



COLORADO
Office of Behavioral Health
Department of Human Services

Colorado's Family Impact Study:

The Impact on Families Caring for a Child or Youth with a Serious
Mental Health Challenge

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PREPARED FOR
The Colorado Department of Human Services Office of Behavioral Health

PREPARED BY
Above The Data



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Executive Summary

The family impact study was conducted in the late Spring of 2016. Families with children/youth with serious mental health concerns across the state of Colorado were asked to participate by Family Advocates, family support partners, or family navigators in their communities. Caregivers completed an online background questionnaire, daily logs of activities related to caring for their child/youth for seven days, and a weekly summary of additional costs and activities related to the care of their child/youth with mental health needs. Additionally, a focus group was conducted with those who recruited the families' participation to provide context for the data that was collected. They will be referred to using the general term "Family Advocates" in the remainder of the report. For detailed results please see the Appendix of this report.

Description of the Caregivers Who Responded to the Surveys

- The overwhelming majority of respondents were biological mothers (27 mothers or 81.8% of caregivers).
- The age of the caregivers ranged from 26-68 with an average age of 42.3 years.
- *The Family Advocates indicated that the mothers are providing the majority of the care to children/youth with mental health challenges in the families with whom they work.*

Description of the Children/Youth

- Children/Youth ranged in age from 7 to 17 years, with an average age of 12.7 years.
- There were slightly more males (18, 54.5%) than females (15, 45.5%).
- Approximately half of the children/youth were white (48.5%), with a third Hispanic (33.3%), and the remainder black (9.1%), multi-ethnic (6.1%), or Native American (3.0%).
- *The Family Advocates recruited families with children/youth with serious mental health needs who have been receiving services for more than a year and more than half (51%) who had been experiencing mental health symptoms for five or more years.*

Description of the Families

- The majority of families have more than one child living at home (75.7%).
- Less than a quarter (19.4%) of families had an income over \$45,000 annually.
- The median family annual income was \$27,600.
- Nearly all (83.9%) children/youth received Medicaid.
- Only about one third (31.3%) of the responding care-givers worked for pay.

- Family Advocates reported difficulty in recruiting families in which caregivers worked for pay because of a lack of time to participate in the study.

Life Events

Table 1: Life Events as a Result of Child/Youth's Mental Health Needs

Life Event	% of Families Experiencing
Changed Jobs	34.4%
Exceeded Paid Time Off	44.4%
Moved	24.2%
Changed Schools	61.3%

- All caregivers who reported changing jobs either decreased from full time to part-time (18.2%), took a job to better accommodate their child's mental health needs (18.2%), or left employment altogether (63.6%).
- More than half (57.9%) of the children/youth who changed schools due to their mental health needs did so two or more times. Some (10.5%) children/youth changed schools five or more times over the course of their educational career.
- Family Advocates confirmed that finding a school willing and able to accommodate Individualized Education Plans (IEPs) or Behavioral Plans (504s) can be challenging for families.

Costs Due to Child/Youth's Mental Health Needs

- Not all families incurred expenses in all the categories surveyed. The percent of youth who did incur costs as well as the mean cost for those specific youth are described in Table 2.

Table 2: Costs Per Youth Who Had Expenses in Each Cost Category

Expenses	% of Youth	Mean/Youth	Mean/Youth/ Month	Mean/Youth/ Year
Dietary Supplements (monthly)	26.7%	\$58.75	\$253.46	\$3,063.39
Bought things to help my child /youth with mental health needs (therapy aids, books/reference materials, safety devices etc.)	33.3%	\$47.00	\$202.77	\$2,450.71
Repaired damage caused by my child/youth	36.7%	\$288.64	\$1,245.26	\$15,050.32
Received extra help because of my child/youth's mental health needs (e.g. house cleaning, child care for siblings, etc.)	23.3%	\$87.71	\$378.42	\$4,573.67
My child/youth with mental health needs participated in respite care	10.0%	\$45.67	\$197.02	\$2,381.19

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Expenses	% of Youth	Mean/Youth	Mean/Youth/ Month	Mean/Youth/ Year
Travel expenses (e.g. attend a training or support group, etc.) – other than mileage (plane/bus/ ticket)	43.3%	\$28.88	\$124.62	\$1,506.13
Extra telephone /internet/ communication expenses because of my child/youth with mental health needs	36.7%	\$42.40	\$182.93	\$2,210.90
Medication for my child/youth with mental health needs (copays and other costs not covered by insurance or Medicaid)	16.7%	\$12.40	\$53.50	\$646.57
Parent Education Materials (books, etc.) related to my child/youth's mental health needs	10.0%	\$41.00	\$176.89	\$2,137.86
My child/youth attended additional educational services (tutoring, outside assessments, etc.)	10.0%	\$41.67	\$179.76	\$2,172.62
Paid a fee to attend a meeting, physical health appointment, therapy, or training session	23.3%	\$35.29	\$152.23	\$1,839.90
Mileage to and from appointments and meetings	86.7%	\$19.15	\$82.62	\$998.50

- 90% of the families that participated incurred some costs during the study week.
- Figure 3 depicts the total cost to the families who participated in the study. For the single week period, a total of \$6,762.79 was spent by 27 families. Three families did not incur any expenses during the study week.
- These weekly costs were extrapolated to estimate a yearly cost. It is estimated that a family caring for a child with a serious mental health concern will incur costs of over \$13,000 annually.

Table 3: Total Costs to Families

Expenses	% of Youth	Total	Mean/Youth	Mean/Youth/Month	Mean/Youth/Year
Total Costs	90.0%	\$6,762.79	\$250.47	\$1,080.62	\$13,060.41

- *Family Advocates provided validation that the percent of families incurring the costs in each category seem accurate, based on their experience, as do the amounts attributed to each family.*

Time Spent on Child/Youth's Mental Health Needs

- In addition to finances, families' time is also greatly impacted.

Table 4: Time Spent on Child/Youth's Mental Health Needs

	% of Youth	Total Minutes	Minutes/ Youth	Min/ Youth/ Day	Hours/ Youth /Year
Communicating (email/by phone or in person) with a professional about my child/youth's mental health needs	90%	5,203	192.7	27.5	167.5
Preparing for a meeting about my child/youth's mental health needs	70%	1502	71.5	10.2	62.2
Attending a meeting about my child/youth's mental health needs	70%	3378	160.9	23.0	139.8
Attending a physical health appointment for my child/youth	40%	1150	95.8	13.7	83.3
Attending therapy (or other intervention)	53%	4385	274.1	39.2	238.2
Attended a training, class, parent education, support group related to my child/youth's MH needs	37%	1237	112.5	16.1	97.7
Total	90%	16,855	624.3	89.2	542.5

- 87% of caregivers reported losing sleep due to their child/youth's mental health needs.
- Nearly an hour and a half each day was spent by the caregiver attending to the child/youth's mental health needs, and this does not include direct care to the child.
- *Family Advocates provided feedback from families that they did not realize the full extent of the time devoted to communicating about and attending to their child/youth's mental health needs.*

Conclusions

- An average of \$13,060.41 is being spent annually by Colorado families to care for the mental health needs of their children/youth with mental health challenges.
 - This is a huge proportion of income (47.3%) given that the median income for these families was \$27,600.00.

- These are *only* direct out of pocket expenses and do not include things like loss of income due to the necessity of changing jobs to accommodate their child/youth's needs (experienced by 34.4% of families).
- Nor does it include loss of income due to unpaid time off work. The sample of working parents was too small to estimate this loss.
- Nearly all children/youth were Medicaid eligible (83.9%), keeping medication and co-pay costs relatively low (\$646.57 annually).
- The sample of families may be biased toward those with at least one parent who does not work for pay.
 - These families may have had more flexibility to devote the time necessary to complete the study materials.
 - If an expansion of the study is conducted, it will be necessary to include more caregivers who work for pay. To do so, study protocols may need to be changed.
- *Family Advocates pointed out that while the study was designed to address the impact of having a child/youth with mental health needs on a family, this impact to siblings was overlooked.*
 - *A follow-up study addressing the impact of a child/youth's mental health needs on their siblings could prove valuable.*

