Colorado Respite Care Task Force

2016 Report to:

MEMBERS OF THE SENATE HEALTH AND HUMAN SERVICES COMMITTEE
COLORADO GENERAL ASSEMBLY

MEMBERS OF THE HOUSE PUBLIC HEALTH CARE AND HUMAN SERVICES COMMITTEE
COLORADO GENERAL ASSEMBLY

In accordance with HB 15-1233:
Concerning the Creation of a Respite Care Task Force

January 29, 2016

Colorado Respite Care Task Force

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TO: Members of the House Public Health Care and Human Services Committee
Colorado General Assembly

Members of the Senate Health and Human Services Committee
Colorado General Assembly

We, the members of the Respite Care Task Force, are pleased to submit this report pursuant to § 26-1-602(4), C.R.S. The statute directs the Task Force to submit to the General Assembly by January 31, 2016, a report of the Task Force's findings and recommendations concerning the supply of, and demand for, respite care services in Colorado.

This work represents the long-term view of Colorado's needs for respite care. The Task Force recognizes that additional funding will be needed to implement many of the recommendations in this report. Despite the current State fiscal constraints, we feel it is important to plan for Colorado's future. As a Task Force, we represent a diverse group of stakeholders who, using a collaborative process, have developed a shared vision for respite care in Colorado and a consensus set of recommendations. This same type of collaboration among respite care providers, community non-profits, federal and state agencies, foundations and other stakeholders will be key to securing the funding to implement our recommendations.

We would like to extend our sincere appreciation to the General Assembly and lead bill co-sponsors Representative Lois Landgraf and Senator Irene Aguilar for their support of the Task Force's work and concern for the respite needs of caregivers in Colorado. As the population ages and childhood diagnoses continue to create a demand for respite, the need for caregiver respite will increase. We believe it is critical for Colorado to address the shortage of respite care providers and barriers to affordable, quality respite—issues discussed in this report.

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Department of Health Care Policy and Financing

Russ DenBraber
Christian Living Communities

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Special Kids, Special Families

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COLORADO RESPITE CARE TASK FORCE REPORT

The Respite Care Task Force was established by HB 15-1233 to study respite care services in Colorado and report its findings to the General Assembly. Respite provides caregivers temporary relief from caring for children or adults of any age with special needs who are unable or need assistance to care for themselves. This report presents the Task Force's findings and recommendations.

Major Findings

- More than 512,000 children and adults with intellectual, developmental or physical disabilities live in Colorado (9.8 percent of the population). In many cases their families devote substantial time to caring for them at home.
- The Family Caregiver Alliance estimates that 843,000 Colorado caregivers (1 in 5 adults) provided 551 million hours of care in 2012.
- State and local caregiver surveys show that one of the most frequently requested support services is respite care.
- Some of the major barriers to respite care services in Colorado are affordability, geographic accessibility, an inadequate supply of culturally competent respite care providers, a shortage of providers who can care for high needs individuals, and restrictions on the types and amounts of respite services covered under the Home and Community Based Services (HCBS) waivers.
- In State Fiscal Year (SFY) 2015, 2,380 Coloradans on HCBS waivers received respite services.
- The largest sources of funding for respite care in Colorado (other than out-of-pocket expenditures) are the Medicaid waiver programs and the National Family Caregiver Support Program through the Older Americans Act, State Funding for Senior Services and local funding. In 2014, respite funding from these sources totaled $10.8 million and helped 3,528 caregivers.
- State General Funds, in conjunction with §18-6.5-107, C.R.S., have provided important stopgap respite care funding for the last three years ($359,000 in SFY 2016).
- Based on the limited data that exist and the experience of Colorado respite care experts, it appears that the need for affordable, geographically accessible, culturally competent respite care--especially for high needs recipients--exceeds the existing supply.

> *Last summer our regular provider wasn't available and the local respite program doesn't run through summer; I have MS and in summer I have a difficult time. I was unable to find anyone else, so at the time of year when we desperately needed help for our 6-year old son who has Autism Spectrum Disorder and ADHD, it was completely unavailable. It is also very costly, as our son does not receive waivers for respite care, so all provider payment is out-of-pocket. We are a one-income family, and I am sure you can understand how difficult that might make paying for this 'extra' expense.*
>
> Angela Woerner, Task Force Member, Brush, CO

Recommendations

The following recommendations address the economic and social value of respite care in Colorado, the supply of respite care providers, community outreach and education, and access to quality, affordable, culturally competent respite care.

- The Task Force recommends that an outcomes assessment/return-on-investment study be completed to demonstrate the economic impact of respite care and its benefits for those served.
- The Task Force recommends development of a comprehensive statewide training system for respite care providers that includes a standardized training format.
- The Task Force recommends expansion of the Colorado Respite Coalition's website to serve as the designated website in Colorado for information about respite care and as an access point for services throughout the state.
- The Task Force recommends development of a centralized community outreach and education program about respite care services in Colorado that includes funding for start-up and ongoing activities, paid staff and leveraging of existing resources to support design and dissemination of materials.
- In addition to General Fund and Medicaid dollars that fund some respite care services for certain populations, the Task Force recommends that the General Assembly consider a tax credit for full-time caregivers and for caregivers' out-of-pocket expenses.
- The Task Force recommends that the General Assembly allow for, and the Department of Health Care Policy and Financing work to, standardize the full continuum of respite care options across all Medicaid waiver programs.
- The Task Force recommends that the State streamline the regulatory requirements for facility-based, short-term, overnight respite care.

The respite service has saved our marriage. We are so thankful.
(David, Silverthorne)

The respite we were granted was a lifesaver.
(Kerry, Colorado Springs)

The Night Lights [respite care program] has been a godsend for us.
(Maria, Denver)

I. BACKGROUND

A. Respite Care Task Force Creation, Charge and Vision

Colorado enacted HB 15-1233, Concerning the Creation of a Respite Care Task Force, in May 2015. The legislation was co-sponsored by Representative Lois Landgraf and Senator Irene Aguilar. The act called for the creation of a 14-member task force within the Department of Human Services (see Table 1 for a list of Task Force members). It directed the Task Force to study respite care services in Colorado and submit a report of its findings to the House Public Health Care and Human Services Committee and Senate Health and Human Services Committee, by January 31, 2016. The legislation called for the report

Table 1

Respite Care Task Force Members

Category of Appointment	Appointee
Licensed home health care agency	Ryan Zeiger, PASCO (Personal Assistance Services of Colorado)
Licensed hospice organization	Kerri Mosinski, HopeWest
Organization that advances research to end Alzheimer's disease	Tina Wells, Alzheimer's Association
Organization that provides services, education and outreach in the area of mental health	Moe Keller, Mental Health America of Colorado
Organization that provides services, education and outreach to seniors	Russ DenBraber, Christian Living Communities
Organization that represents persons with developmental disabilities	Linda Ellegard, Special Kids, Special Families
Owner or operator of a respite care facility	Cynthia Hansford, Foothills Gateway, Inc.
Person from rural area who utilizes respite care	Angela Woerner, caregiver, Brush, CO
Person who provides services, education and outreach for persons with chronic conditions, long-term conditions, and disabling conditions across a lifespan	Lynn Robinson, Easter Seals Colorado
Person who represents a non-profit entity that provides services, education, outreach and advocacy to persons with disabilities	Melanie Worley, Developmental Pathways
Person who represents persons with brain injuries	Brenda Heimbach, Rocky Mountain Healthcare Services
Department of Health Care Policy and Financing	Michele Craig, Community Living Office
Department of Human Services	Mindy Kemp, Division of Aging and Adult Services
Department of Public Health and Environment (non-voting member)	Kristi Uitich, Health Facilities and Emergency Medical Services Division

to address access to and funding of services; availability of culturally competent and patient-centered respite care; and increased availability of affordable respite care throughout Colorado.

At its second meeting, in September 2015, the Task Force brainstormed an ideal vision for respite care in Colorado (see Appendix A). The ideal vision included five respite care goals: diverse funding streams; a full continuum of services and options; a sufficient supply of quality, trained providers to meet demand; broad public awareness and community outreach; and easy access to streamlined processes and supports.

The Department of Human Services contracted with outside consultants to conduct research for, and facilitate the meetings of, the Task Force and draft the final report. Health Management Associates Community Strategies was selected to research information on respite care in Colorado and investigate models in other states. It submitted a 100-page report with its findings to the Task force on November 31, 2015.[1] Appendix B includes excerpts from the report's executive summary and lists the research topics in the report. Lisa Carlson and Barbara Yondorf of Engaged Public provided facilitation and report writing services.

B. Definitions of Key Terms

This report uses several terms that are central to understanding the state of, and recommendations concerning, respite care. They are listed below.

Caregiver. A caregiver is a person who provides unpaid care to a relative or friend of any age that is more than the normal care required of a person of that age. This includes care for, or assistance provided to, a person who has ongoing medical conditions, a serious short-term condition, serious emotional or behavioral problems, and developmental disabilities.

Respite care is temporary relief care for families of children or adults of any age with special needs who are unable or need assistance to care for themselves. Respite care can range from a few hours of care provided on a one-time basis to overnight or extended care sessions. It can be provided at home by a friend, other family member, volunteer or paid service, or in a community-based care setting, such as adult day care or a specific respite facility, to relieve the physical and emotional impact on the caregiver.

Planned respite is care planned in advance of the need for respite. It may be short-term or recurrent, as needed.

Crisis respite occurs on short notice, usually during a family emergency or in a crisis situation. It may be used when an individual cannot be safely supported in his/her home or is at risk of becoming mentally unwell or going to a hospital. Crisis respite offers relief to families under severe stress.

Informal respite is care typically performed by family members, relatives, friends or volunteers.

Formal respite is care provided by individuals who are paid professional and paraprofessional staff.

[1] Health Management Associates Community Strategies, *Respite Care Study Final Report,* presented to the Colorado Department of Human Services, November 30, 2015.

C. Need for and Barriers to Respite Care

1. Need for Respite Care

According to the 2012 U.S. Census, more than 512,000 children and adults with intellectual, developmental or physical disabilities live in Colorado (9.8 percent of the population). Many have families who provide substantial amounts of care for them in the home. The Family Caregiver Alliance estimated that 843,000 Colorado caregivers (1 in 5 adults) provided 551 million hours of care in 2012.[2]

State and local surveys show that respite is one of the support services most frequently requested by caregivers.[3] A national caregiver survey published in 2015 found that 41 percent of respondents caring for a person age 18 or older, who provided more than 20 hours a week of care, said one of the best ways to help them would be having respite services available.[4] A survey of 212 Colorado caregivers who received respite services through the Colorado Respite Care Program were asked to rate their daily stress. More than a third said they were extremely or very stressed—a good indication of the need for respite.[5]

Despite the high priority caregivers place on the need for respite, according to the chair of the National Respite Coalition, respite care is "in short supply, inaccessible, or unaffordable to a majority of the nation's caregivers."[6]

2. Barriers to Respite Care

Many caregivers face significant barriers to respite care services. Surveys of Colorado caregivers and respite care providers have identified a number of barriers; Table 2 lists some of the major ones. The last barrier listed in Table 2 concerns cultural competency. Colorado Latino Age Wave[7] conducted a community assessment in 2012 that identified respite as a major issue for older Latinos.[8] In addition to some of the barriers listed in the table, the survey identified several cultural issues. Examples include:

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[2] Family Caregiver Alliance, *State of the States in Family Caregiver* Support, 2012; https*://www.caregiver.org/sites/caregiver.org/files/pdfs/2012_State_Profiles/merged_state_profile_co_2012.pdf*

[3] Health Management Associates report, p. 19.

[4] AARP Public Policy Institute and National Alliance for Caregiving, *Caregiving in the U.S., 2015 Report,* June 2015; http://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf

[5] Colorado Respite Care Project, *Family Caregiver Survey Results*, 2014.

[6] Public Witness Testimony of Jill Kagan, ARCH National Respite Network, before the U.S. House Subcommittee on Labor, Health and Human Services and Education Appropriations, April 12, 2010; http://archrespite.org/docs/NRC_FY11_House_Testimony_Lifespan_Respite.pdf

[7] Colorado Latino Age Wave is an initiative that supports the well-being of a rapidly growing older Latino adult population in Metro Denver through innovative services and programs.

[8] Survey cited in Health Management Associates report, p. 74.

Table 2

Major Barriers to Respite Care in Colorado

- Fragmented and narrowly targeted services
- Shortage of qualified respite providers to care for high needs recipients
- Affordability of respite services
- Low provider payments, especially for the care of higher needs recipients
- Geographic barriers (e.g., long travel distances)
- Difficulty locating services
- Caregiver reluctance to ask for help, sometimes due to feelings of inadequacy
- Lack of information about how to find or choose a respite care provider
- Concern over the quality of services
- Lack of awareness that respite care services exist or are available locally
- Hours of respite care services may not be convenient for the caregiver
- 24 hour in-home respite service not allowed in certain Home and Community Based Services waivers.
- Cultural competency issues

- Adult day care programs operate during 9-to-5 business hours during the week, which does not fit the working lives of many Latinos.
- Services provided by adult day programs are often not aware of, or sensitive to, the cultural preferences of Latino elders. In care facilities, this extends to details such as the food served, the décor, even background music.
- Elders often do not accept in-home assistance from anyone who is not a family member and especially from care providers whose ethnicity, language and demeanor are outside of the elder's experience.

Finding quality providers is very difficult and took our family years. People who'll do a decent job don't apply for respite care agencies because the pay rate is too low.

Care of Caregivers Survey respondent Colorado 2015

I really did not find respite services at all. I think there is a completely inadequate supply in Colorado and that it is completely unaffordable.

Care of Caregivers Survey respondent, Colorado 2015

D. Value of Respite for Caregivers

The value of respite for caregivers and their families is clear. Among other things, it allows them to recharge; attend to their own health needs; devote more time to other children in the home; take a few days' vacation; and engage in day-to-day activities that others take for granted, such as running errands. More than one person has said that respite care saved their marriage.

> *It is a godsend for our family. My 6-year-old son, Henry, has Autism Spectrum Disorder and ADHD. For years my husband and I had little sleep and no break, mostly because we didn't trust anyone to watch Henry and didn't know where to turn. Once we were told about a local respite program, our lives changed for the better. When Henry is in respite care, we can sleep (something that hasn't happened much since he was born), shop, and even have a (very rare) date!*
>
> Angela Woerner, Brush

Respite care also benefits care recipients. It allows them to have social interactions with others, gives them a needed break and, in the case of out-of-home respite care, may give them a chance to interact with others who have similar physical or behavioral challenges.

> **Comments from Caregivers who Obtained Respite Services from Programs that Help Families Who are Not Eligible for Medicaid Respite**
>
> *The respite we were granted was a lifesaver. We have no family here and as a result, no support system.* Kerry, Colorado Springs
>
> *Respite brings us all closer. We can plan for the future and enjoy the present when we have time off from 24/7 caregiving [for our 6-year old with special needs].* Michael, Centennial
>
> *We are incredibly thankful and would not know what we'd do without such a program. It's given my husband and I time to spend together without worrying.* Rachel, Littleton

II. Utilization, Supply and Demand

A. Utilization

Health Management Associates found little data on the utilization of respite care services in Colorado. There is hardly any data on private-pay and informal respite care utilization and only limited data on respite care utilization in publicly-funded respite care programs.

1. Medicaid Home and Community Based Waivers

In State Fiscal Year (SFY) 2015, 2,380 people in Medicaid Home and Community Based Services (HCBS) waivers received respite services (see Table 3). Three waivers accounted for more than 95 percent of respite clients: Supported Living Services (HCBS-SLS) (for adults with intellectual or developmental disabilities), Children's Extensive Supports (HCBS-CES), and Elderly, Blind and Disabled (HCBS-EBD). The HCBS-CES and HCBS-SLS waivers accounted for more than 92 percent of total expenditures. The HCBS-CES and HCBS-EBD waivers had the highest average numbers of clients and HCBS-CES the highest average cost.

Table 3

Colorado Medicaid Home and Community Based Services (HCBS) Waivers: Respite Care Utilization, Colorado State Fiscal Year 2015

HCBS Waiver	# Clients Receiving Respite	Average # Hours Respite per Client	Total Expenditures SFY 2015
Children with a Life Limiting Illness (HCBS-CLLI)	57	72 hrs	$84,451
Children's Extensive Supports (HCBS-CES)	770	353 hrs	$4,237,516
Elderly, Blind and Disabled Waiver (HCBS-EBD)	406	362 hrs	$693,459
Supported Living Services (HCBS-SLS)	1,130	276 hrs	$5,211,334
Other Waiver Programs: Brain Injury, Community Mental Health Supports, and Spinal Cord Injury	35	482 hrs for four programs	$38,226
TOTAL	2,380 (a)	---	$10,264,986

(a) Numbers sum to more than the number of clients, since there were 18 clients who received waiver respite services in more than one waiver during SFY 2015.

Source: Health Management Associates Community Strategies, *Respite Care Study Final Report,* presented to the Colorado Department of Human Services, November 30, 2015, Tables 3, 4, 5 and 12.

Health Management Associates examined the extent to which authorized respite care was used by HCBS waiver enrollees in SFY 2015. Authorized care means care that a client enrolled in an HCBS waiver may use pursuant to an individualized plan of care for the year. Depending on actual client needs and the availability of services, the types and levels of services actually used during the year may be less than the authorized amount. Health Management Associates found a significant gap between authorized and provided hours, and between authorized and expended dollars. [9]

- With respect to hours of respite care, the waivers authorized 3,457,788 hours, but used only 743,816 (22 percent of authorized hours).
- The waivers authorized $38,032,532 for respite care, but spent only $9,437,191[10] (25 percent).

To find out the reasons for the gap, the Task Force surveyed its members. Task Force members include waiver experts, respite care providers, representatives of caregivers, and state agency staff who administer the waivers and regulate respite care providers. The most frequently cited reasons were some of the same as the barriers listed in Table 3:

- Not enough trained/skilled providers to care for individuals who are medically fragile or have serious behavioral challenges;
- Not enough providers in rural areas;
- Lack of availability during needed hours;
- Inadequate reimbursement, including lack of payment for travel expenses (a particular problem in rural areas);
- Providers who don't accept Medicaid;
- 24-hour in-home respite care is not allowed in some waivers;
- Respite care is only available in alternative care facilities or nursing facilities in some HCBS waivers; and
- Based on the current HCBS waivers limits, families must choose the use of respite versus other HCBS services.

2. Behavioral Health Organizations

Behavioral Health Organizations contract with the Department of Health Care Policy and Financing to provide mental health services to people covered under the Medicaid State Plan (as opposed to a Home and Community Based Services waiver). In SFY 2015, the Department spent $268,520 for 1,211 days of respite care for clients with behavioral health issues.[11] These figures are down from SFY 2014 when the State spent $334,889 for 1,357 days of respite care.

[9] Health Management Associates report, p. 29.
[10] This figure is lower than that shown in Table 3 as it was developed using a somewhat different methodology to calculate provided dollars in order to make for an apples-to-apples comparison with authorized dollars .
[11] Health Management Associates report, p. 40, Table 15.

3. Colorado Respite Care Program

Easter Seals Colorado administers the Colorado Respite Care Program under a contract with the Department of Human Services. Key partners include the State Unit on Aging, Colorado Respite Coalition and the Chronic Care Collaborative. Funding comes from an annual General Fund appropriation, the proceeds from a State surcharge on individuals convicted of a crime against an at-risk person, and a Lifespan Respite Care Grant to the State from the U.S. Department of Health and Human Services. These funds are used to provide respite services for caregivers with low incomes whose families are not eligible or are on a waiting list for Medicaid HCBS waivers. They also are used to provide training, education and outreach for caregivers. The Colorado Respite Care Program reported that in SFY 2014, it distributed 28 grants totaling $137,700 to local respite care programs across the lifespan, in urban and rural areas.

4. Area Agencies on Aging

Areas Agencies on Aging (AAAs) provide respite services. Health Management Associates found that the majority of services are provided to individuals with a caregiver who is 60 to 69 years old. In SFY 2014, AAAs provided 70,066 hours of respite care, of which 16,815 hours (24 percent) were provided in rural areas of Colorado (18 percent of the State is rural).

B. Supply and Demand

At first glance, it would appear that Colorado has a sufficient supply of formal respite care providers. Health Management Associates identified more than 975 organizations that offer respite care in Colorado. However, a closer look at the data and the results of interviews with caregivers and respite care providers suggests there are provider shortages in some parts of the state. Across the state, it also appears that providers who can care for individuals with more challenging conditions and behaviors are in short supply.

Proxy Indicators of the need for respite care services in Colorado suggest a potential gap between demand and supply. Health Management Associates created a map showing the locations of respite care provider organizations in Colorado and the number of people who have low incomes and are disabled, by county—an indicator of potential supply versus need (see Figure 1). The map shows a concentration of respite care provider organizations along the Front Range, while many other parts of the State have few or no providers.

The Colorado Respite Care Program reported that in SFY 2014, it distributed 28 grants totaling $137,700 to local respite care programs across the lifespan, in urban and rural areas. The grants paid for more than 11,800 hours of respite care for more than 500 caregivers who cared for someone not enrolled in an HCBS waiver. However, requests for grant support exceeded available funds. The Project received additional requests from 13 agencies for an estimated 1,800 more hours of care than it could fund. In SFY 2015, it was able to fund only two-thirds of the $257,754 it received in grant requests.[12] In part this

[12] Nineteen grants totaling $199,750 were made in SFY 2015 for a total of 18,627 hours to provide respite care services to 599 families statewide.

was due to applications that did not comply with grant guidelines and requests that exceeded available funds.

Finally, as noted earlier, based on their experience as caregivers, providers and regulators, Task Force members have identified a shortage of providers with the skills to take care of individuals who are medically fragile or have behavioral issues, providers in rural areas of the State, and providers who are willing to accept Medicaid.

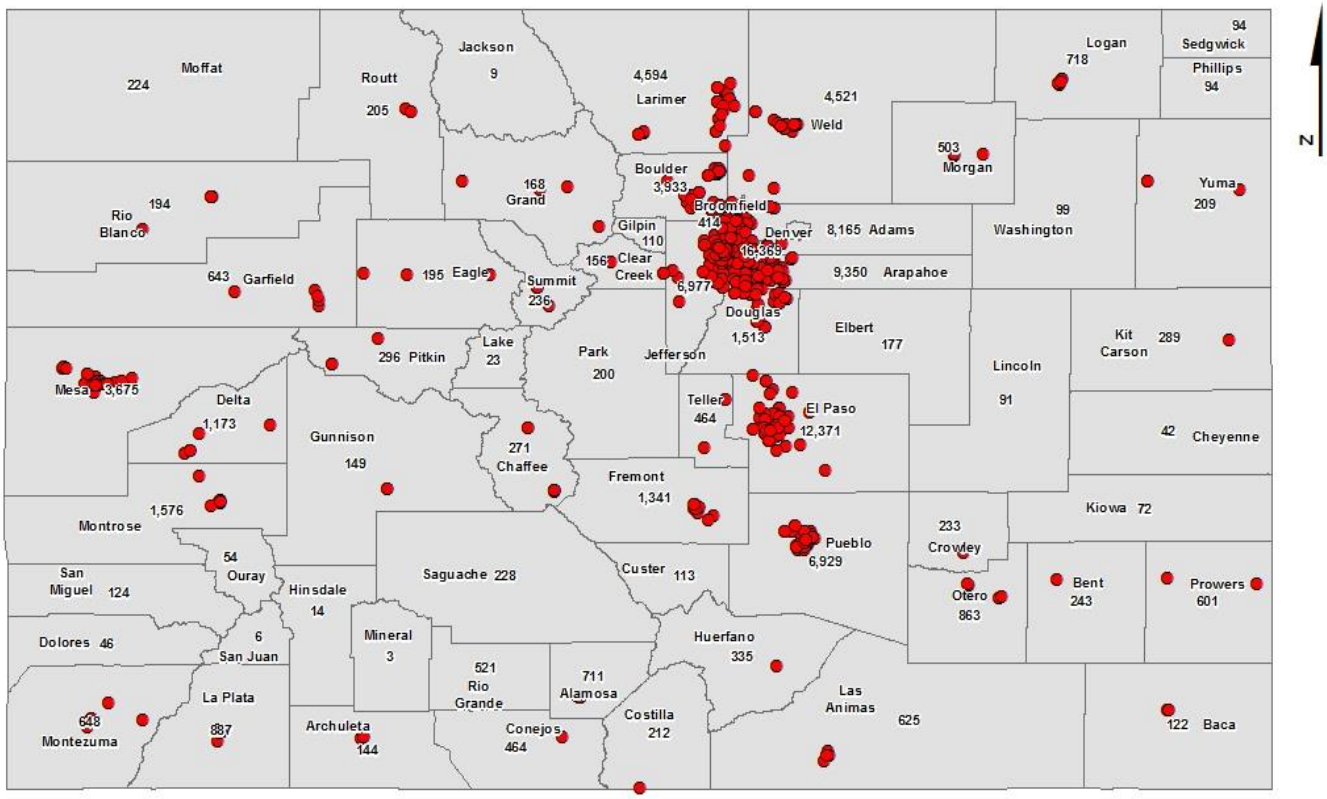
From the limited data Health Management Associates was able to collect, and based on the experience of Colorado respite care experts, it appears that the need for affordable, geographically accessible, culturally competent respite care--especially for high needs recipients-- exceeds the existing supply.

Figure 1.

Colorado Map of Respite Care Provider Organizations and Numbers of People Who have Low Incomes and are Disabled, by County

- ***Respite Care Provider Organization***

Note: Each red dot on the map represents a respite care provider organization with vastly differing capacity, from a single employee to hundreds. While the map shows the counties where provider organizations are located, some agencies may serve more than one county. Also, some agencies may not accept HCBS waivers.



Map: Health Management Associates, 2015
Data source: U.S. Census, 2009-2013

III. Task Force Recommendations

The Respite Care Task Force met eight times between July 14, 2015, and January 15, 2016, and developed recommendations in four areas (see Table 4). They include assessment of the economic and social value of respite care, respite care training, community outreach and education, and access to respite care. Table 4 summarizes the goals for each issue area and associated recommendations. The sections that follow present the recommendations and findings that support them.

Table 4

Respite Care Task Force Recommendations

Goal: Assess the Economic and Social Value of Respite Care in Colorado

Recommendation 1. The Task Force recommends that an outcomes assessment/return-on-investment study be completed to demonstrate the economic impact of respite care and its benefits for those served.

Goal: Ensure Colorado has a Sufficient Supply of Respite Care Providers

Recommendation 2. The Task Force recommends development of a comprehensive statewide training system for respite care providers that includes a standardized training format.

Goal: Educate Caregivers and Others about the Benefits of, and How to Access, Respite Care

Recommendation 3. The Task Force recommends expansion of the Colorado Respite Coalition's website to serve as the designated website in Colorado for information about respite care and as an access point for services throughout the State.

Recommendation 4. The Task Force recommends development of a centralized community outreach and education program about respite care services in Colorado that includes funding for start-up and ongoing activities, paid staff and leveraging of existing resources to support design and dissemination of materials.

Goal: Ensure Caregivers Get the Quality Respite Care They Need When They Need It

Recommendation 5. In addition to General Fund and Medicaid dollars that fund some respite care services for certain populations, the Task Force recommends that the General Assembly consider a tax credit for full-time caregivers and for caregivers' out-of-pocket expenses.

Recommendation 6. The Task Force recommends that the General Assembly allow for, and the Department of Health Care Policy and Financing work to, standardize the full continuum of respite care options across all Medicaid waivers.

Recommendation 7. The Task Force recommends that the State streamline the regulatory requirements for facility-based, short-term, overnight respite care.

A. Assessment of the Economic and Social Value of Respite Care

Goal: To demonstrate the benefits of respite care in Colorado, both in terms of needed relief for caregivers and net savings from avoiding more expensive medical care and other costs—a positive return on investment.

Recommendation 1. The Task Force recommends that an outcomes assessment/return-on-investment study be completed to demonstrate the economic impact of respite care and its benefits for those served.

The study should evaluate existing programs for the following items:

- Evaluate populations in the waiver programs that provide respite and study the differences between those who do and do not use respite services, including the impact on caregivers;
- Identify existing data and identify areas where additional data could be collected from the Department of Health Care Policy and Financing and other respite sources to examine respite utilization, need for support, etc.;
- Show the impact of funds spent on respite versus funds saved in health care or out of home residential placements;
- Use a consistent evaluation tool to assess the waiver respite programs and all Colorado respite programs; and
- Sufficient funding needs to be provided for a study that will identify data points that the Colorado Respite Coalition can use to collect additional complementary data from caregivers using respite services and improve evaluation for agencies to show the impact of respite on caregivers, identify varied needs across programs and geographic areas, and demonstrate cost savings of respite care versus institutionalization and hospitalization.

Discussion. The Task Force believes that more resources need to be invested in respite care. Earlier sections of this report reviewed the need for, and value of, respite care and pointed out the apparent gap between the demand for and the supply of affordable, geographically accessible, culturally competent care. In addition to examining supply and demand, it is important to demonstrate the economic and social benefits of respite care to make the case for devoting more resources to respite care programs. Unfortunately, after examining the literature and data on the economic benefits of respite care, Health Management Associates concluded, "There is a lack of solid research on the value and return on investment of respite services, both nationally and in Colorado."[13]

In order to make the case for the economic and social benefits of respite care, the Task Force recommends that a study be conducted to assess the costs and benefits of respite. Among other things, the study should look at the demographic characteristics and utilization by those who do and

[13] Health Management Associates report, p. 20.

do not use respite care. The Health Management Associates report includes a proposed study design. The Task Force also recommends that the study include identification of data points that the Colorado Respite Coalition can use to collect and analyze additional complementary data about the need for and utilization, costs and benefits of respite services for caregivers caring for someone who is not on Medicaid.

B. Training

Goal: To ensure Colorado has a sufficient number of qualified providers to meet the demand for respite care services.

Recommendation 2. The Task Force recommends development of a comprehensive statewide training system for respite care providers that includes a standardized training format.

The training system should:

- Include an up-to-date online inventory of all training opportunities for Colorado respite care, information about how to become a respite provider, and training modules;
- Make training available in multiple settings and formats (e.g., classroom, online, websites, etc.) to ensure training is accessible throughout the State;
- Have core training programs that are based on national models, use a patient-centered approach, address core competencies, are evidenced-based, and are developed with input from caregivers, respite providers, educational institutions and other stakeholders;
- Establish training programs focused on respite care for individuals with higher needs to ensure providers are capable of providing care for these populations;
- Make training available for primary caregivers;
- Establish multi-tiered training depending on the level of care required and consider providing (but not necessarily requiring) "best practice" certifications; and
- Incorporate cultural competency. This can be achieved using national proven practices to develop and implement culturally competent training for respite care workers throughout Colorado. It should address cultural competency related not only to ethnicity but also to competencies for dealing with other populations, such as people with complicated or special behavioral or physical challenges.

Discussion. The Task Force finds that training for respite care providers needs to be more accessible and with improved quality of consistent content for professional providers. Training should build on existing training programs. A frequently heard complaint from caregivers is the lack of trusted respite care workers trained to care for loved ones with higher needs. The apparent shortage of culturally competent providers, especially for Latino recipients, needs to be addressed (see section I.C.2, Barriers to Respite Care.)

While Colorado has some respite care training programs for providers and volunteers, it needs more. The Colorado Respite Program has partnered with the Adoption Exchange, Metropolitan State University of Denver (Metro) and Easter Seals Colorado to train workers and volunteers. In collaboration with Easter Seals Colorado and Colorado Respite, Metro has the most comprehensive training program. Each year it provides 11 weeks of hands-on training, in addition to classroom training, for 50 to 60 students. To deal with the shortage of providers described in section II.B, Supply and Demand, more and expanded respite care worker training programs are needed.

The adequacy of a trained respite care workforce should be addressed before mounting a large-scale community outreach and education campaign (see Recommendation 4). Educating the community about respite care will likely increase demand for professional respite care providers.

C. Community Outreach and Education

Goal: To educate caregivers, the medical community, policy makers, employers, employees and the public generally about respite care services in Colorado and its benefits; how to access respite services; and how respite services can help caregivers to continue providing care and not burn out.

Recommendation 3. The Task Force recommends expansion of the Colorado Respite Coalition's website to serve as the designated website in Colorado for information about respite care and as an access point for services throughout the State.

The expanded website should:

- Have respite information across the lifespan;
- Include a comprehensive, up-to-date provider locator that has geographic-specific provider information--something that is particularly important in rural areas;
- Include information about respite care training opportunities (see Recommendation 2);
- Make it easy for providers and others to link to it;
- Have a link to information on how to become a provider and who to contact to apply for respite services;
- Use search engine optimization to maximize the number of Internet users who are looking for respite information who are directed to the website;
- Have a link to Colorado's mental health Crisis and Support Line and consider having a link to patient navigators; and
- If the Colorado Respite Coalition's website is used as the central Colorado website, allow for redesign and search engine optimization.

Discussion. A successful community education and outreach effort needs to be able to direct people to a central resource for more information. The Internet is a major information source for caregivers, more so than for others. A Pew Research Center study found that in 2012, 79 percent of family caregivers had access to the Internet, a higher percentage than for non-caregivers, even when controlled for age, educational level and other demographic factors.[14]

The Task Force recommends designating the website maintained by the Colorado Respite Coalition as the one-stop source for respite information in Colorado. While several groups have websites that have respite care information, the Coalition's website has the widest array of information. The Colorado Respite Coalition has more than 180 member organizations (e.g., AARP Colorado, ARC of Colorado, Cross Disability Coalition, Easter Seals Colorado, etc.). Funding to maintain the website comes from the federal Lifespan grant. While the Coalition's website has many of the features of the website that the Task Force is recommending, limited financial and staff resources mean that the Coalition cannot provide comprehensive, up-to-date information on all topics. For example, while the website has a respite provider locator, the information is incomplete. Rarely are all of the following included in any given provider's description: funding accepted, services provided, availability, ages and area served, cost, and disability and other needs for which care can be provided.

To drive people to the website, implementation of this recommendation needs to include search engine optimization. Search engine optimization is the process of maximizing the number of visitors to a particular website by ensuring the site appears high on the list of results returned by an Internet search engine.

Even the best website cannot ensure that people get the information they seek and services they need. Caregivers sometimes complain that they are passed along from agency to agency when what they want is one person they can call directly. Staff need to be available not only to populate and maintain the website but also to answer questions and direct people to the specific agency/person that can address their needs, using a warm handoff.

Recommendation 4. The Task Force recommends development of a centralized community outreach and education program about respite care services in Colorado that includes funding for start-up and ongoing activities, paid staff and the leveraging of existing resources to support the design and dissemination of messaging and marketing materials.

Community outreach and education efforts should use communication vehicles that research has shown are the most effective at reaching caregivers, including social media as a primary marketing tool and public awareness strategy. Community outreach and educational materials should:

[14] Susannah Fox and Joanna Brenner, "Family Caregivers Online," Pew Research Center, July 12, 2012; http://www.pewinternet.org/2012/07/12/main-report-14/

- Be simple, clear, and easy to understand;
- Reflect a broad range of Coloradans living in different places with different needs and cultures;
- Help individuals to identify as caregivers and take action for planned and backup crisis respite;
- Be phrased in a way that caregivers can relate to;
- Focus on prevention and immediate assistance for caregivers on the edge as priorities;
- Get out the message that taking a break does not mean you as a caregiver are failing or that the situation is hopeless, and that trusted, trained respite providers are available to help;
- Foster a culture of: If you break your arm, you go to the ER; if you need respite , you go to the Colorado Respite Coalition website (see Recommendation 3) to find out about respite services in your area; and
- Take into account that different approaches may be needed for different audiences—what may work in urban areas may not be effective in rural areas, what is an effective way to reach younger people may not be the same for older people.

Discussion. Colorado needs a coordinated, statewide, community outreach and education program. The program should educate people about what respite care is and when, where and how to access it. It should include information about the benefits of, cost and financial assistance for, and locations of different types of respite care.

Health Management Associates reported that current efforts to promote awareness of respite services in Colorado appear to be limited and social media outreach relatively inactive. The report noted that while the Colorado Respite Coalition has plans to greatly amplify its respite care materials in persuasive ways, its staff currently lack the capacity to carry out the extensive work to drive these plans forward.

Many caregivers do not self-identify as caregivers. As a result, they don't seek out respite services. Often the terms "caregiver" and "respite" don't resonate; community outreach and education efforts need to use different language to reach them. Other caregivers are reluctant to ask for help. Sometimes this is because they think that seeking respite services is an admission of failure—that they are inadequate to the task of caring for their loved one. Educational outreach needs to let people know that this is not the case, quite the opposite. Another important message that needs to be relayed is that caregivers should seek assistance before they are on the edge of collapsing. They need to know they can get respite care on a regular basis or in a crisis and there are qualified professionals who can help.

Evaluation of the recommended statewide community outreach and education program is an essential component of this recommendation. A key objective is for people to take action. Program evaluation should include such things as whether more caregivers who need respite services get them and whether there are fewer incidences of families who face a care crisis using expensive emergency or hospital care that could have been avoided with crisis respite care.

D. Access to Respite Care

Goal: To ensure caregivers get the quality respite care they need, when they need it.

Recommendation 5. In addition to state General Funds and Medicaid dollars that fund some respite care services for certain populations, the Task Force recommends that the General Assembly consider a tax credit for full-time unpaid caregivers and for caregivers' out-of-pocket expenses.

Discussion. Caregivers who are not eligible for subsidized respite care either pay for respite care out-of-pocket or go without if they cannot afford it. In some cases, caregivers leave employment to stay home and provide care. As a result, they forgo the income, benefits, Social Security contributions and other financial advantages of employment. A study published in 2010 found that women who left the workforce early to care for a parent experienced an average total of $142,693 in lost wages, $131,351 in lost Social Security benefits and $50,000 in lost pensions.[15] One way to offset a portion of lost income and benefits is a tax credit. The credit also should be available for full-time caregivers who may receive some funded respite, as they still have significant out-of-pocket costs.

For a family member who works, federal law provides a child and dependent care tax credit for a portion of the cost of an outside caregiver so the person can work. But a family member who leaves work or stays home to care for a dependent and pays for an outside respite caregiver is not eligible for the tax credit. The Task Force recommends that the General Assembly consider a tax credit for respite care expenses incurred by non-working full-time caregivers that is comparable to the child and dependent care credit.

How revenue collections will be affected as a result of implementing this recommendation depends on several factors, including who and what kinds of services are eligible for the credit, the amount of the credit, whether the credit is refundable, caps on the credit, and potential offsets from such things as reduced emergency room utilization and improved caregiver health.

Recommendation 6. The Task Force recommends that the General Assembly allow for, and the Department of Health Care Policy and Financing work to make available, the full continuum of respite care options across all Medicaid waivers.

Discussion. Caregivers who need respite need the right kind of respite. A survey of Colorado caregivers found, not surprisingly, that all forms of respite care are needed, ranging anywhere from

[15] MetLife Mature Market Institute et al., "The MetLife Study of Care Giving Costs to Working Caregivers," June 2011; http://www.caregiving.org/wp-content/uploads/2011/06/mmi-caregiving-costs-working-caregivers.pdf

a few hours daily to an extended period of time.[16] This also is true for Coloradans who qualify for respite services under an HCBS waiver. However, as was discussed in Section II.A.1, Medicaid Home and Community Based Waivers, one of the reasons that not all of the respite care authorized under the HCBS waivers is used is that, in some cases, the type of respite the caregiver needs is not covered.

Table 5 describes Colorado's HCBS waivers. For each waiver, the table shows the types of respite services that are covered, service unit measures, associated rates, and limits on what is available. The variability from program to program is striking. For example, some waivers cover alternative care facilities or cap the allowable hours of in-home respite while others do not.

The Task Force believes that all of the HCBS waivers should cover the full continuum of respite care options. Consistent rules should govern the use of respite services and the rules should provide for the flexibility necessary to meet the individual needs of clients and caregivers. The Task Force recommends that the General Assembly authorize the Department of Health Care Policy and Financing to administer the waivers accordingly.

Recommendation 7. The Task Force recommends that the State streamline the regulatory requirements for facility-based, short-term, overnight respite care.

Discussion. Facility-based, short-term, overnight respite care is care provided in a home-like setting that allows families a few days of respite. Several Colorado organizations (e.g., Easter Seals Colorado and Hayley House, among others) are interested in establishing a similar program to one in Phoenix, Arizona, called Ryan House. Ryan House provides respite/palliative care for children with life-limiting conditions. A qualified child can stay for up to seven consecutive days and a total of 28 days in a year. Ryan House has six beds for children's respite/palliative care, two beds for pediatric hospice, and four family suites.

The Colorado Departments of Public Health and Environment, Human Services, and Health Care Policy and Financing have different requirements for facility-based, short-term, overnight respite providers. The requirements are not specific to this type of care and, in many cases, are unnecessarily burdensome and may discourage creation of the programs. The Task Force believes that overnight, short-term respite facilities should have standards that are consistent among licensing and certification agencies and are appropriate to the level of care that is provided.

[16] PADCO (Parents of Adults with Disabilities in Colorado), *Care of Caregivers Survey*, 2015.

Table 5

Colorado's Medicaid Home and Community Based Services (HCBS) Waivers

	Type of Respite Service	Unit of Service	Rate	Limits
Brain Injury Waiver (HCBS—BI)				
	In-Home	15 minutes	$ 3.24	A mix of delivery options is allowable as long as the aggregate amount of services is below 30 days, or 720 hours, of respite care. In-home respite is limited to no more than 8 hours a day.
	Nursing Facility	Day	$ 120.30	
Elderly, Blind, an Disabled Waiver (HCBS—EBD)				
	Alternative Care Facility (ACF)	Day	$ 57.01	Combined maximum of 30 days per certification period for Respite Care provided in an ACF, In Home, or Nursing Facility.
	Nursing Facility	Day	$ 127.14	
	In-Home	15 minutes	$ 3.24	Respite providers shall bill at the lesser of a unit rate or daily institutional Nursing Facility rate ($127.14). Maximum 30 days per certification period for respite care provided in an ACF, In Home, or Nursing Facility.
Children's Extensive Supports Waiver (HCBS—CES)				
	Individual	15 minutes	$ 4.95	Use Individual Day Rate when respite care exceeds 40 units (10 hours) in 24-hr period.
	Individual--Day	Day	$ 197.91	
	Group or Camp (Group, Overnight)	Dollar	$ 1.00	Group Respite rates may not exceed the rate paid for Individual Respite
	Maximum of 30 days and 1,880 additional 15 minutes per Service Plan year.			
Children's Habilitation Residential Program (HCBS--CHRP)				
	Level 1	Day	$ 54.78	Respite care for a foster child in a certified foster home other than the child's identified foster home that exceeds the license capacity of the home, for short-term temporary relief of the foster parent for max 7 consecutive days/mo not to exceed 28 days/ year. During the time when respite care for a foster child is occurring, respite home may not exceed 6 foster children or maximum of 8 total children with no more than 2 children under the age of 2.
	Level 2	Day	$ 88.50	
	Level 3	Day	$ 108.13	
	Level 4	Day	$ 131.67	
	Level 5	Day	$ 151.30	
	Level 5	Day	$ 190.15	
Children with Life Limiting Illness Waiver				
	Unskilled--4 hrs or less	15 minutes	$ 5.37	Combined maximum of 30 calendar days per Service Plan year for all Respite Care services.
	Unskilled--4 hours or more	Day	$ 96.63	
	Certified Nursing Assistant (CNA)--4 hours or less	15 minutes	$ 7.04	

(continued on next page)

Table 5 (continued)				
Children with Life Limiting Illness Waiver *(continued from previous page)*				
	CNA--4 hours or more	Day	$ 125.10	Combined maximum of 30 calendar days per Service Plan year for all Respite Care services.
	Skilled RN, LPN--4 hrs or less	15 minutes	$ 15.31	
	Skilled RN, LP--4 hrs or more	Day	$ 275.44	
Community Mental Health Supports Waiver (HCBS--CMHS)				
	Alternative Care Facility	Day	$ 57.01	Combined maximum of 30 days per certification period for Respite Care provided in an ACF or Nursing Facility.
	Nursing Facility	Day	$ 127.14	
	In-Home	15 minutes	$ 3.24	
Supported Living Services Waiver (HCBS--SLS)				
	Individual	15 minutes	$ 4.95	Use Individual Day rate when Respite services exceed 40 units (10 hours) in a 24-hour period.
	Individual Day	Day	$ 197.91	
	Group	Dollar	$ 1.00	Group Respite rates may not exceed the rate paid for Individual Respite.
	Camp (Group, Overnight)	Dollar	$ 1.00	
	For certification period, respite services and other SLS waiver services may not exceed individual Service Plan Authorization Limit.			

Source: Community Living Office, Colorado Department of Health Care Policy and Financing, January 2016

IV. Additional Areas for Discussion

The Task Force identified several issues that it did not have time to fully research but believes warrant further examination. They are briefly discussed below.

- **Determine the feasibility of using the Colorado mental health Crisis Support Line to take crisis respite calls and arrange for follow-up respite services**

Crisis respite is provided on short notice, usually during a family emergency or in a crisis situation. It reduces family stress and may reduce the need for more expensive out-of-home care. It also has the potential to lessen serious impacts on other systems (e.g., the mental health and criminal justice systems). While some agencies offer crisis respite, most caregivers are unaware of the service or don't know where to call to get crisis respite care. Caregivers could benefit from a crisis respite hotline. Colorado already has a statewide crisis hotline for mental health issues--the Crisis Support Line. The Department of Human Services in partnership with Metro Crisis Services operates the hotline. It may be that at very little cost, the Crisis Support Line also could field calls for crisis respite assistance and follow-up.

- **Explore ways to encourage employers to fund respite services directly or include them in their health benefit plans**

Compelling reasons exist for employers to take an active interest in supporting their employees who are caregivers and could benefit from respite care services. A 2006 national study looked at the annual cost to employers of working caregivers.[17] It estimated that employers of full-time, employed, intense caregivers, lost $3.4 billion to absenteeism, $3.4 billion for shifts from full-time to part-time work, $2.8 billion for replacing employees and $2.8 billion for workday interruptions. The Task Force discussed two options to encourage employers to support employees who are caregivers. The first is an employer tax credit. The second is to convene insurers and interested employers to explore inclusion of a respite care benefit in employer health plans. A few employer plans around the country have a respite care benefit. For example, an Oregon insurance company, ODS Health Plan, Inc., sells small employer plans that cover respite care the same as home health and hospice care.[18]

- **Investigate other potential sources of respite care funding**

The only significant sources of funding for respite care in Colorado are the Home and Community Based Services waivers ($38,032,532 authorized for SFY 2015) and National Family Caregiver Support Program through the Older Americans Act, State Funding for Senior Services and local funding ($1.17 million for federal fiscal year (FFY) 2014). Other programs provide limited funding for direct respite care services in Colorado. They include the Native American Caregiver Support Program, Lifespan Respite Grant,

[17] *The MetLife Caregiving Cost Study: Productivity Losses to U.S. Business*, 2006; http://www.caregiving.org/data/Caregiver%20Cost%20Study.pdf

[18] ODS Health Benefit Plan Options for Oregon-based Employer Groups (2-50), July 2012; http://www4.odscompanies.com/pdfs/agents/comm_plans_brochure.pdf

collections from a surcharge on individuals convicted of a crime against an at-risk person,[19] the Woodward Respite Fund and appropriations for respite care that the General Assembly has made for the past three years.[20] The Task Force discussed several additional potential sources of respite support for caregivers with low family incomes who are not eligible for, or enrolled in, an HCBS waiver. One is to include respite in employer-sponsored wellness programs. Bon Secours Health System in Richmond, Virginia, for example, has a Retiree Work Opportunities Program that assists employees caring for elderly parents with in-home nurses and respite care to give their employees a break without worry. A second is a mill levy. Six Colorado Community Centered Boards have county mill levies to provide services for people with intellectual or developmental disabilities that may include funding for respite services. A third is promotion of caregiver co-ops. Caregiver co-ops allow caregivers to "buy" caregiving time for their family members in the co-op through volunteering, usually once a month. The Asian Community Center of Sacramento, California, for example, has operated a Caregiving Cooperative Respite Program for the past four years.[21]

- **Conduct a study to assess the adequacy of reimbursement rates for different types and levels of respite care**

The Task Force believes that inadequate reimbursement rates are a major barrier to the use of respite care services for caregivers in need. This is especially true for the care of recipients who are medically fragile, have serious behavioral issues or have dementia. Low reimbursement rates also may be one of the major reasons for the limited availability of respite care services in rural areas. This issue comes up frequently in discussions with providers and caseworkers about barriers to respite care. It would be useful to conduct an analysis of the costs to provide different types and levels of respite services and compare them to current payment rates to determine if the rates are adequate.

- **Explore ways to increase the availability of informal respite care.**

Relatives, friends, volunteers, faith-based organizations, and other community groups are important potential sources of informal respite care. The availability of informal care is especially important for caregivers who cannot afford to pay for respite care or who live in rural areas that have few formal respite care providers. A 2014 article on rural caregiving observed "Living in a rural area makes the already difficult task of caregiving even more of a struggle."[22] A 2009 study of caregiving in the U.S. found that 68 percent of caregivers of an adult recipient who is not in a nursing home had at least one other unpaid caregiver helping them.[23] Without that support, some caregivers might not be able to continue providing care at home.

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[19] $9,000 in SFY 2016.
[20] $350,000 for SFY 2016.
[21] Caregiver.org/caregiver-cooperative-respite-program
[22] See saved Liza Berger, "Rural Caregiving," Today's Caregiver; caregiver.com; caregiver.com/articles/print/rural_caregivers.htm
[23] National Alliance for Caregiving and AARP, *Caregiving in the U.S. 2009,* p. 7; http://www.caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf

The Task Force discussed two strategies to increase the availability of informal respite care. The first is to encourage Community Centered Boards, Area Agencies on Aging, institutions of higher education, and Single Entry Point agencies to expand their support for programs and arrangements that focus not only on formal but also on informal respite care. This includes such things as conducting training for people interested in informal caregiving, serving as a resource for programs that link caregivers with respite care volunteers and sponsoring mentorship programs. Colorado has several model programs for informal respite care. The Boulder Respite and Companion Volunteer Program, sponsored by the local Area Agency on Aging and local senior services groups, has a network of screened and trained volunteers who are matched to provide one-on-one companionship with an older adult experiencing isolation or some degree of compromised health, providing respite for primary caregivers. Morgan Community College and Northeastern Junior College provide medical support for the Northeast Colorado Health Department's Family Recess respite program. The program provides drop-off care for children with special needs once a month for eight hours during the school year, in Sterling and Fort Morgan. Nursing students from the colleges care for the children under the supervision of a registered nurse. The care is free.

The second strategy to increase the availability of informal respite care that the Task Force discussed is to provide stipends and/or reimbursement for expenses such as mileage that may increase the willingness of people to provide otherwise unpaid respite care. The Health Management Associates report cited Ohio's Individual Options and Level 1 Medicaid waivers as an example of this approach. These waivers reimburse for informal respite by an approved independent provider or friend. The Ryan White program also has a provision for reimbursing informal care.

Appendix A. Ideal Vision for Respite Care in Colorado
Brainstormed by the Task Force at its September 2015 Meeting

Diverse funding streams (need good data to make this happen)	Timeline
• Sustainable and adequate funding levels	Long term
• Funding for high-level needs (i.e., provided by an RN)	Long term
• Funding for Medicaid/non-Medicaid alike, those at risk for placement	Long term
• Dedicated funding source for respite care	Long term
• Funding in place for all needing respite (i.e., vouchers, sliding fees, etc.)	Long term
Continuum of services and options	
• Flexibility in delivery of respite services	**Medium term**
• Emergency and planned respite options	**Medium term**
• Rural areas have same options as urban areas	Long term
• Range of services available	**Medium term**
• Enough multiple offsite facilities for all who need throughout the State	Long term
• Enough diversity of delivery and location of services to give choices	**Medium term**
• Broader range of respite settings (based on need)	**Short term**
• Options for the military	**Medium term**
• Respite available in all Medicaid Waivers with choice/options	**Medium term**
Community outreach and public awareness	
• Medical community embraces link between caregiver health and respite	Long term
• Social media campaign to educate public on respite issues	**Short term**
• Colorado employers support employees who are respite care providers	Long term
• Caregivers honored and respected, leading to abundant supply	Long term
• Good data to support cost/benefit of respite care	**Short term**
• Pilot program to demonstrate effectiveness/value of respite care	**Short term**
Workforce supply and quality	
• Sufficient numbers of providers	**Short term**
• Well-trained providers	**Medium term**
• Staff qualifications aligned with client needs	**Short term**
• Staff training is widely available, ongoing and of outstanding quality	Long term
Easy access, streamlined processes and supports	
• All respite providers have comprehensive intake for continuum of care	**Short term**
• Broadened criteria so more caregivers are eligible for respite services	**Short term**
• Support informal caregivers and caregiver arrangements	**Short term**
• Navigators help caregivers to find their way through the system	**Medium term**
• Coordinated-centralized single entry point	**Short term**
• Well-publicized	**Short term**
• Educate caregivers and families to understand and accept services	**Short term**
• Make caregivers eligible for respite under Medicaid	**Short term**
• Opportunity for follow-up call to check in	**Medium term**
• Respite care meets cultural needs of individual/caregiver	**Medium term**
• Enough diversity to give choices	**Medium term**

Appendix B

Health Management Associates Report on Respite Care in Colorado*
Summary of the Research and List of Research Topics

Summary of the Research

Data are extremely limited, both locally and nationally, on who caregivers are, on the extent of their needs for respite services, and on gaps in respite services. This research leveraged all existing research that could be found within the tight timeframe of the project, and conducted additional analyses using data sets that could be accessed within the timeframe. In some cases, existing research that was not conducted in Colorado was used to explore findings and best practices from other states and nationally. In other cases, proxy data were used to explore where needs might be greatest in Colorado and where resources might be located. Analyses, including "hotspot" maps of potential need and existing providers are provided in this report. Additionally, interviews were conducted with providers, with experts on respite, and with caregivers, to fill in more detailed information about needs, supply, gaps, and barriers to accessing respite services. The research contained in this report provides strong indications of needs and gaps in respite services in Colorado, including variation in needs and supply across the state, as indicated by provider maps, hotspots, population projections, utilization patterns and qualitative data from caregivers and others. The data suggest that needs may be greater in rural areas, where there are fewer providers and may be a higher percentage of caregivers.

In terms of return on investment (ROI), almost no rigorous data on ROI in respite services exists, despite overwhelming anecdotal and qualitative evidence that respite services are valued by caregivers and care receivers, that these services improve the lives of caregivers, as well as care receivers, and that respite services may help allow individuals to remain in their homes and communities longer. The limited research on ROI is summarized in this report, and a potential plan for future research is provided.

In terms of public awareness campaigns about caregiving and respite services, this report explores other states' best practices for helping caregivers become aware of their role as a caregiver, their needs, and the availability of respite services. This research is summarized, and estimates of the costs for conducting such campaigns is provided here.

Last, research on best practices for providing training to respite providers, ensuring both cultural and disability competence among respite providers, and on informal respite is summarized, from a scan of the literature and interviews with other states.

* The report is available online under Resources at https://drive.google.com/folderview?id=0B1J3_PFQQ67nfnB0TUFna25UaEtSOHlrM0Nyc3p4TWZ0Z2x4OEJpSl9pT2xxZWNLZUplZGc&usp=sharing_eid

Research Topics Covered in the Report

- Return on investment
- Proposed research study
- Funding
- Colorado supply and demand and access to respite across the lifespan
- Colorado needs, gaps, providers and “hotspots”
- Awareness and Marketing
- Disability competence
- Cultural competency
- Provider training
- Informal respite
- Access to respite services
- Impact, barriers and measures for evaluation of respite care services