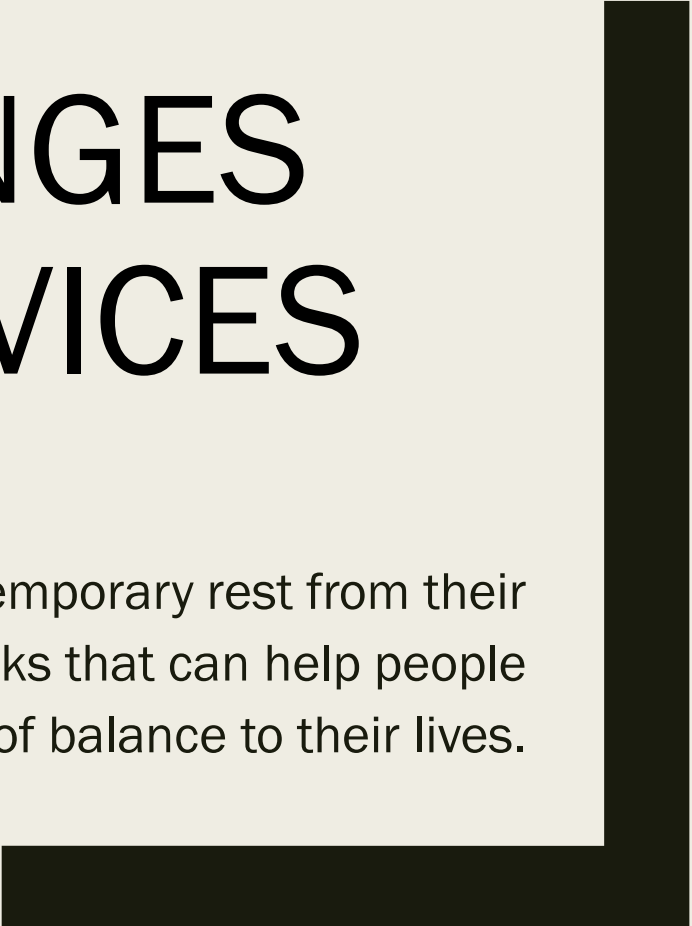




ACCESS CHALLENGES FOR RESPITE SERVICES

Respite provides caregivers with the opportunity for temporary rest from their primary provider duties. Respite provides short-term breaks that can help people relieve their stress, renew their energy and restore a sense of balance to their lives.



The Demand

- The Family Caregiver Alliance estimated that 843,000 Colorado caregivers provided 551 million hours of care in 2012.
- 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.
- “Any [kind of respite] would be appreciated. I am often told I should be seeing a therapist to help me cope with the stress I'm under 24/7, but I have no one to step in so I'm kinda stuck, No therapists do house calls” - *parent of an adult child with a disability.*
- “As a caregiver of a person who has severe behavioral issues... after you live for so long under such high levels of stress that do not relent, you begin to question your own mental health. I'm certain it is reducing my life span” - *parent of an adult child with a disability.*

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.

Colorado Respite Care Project, Family Caregiver Survey Results, 2014.

The Demand

- Free family caregiver provided care estimate - \$375 billion
- Paid homecare and nursing home services - \$158 billion
 - *Evercare Survey of the Economic Downturn and Its Impact on Family Caregiving; National Alliance for Caregiving and Evercare. March 2009*
- Estimated Loss to U.S. employers due to stressed working caregivers - \$17.1-\$33.6 billion
 - *(Metropolitan Life (MetLife) Mature Market Institute, 2006)*
- “When there's no light at the end of the tunnel, when you have to take care of someone else even when you are sick and personally debilitated, this situation has a negative effect on mental health and health outcomes in general. When people are properly supported to have productive lives, both parents and children, health outcomes are better for everyone, and thus, a therapeutic level of respite saves lives and money for our nation.” - *parent of an adult child with a disability.*

Benefits of Respite

“Respite gives you the chance to breath deep & be free and feel the responsibility off your shoulders for just a little bit, and that makes you stronger when you come back” – *daughter providing 24/7 care for aging mom*

Benefits of Respite According to The Colorado Respite Coalition

- **Relaxation:** Respite gives families peace of mind, helps them relax, and renews their humor and their energy
- **Enjoyment:** Respite allows families to enjoy favorite pastimes and pursue new activities
- **Stability:** Respite improves the family's ability to cope with daily responsibilities and maintain stability during crisis
- **Preservation:** Respite helps preserve the family unit and lessens the pressures that might lead to institutionalization, divorce, neglect, and child abuse
- **Involvement:** Respite allows families to become involved in community activities and to feel less isolated
- **Time Off:** Respite allows caregivers to spend time with their families and take care of themselves too
- **Enrichment:** Respite makes it possible for family members to establish individual identities and enrich their own growth and development

Major Barriers to Respite in Colorado

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

Access Issues - Utilization

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.

The waivers authorized 3,457,788 respite hours, but used only 743,816 22% of authorized hours.

The waivers authorized \$38,032,532 for respite care, but spent only \$9,437,19110 or 25%.

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 .

One Respite Providers Financial Perspective of Providing Respite

Direct Expense of Providing Respite

Reimbursement rate for respite = \$4.95 / 15 minutes or \$19.80 an hour

We pay direct service providers \$12.00 - \$13.00 an hour which equates to employee expense of \$15.00 - \$16.25 an hour.

Remaining “Administrative Fee” = \$3.55 - \$4.80 an hour

Administrative Fee Covers

- Employee Training
- Health Insurance / Benefits
- Workers Compensation/Liability Insurance
- Mileage Reimbursement
- Administration Costs

Non-Reimbursed Direct Service Provider Training

- Training for a Direct Service Provider providing respite services
 - *7 hours of Orientation*
 - *6 hours of Safety Care (prevent, minimize, and manage behavioral challenges) annually*
 - *4 hours of QMAP (qualified medication administration person) annually*
 - *3 hours of G-tube annually – includes nurse supervising 1st feeding*
 - *2 hours of Skills Training & Evaluation annually*
 - *4 hours of CPR / 1st Aid annually*
 - *2 hours for Training & Delegation with Nurse annually*
 - *2 hours of Individualized Training 1-1 with Client annually*
 - *4 hours of Continuing Education annually*

Up to 30 hours of training before working with a client and 27 hours of training annually

Administrative Support – Just Intake

- Intake for a person on the CES or SLS waiver
 - *45 minutes of coordination with parent and case manager*
 - *3 hours in person intake to complete all required paperwork and documentation*
 - *2 -3 hours in office completion of Goal Assessment Records, Individual Goal Statement & creating, Home Binder of Service Provision Materials*
 - *1 hour of Care Coordination with other providers & case manager*

with medical needs

- *2 ½ hours for intake set-up, initial assessments, evaluation & data gathering*
- *3 hours to create individualized protocols*
- *2 hours of training & delegation per direct service provider*
- *1 ½ hours of G-tube feeding monitoring per direct service provider*
- *1 MD orders and create Medication Administration Review*

About 15 hours of Administrative Staff hours just to get the client in the door.

The Numbers Just Don't Work -

Gross Margin for all services provided under Supported Living Services and Children's Extensive Services Waivers

	JAN	FEB	MAR	APR	MAY	JUNE
Total Revenue	\$ 34,285.46	\$ 32,677.28	\$ 31,070.91	\$ 30,532.75	\$ 32,116.52	\$ 36,914.63
Total Expense	\$ 46,253.02	\$ 44,577.96	\$ 42,450.11	\$ 38,680.00	\$ 36,982.86	\$ 42,592.07
Gross Margin	\$ (11,967.56)	\$ (11,900.68)	\$ (11,379.20)	\$ (8,147.25)	\$ (4,866.34)	\$ (5,677.44)

	JULY	AUG	SEPT	OCT	NOV	DEC
Total Revenue	\$ 42,147.35	\$ 38,716.31	\$ 29,367.18	\$ 48,594.54	\$ 45,676.14	\$ -
Total Expense	\$ 55,496.79	\$ 45,440.63	\$ 47,696.42	\$ 52,613.23	\$ 53,103.06	\$ -
Gross Margin	\$ (13,349.44)	\$ (6,724.32)	\$ (18,329.24)	\$ (4,018.69)	\$ (7,426.92)	\$ -

Gross Margin = Reimbursement for services minus **ONLY the direct costs of services**. This does not account for the overhead expense of HR, Legal, Billing, Payroll, Record Keeping, Central I/DD Admin Team.

PASCO remains committed to making this a viable service because it is critically important to the families that we serve, BUT it is being sustained by reimbursement from other programs and we need to figure out how to make it stand on its own in the coming months.

What Would it Take for the Numbers to Work?

	JAN	FEB	MAR	APR	MAY	JUNE
Total Revenue	\$ 34,285.46	\$ 32,677.28	\$ 31,070.91	\$ 30,532.75	\$ 32,116.52	\$ 36,914.63
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Gross Margin	\$ (11,967.56)	\$ (11,900.68)	\$ (11,379.20)	\$ (8,147.25)	\$ (4,866.34)	\$ (5,677.44)
Break Even Increase	35.00%	36.50%	36.70%	26.80%	15.20%	15.40%
Gross Margin	\$ 32.35	\$ 26.52	\$ 23.83	\$ 35.53	\$ 15.37	\$ 7.41

	JULY	AUG	SEPT	OCT	NOV	DEC
Total Revenue	\$ 42,147.35	\$ 38,716.31	\$ 29,367.18	\$ 48,594.54	\$ 45,676.14	\$ -
Total Expense	\$ 55,496.79	\$ 45,440.63	\$ 47,696.42	\$ 52,613.23	\$ 53,103.06	\$ -
Gross Margin	\$ (13,349.44)	\$ (6,724.32)	\$ (18,329.24)	\$ (4,018.69)	\$ (7,426.92)	\$ -
Break Even Increase	31.80%	17.50%	62.50%	8.40%	16.30%	-
Gross Margin	\$ 53.42	\$ 51.03	\$ 25.24	\$ 63.25	\$ 18.29	\$

On average it would take a 25.81% rate increase for us to “gross” \$34.90 a year.

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Quotes from parents pulled from Care of Caregivers 2015 Survey conducted by PAD-CO Parents of Adults with Disabilities in Colorado.