potential implications.
The Long-Term Financial Cost of Caregiving for Caregivers

More than three out of four caregivers experience long-term financial impacts from their caregiving responsibilities. Among all caregivers, 49 percent said that they experienced “reduced capacity to save for their own long-term care,” followed by 43 percent who reported “diminished retirement savings,” with 32 percent who experienced “reduced hours at work,” and 13 percent who reported “early retirement.”

In Figure 25, it can be seen that caregivers ages 18 to 44 years and ages 44 to 64 years are impacted more financially than caregivers ages 65 and older. For example, 80 percent of working-age caregivers (those age 18 to 64 years) experience reduced hours at work (thus lower annual salary) compared to 32 percent of all caregivers. Fifty-seven percent of caregivers ages 18 to 44 years old experience reduced capacity to save for their own long-term care. Similarly, 48 percent of caregivers ages 44 to 64 years experienced an impact of diminished retirement savings compared to 43 percent of all caregivers. These younger and middle age groups of caregivers are experiencing the largest financial impacts of caregiving right at the time when it is most important for them to be saving for their retirement. In addition to being able to save less for retirement, caregivers ages 44 to 64 years are 29 percent more likely to experience early retirement than other caregivers.

These findings imply that this age group of caregivers in particular (those ages 44 to 64 years) may be at higher risk for significant negative financial impacts as a result of their caregiving responsibilities. As has been described in another component of the Colorado Respite Care Impact Study – the Economic Model – such negative financial effects may be exacerbated by the fact that this age group also is one of the fastest growing demographics. Again, these are findings that bear further research to more deeply understand how policy makers and program administrator may be able to address these issues.
The Financial Cost of Caregiving for Caregivers: Employment and Income Stability

Approximately one in four (26%) caregivers responding to the survey reported that they are unable to be employed due to caregiving responsibilities, while another 14 percent reported that “they work part time instead of full time due to my caregiving responsibilities.” Additionally, 37 percent of respondents said that they work or go to school part-time or full-time outside of the home. Of the caregivers who work, many indicated that they missed on average 21 days of work or school in a year because they were sick/injured as a result of caregiving. The median number or typical number of days missed was fewer at 10 days.

Of those respondents who work, caregivers indicated that they have adapted or made decisions regarding how much and when they work in a variety of ways, as shown in Figure 26. More than half (54%) reported that they use vacation days, sick days or personal days to take time off for caregiving. Missing days of work, as well as reducing hours at work, are other strategies caregivers use to manage both their professional work responsibilities and their caregiving responsibilities. A handful of caregivers (11%) reported that they did the opposite; they took on additional hours to pay for the cost of their caregiving. These impacts have real cost implications for not only the caregiver but also employers. Caregiving impacts on the employer deserves further inquiry which the Economic Model, a component of the Colorado Respite Care Impact Study, could explore in the future.

“I can’t get a promotion because I would have to dedicate more time to work and I just can’t afford that.”

– Caregiver of young child with autism
Figure 26: How Caregivers Work Has Been Affected by Their Caregiving

<table>
<thead>
<tr>
<th>Behavior</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Used vacation, sick days, and/or personal days</td>
<td>54%</td>
</tr>
<tr>
<td>Missed days of work</td>
<td>48%</td>
</tr>
<tr>
<td>Reduced my work hours</td>
<td>45%</td>
</tr>
<tr>
<td>Reduced job responsibilities</td>
<td>34%</td>
</tr>
<tr>
<td>Began working an alternative schedule</td>
<td>33%</td>
</tr>
<tr>
<td>Switched to a less demanding job</td>
<td>32%</td>
</tr>
<tr>
<td>Began to work remotely</td>
<td>27%</td>
</tr>
<tr>
<td>Quit a job</td>
<td>20%</td>
</tr>
<tr>
<td>Unpaid leave of absence from my employer not...</td>
<td>12%</td>
</tr>
<tr>
<td>None of the above</td>
<td>12%</td>
</tr>
<tr>
<td>Unpaid leave of absence from my employer covered by...</td>
<td>12%</td>
</tr>
<tr>
<td>Took on additional hours to pay for cost of caregiving</td>
<td>11%</td>
</tr>
<tr>
<td>Taken a paid leave of absence from my employer</td>
<td>9%</td>
</tr>
<tr>
<td>Lost a job</td>
<td>7%</td>
</tr>
<tr>
<td>Quit a job</td>
<td>4%</td>
</tr>
</tbody>
</table>

The Impacts of Respite Care Services on Alleviating Economic Cost to Caregivers

As Figure 27 below shows, of those respondents who work, caregiving has a “somewhat negative impact” on whether they go to work or school as much as they need or want to, with an average score of 3.3 on a scale of one to five (1 being the little or no impact and 5 being the greatest negative impact).

Figure 27: The Degree to which Caregiving Has Impacted Caregivers’ Work

Shown in Figure 28 below, respondents reported that getting respite services has “little to no impact” to “somewhat positive impact” in their ability to work or go to school as much as they need or want to, with an average score of 2.2 out of five (with 1 being the little or no impact and 5 being the greatest positive impact).
The role that respite services plays in a caregiver’s capacity to work was explored further in the interviews. Caregivers who were interviewed described that many times the amount or quality of the respite care is not what they need for their care recipient, and does not really allow them to continue working, or work as much as they would like. They indicated that this is due, in part, to availability of qualified respite care providers, as well as affordability.

For some respondents (12%), respite services did play a greater role in both their decision to work and how much they worked. For some caregivers, the availability of respite allowed them to keep their full-time jobs, while for others, access to respite care services allowed them to take on part-time employment. Others said they utilize respite to catch up on tasks to manage the businesses that they run from their homes.

These findings support conclusions from other research that indicates that caregivers are impacted in their capacity to work due to their caregiving responsibilities. The 2015 AARP study Caregiving in the U.S., found that 35 percent of caregivers give up work entirely as a result of caregiving responsibilities, and another 37 percent reduce work from full time to part-time status. Colorado caregivers reported in the survey lower rates of impact when it comes to work, specifically 26 percent of caregivers reported that they were unable to be employed due to caregiving responsibilities, while 14 percent reported that “they work part time instead of full time due to my caregiving responsibilities.” These types of findings are what is explored
more in the Economic Model that is part of the larger Colorado Respite Care Impact Study. Understanding how respite can impact a caregiver’s ability to work is important so benefits can be designed in ways that maximize financial independence for both caregivers and care recipients.

The Physical Health Impacts of Caregiving and the Role of Respite Care Services

In general, caregivers reported their physical health to be “good” and that their caregiving responsibility only “somewhat negatively impacted” their health. Twelve percent of caregivers reported that caregiving has a “great negative impact” on their health, while 16 percent reported that their caregiving had “little or no impact” on their physical health (of which 11% report “no impact”).

When asked to describe how caregiving impacted their physical health, as shown in Figure 29 below, more than half of respondents indicated “feeling depressed and/or anxious” (62%), and 58 percent said they “experienced changes in their sleeping patterns,” while 53 percent “experienced physical stress/strain.” About one in five caregivers reported that they experienced “higher blood pressure” (20%), “feel sick more often” (20%), and experience “changes in appetite” (19%).

Figure 29: How Caregiving Has Impacted Caregivers’ Health

![Figure 29: How Caregiving Has Impacted Caregivers’ Health](image)

Again, the Economic Model that is a component of the larger Colorado Respite Care Impact Study explores the costs of these kinds of health impacts on caregivers and compares them to the benefits and costs of respite care services. As that analysis shows, respite care services can have a significant impact on both the health and the healthcare costs of caregivers. It begins to reveal the economic impact of these health conditions brought on by caregiving and provides evidence through existing research on the prevalence of these types of diagnoses among caregivers when compared to non-caregivers. For example, the Model assumes and calculates that if, by utilizing respite care services to reduce levels of insomnia (as one example of a type of change in sleeping patterns) among caregivers to the same levels
of insomnia among non-caregivers, health care costs avoided potentially could amount to as much as $19.6 million per year in reduce insomnia treatments costs.\textsuperscript{74}

To assess the health impacts of caregiving further, the survey explored the prevalence of new diagnoses of chronic medical conditions and the extent to which caregivers perceive that role of caregiving in that new diagnosis. Since becoming a caregiver, 30 percent of respondents reported being diagnosed with a new chronic medical condition. Among the new conditions respondents reported having, an anxiety diagnosis was most common (21%), followed by depression (19%), and high blood pressure (13%). Using a scale of 1 to 5 (with 1 being “not at all” and 5 being “very much”), caregivers indicated an average ranking of 3.8 in believing that caregiving has bought on the new diagnosis, and thus caregiving had a fairly significant negative impact on their physical health and caused them to have conditions they might not otherwise have had. Specifically, of these caregivers with a new diagnosis, 59 percent report that that caregiving brought on the new diagnosis. Eleven percent said they did not think caregiving impacted or brought on their new condition(s) at all.

For those who utilized respite care services, 21 percent of caregivers reported that getting respite services “very much helped with their physical health.” On average, however, caregivers felt that respite care services more commonly helps their physical health only “somewhat,” with an average score of 3.4 out of five (one being “not at all” to five being “very much”), as shown in Figure 30.

\textbf{Figure 30: The Role Respite Care Services Has Played in Caregivers’ Health, by Age of Caregiver}

\begin{figure}[h]
\centering
\includegraphics[width=\textwidth]{figure30.png}
\caption{In general, getting respite services has helped with my physical health}
\end{figure}

\textsuperscript{74} The Economic Model component describes the limitations of this calculation, including that while prevalence of conditions (such as insomnia) are known among caregivers, what is unknown is how many of these conditions are actually treated. Therefore, these costs may represent the highest potential costs savings if treatment rates for insomnia decrease among caregivers.
To explore these findings further, most of the caregivers who were interviewed said that the top benefit of respite care services for their physical (and mental) health was the ability to rest or care for themselves. For example, they said that respite care services allow them to attend their own doctors’ appointments, attend physical therapy, or exercise. Some of the interviewees also reported that respite care services gave them time to sleep.

The survey also asked caregivers to what degree they believe respite care services helped them stay healthy and out of the emergency department (ED) and/or hospital. On average, caregivers reported that respite care services “somewhat” helped in this way. Only 12 percent of caregivers said that respite “very much” helped them to stay out of the ED and/or hospital, while 13 percent reported that respite care services had no impact at all on keeping them out of the ED and/or hospital. This begins to reveal the impact that respite care services can have on reducing caregivers’ healthcare costs. This also is examined more closely in the Economic Model analysis component of the Colorado Respite Care Impact study. For example, as shown in Figure 30 below, using data from that study and assuming that each caregiver avoids just one ED visit (using the average costs for an ED visit in 2018 to St Joseph’s Hospital in Denver), if 12 percent of the estimated 584,000 caregivers in Colorado (about 70,000 caregivers) are not using the ED and/or hospital as much as they might without access to respite care services, utilization of respite care could potentially prevent from about $10 million to as much as $122.6 million in healthcare costs (depending on the level of care). Similarly, the avoided costs of just a one-day reduction in inpatient hospital days for these 70,000 caregivers could be as much as an estimated $184.7 million.

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Respite care provides caregivers the opportunity to work on their own health, to better serve those they care for.

“The physical toll has been great. My neck and back were hurting every day from carrying a 33-pound child. Respite has allowed us to go to physical therapy for our chronic pain. And just reduced physical pain has a huge overwhelming effect.” – Caregiver of a child with cerebral palsy

“Respite care helps you with your physical health as it provides time to exercise.”

- Caregiver of an adult child with disabilities

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The Colorado Respite Care Impact Study

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The Mental Health Impacts of Caregiving and the Role of Respite Care Services

In general, caregivers reported their mental health as “good,” and indicated that their caregiving responsibilities had a “somewhat negative impacted” their mental health, as shown in Figure 31. Specifically, on a scale of one to five (1 being “not at all” to 5 being “very much”), the average response was 3.0. There is a similar response across all caregiver age groups.

Figure 31: Caregiver Estimation of the Impact of Caregiving on their Mental Health

Overall, caregivers said getting respite care services help their mental health “somewhat” to “very much.” As shown in Figure 32, on a scale of one to five (1 being “not at all” to 5 being “very much”), the average response was 3.8. Similar patterns are seen across all caregiver age groups. Specifically, 29 percent of all caregivers responded that respite services “very much” helped with their mental health.

Avoided Costs as a Result of Respite Care Services Assuming 70,000 Caregivers Avoid One ED Visit

<table>
<thead>
<tr>
<th>Description</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Average cost per ED visit (for ED serving +8,000 patients, in 2013)</td>
<td>$2,168 x 70,000 = $151.8 M</td>
</tr>
<tr>
<td>Colorado Level One Care cost per ED visit (St Joe's Hospital, in 2018)</td>
<td>$143 x 70,000 = $10.01 M</td>
</tr>
<tr>
<td>Colorado Level Five Care cost per ED visit (St Joe's Hospital, 2018)</td>
<td>$1,752 x 70,000 = 122.6 M</td>
</tr>
</tbody>
</table>

Avoided Costs as a Result of Respite Care Services Assuming 70,000 Caregivers Avoid One Inpatient Day

<table>
<thead>
<tr>
<th>Description</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average cost per inpatient day across all hospital types</td>
<td>$2,639 x 70,000 = $184.7 M</td>
</tr>
</tbody>
</table>
Figure 32: Caregiver Estimation of the Impact of Respite Care on their Mental Health, by Age of Caregiver

In general, getting respite services has helped with my mental health

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Impact Level</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>All (n=630)</td>
<td>Little or No Impact</td>
<td>3.8</td>
</tr>
<tr>
<td>65 Years and Older (n=60)</td>
<td>Somewhat Negative Impact</td>
<td>3.7</td>
</tr>
<tr>
<td>44 to 64 Years (n=175)</td>
<td>Great Negative Impact</td>
<td>3.7</td>
</tr>
<tr>
<td>18 to 44 Years (n=95)</td>
<td></td>
<td>3.9</td>
</tr>
</tbody>
</table>

Respite care provides peace of mind and rest from the worries of caregiving for higher-need care recipients.

“It gives me a break so that I’m not having to constantly worry about where Dad is and what he’s doing or if he’s going to get into something. It’s like watching a three-year-old take off on a walk without me knowing where he is; so, it [respite care] gives a mental and physical break.”

- Caregiver of an adult with dementia

“Isolation is huge [as a caregiver]. You become very isolated because you can’t leave or go out with your friends. People come over less and less so you lose touch with the world; it’s a very lonely business.”

- Caregiver of a spouse

There is a perception among caregivers that respite care results in benefits for their mental health. Which is important as many studies reveal that rates of depression are higher among caregivers than non-caregivers. If respite is perceived to have a role in improving mental health, this is an important finding to identify ways to maximize utilization of respite and this benefit for alleviating healthcare costs, let alone improving quality of life. For example, according to one study, more than half of caregivers (54%) experience depression compared to 32 percent of non-caregivers. Treating depression costs $8,187 per person per year (2014 dollars). The Economic Model (a part of the larger Colorado Respite Care Impact study), shows respite care has the potential to save $611.0 million in costs to treat depression just among working Colorado caregivers. Survey and interview

77 The Economic Model component describes the limitations of these calculations, including that while prevalence of these conditions (insomnia and depression) are known among caregivers, what is unknown is how many of these conditions are actually treated. Therefore, these costs may represent the highest potential costs savings if treatment rates decrease among caregivers.
findings strengthen the positive link between respite care services and mental health benefits for caregivers.

**Impacts on Caregiver Quality of Life**

Caregivers were asked to what degree they believe that respite care services improved their quality of life. Overall, getting respite care services generally help with caregiver quality of life “somewhat” to “very much.” Specifically, on a scale of one to five (1 being “not at all,” 5 being “very much”) the average response was 3.9. Of those that received respite care, 42 percent of caregivers reported that respite “very much” helped improve their quality of life, while only 2 percent reported “not at all.” Similar patterns are see across all caregiver age groups. This is shown in **Figure 33**.

**Figure 33: The Role of Respite Care in Caregiver’s Quality of Life, By Age of the Caregiver**

Survey respondents were provided the opportunity to describe the impact that respite care services have had on their quality of life. For many, respite care services offer a break to concentrate on other responsibilities or connect with family and friends. In many cases, the respite care services provide a confidence and security among caregivers that their care recipient is being cared for and is safe. For others, the quality of life improvements of respite care services stem from the ability to provide benefits to their care recipient. For example, one caregiver described the impact of respite care services on their quality of life by saying, “It is encouraging to see my child happier by getting out with peers.” Another respondent said, “My [care recipient] is much more cheerful and cooperative” knowing she is receiving respite care services.

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**Respite care allows for opportunities to have time with other people, supporting and strengthening relationships for both caregivers and care recipients.**

“I am able to catch up with my husband.”
– Caregiver of an elderly parent

“With respite care, I am a happier person and so relationships are better.”
- Caregiver of teen with Down Syndrome and ADHD

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For those respondents who did not feel that respite care services improved their quality of life, it is in part due to the lack of affordable, reliable, and qualified respite care services. The infrequency was also indicated as a problem. For example, regarding qualified providers, one respondent said, “Some respite workers are better than others. Sometimes it was a waste of time to have them ‘help’ and other times it was immense help.” Caregivers indicated that many times the respite care service providers are not reliable or consistent. Each time there is a new provider, it requires significant amounts of training and time to ensure that the provider understand the needs of a care recipient. The time to re-train and build trust in a provider and know that their care recipient is safe is an example of how respite care services may bring about different stresses and anxiety for caregivers, as well as for the care recipient.

As for affordability, another caregiver said, “Respite services help only so much because I can’t afford to pay for more of it.” Sixty percent of caregivers responded that they did not think respite care services were affordable in their community. Several indicated that they would not be able to afford respite care services if not for their care recipients’ Medicaid HCBS waiver benefits. For example, one caregiver said, “With the Medicaid waiver, [respite care] is affordable. Without it we could not afford it.”

To learn more about the role of respite care services in quality of life improvements, caregivers were asked to what extent they agree with several statements and how that agreement changed in response to respite care service. As shown in Figure 34, statements regarding their level of exhaustion, time to themselves, and their relationships begin to quantify quality of life improvements. The chart reveals that with access to respite care services, caregivers were less exhausted and had fewer strained relationships. There were more likely to be able to handle the things they needed to do and were the kind of person they wanted to be for their care recipient.
Via the interviews, most caregivers reported that while their health may be declining slightly, the quality of their life is fine or unwavering. For others, the quality of life improvement as a result of respite care services was greater because of the addition of “balance and predictability” in their lives as caregivers.

Together, caregivers suggest that respite care services have potential to bring about great quality of life improvements to both the caregiver and the care recipient. However, the limitation of that benefit is the access to that appropriate, affordable, and reliable respite care.

**Challenges Caregivers Face and Why They Seek Respite Care Services**

Other research reveals that lack of time for other activities, as well as emotional, mental, financial, and physical stress, all are challenges faced by caregivers. Figure 35 shows that this survey’s findings echo that research. For caregivers supporting both younger and older care recipients, lack of time for other activities and emotional stress and burnout topped the list of challenges they face as a result of caregiving. Across all the challenges listed in the survey, caregivers supporting younger care recipients consistently reported higher rates of challenges from caregiving and accessing respite than caregivers supporting older care recipients. However, as discussed earlier in this report, caregivers supporting younger care recipients were more likely to use informal respite supports (e.g., family, friends), benefits

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**Respite care adds balance and predictability to the lives of caregivers.**

“It kind of helps break up the day little bit. Respite helps make the day more predictable. If I know that respite is coming I plan my day around that time. I know when I can get a break or run errands.”

— Caregiver of a child with special needs
Caregivers seek respite care for many reasons, as Figure 36 demonstrates. Leading among reasons noted by the survey respondents is to “relieve stress,” followed by “to run errands,” and “care for my own health.” Caregivers for younger care recipients, however, responded that they are more likely to seek respite to “spend time with my spouse or partner” than for running errands or caring for their own health needs. This finding suggests that respite care perhaps has a larger role to play in a caregiver of a young recipient in their quality of life, compared to their physical or mental health, and may have a role in maintaining marriages.

Several studies have looked at the impact of caregiving, specifically caring for a child with an intellectual and/or developmental disability (I/DD), and divorce rates. Findings from these studies suggest varying degrees of connection between caregiving for a child with I/DD and divorce rates, but any time and resources available to spouses and partners to share time together has potential to mitigate the risk of divorce, and therefore the impacts of divorce on the caregiver and care recipient. For example, single parents have much lower incomes and higher poverty rates than married counterparts, as well as experience many other economic and social impacts.

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Impacts of Caregiving and Respite Care Services on Care Recipients

Physical Health and Mental Health Impacts

Overall, Figure 37 shows that caregivers reported that on average their care recipient’s physical and mental health was “poor to fair,” (on a scale of 1 being “poor” to 5 being “excellent”). Five percent of caregivers reported their care recipient’s mental health as “excellent,” and 4 percent reported their physical health as “excellent.”

Figure 37: Caregivers’ Estimation of Their Care Recipient’s Physical and Mental Health

Caregivers were asked to estimate the role of respite care in keeping their care recipient physically healthy. Overall, of the caregivers who received respite, they felt that respite care “somewhat” helped
their care recipient’s physical health, with an average score of 2.9 on a scale of one to five (1 being “not at all,” 5 being “very much”). The response was similar for those caregivers caring for a young care recipient and those caring for an older care recipient, as shown in Figure 38, with an average score of 2.7 and 2.8, respectively. Specifically, 31 percent of caregivers caring for a young care recipient reported that “not at all” respite care has an impact on their recipient’s life compared to 25 percent of caregivers caring for an older person. The percent of caregivers who responded that it helped “very much” was 19 percent among those caring for younger people and 17 percent among those caring for older people.

Figure 38: Caregivers Estimation of The Role of Respite Care in Helping the Physical Health of their Care Recipient, by Age of the Care Recipient

Caregivers also were asked to assess the degree to which respite care services helped their care recipient stay healthy so the care recipient could stay out of the ED and/or the hospital. Among those caregivers who received respite care, the average response was 2.6 - just below “somewhat”, as shown in Figure 39. Eleven percent of caregivers did believe “very much” that respite care services helped their care recipient stay out of the roomed and/or hospital, while 21 percent reported “not at all.” Again, the response was similar for those caregivers caring for a young care recipient and those caring for an older care recipient, with an average score of 2.5 and 2.7, respectively. The percent of caregivers who responded that it helped “very much” was 19 percent among those caring for younger people. However, among those caring for older people, just 10 percent felt that respite care “very much” helped keep their care recipient out of the ED and/or hospital. This may be due to the life stage of the care recipient, and that they may require more acute care in these types of settings relative to younger care recipient’s. These findings suggest that to some extent, respite care has a role in preventing ER and/or hospital utilization but that it may not be sufficient to overcome the natural life events of older adults.
Interview with caregivers help to explore the role of respite care in care recipient health. For example, caregivers report that respite providers often help to carry out the exercises that they (the caregiver) would not be able to do on their own due to lack of training, divided attention, or other factors.

Caregivers were asked to estimate the role of respite care in the mental health of their care recipient. Overall, of the caregivers who received respite, they felt that respite care “somewhat” helped their care recipient’s mental health, with an average score of 3.2 on a scale of one to five (1 being “not at all,” 5 being “very much”). The response was similar for those caregivers caring for a young care recipient and those caring for an older care recipient, as shown in Figure 40, with an average score of 3.2 and 3.0, respectively. Specifically, 16 percent of caregivers caring for a young care recipient reported that respite care has “not at all” had an impact on their recipient’s mental health compared to 23 percent of caregivers caring for an older person. The percent of caregivers who responded that it helped “very much” was 22 percent among those caring for younger people and 21 percent among those caring for older people.

Overall, when comparing the role of respite care in the mental and physical health of a care recipient, caregivers are more likely to feel that respite care “very much” helped mental health compared to the physical health of their care recipient. Interviews with caregivers begin to enlighten why this might be
the case. For example, many caregivers responded that respite gives their care recipient a friend, an opportunity to engage with others, and the option to participate in activities outside of the home. These behaviors and opportunities are all more influential in a person’s mental health and well-being rather than the physical health. This finding also supports the positive role of respite care in improving the quality of life for the care recipient, as described further below.

Impacts on Care Recipients’ Quality of Life

Respite care services appear to have a greater impact on improving a care recipient’s quality of life related to their health. Caregivers were asked to assess to what degree they believe that respite care services have improved their care recipient’s quality of life. On scale of one to five (1 being “not at all” to 5 being “very much”) they reported on average a score of 3.6 (compared to 2.9 for improvement in physical health and 3.2 for mental health), as Figure 41 demonstrates. The response was similar for those caregivers caring for a young care recipient with an average score of 3.8. Specifically, just 6 percent of caregivers caring for a young care recipient reported that “not at all” respite care has an impact on their recipient’s life compared to 38 percent who reported “very much”.

Overall, caregivers caring for older adults estimated a slightly lesser impact of respite services on their care recipient’s quality of life when compared to those caregivers caring for younger care recipients. Caregivers estimated the impact to be on average a 3.4 (compared to the 3.8 among caregivers of younger care recipients). Specifically, 14 percent of these caregivers of older care recipients reported that respite did “not at all” impact the quality of life for their older care recipient (compared to 6 percent among caregivers of younger care recipients) with 27 percent estimating it “very much” did have an impact (compared to 38% of caregivers of younger care recipients).

Figure 41: Caregiver Estimation of Respite Care Services Impact on Their Care Recipients’ Quality of Life, by Age of Care Recipient

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Caregiver Estimation</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>24 Years and Younger</td>
<td>Not at All</td>
<td>3.8</td>
</tr>
<tr>
<td></td>
<td>Somewhat</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Very Much</td>
<td></td>
</tr>
<tr>
<td>65 Years and Older</td>
<td>Not at All</td>
<td>3.4</td>
</tr>
<tr>
<td></td>
<td>Somewhat</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Very Much</td>
<td></td>
</tr>
<tr>
<td>All</td>
<td>Not at All</td>
<td>3.6</td>
</tr>
<tr>
<td></td>
<td>Somewhat</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Very Much</td>
<td></td>
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</tbody>
</table>

To what degree do you believe that respite services have improved your care recipient’s quality of life?
Interviewees indicated that improvements in their recipients’ quality of life are related to the respite care service providers, and the relationships developed between the providers and care recipients. For example, some caregivers reported that their care recipients really like their respite providers and see them as friends. They reported increased socializing and confidence with building friendships gained through respite care services outside of the home, and that their care recipients seemed better able to interact with new people as a result of this kind of respite care services. Others said they saw increased social confidence felt by their care recipients. Lastly, many caregivers also identified how respite care services help their care recipients meet developmental and health milestones.

Reduction in or Avoidance of Institutionalization for Care Recipients

Caregivers were asked to assess to what degree they believe that respite care services have helped their care recipients avoid a nursing home stay. Figure 42 shows that on a scale of one to five (1 as “highly likely” and 5 as “highly unlikely”), caregivers on average feel that respite care services have “somewhat” helped their care recipients avoid this kind of care, as shown by the average score of 2.8. Specifically, 18 percent of caregivers felt that respite care services “very much” helps their care recipient avoid a nursing home stay. About one in four (24%) caregivers feel that respite care services do “not at all” help to avoid a nursing home stay.

The age of the care recipient appears to have some degree of influence of the extent to which caregivers believe respite care services help to avoid nursing home stays. Caregivers of older care recipients are more likely to believe that respite care “somewhat” helps to avoid stay, with an average score of 3.3, compared to those caring for younger care recipients, with an average score of 2.5. Specifically, more than half (52%) of caregivers for younger care recipients believe that respite does “not at all” help their care recipient avoid nursing home stay compared to 19 percent of those caring for an older care recipient.

Figure 42: Caregiver Estimation of the Impact of Respite Care Services in Avoid Nursing Home Stays for their Care Recipient, by Age of Care Recipient

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Respite can allow for personal growth by exposing the care recipient to new people and experiences.

“Respite care provides new experiences for her to do independently. It builds her confidence to go out and do something by herself.”

- Caregiver of an adult child with spinal injury
When asked to what extent caregivers feel that without respite care services their care recipient would be placed in an out-of-home setting, most responded “not sure.” Specifically, on a scale of one to five (1 being “highly unlikely” and 5 being “highly likely”), caregivers on average felt that they are “not sure,” with an average score of 3.2, as shown in Figure 43. Twenty-four percent of caregivers responded “highly unlikely,” while 14 percent responded “highly likely.” The age of the care recipient appears to have some degree of influence of the extent to which caregivers believe that without respite care, their care recipient might be placed in an out of-home setting. Caregivers of young care recipients were slightly more likely to respond that it was “unlikely”, with an average score of 2.6, compared to an average score of 3.1 for those caring for older adults. Specifically, more than half (52%) of caregivers caring for younger recipients responded that it was “highly unlikely” compared to 14 percent of caregivers caring for older adults.

Figure 43: Degree to Which Caregivers Believe Respite Care Services Help Their Care Recipients’ Avoid Nursing Home stays

<table>
<thead>
<tr>
<th>Without respite care, how likely is it that your care recipient may be placed in an out-of-home setting?</th>
</tr>
</thead>
<tbody>
<tr>
<td>All (n=596)</td>
</tr>
<tr>
<td>65 Years and Older (n=183)</td>
</tr>
<tr>
<td>24 Years and Younger (n=243)</td>
</tr>
<tr>
<td>1 Highly Unlikely</td>
</tr>
<tr>
<td>2 Not Sure</td>
</tr>
<tr>
<td>3 Highly Likely</td>
</tr>
<tr>
<td>4</td>
</tr>
<tr>
<td>5</td>
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Interviews with caregivers shed some additional light on the reasons why as well as the limitations of respite care services in preventing nursing home or other institutional stays. Respite care helps to prevent caregiver burnout, and therefore, sustain this informal caregiving workforce. Caregivers generally want to be with their care recipients and support them for as long as they can. Respite care, for some, helps to sustain their capacity to do so.

Limitations of respite care, including the availability and affordability of respite care services, prevents some caregivers from accessing the needed amount for themselves and their care recipients to keep their care recipient out of institutional or nursing home care. As discussed in more detail below, there are many barriers and limitations to accessing the respite that is required to support caregivers and ultimately sustain their ability and desire to provide care.
Generally, these findings indicate that caregivers may not yet have thought much about this as an issue for their care recipients, or that they see institutionalization as more “black and white.” In other words, there is a point at which they simply will not be able to support their care recipient and they know the only option is a facility or they would not ever consider out-of-home placement as an option. This is an area worth additional examination, particularly because the cost implications of institutionalization are very significant.

Barriers to and Limitations of Respite Care

Findings described above begin to reveal the impact of respite care services for caregivers and their care recipients. However, it is apparent that in many cases the full impact of respite care services is not realized. Caregivers indicated many barriers to respite care services, which in part limit their impact.

As previously mentioned, 40 percent of survey respondents indicated they receive no respite care services, suggesting a significant unmet need among Colorado caregivers. To explore this further, the survey asked caregivers how many times in the last 12 months they were unable to find respite services when they were needed. Approximately one in five (20%) reported “always.” In other words, 20 percent
of caregivers said they were not ever able to find respite care services when they were needed, as shown in Figure 44. Of those caregivers who reported living along the Front Range Urban Corridor, 19 percent said they “always” were unable to find respite services when they were needed, compared to 27 percent of caregivers who live someplace else in Colorado. However, 44 percent of caregivers reported that they were unable to find needed respite care services only three times or less within the last 12 months, while 36 percent reported “never” having an issue finding needed respite care services.

Figure 44. In the last 12 months, how many times have you been unable to find respite services when you needed them, “Always”

Caregivers were asked in the survey about what barriers they face in getting respite care services, as shown in Figure 45. Nearly half of respondents reported that financial limitations are the number one barrier (46%), followed by the lack of respite programs available (44%), and lack of trained providers in their community (36%).

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The top three barriers were explored further to understand if where a caregiver lived in Colorado made a difference in prevalence of the barriers, as shown in Figure 46. Caregivers who live outside of the Front Range Urban Corridor reported more often that they experienced lack of trained providers (41% compared to 35% among those living along the urban corridor) and lack of respite care programs (52% compared to 43% among those living along the urban corridor).

Figure 45: Barriers to Getting Respite Care

Figure 46: Barriers Faced in Getting Respite Care, by Caregiver County
In the survey, 18 percent of caregivers took the opportunity to describe other barriers they face in accessing respite care. One of the most common reasons described is not knowing about respite care services or having enough knowledge about what respite care services can offer. Another common problem is that care recipients sometimes have too many intense needs that are not typically covered by respite care services providers, such as tube feeding or bathing. Or because of those intense needs, families are unable to utilize respite care services for long periods of time, making the service unhelpful. Another issue is that it can be challenging to find space in a respite care service program, if one even exists in a community. Caregivers indicated that they have difficulty getting their care recipient into programs because of issues of discernment against certain types of disabilities, being able to meet eligibility criteria (e.g., either requiring too much care or not enough), and programs that do not have services for children. Finally, another barrier for some caregivers is that they do not feel comfortable trusting strangers to take care of the care recipients or they are not interested in using respite care services, so they do not ever access them.

Waiting lists for respite care services are another barrier for 24 percent of caregivers, as shown in Figure 47. Among those caregivers who identified as having a care recipient who was enrolled in a Medicaid HCBS waiver, 29 percent reported having been on a wait list for respite care services, compared to 23 percent of those caregivers whose care recipient is not enrolled in a Medicaid HCBS waiver. Among those caregivers who reported living on the Front Range Urban Corridor, 26 percent said they have been on a waitlist for respite care services, compared to 16 percent of those caregivers who live elsewhere in Colorado.

**Figure 47. Percent of Caregivers who said they have been on a waitlist for respite care**

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**Respite is demanding and personal work with high turnover and non-competitive pay.**

“A little hit or miss and trouble keeping a consistent care provider, there is a lot of turnover. She needs to get used to people, and it’s hard for her to get used to people helping her with sensitive activities...”

- Caregiver of child with complex needs
Additionally, another barrier is affordability of respite care. Sixty percent of caregivers do not find respite care services affordable in their community. This increases to 73 percent among caregivers who reported living outside of the Front Range.

Summary of Key Findings
The information included in this survey and interview analysis focused on understanding several factors that impact both caregivers and care recipients to begin to define the impact of respite care.

The following presents key findings to each of the areas of inquiry:

1. **Employment and income stability:** Younger and middle-aged groups of caregivers (those ages 44 to 64 years) experience the largest financial impacts of caregiving – including employment impacts and reduced savings. This is occurring right at the time when it is most important for them to be saving for retirement and their own future long-term care needs. These findings imply that this age group of caregivers in particular may be at higher risk for significant negative financial impacts as a result of their caregiving responsibilities.

2. **Continued improved quality of life, mental, and physical health:** Respite care services have a larger impact on improving caregivers’ and care recipients’ quality of life than their mental health and physical health. Specifically, 42 percent of all caregivers who use respite care services reported that respite care “very much” impacted their quality of life, compared to their mental health (29%), and their physical health (21%). However, the mental health benefits of respite care services are much higher among caregivers ages 28 to 44 years old – where 42 percent said respite “very much” helps their mental health.

3. **Reduction in/avoidance of institutionalization:** On average, overall, respite care was found to have a limited impact on reducing or avoiding institutionalization. However, a little more one in four caregivers reported that it “very much” to nearly “very much” had an impact. Specifically, 26 percent of caregivers of care recipients 24 years and younger and 31 percent of caregivers of care recipients 65 years and older reported that respite care “very much” avoiding an institutional stay for their care recipient.

Conclusion
Some key takeaways from the surveys and interviews are that, on average, caregivers reported that respite care services “somewhat” have an impact on their quality of life, mental health, and physical health. Further analysis of the responses suggests that one reason for the limited impact may be related to barriers to accessing respite care services - such as finding appropriate, affordable, and reliable care - that prevents full realization of the benefits of respite care services. Fully 40 percent of respondents indicated they receive no respite care services in the past 12 months, suggesting a significant unmet need. This was in part found to be relieved for those living in an urban setting and for those with a care recipient enrolled in a Medicaid HCBS waiver. Additionally, understanding how respite care services can impact a caregiver’s ability to work and save is also important, so benefits can be designed in ways that maximize financial strength for both caregivers and care recipients. Finally, the findings regarding quality of life and health (mental and physical) impacts suggest the need for much more understanding of these issues and highlights some of the challenges in trying to quantify the benefits of respite care.
Overall Study Findings
The Colorado Respite Care Impact Study was designed to provide useful information for policymakers, providers, payers, and patients, and to stimulate further research to extend and refine the collective knowledge about the benefits of respite care services.

The findings from each of the four components within the study begin to uncover some of the many important nuances and complexities of the impact of respite care services on caregivers and their care recipients. A summary of key findings includes:

- The Respite Care Services and Medicaid Costs analysis found substantial cost avoidance that mitigates part, albeit not all, of the cost of providing respite care (costs avoided were about half as large as the total costs). They are not trivial numbers; and in some cases, the savings potential is significant, for example when nursing home admissions can be delayed or avoided.
- The study’s Economic Model found that the costs of the equivalent of two weeks’ worth of 24/7 respite care services are more than offset by the cross-sector savings, including health, health care, and economic sectors, with an ROI in the range of $4 to $5 or more in savings per $1 invested in respite care.
- The Colorado Caregiver Survey and Caregiver Interviews found that respite care services have a larger impact on caregivers’ and care recipients’ quality of life relative to their mental health and physical health, with 42 percent of all caregivers who use respite care services reporting that respite care “very much” impacted their quality of life, compared to their mental health (29%) and their physical health (21%). Utilization of respite care services varies greatly across caregivers depending on their age, the care recipient’s age, where they live, and whether the care recipients are enrolled in a Medicaid HCBS waiver.

Recommendations for Further Research
There are numerous findings in this report that deserve further analysis to better understand the impacts of current and future respite care service policies and programs across multiple stakeholders. It is hoped that the Colorado Respite Care Impact Study will provide a platform for those stakeholders to continue this critical research. Based on some of the findings and limitations of this study and its components, areas the state should consider for additional research and evaluation include:

1. **Further Explore the Urban/Rural Dynamic of Caregiving in Colorado** and the extent to which respite care service impacts vary and why they vary by geographic location. This could help to understand better why fully 40 percent of the caregivers who responded to the study’s survey said they had not accessed respite care services at all in the past 12 months and the study’s finding that living in an urban setting and having a care recipient who is enrolled in a Medicaid HCBS waiver appear to be mitigating factors for the risk of caregivers not receiving respite care. Additional study should identify specific urban and rural communities (include mix of rural and mountain) in which to focus an analysis, and examine availability, quality, and type of respite care services and programs relative to what is needed by caregivers and their care recipients living in those communities. Both quantitative methods and qualitative methods should be considered in this further exploration of urban/rural differences.
2. **Expand the Economic Model** to include additional relevant scenarios, such as the differences in impact between the caregiver for a young care recipient versus a caregiver for an older adult care recipient. Findings from the Caregiver Survey and Interviews component reveal that there are differences in perception of impact of the respite care services depending on the age of the care recipient. Expanding the Economic Model to quantify the economic impact of these differences would help to further build the case for respite care services and understanding of how to better tailor benefits and programs. Respite care is a complex issue with no easy answers or silver bullets. Caregivers (and their care recipients) have substantial needs, and there are multi-faceted benefits and costs associated with meeting such needs. The ability to add factors to the model makes this a powerful tool that can be used on an ongoing basis to explore and better understand opportunities for savings by providing targeted respite services to specific populations.

3. **Additional Medicaid claims data analysis** should be conducted to disaggregate the data further into subpopulations and how the subpopulations vary in their use of different types of respite care services and health care utilization outcomes. For example, this could analyze data by regions, by various beneficiary demographics (age, race/ethnicity, gender, income), and by type of health care utilization.

4. **Additional Medicaid claims data analysis** should be conducted to include more types of respite care service benefits offered through the HCBS waivers and their role in health care utilization of waiver beneficiaries. This would be responsive to the caregiver survey and interviews that found that in addition to the actual respite care benefit, caregivers are using a much broader range of HCBS waiver services as “respite care.” It would also help to expand the understanding as to why not as much respite care is utilized as might be expected as a waiver benefit. For example, one aspect of the analysis should include expanding the types of benefits that are considered respite care services. This study defined respite care services as only the respite care benefit and the adult day services benefit. However, as was indicated through the Caregiver Interviews, there are other benefits such as Day Habilitation and Personal Care that caregivers may use as “respite care.”

5. **Exploration of respite care services through private payers** and for individuals who do not have access to publicly-funded respite care services. While this type of research could be challenging, it also would help to create a more complete picture of the need for, use of, and impacts of respite care services by a large and growing population of caregivers and care recipients.

### Conclusion

The **Colorado Respite Care Impact Study** was designed to identify ways in which both caregivers and care recipients are impacted by access to respite care services, or the lack thereof. It was commissioned in response to direction from the Colorado State Legislature through HB 16-1398, which required the Respite Care Task Force to “Ensure that a study is conducted to demonstrate the economic impact of respite care and its benefits for those served.”

This study was a significant undertaking, and represents a need for increased understanding about an important and complex issue facing Colorado. As was described in the Introduction and Purpose section of this report, Colorado is experiencing the same trends happening across the county: the population over the age of 65 is projected to be nearly 20 percent of the total state population by 2040, while at the same time the labor force growth is expected to slow down considerably. This suggests both that there will be more older adults who need caregiving and that more of the caregivers also will be older.
Additionally, there number of parents caring for children with disabilities is growing. Most of these caregivers are supporting their children and youth with special needs, as well as working full- or part-time jobs. These factors alone indicate there will be increased demands and needs for respite care services.

One important outcome of this study is that it highlights the complexity and myriad nuances of what respite care services are, how Coloradans access and pay for them, and the value they bring to both caregivers and care recipients. These are not simple questions with easy answers; and there are significant implications of how the state approaches gathering and using the information from this, and other studies like it, to inform its short- and long-term approach to providing respite care services. This study also underscores the need for additional investigation and exploration of the types of questions raised here.

More specifically, what this study shows is that Colorado can and should take the opportunity to develop a multi-pronged action plan to support caregivers who have taken on the tremendous task of caring for a child or adult who needs constant care. Certainly, a compelling case can be made to do this as part of a compassionate approach to better supporting Coloradans who are helping their family members and friends. These caregivers make personal and professional sacrifices every day to help others, and for this they deserve a helping hand from the community.

However, beyond the moral responsibility, this study shows that there is a good “business case” for improving supports for the unpaid workforce of caregivers. For example, the study found that respite care is associated with offsetting savings. A substantial amount of such savings takes the form of reductions in the use of avoidable medical care in high-cost settings, for both caregivers and care recipients. Other savings occur in the work place, involving a return to work or more hours worked by caregivers, and savings to employers associated with higher productivity and lower turnover.

The results from this study validate the need for Colorado to develop a package of services and supports that includes paid respite care designed to keep individuals in the community – such as the Home and Community Based Services (HCBS) programs in Medicaid – and to ensure those programs are effectively implemented and accessible to those who need them. Doing so has the potential to yield savings for the state, as well as improve overall health outcomes for caregivers and care receivers.

As Colorado looks ahead to accelerated grow of an aging population, as well increasing needs among disabled children and young adults, leaders in state government and the private sector should come together to develop clear blueprint for supporting the unpaid workforce of caregivers who are frequently obscured from view, but vital to caring for the state’s most vulnerable residents. A centerpiece of such a blueprint should be a bold and creative plan to make respite care services more widely available and affordable for all. Core components of this centerpiece would be strategies to support caregivers in the work place, bring caregivers a measure of financial relief, and ensure access to social services for care recipients that are important complements to their physical and behavioral health care.
## Appendix A: Medicaid HCBS Waiver Procedural Codes used to Identify Respite Care Services

<table>
<thead>
<tr>
<th>HCBS Waiver Program</th>
<th>Types of Respite Provided</th>
<th>Units</th>
</tr>
</thead>
</table>
| 1. Waiver for Persons with Brain Injury | • Adult Day Services (S5102_U6)  
• Respite Care, In Home (S5150_U6)  
• Respite Care, Nursing Facility (H0045_U6) | • 1 unit = 1 day  
• 1 unit = 15 minutes  
• 1 unit = 1 day |
| 2. Waiver for Children with Life Limiting Illness | • Respite Care – Unskilled (4 hours or less) (S5150_UD)  
• Respite Care – Unskilled (4 hours or more) (S5151_UD)  
• Respite Care – CNA (4 hours or Less) (T1005 UD)  
• Respite Care – CNA (4 hours or more) (S9125_UD)  
• Respite Care - Skilled RN, LPN (4 hours or less) (S9125_UD or TD)  
• Respite Care - Skilled RN, LPN (4 hours or more) (S9125_UD or TD) | • 1 unit = 1 hour  
• 1 unit = 1 day  
• 1 unit = 15 minutes  
• 1 unit = 1 day  
• 1 unit = 15 minutes  
• 1 unit = 1 day |
| 3. Waiver for Persons with Spinal Cord Injury | • Adult Day Services, Basic (S5105_UI or SC)  
• Adult Day Services, Specialized (S5105_UI or SC or TF)  
• Respite Care, Alternative Care Facility (S5151_UI or SC)  
• Respite Care, Nursing Facility (H0045_UI or SC)  
• Respite Care, In Home (S5150_UI or SC) | • 1 unit = 3-5 hours  
• 1 unit = 3-5 hours  
• 1 unit = 1 day  
• 1 unit = 1 day  
• 1 unit = 15 minutes |
| 4. Children’s Extensive Support Waiver | • Respite Care, Individual (S5150_U7)  
• Respite Care, Individual (S5151_U7)  
• Respite Group (S5151_U7 or HQ)  
• Respite Group Overnight (T2036_U7) | • 1 unit = 15 minutes  
• 1 unit = 1 day  
• Dollar  
• Dollar |
| 5. Supported Living Services Waiver | • Respite Care, Individual (S5150_U8)  
• Respite Care, Individual (S5151_U8)  
• Respite Group (S5151_U8 or HQ)  
• Respite Group Overnight (T2036_U8) | • 1 unit = 15 minutes  
• 1 unit = 1 day  
• Dollar  
• Dollar |
| 6. Waiver for Community Mental Health Supports | • Adult Day Services, Basic (S5105_UA)  
• Adult Day Services, Specialized (S5105_UA or TF)  
• Respite Care, Alternative Care Facility (S5151_UA)  
• Respite Care, Nursing Facility (H0045_UA) | • 1 unit = 3-5 hours  
• 1 unit = 3-5 hours  
• 1 unit = 1 day  
• 1 unit = 1 day |
| 7. Waiver for Persons Who are Elderly, Blind, and Disabled | • Adult Day Services, Basic (S5105_UI)  
• Adult Day Services, Specialized (S5105_UI or TF) | • 1 unit = 3-5 hours  
• 1 unit = 3-5 hours  
• 1 unit = 1 day |
<table>
<thead>
<tr>
<th>Services</th>
<th>Units</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respite Care, Alternative Care Facility (S5151_UI)</td>
<td>1 unit = 1 day</td>
</tr>
<tr>
<td>Respite Care, Nursing Facility (H0045_UI)</td>
<td>1 unit = 15 minutes</td>
</tr>
<tr>
<td>Respite Care, In Home (S5150_UI)</td>
<td></td>
</tr>
</tbody>
</table>
Appendix B: Colorado Respite Care Survey Questionnaire

Thank you for responding to this survey.

The information you provide will be used by Easterseals Colorado to help understand the quality of respite services, what unmet needs there are in the community for respite services, and other issues related to caregiving. The survey will take approximately 15 to 20 minutes to complete. Upon completion of the survey, you have a chance to win a $100 Visa gift card. If you choose to enter the drawing, you will be asked to enter your contact information at the end of the survey. 10 people will win!

Your name and the name of the care recipient will not be shared with anyone outside of Easterseals Colorado and the researchers who are helping Easterseals Colorado. All responses will be kept confidential. Responses will be grouped together and will only be shared as a group, without personal information such as names.

If you have any questions about this survey, please contact Meghan Kluth, Program Manager at Easterseals Colorado at mkluth@eastersealscolorado.org or at 303-233-1666 x257.

Please answer these questions as the primary caregiver. If the question is about the care recipient, that will be specified.

Please note that you may only complete this survey if you are over 18 years of age.

1. Please read the following statement and answer the question below:
   Some people provide regular paid or unpaid care or assistance to a family member or friend who has a health condition, long-term illness or disability. They provide this care so that their family member or friend can maintain an independent lifestyle. This family member or friend could be an adult or a child. Assistance can range from a few hours of shopping and cleaning to intensive medical or personal care. Tasks can include shopping, house cleaning, cooking, giving medications, toileting assistance and so forth.

   During the past 12 months, did you provide this kind of paid or unpaid care or assistance to a family member or friend?
   - Yes
   - No

2. Are you over 18 years of age?
   - Yes
   - No

3. Please read the definition of respite care below and answer the questions that follow.
   Respite care is temporary or short-term care of an individual that is provided by someone other than the person's normal caregiver. It is designed to give the caregiver brief personal time away from the daily tasks of caregiving. Respite care is provided either in-home or out-of-home. It is offered by community organizations such as mental health centers, nursing homes, churches, or private agencies. These organizations provide either a paid worker or a trained volunteer to provide respite care.

   Before you read the definition above, did you know what respite care was?
   - Yes
   - No

4. In the past 12 months, have you received respite care services (including help from a family member or friend)?
   - Yes, regularly
   - Yes, a few times
   - No

5. How often do you access respite services?
6. What agency or organization most recently provided respite services to you?
   - I do not receive respite services
   - Friend/family member
   - Agency or organization that most recently provided respite services to you:

7. What type(s) of respite have you used? Please select all that apply.
   - I do not receive respite services
   - In-home day respite
   - Day program (out of home) for adults or children
   - In-home overnight respite
   - Out of home overnight or weekend respite
   - Emergency respite care
   - Other community-based respite, such as recreational programs (YMCA's, recreational centers, neighborhood walks or runs)
   - Other (please specify)

8. What type(s) of respite care services would you want to use more of? Please select all that apply.
   - I do not receive respite services
   - In-home day respite
   - Day program (out of home) for adults or children
   - In-home overnight respite
   - Out of home overnight or weekend respite
   - Emergency respite care
   - Other community-based respite, such as recreational programs (YMCA's, recreational centers, neighborhood walks or runs)
   - Other (please specify)

9. Which of the following do you receive for your caregiving duties? Please select all that apply.
   - I do not receive any form of payment as a caregiver.
   - I receive payment from the care recipient.
   - I receive payment from family members other than the care recipient.
   - I receive payment for respite care services through my care recipient’s Medicaid waiver (e.g. Children’s Home and Community-Based Services (HCBS), Children with Autism (CWA), Children’s Extensive Support (CES), Children’s Habilitation Residential Program (CHRP), Children with a Life Limiting Illness (CLLI), Brain Injury (BI), Supported Living Services (SLS), Elderly, Blind, and Disabled (EBD), Developmental Disabilities (DD), Community Mental Health Supports (CMHS))
   - I receive payment from a church or charity.
   - I receive payment from a community based organization or nonprofit agency.
   - I receive payment/benefits from my private health care insurance
   - I receive payment from my local Area Agency on Aging (AAA) or Aging and Disability Resources for Colorado (ADRC)
   - Other (please specify)

10. Which of the following do you use to pay for respite care? Please select all that apply.
    - I do not receive respite care services.
    - I use funds from the care recipient.
    - I use funds from family members other than the care recipient.
    - I use funds for respite care services through my care recipient’s Medicaid waiver (e.g. Children’s Home and Community-Based Services (HCBS), Children with Autism (CWA), Children’s Extensive Support (CES), Children’s Habilitation Residential Program (CHRP), Children with a Life Limiting Illness (CLLI), Brain Injury (BI), Supported Living Services (SLS), Elderly, Blind, and Disabled (EBD), Developmental Disabilities (DD), Community Mental Health Supports (CMHS))
    - I use my local Area Agency on Aging (AAA) or Aging and Disability Resources for Colorado (ADRC)
    - Other (please specify)
11. Of the following waiver services you use, how often do you use the service as a form of caregiving respite?

(Being on a waiver means that an individual is receiving Medicaid benefits and an additional set of Medicaid services to help meet their needs through long-term care services and supports in their home or community. A waiver service may mean your care recipient has received an in-home assessment of your activities of daily living by your local Community Center Board or Single Entry Point, developed a care plan, and accessed services that are not in a typical health care clinic or hospital.)

<table>
<thead>
<tr>
<th>Service Description</th>
<th>My care recipient is not on a Medicaid waiver</th>
<th>I do not use this service</th>
<th>Up to 25% of the time</th>
<th>About 25 to 50% of the time</th>
<th>More than 50% but less than 75% of the time</th>
<th>75% or more of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day treatment (mental health treatment along with special education)</td>
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<tr>
<td>Adult day services (daytime supervision of individuals in a group environment in a center or location)</td>
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<tr>
<td>Homemaker services (assistance with general household activities needed to maintain a healthy and safe living environment, such as housekeeping, meal preparation and laundry)</td>
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<tr>
<td>Personal care services (bathing, grooming, dressing, feeding, etc.)</td>
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<tr>
<td>Specialized habilitation services (self-feeding, toileting, self-care, sensory)</td>
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</tbody>
</table>
12. Why did you seek respite services within the past 12 months? Please select all that apply.
   - Relieve stress
   - Spend time with my spouse or partner
   - Care for my own health
   - Care for medical needs of another family member
   - Safety issues (personal safety to either myself, family, and/or care recipient)
   - Prevent alcohol or substance abuse
   - To avoid missing work
   - Run errands and attend to or take care of other personal responsibilities
   - Participate in support group/services
   - I do not receive respite services
   - Other (please specify)

13. In the last year, have you received resources for your caregiving, such as training, education, or participation in support groups? (Select all that apply)
   - No, I have not received resources for my caregiving
   - Caregiver Training and Education
   - Caregiver Support Groups
   - Other (please specify)

14. As a caregiver, which of the following challenges, if any, do you face by providing care? Please select all that apply.
   - Financial strain
   - Lack of time for other activities
   - Conflict with job
   - Conflict with school
   - Understanding and applying for state/local respite care funding
   - Conflict in my family
   - Emotional strain/burnout
   - Physical health strain
   - Mental health strain
   - Transportation
   - Lack of social support
   - Lack of respite care
   - I have no challenges.
   - Other (please specify)

15. Approximately how much money, paying out-of-pocket, do you spend each month to cover expenses for the care recipient (e.g. for groceries, over-the-counter medications, gas, parking)?
   - $1,000 or more
   - $700 to less than $1,000
   - $500 to less than $700
   - $300 to less than $500
   - $200 to less than $300
   - $100 to less than $200
   - $1 to less than $100
16. What have been the personal financial impacts of your caregiving duties? Please select all that apply.
   - There have been no personal financial impacts of my caregiving duties.
   - Reduced capacity to save for my own long-term care
   - Diminished retirement savings Reduced hours at work
   - Early retirement
   - Please tell us more here:

17. Do you currently work outside the home?
   - I choose to work outside the home (part-time or full-time).
   - I am a student.
   - I am retired.
   - I choose not to work.
   - I am unemployed.
   - I am unable to be employed due to caregiving responsibilities.
   - I work part-time instead of full-time due to my caregiving responsibilities.

18. Do you work or go to school full time outside of the home?
   - Yes
   - No

19. To what degree would you say that being a caregiver has impacted your ability to work or go to school as much as you need or want to?
   
<table>
<thead>
<tr>
<th>1 - Little or no Impact</th>
<th>2</th>
<th>3 – Somewhat negative impact</th>
<th>4</th>
<th>5 – Great negative impact</th>
<th>N/A</th>
</tr>
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</table>

20. To what degree would you say that getting respite services has impacted your ability to work or go to school as much as you need or want to?
   
<table>
<thead>
<tr>
<th>1 - Little or no Impact</th>
<th>2</th>
<th>3 – Somewhat negative impact</th>
<th>4</th>
<th>5 – Great negative impact</th>
<th>I do not receive respite services</th>
</tr>
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</table>

21. Which of the following have you done as a result of becoming a caregiver? Select all that apply.
   - Reduced my work hours
   - Reduced job responsibilities
   - Switched to a less demanding job
   - Taken an unpaid leave of absence from my employer covered by the Family and Medical Leave Act
   - Taken an unpaid leave of absence from my employer not covered by the Family and Medical Leave Act
   - Taken a paid leave of absence from my employer
   - Retired early
   - Quit a job
   - Lost a job
   - Used vacation, sick days, and/or personal days off to be a caregiver
   - Missed days of work
   - Began working an alternative schedule
   - Began to work remotely
   - Took on additional hours to pay for cost of caregiving
   - None of the above
22. Approximately how many days of work or school do you miss in a year because you are sick/injured as a result of caregiving?

23. In general, my physical health is:

<table>
<thead>
<tr>
<th></th>
<th>Poor</th>
<th>Fair</th>
<th>Good</th>
<th>Very Good</th>
<th>Excellent</th>
</tr>
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<tbody>
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</table>

24. In general, how have your caregiving responsibilities impacted your physical health?

<table>
<thead>
<tr>
<th>1 - Little or no Impact</th>
<th>2</th>
<th>3 – Somewhat negative impact</th>
<th>4</th>
<th>5 – Great negative impact</th>
<th>I do not receive respite services</th>
</tr>
</thead>
<tbody>
<tr>
<td>o</td>
<td></td>
<td>o</td>
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<td>o</td>
<td>o</td>
</tr>
</tbody>
</table>

25. Has caregiving impacted your physical health? If so, how? Please select all that apply.

- Feeling depressed and/or anxious
- Experiencing changes in my sleeping patterns
- Seeing changes in my appetite
- Seeing changes in my weight
- I am getting sick more often
- Higher blood pressure
- Physical stress/strain
- Needed surgery
- There has been no impact.
- Other (please specify)

26. Since becoming a caregiver, have you been diagnosed with a new chronic medical condition? If so, select all that apply.

- Depression
- High blood pressure
- Diabetes
- Heart disease
- Lung disease
- Anxiety
- Substance abuse disorder
- None
- Other (please specify)

27. To what degree do you believe that caregiving has brought on this new diagnosis?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Somewhat</th>
<th>Very much</th>
<th>I have not had a new diagnosis</th>
</tr>
</thead>
<tbody>
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<td>o</td>
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</table>

28. In general, getting respite services has helped with my physical health:

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Somewhat</th>
<th>Very much</th>
<th>I do not receive respite services</th>
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<td>o</td>
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<td>o</td>
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</table>

29. In general, would you say your mental health (currently) is:

<table>
<thead>
<tr>
<th>1 - Little or no Impact</th>
<th>2</th>
<th>3 – Somewhat negative impact</th>
<th>4</th>
<th>5 – Great negative impact</th>
<th>I do not receive respite services</th>
</tr>
</thead>
<tbody>
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<td>o</td>
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<td>o</td>
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<td>o</td>
</tr>
</tbody>
</table>
30. In general, how have your caregiving responsibilities impacted your mental health?

<table>
<thead>
<tr>
<th>1 - Little or no Impact</th>
<th>2</th>
<th>3 – Somewhat negative impact</th>
<th>4</th>
<th>5 – Great negative impact</th>
<th>I do not receive respite services</th>
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<td>○</td>
</tr>
</tbody>
</table>

31. In general, getting respite services has helped with my mental health:

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Somewhat</th>
<th>Very much</th>
<th>I do not receive respite services</th>
</tr>
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</table>

32. In the last 12 months, how many times did you go to an emergency room for a physical health problem (for yourself)?
- None
- 1 time
- 2 times
- 3 or more times

33. In the last 12 months, how many times were you hospitalized for a physical health problem?
- None
- 1 time
- 2 times
- 3 or more times

34. To what degree do you believe that respite services have helped you stay healthy so you can stay out of the emergency room and the hospital?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Somewhat</th>
<th>Very much</th>
<th>I do not receive respite services</th>
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<td>○</td>
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</tbody>
</table>

35. In the last 12 months, how many times did you go to an emergency room or crisis center to get counseling or mental health services?
- None
- 1 time
- 2 times
- 3 or more times

36. To what degree do you believe that respite services have improved your quality of life?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Somewhat</th>
<th>Very much</th>
<th>I do not receive respite services</th>
</tr>
</thead>
<tbody>
<tr>
<td>○</td>
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<td>○</td>
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</table>

Other (please specify)
37. Thinking about times when you did not have access to respite services, how much does (or did) each of the following statements describe you?

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not at all</th>
<th>Somewhat</th>
<th>Quite a lot</th>
<th>Completely</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am exhausted when I go to bed at night.</td>
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<td></td>
</tr>
<tr>
<td>I have more things to do than I can handle.</td>
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<tr>
<td>I don’t have time just for myself.</td>
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<tr>
<td>I work hard as a caregiver but never seem to make any progress.</td>
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<tr>
<td>I am not able to be the person I want to be when I am with my care recipient.</td>
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</tr>
<tr>
<td>Being a caregiver has put a strain on my relationships.</td>
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</tbody>
</table>

38. As a result of accessing respite, have you seen any improvement in the following areas? Please check all that apply.
   - I am less exhausted when I go to bed at night.
   - I can handle all or most what I have to do.
   - I have time just for myself.
   - I work hard as a caregiver and seem to make progress.
   - I am able to be the person I want to be when I am with my care receiver.
   - Being a caregiver has not put a strain on my relationships.
   - I do not receive respite services.

The following questions are about the person for whom you provide care.

39. In general, would you say your care recipient’s physical health is:

<table>
<thead>
<tr>
<th>Physical Health</th>
<th>Poor</th>
<th>Fair</th>
<th>Good</th>
<th>Very Good</th>
<th>Excellent</th>
</tr>
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<tbody>
<tr>
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</tbody>
</table>

40. Would you say that getting respite services has helped with the physical health of your care recipient?

<table>
<thead>
<tr>
<th>Helpfulness</th>
<th>Not at all</th>
<th>Somewhat</th>
<th>Very much</th>
<th>I do not receive respite services</th>
</tr>
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<td>○</td>
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</table>

41. In the last 12 months, how many times did your care recipient go to an emergency room for a physical health problem?
   - None
   - 1 time
42. In the last 12 months, how many times was your care recipient hospitalized for a physical health problem?
   - None
   - 1 time
   - 2 times
   - 3 or more times

43. To what degree do you believe that respite services have helped your care recipient stay healthy so they can stay out of the emergency room and the hospital?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Somewhat</th>
<th>Very much</th>
<th>I do not receive respite services</th>
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44. In general, would you say your care recipient’s mental health is:

<table>
<thead>
<tr>
<th>Poor</th>
<th>Fair</th>
<th>Good</th>
<th>Very Good</th>
<th>Excellent</th>
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<td></td>
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45. Would you say that getting respite services has helped your care recipient’s mental health?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Somewhat</th>
<th>Very much</th>
<th>I do not receive respite services</th>
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</table>

46. In the last 12 months, how many times did your care recipient go to an emergency room or crisis center to support their mental health?
   - None
   - 1 time
   - 2 times
   - 3 or more times

47. To what degree do you believe that respite services have improved your care recipient’s quality of life?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Somewhat</th>
<th>Very much</th>
<th>I do not receive respite services</th>
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48. To what degree do you believe that respite services have helped your care recipient:

<table>
<thead>
<tr>
<th>Avoid hospitalization?</th>
<th>Not at all</th>
<th>Somewhat</th>
<th>Very much</th>
<th>I do not receive respite services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Avoid a nursing home stay or other institutional stay?</td>
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</table>

49. Without respite care, how likely is it that your care recipient may be placed in an out-of-home setting?
For the following questions, please think about respite services you have received in the past 12 months. If you have received respite services from more than one provider, answer these questions in terms of the provider who has provided the most services to you and the person for whom you provide care.

50. How would you rate the help you have received from respite care providers in the last 12 months?

<table>
<thead>
<tr>
<th>Worst help</th>
<th>Neutral</th>
<th>Best help</th>
<th>I do not receive respite services</th>
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<td></td>
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</table>

51. How well trained were the people in providing respite services?

<table>
<thead>
<tr>
<th>Not at all trained</th>
<th>Somewhat trained</th>
<th>Well trained</th>
<th>I do not receive respite services</th>
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<td></td>
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52. To what degree do respite providers treat you, and the individual you provide care to, with respect and courtesy?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Somewhat</th>
<th>Very much</th>
<th>I do not receive respite services</th>
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53. Did the respite care provider deliver services with cultural competence and in a language that ensured you and your care recipient’s comprehension?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Somewhat</th>
<th>Very much</th>
<th>I do not receive respite services</th>
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54. How often have the people who provide services to you changed?

<table>
<thead>
<tr>
<th>Frequently changed</th>
<th>Some change</th>
<th>Never changed</th>
<th>I do not receive respite services</th>
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</table>

55. If you have experienced frequent change in providers of respite care services, has that presented any problems for you or the individual you provide care for?

- Yes
- No
- Sometimes
- Please describe if you selected yes or sometimes.

56. Please rate your agreement with the following statement: During the most recent time I received caregiver respite services, the length of time was enough.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
<th>Not sure</th>
<th>I do not receive respite services</th>
</tr>
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</table>

57. How would you feel if respite services were not available?
58. In the last 12 months, how many times have you been unable to find respite services when you needed them?
   - Never
   - One time
   - Two times
   - Three or more times
   - Always

59. Have you ever been on a waiting list for respite services?
   - Yes
   - No
   - I don't know

60. On average, how long did you have to wait for respite services? You may choose whether you respond in number of days, weeks, or months.
   - # of days:
   - # of weeks:
   - # of months:

61. Do you or have you faced barriers in getting respite care? If yes, please select all that apply.
   - Financial limitations
   - Lack of trained providers in my area
   - Lack of respite programs available
   - I have personal discomfort with respite care.
   - I lack transportation to get to locations where respite services are provided.
   - Program/financial assistance qualifications
   - Scheduling challenges
   - I have not faced any barriers in getting respite care.
   - Other (please specify)

62. I think respite care services are affordable in my community.
   - Yes
   - No
   - Other (please specify)

Responding to these demographic questions will help inform the extent to which individuals who responded to the survey are representative of Colorado residents. Demographic data will be used to help understand where additional outreach is needed to ensure that we hear all voices.

63. How are you related to the care recipient?
   - My spouse or partner
   - My parent
   - Parent-in-law
   - My grandparent
   - My aunt or uncle
   - My sister or brother
   - My child
   - My friend
   - My neighbor
64. What is the care recipient’s living situation?
   ○ Lives alone
   ○ Lives with spouse/significant other
   ○ Lives with caregiver
   ○ Other (please specify)

65. Did you voluntarily become a caregiver?
   ○ Yes
   ○ No

66. How did you become a caregiver? Please select all that apply.
   ○ I want to be a caregiver
   ○ I have a close relationship to the care recipient
   ○ I have the time and capacity to do so
   ○ I live in close proximity to the care recipient
   ○ Nobody else was available to do so
   ○ My job is flexible
   ○ Nobody else was willing to do so
   ○ Other (please specify)

67. How long have you been caregiving?
   ○ Less than one year
   ○ 1 to 3 years
   ○ 4 to 10 years
   ○ 11 to 20 years
   ○ More than 20 years but not lifelong
   ○ Lifelong

68. In total, approximately how many hours per week do you spend caring for the care recipient?
   ○ 24/7
   ○ 24/7 except when my child is in school
   ○ Other (provide number of hours only)

69. How much assistance does the care recipient require in a day?
   ○ 1 to 6 hours
   ○ 7 to 12 hours
   ○ 13 to 18 hours
   ○ 19 to 23 hours
   ○ 24 hours occasional assistance
   ○ 24 hours frequent assistance
   ○ 24 hours continuous assistance
   ○ Don’t know/not sure

70. Which of the following are duties you perform for the care recipient? Please select all that apply.
   ○ Running errands
   ○ Housework
   ○ Meal preparation
   ○ Home repairs
   ○ Home modifications
   ○ Companionship
   ○ Basic communications
   ○ Language translation
o Accompanying to medical appointments
o Healthcare coordination
o Health insurance
o Mobility
o Personal care Feeding
o Incontinence care
o Medication management
o Medical treatment administration
o Paying bills/managing finances
o Other (please specify)

71. In what county do you live?

72. In what county does your care recipient live?

73. What is your zip code?

74. What is the zip code where your care recipient lives?

75. What is your age?
   o 18-24
   o 25-34
   o 35-44
   o 45-54
   o 55-64
   o 65-74
   o 75-84
   o 85 or older

76. What is the age of the care recipient?
   o Under 18
   o 18-24
   o 25-34
   o 35-44
   o 45-54
   o 55-64
   o 65-74
   o 75-84
   o 85 or older

77. What is your race? Select all that apply.
   o American Indian or Alaska Native
   o Asian
   o Black or African American
   o Pacific Islander
   o White
   o Other race not listed
   o Don't know
   o Prefer not to answer

78. What is the race of the care recipient? Select all that apply.
   o American Indian or Alaska Native
   o Asian
   o Black or African American
   o Pacific Islander
79. Is your ethnicity Spanish/Hispanic/Latino?
   - No, not Spanish/Hispanic/Latino
   - Yes, Puerto Rican
   - Yes, Mexican, Mexican American, Chicano/a
   - Yes, Cuban
   - Yes, Other Spanish/Hispanic/Latino
   - Prefer not to answer

80. Is the ethnicity of the care recipient Spanish/Hispanic/Latino?
   - No, not Spanish/Hispanic/Latino
   - Yes, Puerto Rican
   - Yes, Mexican, Mexican American, Chicano/a
   - Yes, Cuban
   - Yes, Other Spanish/Hispanic/Latino
   - Prefer not to answer

81. What language do you mainly speak at home?
   - English
   - Spanish
   - Chinese
   - Russian
   - Portuguese
   - Vietnamese
   - Polish
   - Korean
   - Prefer not to answer
   - Some other language (please specify)

82. What is the highest grade or level of school that you have completed?
   - 8th grade or less
   - Some high school but did not graduate
   - High school graduate or GED
   - Some college or 2-year degree
   - 4-year college graduate
   - More than 4-year college degree
   - Don't know
   - Prefer not to answer

83. What is the highest grade or level of school completed by the care recipient?
   - 8th grade or less
   - Some high school but did not graduate
   - High school graduate or GED
   - Some college or 2-year degree
   - 4-year college graduate
   - More than 4-year college degree
   - Don't know
   - Prefer not to answer
84. What is your annual household income?
   - Less than $25,000
   - $25,000 to $34,999
   - $35,000 to $49,999
   - $50,000 to $74,999
   - $75,000 to $99,999
   - $100,000 to $149,999
   - $150,000 to $199,999
   - $200,000 or more
   - Prefer not to answer

85. How many people does this income support?
   - Just myself
   - 2
   - 3
   - 4
   - 5+
   - Prefer not to answer

86. What is your marital status?
   - Married or cohabitating with significant other
   - Single
   - Divorced
   - Widowed
   - Prefer not to answer

87. Do you consider yourself to be:
   - Heterosexual or straight
   - Gay or Lesbian
   - Bisexual
   - Prefer not to answer
   - Another sexual orientation

88. What is your gender identity?
   - Male
   - Female
   - Trans male
   - Trans female
   - Non-binary
   - Prefer not to answer
   - My gender identity:

89. Another component of our study are interviews with caregivers, and if possible, care recipients. The interviews will be conducted via the phone and will be 30 minutes. There is a $20 VISA gift card for those selected to participate in the interview. If we may contact you to participate in an interview, please provide your name, phone number and/or e-mail address. We will not share your information or use it in our reporting of the survey results.

Name:
Phone number:
E-mail address:
Care recipient can participate in the interview. (Yes, No, Maybe):
90. Thank you for completing our survey. If you would like to be placed in a drawing for a $100 Visa gift card, please provide your name and email or phone number. We will use this contact information for the drawing only. We will not contact you for further for information regarding the survey. You will be contacted within one week after the close of the survey if your name is drawn.

Name: 
Phone number: 
Email address: 

Thank you for participating in our survey. As stated previously, the information you provide will be used by Easterseals Colorado to help understand the quality of respite services, what unmet needs there are in the community for respite services, and other issues related to caregiving.

If you have any questions about this survey, please contact Meghan Kluth, Program Manager at Easterseals Colorado at mkluth@eastersealscolorado.org or at 303-233-1666 x257.

In our efforts to make this a state-wide survey effort, we ask that if you know of caregivers living in Colorado to please forward the survey link to them.

Thank you!
Appendix C: Colorado Respite Care Survey Distribution Methodology

The Colorado Respite Coalition (CRC) and Easterseals Colorado’s (ESC) “Colorado Caregiver Survey”, administered by HMA, was distributed principally electronically through direct emails, e-newsletters, Twitter and Facebook advertising. For such correspondence, text explaining the survey’s intended audience and purpose were accompanied by a flyer and/or social media graphic.

Email: Multiple emails were sent to respite providers, advocacy groups, state organizations and health professionals across the state. Recipients of these emails included: Area Agencies on Aging, Aging and Disability Resources for Colorado, Community Centered Boards, the Latino Community Foundation of Colorado, The Center, Latino Age Wave, the Asian Pacific Development Center, the Center for African American Health, JFK Partners, Chronic Care Collaborative, Alliance, Strategic Action Planning Group on Aging, Jefferson County Aging Well, PASCO, El Grupo Vida, Colorado Respite Coalition grantees and voucher providers, Parent to Parent, Family Voices, Alzheimer’s Association, Jefferson County regional health connector, Jewish Family Services, Thrive Center, AARP Colorado

E-newsletters: The survey was distributed three times each via the CRC and ESC e-newsletter contact lists. The ESC mailing list is much larger than CRC’s, with approximately 3,500 and 560 subscribers, respectively. Information on the survey was included in two of ESC’s monthly newsletters (among other news and updates), and was sent once as an e-blast only mentioning the survey. The opposite applies to the CRC list – there were two specific e-blast, and the survey was also included within a larger e-newsletter.

Twitter: Information regarding the survey was also pushed through both the CRC and ESC Twitter accounts. @CORespiteCoalition has 692 followers, and tweeted about the survey twice; @EasterSealsCo has 528 followers, and tweeted the survey once.

Facebook: Again, the survey was promoted via both the Colorado Respite Coalition and Easterseals Colorado’s Facebook pages. The CRC posted about the survey three times (once for the initial deadline, once for the extended deadline, and once on the day of the deadline). ESC posted once for the initial deadline. Facebook “boosts” were used to promote these posts, making them more likely to be seen by individuals with certain targeted demographics. Most boosts were simply targeted to adults living in Colorado. A rural boost was also created, that targeted adults living within a 20-50km radius of each rural or frontier county seat, as indicated by the Colorado Rural Health Center. Approximately $150 was spent on Facebook boosts, between the CRC and ESC Facebook pages. Finally, the Facebook posts were collectively shared a total of 175 times by individuals and partner organizations.

Caregiver anecdotes to the survey:

- “Respite care for caregivers is so lacking. I know…have been doing it for years for my parents and now my husband, to the point where I had to quit working. Major loss of income and no time off except for one hour a week! I keep seeing the “caregivers need to take care of themselves”, sure wish I had any options that would allow me to!”

- “Taking this survey made me bawl. I have been caring for my son for nine years and these questions made me realize the toll it has taken on me physically and emotionally.”
• “There are no services in Colorado for special needs! You have to prove that you are or your child is and why do they have to prove it? That needs to stop!”

• “I’ve been helping and healing my husband for 5 years now. no agency pays me for that.”

• “What good is this? Study a problem you already know exists? Just give people respite. The only reason to study this is to research why there is no respite. Just surveys.”

Aside from these direct quotes, many caregivers commented to ask whether they would be eligible for the survey (foster parents and family caregivers who receive limited reimbursement for caregiving through the family member as a CNA program or a Medicaid HCBS benefit). After explaining that they were eligible, they all expressed gratitude to be included and willingness to share their experiences, by completing the survey. Paraphrased conversations ran along the lines of – “Are you interested in the voices of foster parents? We really appreciate the opportunity to share our perspectives and I will pass this survey along to others in my community who can share their stories also – thank you!”
Appendix D: Colorado Respite Care Interview Questionnaire

Caregiver demographics

(To interviewer: Note these demographics as context for your interview)

- #60 How are you related to the care recipient?
- #62 Did you voluntarily become a caregiver?
- #65 In total, approximately how many hours per week do you spend caring for the care recipient?
- #68 What county do you live in?
  - NOTE to interview – If rural, please (if it feels appropriate) explore issues with living in a rural setting and accessing respite care.
- #72 What is your age?
- #73 What is the age of the care recipient?
- #74 What is your race?
- #76 Is your ethnicity Spanish, Hispanic Latino?
- #81 What is your annual household income?
- #86 Mailing address for gift card

Introduction

We are working with Easterseals Colorado to explore the benefits of respite services to both caregivers and the people they care for. You recently participated in a survey about the caregiving you provide to someone. The purpose of this interview is to help us understand in more detail your experience as a caregiver and some of the issues or challenges you face in your community or with your particular care recipients’ needs.

As you saw from the survey, the research we are doing will help with an overall project funded by the Colorado State Legislature to study the costs and benefits of respite services. We will not attribute any of the information from our interview with you today specifically to you; our report will only include high-level themes for Easterseals, who will share the final with the Colorado State Legislature and the Colorado Department of Human Services.

<<Note to Interviewee: Take time here to introduce who is all on the phone and their roles, and check with interviewee(s) that it is OK.>>

For your time, we’d like to offer you a $20 VISA gift card. We’ll be sure to double check your mailing address at the conclusion of the interview.

Just to ensure we are working from the same understanding, what we mean by caregivers is someone who is caring for children or adults of any age with special needs who are unable to care for themselves.

What we mean by “respite” is temporary relief for these caregivers. It can be a few hours provided on a one-time basis, or it could be overnight, or even a longer period of time. Respite can be provided at home — by a friend, other family member, volunteer or paid service — or in a care setting, such as adult day care or a residential facility. It can be planned in advance, or it could be something that is provided in a time of crisis.
We know your time is valuable, so we very much appreciate you taking the time to talk with us today. If you do not have any questions, we are ready to start!

**Questionnaire**

*Note to interviewer: In advance of each interview, assess each interviewee’s survey responses. The #’s indicate the survey question that may be used to inform the questioning.*

**Respite care utilization**

We want to ask a few questions regarding how much respite care services you use and why.

*In the survey, you indicated that you DO or DO NOT use respite services.*

- #1 In the past 12 months, have you received respite care services (including help from a family member or friend)?
- #2 How often do you access respite services?
  - If they do use respite: Has the respite care you have been able to use been enough?
  - If they do no use respite: What has prevented you from being able to access respite services?

**Tell us about your experience with identifying and utilizing different funding sources for respite**

- #6 Which of the following do you receive for your caregiving duties?
- #7 Do you (or does someone else, or Medicaid or insurance) pay for respite care? If so, how, private pay, Medicaid waivers, grant funds, etc. Note whether the interviewee selected Medicaid funds option “I use funds for respite care services through my care recipient’s Medicaid waiver”
- #11 As a caregiver, which of the following challenges, if any, do you face by providing care? If they respond “Understanding and applying for state/local respite care funding,” explore what those challenges are.
  - Is it hard to figure out how to pay for respite care? Describe why it is or is not.
  - Is the payment amount you receive sufficient?
  - What challenges do you experience with the respite care you are able to access? For example, is it hard to find qualified providers, is it hard to figure out how to pay for respite care, are there issues with respite providers understanding your loved one’s needs?

**Caregiver Impacts**

We know that being caregiving can impact many aspects of your life, including your ability to work, your health, and overall quality of life. We want to take a moment to explore these impacts and the role that respite care services has in supporting you as a caregiver do the things you need to do to take care of yourself as well as your care recipient.

**Economic/workforce impacts:**

*Tell us about the role that respite services has played in your decision to work or not to work?*

- #13 What have been the personal financial impacts of your caregiving duties?
- #14 Do you currently work outside the home?
• #17 To what degree would you say that getting respite services has impacted your ability to work or go to school as much as you need or want to?
  o Prompt: If respite has impacted their ability to work or not work: Tell us a little more about that impact and the role that respite plays in your decision-making regarding working or not working.

Health impacts

What have been the physical and mental health impacts of caregiving, and to what extent has respite care alleviated those impacts?

• #22 Has caregiving impacted your physical health? If so, how?
• #23 Since becoming a caregiver, have you been diagnosed with a new chronic medical condition?
• #24 To what degree do you believe that caregiving has bought on this new diagnosis?
• #27 In general, how have your caregiving responsibilities impacted your mental health?
• In the last 12 months, how many times were you hospitalized for a physical health problem?
• #25 In general, getting respite services has helped with my physical health:
• #28 In general, getting respite services has helped with my mental health:
• #31 To what degree do you believe that respite services have helped you stay healthy so you can stay out of the emergency room and the hospital?
  o Prompt if they had a new diagnosis as a result of caregiving: To what extent do you think that caregiving contributed to this condition? Describe that connection for us.
  o Prompt if they had hospitalizations: To what extent do you feel caregiving contributed to the need for hospitalization? Describe that connection for us.
  o Prompt if yes that respite helped them to stay healthy: How is it that respite has contributed to your health? Do you feel it has helped more or less or the same with your physical health and mental health?

Quality of Life Impacts

How has your quality of life – your relationships, hobbies, etc... – been impacted by caregiving, and to what extent does respite care effect this quality of life?

• #33 To what degree do you believe that respite services have improved your quality of life?
  • Prompt: Have there been any changes in your family or social life from receiving respite care? For example, have your relationships improved or strengthened?
  • Prompt if they report perceived benefits: “What do you feel has been the #1 benefit of respite for you as the caregiver?”
  • If there are no perceived benefits, why not?

Care Recipient Impacts

((Note to interviewer: If care recipient is on the phone, direct this line of inquiry to them. Remember though that the caregiver responded to the survey so responses reflect their point of view, not necessarily the care recipients.))
Just as respite care may affect the caregiver, it can affect the care recipient too. We want to now explore similar questions but from the perspective of your care recipient.

**Health impacts**

*How have respite services impacted the health of your care recipient? What health changes have you experienced?*

- #37 Would you say that getting respite services has helped with the physical health of your care recipient?
- #42 Would you say that getting respite services has helped your care recipient’s mental health?
  - Prompt if they report perceived benefits: *What about respite care brings about these benefits to you <<the care recipient>>?*

**Quality of Life Impacts**

- #44 To what degree do you believe that respite services have improved your care recipient’s quality of life?
  - Prompt: *Have there been any changes in your family or social life with respite care? For example, have your relationships improved or strengthened?*
  - Prompt if they report perceived benefits: *“What do you feel has been the #1 benefit of respite care for you <<your care recipient>>?”*

**Prevention of Institutionalization**

- #45 To what degree do you believe that respite services have helped your care recipient:
  - avoid hospitalization?
  - avoid a nursing home stay or other institutional stay?
- #46: Without respite care, how likely is it that your care recipient may be placed in an out-of-home setting?
  - Prompt: *Tell us more about how access to respite services influences your decision-making regarding placement in an out-of-home setting? What other influences are at play in that decision? Would having more or less respite care services influence your decision-making?*

**Improvements in Respite Care**

- Based on the information you provide in the survey, and what you also are telling me today, what do you think could be done to help improve access to the kind of qualified and reliable respite care your care recipient needs?

**Experience responding to this survey**

- When you took the survey regarding your satisfaction with respite care services, did you feel it asked the right questions? What would you like to have been asked and/or how would you like to have been asked?

**Conclusion**
Thank you again for your time. Your input has been invaluable. We know that it is important to Easterseals that you seem the outcome of this effort. Stay tuned for information on the study findings and final report.

To just double check your address for the gift card – **SURVEY QUESTION #86**