Partnering with Family Advocates to Understand the Impact on Families Caring for a Child with a Serious Mental Health Challenge

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Abstract

Family-driven care is a key principle of the system of care framework, but little research has documented the impact caring for a child with a serious mental health challenge has on families. In partnership with family advocates, this prospective, descriptive study was conducted to understand the impact a child's mental health challenge has on families' time, finances, life events, and caregiver employment. Study results showed the average family spent over $250 a week in unreimbursed costs, even though 84% of the children in the study received Medicaid. Caregivers spent approximately 10 h per week attending to the child's mental health needs, not including direct care for the child. Caregivers also reported a substantial impact on their employment. The results of this study have implications for the system of care supports for families. Perhaps most importantly, systems must utilize two-generation strategies in systems of care to minimize the impact on caregiver employment.

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Introduction

Mental health disorders rank at the top of the costliest child health conditions, even higher than asthma.[1] In 2011, nationwide direct medical expenditures on children's mental health treatment amounted to $13.8 billion, approximately half of which is paid by Medicaid.[1] Having a serious mental health challenge contributes to overall greater health care expenditures, and mental health services are a driver of health care costs. In a study of over 3.5 million children with Medicaid insurance from ten states, 19.4% of the sample received mental health services.[2] However, in the highest-expenditure group, 71.4% received mental health services, compared to 12.2% in the lowest-expenditure group.[2] A similar pattern was seen for inpatient hospital care, but not for primary care or dental care. Mental health care accounted for 20.5% of total Medicaid spending on the children in the sample, just under the amount spent on hospital care.[2] The association between mental health disorders and higher cost of care is found among children with private insurance as well. Among children with commercial insurance, those with co-occurring behavioral health disorders and chronic medical conditions have substantially higher costs than those with other chronic medical conditions alone.[3]

Numerous studies have documented the cost of children's mental health disorders to the health care system.[1–6] Costs of children's mental health disorders to other-child serving systems such as child welfare, education, and juvenile justice have also been studied as researchers and policymakers have looked for ways to lower system costs.[7] A few of these studies have included some costs borne by the caregivers when calculating the total cost of illness.[3,5,8] One study examined out-of-pocket costs for caregivers such as medication and treatment co-pays and estimates for parents' missed time at work for parents of children with attention-deficit/hyperactivity disorder (ADHD) but did not include other categories of family expenditures such as travel to appointments, dietary supplements, repairing the damage done by the child, or therapy aides.[8] Even without these other categories of costs, however, children with ADHD incurred 58.4% more expenditures than children without ADHD. Research on autism spectrum disorder (ASD) costs has provided a lifetime estimate of $2.4 million for the care of those with ASD and intellectual disability and $1.4 million for the lifetime care of individuals with ASD without intellectual disability.[9] These costs are borne by a combination of government agencies, insurance systems, and families. Lindley and Mark examined families' financial burden for various types of health conditions using the National Survey of Children with Special Health Care Needs.[10] They found several child health conditions were significantly associated with the family financial burden, including emotional disorders.[10]

Though the existing literature suggests parents contribute significantly to the care of children with mental health challenges, there is insufficient research to understand the comprehensive impact on families, including the full range of out-of-pocket expenses. The current study documented the impact caring for children with serious mental health challenges has on families by examining unreimbursed costs, time, life events, and caregiver employment. Time spent attending to the child's mental health needs, life events such as moving and changing schools, and impacts on caregiver employment have important but under-studied impacts on families. This study's unique contributions include the wider range of family impact captured by the prospective design, which included more categories of out-of-pocket expenses, caregiver time, and impact on employment. Policymakers and system administrators must understand the full impact on families in order to design services and supports to best address their needs. These impacts are rarely addressed by conventional mental health or social services and may require system reform.

The current study was designed by the state project management of the system of care initiative in a mountainous Western state with many rural and frontier counties in partnership with family advocates across the state. The state's chapter of the Federation of Families for Children's

Mental Health facilitated the partnership between the system of care management and the family advocates. The study was conducted by contracted researchers and approved by the Institutional Review Board of the Center for Research Strategies in Denver, CO. A system of care is defined as "a spectrum of effective, community-based services and supports for children and youth with or at risk for mental health or other challenges and their families, that is organized into a coordinated network, builds meaningful partnerships with families and youth, and addresses their cultural and linguistic needs, in order to help them to function better at home, in school, in the community, and throughout life."[11(p.1)] System of care initiatives often prioritize two-generation approaches, which simultaneously address the needs of parents and children to improve outcomes for the whole family and reduce the risk of the child being placed out of the home.[12] Family advocates are individuals with lived experience caring for a child with a mental health challenge who have been trained to assist other families receiving mental health services for a child within a system of care.[13] Family advocates are employed by community mental health centers, family resource centers, or nonprofit agencies, and they often assist families involved in wraparound or other two-generation services. The current study capitalized on the expertise of family advocates for the study design and implementation. Because of their lived experience caring for their own children with mental health challenges, family advocates were able to help the research team design meaningful research questions that reflected the real-life experiences of families, design and support data collection that was accessible to families, and contextualize the study findings.

Methods

Design

The system of care management at the state behavioral health authority had an established partnership with the state's chapter of the Federation of Families for Children's Mental Health (FFCMH), a family-run advocacy agency, to support the design and implementation of a system of care for children with mental health challenges. A representative from the state's chapter of the FFCMH was on the system of care advisory committee. The local system of care sites receiving grant funds to implement the system of care services were required to employ a family advocate to serve families, and the FFCMH chapter had a contract with the state agency to train and support the family advocates within the local communities. A lead family advocate who was employed by the state's chapter of the FFCMH led the partnership with the researchers for this study. The lead family advocate participated in numerous working meetings with the researchers and then obtained feedback from other family advocates from across the state. The data collection instruments were developed and tested through an iterative process of feedback and revisions between the family advocates and the research team, facilitated by the lead family advocate. The lead family advocate was paid for her time working on the study through the state's contract with the FFCMH chapter, and the local family advocates participated in the development of the survey instruments during their regular work hours.

Family advocates were essential members of the research team. Data collection instruments were co-created by professional evaluators and family advocates to ensure that the lived experiences and challenges families faced were represented in the questions. The breadth of life events and cost categories included in the study were a direct result of the partnership with family advocates. Family advocates included cost categories the researchers would not have considered, but which turned out to be highly endorsed by caregivers in the study. Family advocates were responsible for recruiting families, obtaining informed consent, and supporting families to complete the data collection instruments.

Measures

The study included three data collection instruments: (1) a one-time online survey to gather background information, (2) a prospective daily log of time and expenses participants were asked to complete for 7 consecutive days on paper, and (3) a one-time weekly summary of additional expenses and activities that occurred in the past week.

The one-time online survey included questions about family structure, information about the child or youth, the child/youth's mental health history, caregiver's current employment and income, changes in employment, living situation including life events related to the child/youth's mental health challenges, barriers, and the child/youth's education employment, living situation including and school situation, including changing schools because of the child/youth's mental health challenges and the number of times they changed schools. See Table 1 for the full list of questions in this survey.

The prospective daily log of time and expenses included questions about time spent attending appointments and meetings with, or on behalf of, the child and communicating with professionals about the child's mental health needs. Questions about fees and co-pays for therapy appointments were included in the daily log, as well as time for travel and miles driven. See Table 2 for the full list of questions in this instrument. The weekly cost summary administered one time at the end of the study week included questions about purchases and travel expenses other than fees and co-pays for attending therapy or appointments. See Table 3 for the full list of questions in this instrument.

Procedure

Family advocates in local communities were trained by the researchers to explain the study procedures and obtain informed consent from participants. The family advocates assigned unique identification numbers to families to ensure researchers could not link data back to individual families. Family advocates recruited families to participate from their current caseloads as well as other families they knew in their communities. All eligible families served by the family advocates were invited to participate. When necessary, the family advocates assisted families with data collection, such as meeting them at public libraries to complete the one-time online survey as well as walking them through the paper data collection instruments step-by-step. Thirty families completed the required data collection instruments. Caregivers who completed all the required instruments were compensated with a $45 gift card. Family advocates who recruited at least five families who participated in the study were also given a $45 gift card. Results were analyzed using IBM SPSS Statistics for Windows, version 24.

Participants

To be eligible for the study, participants had to have a child under the age of 18 with a mental health diagnosis who had been receiving mental health services for at least 1 year. Other than confirming eligibility based on these criteria, mental health service data was not collected for this study. Children with comorbid intellectual or developmental disabilities were not excluded. Eleven families (36.67%) were recruited by family advocates working in rural areas, and nineteen families (63.33%) were recruited by family advocates working in urban areas. Most (81.8%) respondents in the study were the biological mothers of the identified child with a mental health challenge. Caregivers ranged in age from 26 to 68 years ($M = 42.3$ years). The sample of children in the study was 54.5% male and ranged in age from 7 to 17 years ($M = 12.7$ years). Approximately half the children identified as White (48.5%), with a third identifying as Hispanic (33.3%), and the remainder as Black (9.1%), multi-ethnic (6.1%), or Native American (3.0%). More than half the caregivers (51%) reported their child had been experiencing symptoms for 5five or more years. Most (83.9%) children in the sample received Medicaid, and the median family income was $27,600, with less than a quarter (19.4%) of

Table 1

One-time online survey questions

Question	Question type
Family structure	
How old are you?	Open-ended
I am (gender identity):	Multiple choice
How many children/youth do you care for in your home?	Multiple choice
How many of these children/youth have mental health needs?	Multiple choice
Child/youth information	
What is your relationship with this child/youth?	Multiple choice
How old is this child/youth?	Open-ended
Is this child/youth (gender identity)?	Multiple choice
Please describe this child/youth's race and ethnicity	Multiple choice
Mental health history	
What is your child/youth's mental health diagnosis?	Open-ended
How long has your child/youth been experiencing mental health issues?	Multiple choice
How long has your child/youth been receiving mental health services?	Multiple choice
Does your child/youth have another diagnosis, such as a developmental disability or medical condition?	Multiple choice
What is your child/youth's other diagnosis?	Open-ended
Caregiver's current employment and income	
What is the total income that supports your household (please include any source of income e.g., salary, benefits, child support)?	Open-ended
Do you do any type of work for pay? (remaining questions in this section only asked if the answer to this question is yes)	Multiple choice
How many hours per week do you typically work?	Open-ended
Do you have more than one paid job?	Multiple choice
Are you paid hourly or paid a salary?*	Multiple choice
What is your hourly wage?*	Open-ended
What is your monthly salary?*	Open-ended
Is this the amount you take home or your salary before taxes?*	Multiple choice
Do you have paid time off at your job?	Multiple choice
Do you usually exceed your paid time off?	Multiple choice
Do you exceed the amount of paid time off because of caring for your child/youth with mental health needs? (asked if the answer to the previous question was yes)	Multiple choice
Changes in employment	
Do you have the same work situation as you did when your child/youth started having mental health challenges?	Multiple choice
How is your job different now? (asked if the answer to the previous question was no)	Multiple choice
Did the change in employment have to do with caring for your child/youth with mental health challenges? (asked if the answer to the first question in this section was no)	Multiple choice

Table 1
(continued)

Question	Question type
Did the change in employment impact your ability to save for retirement or pay into Social Security? (asked if the answer to the first question in this section was no)	Multiple choice
Living situation	
Have you experienced any of the following since your child/youth began experiencing mental health challenges? Answer options: divorce; separation (include any times when a co-parent has lived outside of the home); marriage; additional caregiving adults moving into the household (grandparents, significant other, etc.); caregiving adult left the household; no changes in our family situation since my child/youth began experiencing mental health symptoms; others (please specify)	Multiple choice (check all that apply)
Do you still live in the same home as you did when your child/youth started experiencing mental health challenges?	Multiple choice
Did you move because of your child/youth's mental health needs? (asked if the answer to the previous question was no)	Multiple choice
Why did you move? (asked if the previous answer was yes) Answer options: to be closer to services for my child/youth (including school); can no longer afford the home we lived in; to be closer to family; my child/youth's behavior made a move necessary; others (please specify)	Multiple choice (check all that apply)
Have you been without a home of your own since your child/youth began having mental health concerns? This would include living with friends or relatives	Multiple choice
Barriers	
Do you have health insurance for your child/youth?	Multiple choice
Does your child/youth have Medicaid?	Multiple choice
Do you have reliable transportation?	Multiple choice
Do you have reliable child care for other siblings for times when you need to attend meetings or therapy for your child/youth with mental health needs?	Multiple choice
Education	
Does your child have an IEP?	Multiple choice
Has your child/youth changed schools because of their mental health needs?	Multiple choice
How many times has your child/youth changed schools because of their mental health needs? (asked if the answer to the previous question was yes)	Open-ended
Does attending the current school mean additional transportation costs or time for your family?	Multiple choice
How many miles do you travel to school (each way)? (asked if the answer to the previous question was yes)	Open-ended
How long does it take (each way)? (in minutes)	Open-ended

[*] Questions were repeated for each job if the respondent indicated they worked more than one job for pay

Table 2

Prospective daily log of time and expenses

	How long (in minutes)?	*Did you have to take time off work? (Circle)*	*Was the time off paid? (Circle)*
Communicating (email/phone or in person) with a professional about my child's mental health needs		Yes No N/A	Yes No N/A
Preparing for a meeting about my child's mental health needs		Yes No N/A	Yes No N/A

	How long (include travel time)?	*Did you have to take time off work? (Circle)*	*Was the time off paid? (Circle)*	*Did you pay a fee or co-pay?*	*How many miles did you drive?*
Attending a meeting about my child's mental health needs		Yes No I do not have a job	Yes No Did not take time off	Yes No How much $_____	
Attending a physical health appointment for my child		Yes No I do not have a job	Yes No Did not take time off	Yes No How much $_____	
Attending therapy or other intervention		Yes No I do not have a job	Yes No Did not take time off	Yes No How much $_____	

Did you lose sleep last night because of your child's mental health? (Circle) Yes No

If so, did this nighttime activity impact your responsibilities today? (Circle) Yes No

If so, did you miss time at work? (Circle) Yes No How much? _____ (minutes)

Was time off PAID or UNPAID (Circle)?

Table 3

One-time weekly summary of expenses and activities

Activity	*Monday*	*Tuesday*	*Wednesday*	*Thursday*	*Friday*	*Saturday*	*Sunday*
Bought things to help my child/youth with mental health needs (therapy aids, books, safety devices, etc.)	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____
Repaired damage caused by my child/youth	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____
Received extra help because of my child/youth's mental health needs (child care for siblings, etc.)	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____
My child/youth with mental	Yes No	Yes No	Yes No	Yes No	Yes No	Yes No	Yes No

families having an annual income of over $45,000. Only about one-third (31.3%) of the responding caregivers worked for pay, and the majority (75.7%) of families had more than one child living at home at the time of the study.

Table 3
(continued)

health needs participated in respite care	Cost $_____	Cost $_____	Cost $_____	Cost $_____	Cost $_____	Cost $_____	Cost $_____
Travel expenses to attend a training or support group, etc.; other than mileage (such as plane/bus ticket)	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____
Extra phone/internet expenses because of my child/youth with mental health challenges	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____
Medication for my child/youth with mental health needs (co-pays and costs not covered by	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____

The children in the study were most commonly diagnosed with attention-deficit hyperactivity disorder (ADHD; 48.5%), anxiety (27.3%), and bipolar disorder (18.2%). Approximately 9% of children were reported to have a comorbid developmental disability, and 12.1% had an autism

Table 3
(continued)

insurance or Medicaid)							
Parent education materials (books, etc.) related to my child/youth's mental health needs	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____
My child/youth attended additional educational services (tutoring, assessments, etc.)	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____	Yes No Cost $_____

diagnosis. Just over 15% had a learning disability. Some children had multiple diagnoses and/or disabilities.

Debriefing with family advocates

After the quantitative study results were analyzed, the researchers presented the findings to the family advocates who recruited participants and supported the study. This allowed the researchers both to honor the time and effort of the family advocates by engaging in reciprocity and to gather additional feedback validating the study results and suggestions for the future. Quantitative results were presented in the same order as the results section below. Family advocates were asked if the results were consistent with their own experiences and the experiences of the families in their communities, to the extent of their knowledge. Researchers also asked the family advocates about the study's procedures and what suggestions family advocates had for future studies or based on the findings.

Results

Life events and caregiver employment

The majority of respondents reported having experienced at least one of the life events (moving or changing schools) as a direct result of their child's mental health challenge. Changing schools due to the child's mental health needs was the most common life event, experienced by 61.3% of families. More than half (57.9%) of the children who had changed schools due to their mental health needs had done so two or more times. Some (10.5%) children had changed schools five or more times. Almost a quarter (24.2%) of families had moved due to the child's mental health challenge. The most common reason families reported moving due to the child's mental health challenge was because they could no longer afford their home (15.2%). Respondents also reported a substantial impact on their employment, with almost half (44.4%) of caregivers reporting they had exceeded their paid time off as a direct result of the child's mental health challenge. Of the 34.4% of caregivers who had changed jobs due to their child's mental health challenge, 63.6% reported having left employment altogether, while others had either decreased from full-time to part-time (18.2%) or had taken a job that better accommodated their child's mental health needs (18.2%). A number of caregivers also reported marital and family events such as divorce (24.2%), separation (18.2%), and other caregivers moving into the home (15.2%). See Table 4 for life events reported as a result of the child's mental health challenge.

Unreimbursed cost to families

Ninety percent of the families who participated incurred some costs during the study week directly related to the child's mental health needs. Not all families incurred expenses in all the categories surveyed. The percent of children who did incur costs, as well as the mean costs for those children's expenses, are in Table 5. Expense categories are in rank order in the table with the highest mean expense category at the top. Given that 84% of children in the sample were covered by Medicaid, therapy and medication co-pays were relatively low compared to other expense categories. The highest cost category was repairing damage caused by the child, followed by child care costs for siblings or paying for extra help around the house due to the child's mental health challenge. Purchasing dietary supplements was the third-highest expense category, reported by over a quarter (26.7%) of caregivers. All three of the highest cost categories were included in the study as a result of the co-creation of the data collection instruments with family advocates. See Table 5 for the out-of-pocket costs caregivers paid for the treatment and management of their child's mental health challenge during the 7-day study period.

The total amount participants spent due to the child's mental health challenge was calculated to give an estimate of an average out-of-pocket cost to families per year. During the 7-day study

Table 4
Life events as a result of a child's mental health needs

Life event	% of families
Changed jobs	34.4%
Exceeded paid time off	44.4%
Moved	24.2%
Changed schools	61.3%
Divorce	24.2%
Marital separation	18.2%
Other caregivers moving into the home	15.2%

Table 5

Unreimbursed costs due to the child's mental health needs during the 7-day study period

Expense category	% of families	Mean/child during 7-day study period	Standard deviation
Repaired damage caused by my child	36.7%	$288.64	$470.11
Received extra help because of my child's mental health needs (e.g., house cleaning, child care for siblings)	23.3%	$87.71	$78.72
Dietary supplements	26.7%	$58.75	$64.63
Bought things to help my child with mental health needs (therapy aids, books/reference materials, safety devices, etc.)	33.3%	$47.00	$48.91
My child with mental health needs participated in respite care	10.0%	$45.67	$40.08
Extra telephone/internet/communication expenses because of my child with mental health needs	36.7%	$42.40	$23.93
My child/youth attended additional educational services (tutoring, outside assessments, etc.)	10.0%	$41.67	$42.52
Parent education materials (books, etc.) related to my child's mental health needs	10.0%	$41.00	$13.89
Paid a fee to attend a meeting, physical health appointment, therapy, or training session	23.3%	$35.29	$18.83
Travel expenses (e.g., attend a training or support group,)—other than mileage (plane/bus/ticket)	43.3%	$28.88	$26.46
Mileage to and from appointments and meetings	86.7%	$19.25	$28.87
Medication for my child with mental health needs (co-pays and other costs not covered by insurance or Medicaid)	16.7%	$12.40	$10.43

period, a total of $6762.79 was spent by 27 families, yielding an average of $250.47 per child per week. This extrapolates to $1080.62 per month or $13,060.41 per year.

Impact on caregivers' time

The study protocol examined caregivers' time spent on the child's mental health challenge as well as expenses. Because a mental health challenge can impact a child's physical health, such as taking psychotropic medications that cause physical health side effects, appointments with physical health providers were included as a time category. Note, however, that the time categories do not include direct care of the child other than attending appointments and meetings with, or on behalf of, the child. The results showed the largest time category impacting caregivers was attending therapy, followed by communicating with professionals about the child's mental health needs (in person, by phone, or by email). On average, caregivers spent 89.2 min per day attending to the child's mental health and health needs. This amounts to over 10 h per week or 542.5 h annually. Additionally, a separate question inquired whether caregivers lost sleep due to the child's mental health challenge. Eighty-seven percent of respondents answered yes. See Table 6 for the results for six categories as well as the total time spent attending to the child's mental health and health needs.

Family advocate feedback

The researchers met with the family advocates who recruited participants for the study to debrief and contextualize the study results. The family advocates validated that the costs and time spent by the families were consistent with their own experiences and the experiences of the families they knew in their communities. They also confirmed the frequent impact caring for a child with a mental health challenge has on caregiver employment, changing schools, and moving. The researchers mentioned the lack of participation from caregivers who worked for pay, which impacted the ability to present findings on some financial data. The family advocates suggested to the researchers that the time required to complete the study data collection instruments may have biased the sample toward families with at least one caregiver who did not work for pay. The family advocates also expressed that many of the caregivers wanted to work but were unable to find jobs flexible enough to accommodate their child's needs.

Discussion

Unique contributions of the study

This study provides the broadest scope of families' out-of-pocket expenses related to a child's mental health challenge found by the authors in published literature. Most previous research that has been published on the topic of families' expenditures has been limited to direct medical expenses such as prescription medications and therapy co-pays.[14–16] This study shows that the impact a child's mental health challenge has on a family is much more substantial than direct medical expenses, and these other costs must be considered when examining the economic impact of a child's mental health challenge. Understanding what families spend on services without a payor source (respite care and extra child care for siblings), ancillary purchases (dietary supplements, books, therapy aids, and safety devices), transportation to appointments, and repairing damage caused by the child provides a greater understanding of families' needs. Additionally, the impact on caregivers' time and employment must be considered to fully understand the economic consequences.

Table 6

Caregiver time spent on the child's mental health needs

Time category	% of families	Total minutes in the 7-day study period	Minutes/child during the 7-day study period	Minutes/child/day	Hours/child year
Attending therapy	53%	4385	274.1	39.2	238.2
Communicating (email, phone, or in person) with a professional about my child's mental health needs	90%	5203	192.7	27.5	167.5
Attending a meeting about my child's mental health needs	70%	3378	160.9	23.0	139.8
Attended a training, class, parent education, or support group related to my child's mental health needs	37%	1237	112.5	16.1	97.7
Attending a physical health appointment for my child with a mental health challenge	40%	1150	95.8	13.7	83.3
Preparing for a meeting about my child's mental health needs	70%	1502	71.5	10.2	62.2
Total	90%	16,855	624.3	89.2	542.5

Comparison with previous research

The study's results suggest it is approximately a 0.25 FTE responsibility to attend to the mental health needs of a child with a serious mental health challenge, so it is not surprising that a number of caregivers have exceeded paid time off, switched to part-time employment, or left employment due to their child's mental health challenge, particularly given that many of the care activities must occur during regular business hours. Other situations, such as frequent unplanned early school pickups due to the child's crisis behaviors, may further increase the risk of caregivers being unable to hold down a job. The reduction in caregivers' available working hours, including unpredictable crises, in addition to the unreimbursed costs borne by the family, may be contributing to issues such as families moving because they can no longer afford their homes.

The impact on caregivers' time and employment found in this study is generally consistent with previous research on this topic. The 2009–2010 National Survey of Children with Special Health Care Needs found that 10.5% of families with a child with any special health care need spend 5–10 h per week providing and/or coordinating their child's health care, and an additional 13.1% of families spend 11 or more hours per week.[17] Gould constructed a model of the effects of children's health conditions on mother's employment.[18] The study examined various health conditions, controlled for the financial burden, and found that time-intensive and unpredictable illnesses predicted that single mothers would work fewer hours and married mothers were less likely to work, or worked fewer hours. An empirical test of the model confirmed this effect.[18] In Gould's study, attention-deficit hyperactivity disorder was found to have both an unpredictable time component and a high time requirement, while autism and developmental delays were classified as having a high time requirement. Given these results, it is not surprising that the 10 h per week spent by caregivers in the current study is consistent with the highest quartile of responses in the National Survey of Children with Special Health Care Needs. The results of these studies indicate the complexity of serious mental health challenges in childhood, which may have even more of an impact on a child's functioning in the family and in school than other types of health conditions. The complexity may in turn have a greater impact on caregivers' time and employment.

Family expenditures on a child's mental health disorder differ from system expenditures. One of the primary expenses Medicaid and insurance companies pay for children's mental health conditions is psychotropic medications.[4,19] In the current study, families' co-pays for medication were very low, but other costs were substantial, reaching almost half the family income. Newacheck et al., examining health care utilization and expenditures for children with various types of disabilities, found that even after controlling for health insurance coverage, low-income families experienced greater financial burden than higher-income families and were more at risk for catastrophic out-of-pocket expenses.[16] Though the current study did not compare families across a range of incomes, most families in the study were living with low income, and the out-of-pocket expenses represent an obvious financial burden for the families.

Limitations and recommendations for future research

The median family income in the study was $27,600 per year, with a median family size of 4. This is approximately 7% above the poverty threshold. Given that families are spending such significant amounts of money on the treatment and management of the child's mental health needs, further research should examine the economic impact in a greater context. The current study did not assess whether families were receiving other types of public assistance, going into debt, unable to save for retirement, or otherwise experiencing financial hardship due to the child's mental health challenge.

The study questions included items that would have allowed the researchers to calculate lost wages from taking unpaid time off work or reducing working hours. However, there were not enough working caregivers in the study to report this data. A follow-up study offering participants the option

to respond to daily phone calls or email surveys, instead of requiring caregivers to complete written data collection instruments and mail them back, could attempt to recruit more working parents so these costs can be measured. Additionally, the study did not assess caregivers' desire to return to work or future plans to do so.

The study was designed to measure the impact caring for a child with a serious mental health challenge who is receiving ongoing treatment for their diagnosis has on families. The population sampled included families of a child who had been receiving services for at least 1 year. Most received services from a community mental health center or other Medicaid provider agency. Thus, few families paying out-of-pocket for services from private pay clinicians or paying private insurance deductibles and co-pays were included in the sample. Additionally, the study did not capture the impact of the child's mental health challenge on families on waiting lists or otherwise unable to access treatment for their child. It is likely that the costs to and impact on these groups (self-pay, private insurance, and unable to access treatment) may be quite different from the costs to and other impacts on families in a majority-Medicaid sample connected to services. Future research should examine the impact on these populations as well. Finally, it should be noted that the study was conducted prior to the COVID-19 pandemic. It is possible the circumstances created by the pandemic, such as remote schooling and workforce shortages in the education and child-serving systems, have further exacerbated the impact caring for a child with a serious mental health challenge has on families.

This study provides evidence that caregivers are impacted in multiple ways in addition to experiencing an economic impact. Nearly all caregivers reported losing sleep, and a number had experienced marital and family events such as divorce and having other caregivers move into the home to help care for the child. Future research should also seek to illuminate the health, mental health, and social impacts on caregivers, taking a deeper look at the experience and effects of caregiver strain. Lastly, the family advocates involved in the study pointed out that this study did not assess the impact on the siblings of the child with a mental health challenge. This should also be investigated so the impact on siblings' well-being can be mitigated.

Implications for behavioral health

The strength of this study was partnering with and including family advocates with lived experience on the evaluation team to co-create instruments, recruit participants, collect data, and validate findings. Though this study did not directly assess the engagement of the caregivers working with the family advocates, the effective use of the study's methodology implies family advocates can successfully engage caregivers in research, program evaluation, and services. The family advocates in this study were able to successfully build trust with caregivers and engage them in a research protocol that asked sensitive questions about family income and employment as well as personal activities and finances related to their child. The authors believe it is the family advocates' lived experience caring for a child with a mental health challenge that led to their success in engaging caregivers.

The study also suggests that policies that reduce health care benefits and shift costs to patients and their families may have devastating consequences for families. Behavioral health systems need to provide more comprehensive support for families raising children with mental health challenges, including flexible hours for appointments and in-home or school-based services that allow caregivers to maintain employment. One intervention suggested by a family advocate in the study was providing sufficient training and support to schools to prevent and effectively respond to crisis behaviors associated with serious mental health conditions to reduce the frequency of unpredictable school pickups. Additional flexible funds could help alleviate the out-of-pocket costs to caregivers. Perhaps most importantly, behavioral health systems must utilize two-generation strategies in systems of care to enhance family well-being and stability. Two-generation approaches simultaneously provide

services to meet the child's needs and services for caregivers, which may include job training, employment supports, and behavioral health services. Job training and employment supports may help caregivers find more flexible employment that allows them to remain employed while caring for their child's needs. Behavioral health services, family therapy, and marital counseling can support caregivers' mental health and family stability. Improved household functioning and parental mental health reduce the child's exposure to adversity, which may reduce their mental health symptoms and build resilience.[20] The use of two-generation approaches, which can be supported with family-driven intensive care coordination like high-fidelity wraparound, may improve outcomes for children with mental health challenges and their families and allow them to live successfully in their homes and communities.[21]

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Declarations

Conflict of Interest The authors declare no competing interests.

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