



MARYLAND COALITION
OF FAMILIES

Listening and Learning From Families:

Crisis Services and the
Experiences of Families Caring
for Children and Youth with
Behavioral Health Needs

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Author

Ann Mahing Geddes, PhD, Director of Public Policy
Maryland Coalition of Families

The Coalition hopes that this information will be disseminated widely.
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Our Coalition

Maryland Coalition of Families (MCF) helps families who care for someone with behavioral health needs. Using our personal experience, we connect, support and empower Maryland's families. Our staff provide one-to-one peer support to people who care for a loved one with a behavioral health issue, and to families with youth involved with the Department of Juvenile Services.

MCF empowers families by:

- Helping them access and navigate services and systems
- Providing them with tools to advocate
- Connecting families to each other
- Ensuring their voice and perspective is heard
- Raising public awareness and fighting stigma

Founded by a coalition of family support organizations, Maryland Coalition of Families was incorporated in 1999 as a nonprofit organization. Our name changed from "Maryland Coalition of Families for Children's Mental Health" to "Maryland Coalition of Families" in 2016. MCF is governed by a volunteer Board of Directors comprised of at least 51% adult caregivers of a family member with a behavioral health or substance use issue, or a child involved with the Department of Juvenile Services. All of our family support staff have cared for a loved one with behavioral health needs and have been trained to help other families.

Our Mission

Using our personal experience caring for loved ones with behavioral health needs, we connect, support and empower Maryland's families and advocate to improve systems that impact individuals with behavioral health challenges.

For Information Contact:

Maryland Coalition of Families (MCF)
10632 Little Patuxent Parkway, Suite 234
Columbia, MD 21044
410.730.8267
info@mdcoalition.org, www.mdcoalition.org

Introduction

The use of crisis services among families of children and youth with behavioral health needs (mental health and/or substance use) has been in the spotlight for some time. Under a Children's Health Insurance Program Reauthorization Act (CHIPRA) grant, in 2013 MCF held focus groups with families to get their perspectives on crisis services. At the end of the focus groups, caregivers were asked to complete an extensive survey in order to capture some hard data. This report can be found at www.mdcoalition.org. Since then, the topic has continued to receive much attention. In the 2020 legislative session, Senator Benson and Delegate Charles introduced a bill (SB 624/HB 1140) requiring that the Behavioral Health Administration (BHA) study the Mobile Response and Stabilization Services (MRSS) model for children and families and oversee the implementation of the model in Maryland. This model, originally developed in New Jersey and adopted by a number of other states, has among its components:

- Anything that a family defines as a crisis is a crisis to that family
- Intervention and support should be provided in-person at the earliest moment when families identify that help is needed
- Mobile teams that are dedicated to serving children and families
- Mobile teams should be available 24/7, 365 days/year, within one hour
- Stabilization services from mobile teams should be available to the child and family for 72 hours following a request for help
- Mobile teams should connect families to additional resources, and may, as needed, continue to follow-up in the home with a family for up to eight weeks following an initial call

The bill did not pass, but since it was introduced, BHA and the Child, Adolescent and Young Adult Division of BHA have devoted much effort into planning for the development of a

robust crisis system across Maryland for all people, as well as services designed specifically for children, youth and families. The impact of COVID has made this effort even more important. With dollars coming down from the federal government, planning has the opportunity to become a reality.

In addition to the work of BHA, in 2020 the Maryland Health Services Cost Review Commission (HSCRC) awarded three grants to develop behavioral health crisis services. The largest of these, the Greater Baltimore Regional Integrated Crisis System (GBRICS), dedicated to serving the population in Baltimore City, and Baltimore, Carroll and Howard Counties, has also been looking at how to best serve children, youth and families.

With all of these efforts underway, it seemed like a good time to again ask families questions about their experiences with using crisis services, their needs, and their suggestions for addressing those needs.

Methodology

In October of 2021, MCF sent out an online survey to some 4,000 family members on its list-serv. We asked caregivers to complete the survey who had used crisis services (defined as law enforcement/911, Mobile Crisis Services, Emergency Departments, or Walk-in Crisis Centers) for a behavioral health issue in the last three years for a child under the age of 21. A total of 173 families responded to the survey, but not all respondents replied to all questions - for most of the questions, there were 130-140 responses.

The results of the survey were then used to develop further questions to ask in focus groups. In November 2021, virtual focus groups were held across the state with a total of 13 participants. In the focus groups, one MCF staff member facilitated the discussion while another took notes. A \$25 Amazon gift card was provided to participants.

Demographic Survey Data

The 173 caregivers who completed the survey monkey reported the following demographic data:

The majority of the children were male (65%) and the most frequent age was 14-17 years (36%), followed closely by 10-13 years (32%). Seventeen percent were aged 0-9, and 15% were aged 18-21.

Fifty-three percent identified as white and 33% identified as African American. These percentages quite closely resemble the general demographic data for Maryland (US Census

Bureau, 2019). Thirteen percent identified as bi-racial. Just 7% identified as Hispanic, under the 10.6% reported in the 2019 census.

One question on the survey asked about health insurance coverage. Eighty-three percent of the children and youth were covered by Maryland Medicaid. This is quite high, compared to the Medicaid/CHIP penetration rate for Marylanders aged 0-18 being 38%.¹ Two caregivers reported that their child had no health insurance.

Children and Families in Crisis

In the Mobile Response and Stabilization Services Model, crises are defined as those times when a family feels that they and their child need help. Indeed, many of the crises reported by caregivers did not conform to the more typical definition of a behavioral health crisis -- when an individual is presenting a danger to themselves or others.

The majority of families (70%) utilized crisis services when their children were displaying “out-of-control behavior.” This sometimes was accompanied by feelings that the children were potentially dangerous to themselves or others.

“He got angry and broke my mom’s van door handle.”

“His behavior escalated from shouting, to breaking things, to making threats”

“Violent, threatened to stab me, destroyed property, and assault”

“He had emotional outbursts.”

In the survey, caregivers were given the option of picking multiple answers to their reasons for reaching out for crisis services:

Table 1. Families' responses describing the nature of the crisis. n=148

Behaviors	# Responses	% Responses
Danger to Self	66	45%
Suicidal Ideation	45	30%
Suicide Attempt	19	13%
Danger to Others	52	35%
Out of Control Behavior	104	70%
Agitation	63	43%

Other responses included the use of substances, overdose, being withdrawn, running away, and self-harm. Families seek help for a multitude of reasons, but needing help managing a

¹ Kaiser Family Foundation, "Health Insurance Coverage of Children 0-18," analysis of American Community Survey data 2019, <https://www.kff.org/medicaid/state-indicator/medicaid-enrollment-by-age/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>

child's behavior is the chief reason they use crisis services. Efforts to design a crisis system to support children and families must be based on this fundamental fact.

While the majority of incidents were reported as occurring in the home, caregivers reported that 25% of the time the incident had occurred in their child's school. When developing any crisis response system for children and youth, the needs of children in school must be included in all plans.

Survey Structure

After gathering general data, the survey split respondents into two groups: those that had used crisis services one to three times in the last three years, and those that had used crisis services four or more times in the last three years. This was done since we felt that concrete data on families' use of crisis services would be helpful, but families that had experienced four or more incidents in the last three years (some reported as many as 15 occurrences; others said more incidents had happened than they could remember) would be unable to detail precisely what services they used on each occasion and what the various experiences were. These families were asked to respond with narrative answers only that summed up their experiences. Therefore the hard data that was captured in this survey only reflects those who used crisis services one to three times in the last three years. It should be noted, however, that in most cases the narrative answers align with what was captured in the data.

Thirty-nine percent (n=45) of the families who responded to this question on the survey had used crisis services four or more times in the last three years (this in itself points to a broken system – families are not getting the help that they need and so continue to resort to using crisis services). The total number who reported reaching out for crisis services one to three times equaled 85. The following data listed in this report reflects the responses given by the 85 caregivers who experienced using crisis services one to three times. The comments cited, however, are taken from both cohorts of families.

Families' Responses to Crisis

Most families used either law enforcement or the emergency department when they felt that their family needed help; sometimes this included both. Sixty-three percent of the families surveyed used law enforcement when they felt in crisis, and 54% used the emergency department. While this remains high, it is significantly lower than what families reported in the 2013 survey, wherein 72% reported calling law enforcement and 85% reported using the emergency department. This data reflects a reported decline in the use of law enforcement by 9% and a reported decline in the use of emergency departments by 36% since 2013. This change is likely due to the expansion of mobile crisis services over the last eight years and an increased awareness of the availability of these services.

Law Enforcement Agencies

In an emergency situation, the automatic response remains to call 911. Countless agencies and private practitioners have a message on their voice mail that says “in the event of an emergency, call 911.” It is not surprising to find that law enforcement officers are often the first line of response when a caregiver decides that their child and family need help.

Sixty-five percent of the families that used law enforcement reported that they had found it helpful. This number, however, declined for families who used law enforcement for more than one crisis – it dropped to 54% for a second episode and to 55% for a third episode. Across all episodes, approximately half of the time, law enforcement transported the child to the emergency department.

Experiences regarding law enforcement response varied widely. Many families had positive things to say:

The county sheriffs were helpful, kind and supportive. They did transport our foster son to the ED. On one occasion they did ask to take his booster seat and on the other occasion they did not. On one occasion they put him in zip tie handcuffs and on the second occasion they did not.

Yes (they were helpful). Each time the police were extremely professional and calmly transported my son to the ED.

Law enforcement has always come with calm energy and encouragement of what my son needs to do.

Other families reported negative experiences:

Law enforcement was not helpful. I don't believe they had the knowledge or training to fully assist us. By the time they arrived the crisis had essentially passed and they could not do anything further.

The police did nothing but blame me as the parent. They told me there was nothing that they could do.

The officer turned it on me and told me that they couldn't keep coming back because I couldn't control my daughter

A few families noted that the experience with law enforcement varied depending on the officers who arrived:

Some of the visits the law enforcement officers seemed to have an understanding of behavioral health needs while others the officers just didn't get it.

At times they were helpful and others not. It depends on the responding officer and there needs to be more consistent training.

In summary:

- It was not unusual for a child to be placed in handcuffs when being transported by law enforcement to the emergency department, and most families found this unnecessary and traumatizing.
- While some families found law enforcement helpful at deescalating the situation, others reported that their presence made the episode worse.
- A number of families felt blamed by the officers for being a bad parent.
- In many instances families reported that they ultimately found law enforcement helpful not so much for how they responded to the incident, but because law enforcement transported their child to the emergency department, which was what the families wanted to see happen.
- The training of officers varied widely.

Emergency Departments

The emergency department was the second most commonly accessed crisis service by families, even though families consistently reported they had poor experiences with emergency departments. Sometimes a child arrived at the emergency department after being transported by law enforcement or ambulance, but 62% of families said that they had driven their child to the hospital themselves.

While 53% of the time the families who reported using the emergency report said they found it helpful, it is clear that this often was because they felt that their child needed inpatient hospitalization, and the emergency department was a necessary step to getting there.

We have used the emergency department often. There were many times they were helpful and my children were admitted to adolescent psychiatric treatment.

In most cases the ED was helpful. The wait is painfully long (at least five hours).

My son was admitted 5 times to in-patient and only once were we told that "no beds were available."

Yes they were helpful as well. She was admitted for five days.

Even families who reported that the hospital was helpful, however, reported negative experiences. Long waits (sometimes for days), having to wait captively in their child's

room while in the emergency department, feeling judged by hospital staff, and not being listened to were the primary areas of concern.

*The emergency dept is exhausting to wait in. I have waited up to 4 days in an er bed with my daughter for placement into a crisis center.
You get little support in the er and no communication.*

*The ER at _____ was awful. They had no child-friendly facility.
One of us had to stay with him literally 24 hours a day for like 4 days,
and they had zero resources to help.*

The wait was terrible. It increased the trauma. Options for mental health treatment for teens are very few!!!

An important question is: did the child really need to be seen in the emergency department? It is clear that families felt they were in desperate need of help – they would not take such an extreme measure as going to the emergency department if this were not the case - but clearly hospital staff often did not feel that the visit was necessary.

They sent him home and said nothing was wrong with him. To this day he is still out of control and I can't get the help I need.

ER hospitals try to dodge responsibility and send children home knowing they are unsafe.

When we arrive at the er, I often have to wage war with the er staff to not get sent back home...one hospital tried to intimidate us not to come back.

In the survey responses, only 47% of the time was a child admitted to inpatient care after going to the emergency department, which gives rise to the idea that emergency department visits were often unnecessary. This points to the need for a lower level of care than emergency departments, and in the absence of children's crisis beds, further investments must be made to augment the mobile crisis system.

Emergency Departments and Children with Autism

Families whose children were admitted for an inpatient stay were asked how long they waited in the emergency department for an inpatient bed: 31% reported more than 30 hours. This high number was undoubtedly skewed by the number of families with a child diagnosed with autism spectrum disorder (who were waiting for a scarce inpatient bed in a neuropsychiatric unit): 37% of the families who used the emergency department reported that their child had an autism diagnosis. One caregiver described their situation:

My son was diagnosed with autism...Due to the severity of my child's symptoms and behaviors...we've been to several ERs on an annual basis more times than I'd care to

admit...In order to get the Sheppard admission he couldn't be admitted, he always had to remain in the ER. We've waited sometimes up to two weeks for a bed.

Another caregiver said:

My son has autism spectrum disorder. Local ER staff were kind. Facility not adequate for assisting my son with personal hygiene/potty issues...Dad and I went there every day to clean him up...Waited in ER 5 weeks trying to get into Sheppard Pratt...We were worn out with no certainty of when a bed would be available so we brought him home.

The fact that 37% of the families who used the emergency department reported that their child had an autism diagnosis is significant. MCF does not intentionally serve caregivers with children with autism – we don't turn families away, and we always try to offer support to families, but families with children with autism are not among our target populations. Nonetheless, a large number of respondents to our survey had a child with an autism diagnosis. Their need is tremendous. When designing a crisis system for children and families, the needs of children with autism spectrum disorders must be incorporated into any plan.

Mobile Crisis Teams

When asked if a mobile crisis team was available in their community, 54 (65%) of the 83 families that answered this question responded "yes." This is 19 percentage points higher than when we asked this question of families in 2013. Presumably this is because there are more mobile crisis teams in existence than there were in 2013, and there has been a concerted effort to make the presence of mobile crisis teams better known. Still, just 38% of the caregivers who reported that their community had access to a mobile crisis team actually used the team.

Sometimes lack of use was not for lack of trying. Caregivers mentioned a number of times that calls for help did not result in a mobile crisis team coming out.

I called several times only to be told if I needed immediate crisis support, I'd be better off at the ER.

I called the MCT on 2 different occasions for their help and because my child was 9 yrs old they refused to come out and help or talk to him on the phone.

We asked for mobile crisis but they were never sent.

When families did use mobile crisis services, they more often than not reported a positive experience. Seventy-five percent of the families who used a mobile crisis team said that

they had been helpful. Compare this with 58% of families overall reporting finding law enforcement helpful and 53% of families reporting finding emergency departments helpful. Not only did caregivers report finding mobile crisis helpful, they had a number of positive things to say:

They have been to our home to help make sure that we were connected to the services we needed. They were very helpful.

They did respond quickly on all occasions and were helpful in all situations. We were able to get her help and more services as a result of one visit and they were able to prevent hospitalization from another visit.

MCT was called a number of times and each time resulted in a prompt and professional experience. They have been extremely helpful the past year.

Reasonable response time, professional, did prevent an ED visit.

I have utilized the MCT and they have always been extremely helpful giving advice on how to proceed with the situation.

MCT responded quickly and were very helpful in defusing behavior and substance abuse issues.

Fifty-eight percent of the time families reported that the result of the mobile crisis team coming out was that the crisis was resolved. Only 12% resulted in a hospitalization. A number of families explicitly said they believed that mobile crisis had averted a hospitalization. As Maryland is trying to address the issue of bed capacity and hospital overstays, the expansion of mobile crisis services is clearly one answer.

Wait times for mobile crisis were usually minimal – 64% of the families who used mobile crisis teams waited less than one hour, and 28% waited one to two hours. No one reported a wait time longer than four hours (although presumably these were the families who reported that they ended up not using mobile crisis and just called 911 since the wait for mobile crisis would be too long).

When families had negative things to say about mobile crisis services, it was almost always because of the wait time:

It took a loooong time for them to come the one time they did come. And there were many times we decided not to call in the MCT because we were told the wait time would be far too long. The one time they did come, they were nice, but he had already finished his tantrum.

We had the mobile crisis team come out once. It took over an hour for them to come. We'd requested the team multiple occasions previously, but been told that either one wasn't available or that it would be several hours before one arrived. By the time they got there, the imminent crisis had passed.

There have been occasions when I have called the MCT for assistance that I have been told to call the police because they had no one to send.

Not surprisingly, timeliness must be a key component of any mobile crisis response system. If the delay for a team to come out is too long, families then turn to law enforcement or emergency departments for help.

Indeed, when families were asked in the survey “What would deter you from using alternate crisis services (other than calling 911 or going to the emergency department)?” The most common answer was “Lengthy delay to receive help.”

Another reason frequently given (30% of the time) for not using a mobile crisis team: families responded that their “child needed an inpatient stay.” A barrier to developing a successful mobile crisis response model will be:

- making it known that the result of a mobile team coming out may be a trip to an emergency department or other facility, if needed, and
- persuading families that an inpatient hospitalization is often not the best course for a child.

These will be significant hurdles to overcome, and require a large amount of targeted messaging.

There were two other concerns about mobile crisis services that are worth noting. One was related to law enforcement:

We had only positive interactions with MCT. I just wish we could have had them come independent of the police.

I think Crisis team was great and being able to come out and help with the situation. What did not help was having a cop have to come also. It wasn't extreme enough to have to have a cop involved.

I think there should be a way that a parent or guardian can call for a crisis response without having to have the cops involved every time...I think the crisis team should evaluate the situation and let them decide if a cop is required or if they could handle the situation without cops.

Not all mobile crisis providers require that teams be accompanied by law enforcement officers, but some do, and families reported that this was not necessary and even unhelpful.

Finally, in two instances families stated that they were unable to use the mobile crisis team because they had private insurance.

In all incidents, we would have called for mobile crisis if it was available in our area.

We live in Baltimore City and it is only available for people on Medicaid (we have private insurance).

While most mobile crisis units in Maryland respond regardless of insurance status, some do not. As was noted in the section summarizing the demographic data, 83% of the children whose families who responded to the survey were covered by Medicaid. With a different pool of respondents, there may have been more reports of being unable to access crisis services because of insurance status. Maryland has a Medicaid penetration rate of 38% for 0-18 year-olds, and we know that mental health crises do not discriminate based on income. Any mobile response system developed must be able to serve families regardless of the child's insurance status.

Crisis Walk-in Centers

Crisis walk-in centers were the least used service, and this is not surprising given their limited number. Twenty-two percent of respondents reported that a crisis walk-in center was available in their area, and this number is an overstatement, since it is clear that a few people interpreted "crisis walk-in centers" to be emergency departments. This means that the number who reported using a crisis walk-in center (n=16) also is overstated. Given this misunderstanding, it is impossible to draw any conclusions from the data. Families that did use an actual crisis walk-in center had mostly positive things to say about the experience:

I had to use Sheppard Pratt crisis walk in center several times and they are the best in helping in a crisis situation.

Sheppard Pratt walk in clinic was helpful to an extent.

Yes. We have been several times and most times he came home better.

In the focus groups, the definition of "crisis walk-in center" was able to be more thoroughly explained, but unfortunately none of the 13 participants had used the service so could not provide any feedback.

Further investigation is needed on families' use and experiences with crisis walk-in centers.

Additional Information

- All of the survey respondents were asked, “When you used crisis services, what was your desired result?” Caregivers were allowed to select more than one answer. The most frequent response (62%) was “Connection to Services.” A close second (60%) was “Child Stabilized in the Home.” This marks a change: in the 2013 focus groups the most common response was “hospitalization.” More families are identifying that they and their child’s needs can be met by something other than hospitalization. Still, 42% of families said they wanted an inpatient hospitalization for their child, and when asked what could be done to improve crisis services, a number of caregivers responded “more inpatient beds.” One caregiver said:

*I think parents should have more rights as far as putting
their kids in inpatient.*

- All survey participants were asked “How did you learn about alternate crisis services (other than calling 911 or going to the emergency department)?” The most common response was from a behavioral health provider (36%). Nineteen percent said from their child’s school, and 13% said from their child’s pediatrician. These are the places that should be targeted to spread information about the availability of crisis warmlines, mobile teams, and walk-in centers.
- When families were asked what had been the most helpful crisis service they had utilized, the top responses were:

Mobile Crisis Team	11%
Police	8%
Inpatient hospitalization	8%
Behavioral Health provider	7%
Maryland Coalition of Families	6%
Emergency Department	6%
Crisis Walk-in Center	3.5%
Hotline	3.5%

There was a wide array of answers, with many people saying “nothing.” Mobile crisis teams rising to the top aligns with the narrative comments and the responses to questions about whether or not a service had been helpful, wherein 75% of caregivers reported that the mobile crisis team had been helpful.

- One question asked “What additional crisis services do you feel would be helpful in your community?” A wide variety of answers were given. Some that rose to the top were:

More or improved MCTs	9
More inpatient beds or hospitals units	8
Walk-in clinics	5

Supports for parents	4
More services for people with private insurance	4
Hotline	2
Crisis services just for youth	2
Anything – “we have nothing”	4

Some caregivers simply commented on what they thought was needed in the system of care for children and youth with behavioral health needs: integration between community services and the school system; coordination of care for children with mild to severe behaviors; mentorship programs; afterschool programs; and peer support for adolescents. A few families said that more prevention programs were needed. One caregiver commented:

I had seen us heading toward a crisis for months but until we hit the point of hospitalization I couldn't get our family the support we needed.

Recommendations

The information garnered from the survey and in focus groups lead to the following recommendations:

- 1. Expand the number of 24/7 mobile crisis teams that are:**
 - a. dedicated to working with children
 - b. trained in deescalating behaviors
 - c. trained in working with children with autism spectrum disorders
 - d. able to respond within one hour
- 2. Adopt policies that permit mobile crisis teams to be deployed without police accompaniment.**
- 3. Ensure that mobile crisis teams are available to families regardless of a child's insurance status.**
- 4. Enact policies that allow mobile crisis teams to respond to incidents that occur in schools.**
- 5. Work with behavioral health providers, schools and pediatricians to promote the use of mobile crisis teams and provide information to families about what to expect when a mobile crisis team responds.**

6. Continue to improve the array of intensive community-based services available to all families, to prevent the repeated use of crisis services with no resolution.

Thanks to the many families who gave of their time to complete the surveys and participate in the focus groups. Their voices must be used in the development of any crisis system.