LISTENING AND LEARNING FROM FAMILIES:

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

December 2013

Maryland Coalition of Families for Children's Mental Health

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Dedication

This handbook is dedicated to all families struggling to access crisis services for the child with mental health needs.

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

The Maryland Coalition of Families (MCF) is the statewide voice for children's mental health and is dedicated to:

- Building a family-driven network of information and support
- Improving services in all systems of care for children, youth and their families
- The Coalition represents families across Maryland who are caring for a child with mental health needs. Many children have been in a psychiatric hospital, residential treatment center, juvenile justice facility, or special education program.

Families struggle to find appropriate services for their child and many families face staggering costs for treatment and other special services their child may need.

Even with the challenges of raising a child with serious emotional or behavioral needs, families have strengths and want to be full partners with professionals in planning for their child's treatment and care.

We Believe

- Children and youth with mental health needs are valued and require individualized services to achieve their full potential.
- Families are a constant in a child's life and are equal partners in planning, implementation, monitoring and evaluation of services.
- Services for children, youth and their families are provided from a strength-based approach and are responsive to the needs of the whole child and entire family.
- Local and state systems of care are family-driven and culturally competent.

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Introduction

In 2011, The United States Department of Health and Human Services, Centers for Medicare & Medicaid Services (CMS) awarded a Children's Health Insurance Program Reauthorization Act (CHIPRA) grant to the Maryland Department of Health and Mental Hygiene for its collaborative proposal with the States of Georgia and Wyoming. The Institute for Innovation and Implementation (The Institute) at the University of Maryland, School of Social Work in partnership with the Center for Health Care Strategies provides project management and technical assistance to Maryland, Georgia and Wyoming to support the multi-state collaborative goal of improving quality and better controlling the cost of care using a Care Management Entity structure for children with serious behavioral health disorders enrolled in Medicaid or the Children's Health Insurance Program.

Under the CHIPRA grant, one of Maryland's specific goals is to assess existing crisis response services for youth in each of the state's 24 jurisdictions, research best practices and propose a redesign of Maryland's crisis response and stabilization system for children, youth, young adults and their families.

To this end, a workgroup was established in December 2011. The crisis workgroup undertook a number of activities, including, among others:

- Conducting national research and site visits to states and communities with successful crisis response and stabilization models;
- Analyzing psychiatric emergency department (ED) and hospital utilization and cost data from Fiscal Years 2007-2012 by youth's jurisdiction of origin and hospital accessed;
- Developing a continuum of recommended essential core components of a crisis response and stabilization system specific to Maryland; and,
- Conducting a gap analysis in partnership with the local Core Service Agencies to determine availability of recommended core services in each of the 24 jurisdictions in Maryland.

The Institute contracted with the Maryland Coalition of Families for Children's Mental Health (MCF) to conduct a series of focus groups with families to learn about their experiences, since the voices of families in Maryland who had accessed or tried to access crisis services for their youth had not been heard. The Institute, in conjunction with MCF, also developed a survey to have families complete at the end of the focus groups to gather more data regarding crisis services in Maryland.

Methodology

In the summer of 2013, MCF held seven focus groups with families in different regions of the state. In the focus groups, one MCF staff member facilitated the discussion while another took notes. The first focus group was held as a break-out session at the Maryland

Systems of Care Training Institutes hosted by The Institute. At this focus group, families from around the state participated. The remaining focus groups were held in Allegany, Dorchester, Howard, and Baltimore Counties and in Baltimore City. A focus group for Spanish-speaking families was also held in Montgomery County. Participants were required to be 1) a caregiver of a youth under age 22 whose child has used crisis services in the last two years and 2) a resident of Maryland. In all, 48 eligible family members attended the focus groups. A $20 stipend was provided to family members, along with dinner. At the Baltimore County focus group, child care was also provided.

During each focus group three questions were asked to facilitate discussion:

1. What did you do when your child was in crisis?
   a. What made you decide to reach out for help?
   b. How did you know what to do?
   c. How hard or easy was it to access help?
2. What was your experience with in accessing help?
   a. What was most helpful?
   b. Were follow-up supports, resources or referrals provided?
   c. The next time there was a crisis did you know where to go more quickly for help or even before it got to a crisis?
3. How would you improve the crisis response system in Maryland?

At the conclusion of each focus group, families were asked to complete an extensive survey to provide additional information about their experiences. Not all families responded to each question. A copy of the survey can be found on the MCF website, www.mdcoalition.org. [i]

Participants

A total of 48 family members from 11 jurisdictions in Maryland participated in the seven focus groups. The participants' children can be characterized as children with serious complex mental health disorders including:

Attention Deficit/Hyperactivity Disorder (ADHD)	33	Post-Traumatic Stress Disorder	10
Anxiety Disorder	24	Sleep Disorder	9
Mood Disorder Not Otherwise Specified	23	Conduct Disorder	8
Depression	22	Self-injurious Behavior	8
Bipolar Disorder	19	Trauma History	7
Oppositional Defiant Disorder	19		

The majority of the children were male (69%) and the most frequent age was 14-17 years (50%). Thirty-nine children (81%) were taking medication for mental health disorders and the average number of medications was 4.4. These children were also involved with multiple agencies:

Department of Social Services or Foster Care	28	Juvenile Services	17
Special Education	39	Substance Abuse Services	9

Additional information on demographics is included in Appendix A.[ii]

Children and Families in Crisis

Crisis is defined as a time of intense difficulty, trouble, or danger with an inability to stop it or protect ourselves or others from it.

"Rage attacks; Screaming, pounding of walls and doors."

The majority of families (77%) utilized crisis services when their children were displaying out-of-control behavior, which often was accompanied by feelings that the children were potentially dangerous to themselves or others. Families frequently described their children's behavior as "threatening," or "aggressive," and often reported there had been physical violence toward people or property. Families expressed fear for their safety, as well as the safety of other children in the home or neighborhood. During these conversations, families were very emotional and appeared desperate, fearful and often hopeless. At times, families indicated that their children's aggressive behavior was accompanied with dangerous behaviors toward themselves.

The following are some responses received when families were asked to describe the nature of the crisis.

"He was extremely aggressive – breaking items, putting holes in the wall, threatening to harm the people in the house."

"Threatened me and hit me and pushed me down. Child violence against me and destruction of property in the house"

"Threats, violence, yelling, cussing, defiant."

"Threatening, suicidal, abusive to us."

"Running away/elopement, self-injurious behavior, aggression towards Mom and Dad, suicidal/homicidal ideation."

"Threatened suicide, self-injury (head banging, scratching herself and drawing blood, hair pulling) threatened siblings, extreme anger, property destruction."

"Her siblings didn't even want to go to sleep. They were afraid of her. I had to hide all of the knives."

Table 1. Families' responses describing the nature of the crisis. n=48

Behaviors	# Responses	% Responses
Danger to Self	23	47%
Suicidal Ideation	16	33%
Suicide Attempt	3	6%
Danger to Others	23	47%
Out of Control Behavior	37	77%
Psychotic Behavior	12	25%

Families' Responses to Crisis

Most families in crisis used either law enforcement or the emergency department or both when their child was in a crisis. Thirty-three families (85% of the 39 who responded) reported using the emergency department; twenty-eight families (72% of the 39 who responded) reported calling law enforcement. These two services were what families relied on the most when dealing with a crisis.

Law Enforcement Agencies

In an emergency situation, the automatic response is to call "911." Countless agencies and private practitioners have a message on their voice mail that 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 child is experiencing a mental health crisis.

"We called 911 or the school called 911. Police showed up – ranged from very helpful to a police officer who in 10 seconds tased my son."

While 911 may be a universal number to call, the police response may come from many different agencies with varying levels of training or experience in children's mental health. Maryland has no less than 29 county law enforcement agencies, including sheriff's departments and county police. In addition to county agencies, there are 60 city police agencies across the state. This does not include state police or the many school districts that employ school police officers who may or may not be connected to the county law enforcement agency.

Experiences regarding law enforcement response to a child in crisis varied widely. These varied experiences with law enforcement are reflected in families' answers to the question, "Did you feel that the presence of the police was helpful to address the crisis?" Of the 28 families who reported having used the police, 16 families answered "yes," and 12 families answered "no." These differences with law enforcement were reported in all seven jurisdictions where focus groups were held, indicating that difficulties with law enforcement response is widespread and is not limited to one jurisdiction or region. Some law enforcement officers were clearly better equipped to deal with a child's mental health crisis than others. Those law enforcement officers with less training did not seem to recognize that the situation was a mental health crisis. Families expressed frustration that

officers often came and lectured their children or made idle threats about locking the children up. Officers seemed to approach the situation as a "parenting issue" rather than a mental health crisis. Parents also felt that officers spoke to them in a condescending way in front of their children.

"We called 911 three times. The police are responsive. The first couple of times a team of two came out. They were extremely well trained – knew exactly how to talk to a tween. We were so impressed. The second time it happened that the same team came out. They were extremely good. They took us to the hospital. The third time two police officers came who were not well-trained."

"I've had the gamut. I had a paramilitary action. I've had law enforcement say they can't do anything – to take him to the hospital…I've had some very professional police officers in my house."

"The Police are a hit and miss game – you get somebody who knows something and doesn't blame the parent, and then you get someone who doesn't know."

"The problem with the police is that they are not trained. They escalated the situation more …They act like you don't know how to control our child."

"The police should be a whole lot more sensitive when they come out. They need training on mental health issues. They are trained on mental health issues but not children. It's easily mistaken for delinquency when it's not – it's mental health."

While families had mixed experiences with police officers, the families who had contacted the sheriff's department in varying jurisdictions reported positive experiences.

"The sheriff's department was great. They are more empathetic than the city police."

"The sheriff's department is a lot more caring."

"The sheriffs and state troopers are always very professional."

"Usually the sheriff's department comes. They have been very good."

Some families experienced unanticipated consequences as the result of calling law enforcement. Involving law enforcement could result in assault charges or destruction of property charges against the child and send them on a trajectory into the juvenile justice system rather than the mental health system.

"I called the police since there was no other option…So now we have a parole officer."

"He assaulted me. Police were called and he was taken to the detention center."

"They charged him with destruction of property so I had to go to court. It didn't get me any services. Just gave him a record."

Only one Spanish-speaking family called law enforcement, after her son had disappeared for 24 hours. The Spanish-speaking families were much more likely to use the Montgomery County crisis center, where "there was always a person who spoke Spanish," or to rely on a relative or family friend to intervene and de-escalate the situation.

Law enforcement policies were of grave concern to families. Handcuffing or tasing were traumatizing to children, and parents often felt it reflected unnecessary force for a child experiencing a mental health crisis.

"I had to call the cops 3 times…they threw (the child) down and tasered him."

"(The child) had a stick. The police told him to drop the stick. The police pulled their service revolvers and took him down (he was 11). We stopped using the police."

Emergency Departments

The emergency department was the service accessed the most often by families with a child in crisis, even though families consistently reported they had poor experiences with emergency departments.

Transportation to the hospital emergency department was in itself a major challenge to overcome. Seventeen families (of the 33 that reported using the emergency department) stated that they had transported their children to the emergency department themselves. At times this posed a serious safety issue, as families reported their children attempted to jump out of the car or tried to put the car in reverse.

"How do you drive your child when they are out of control?"

Sixteen families stated that the law enforcement transported their children to the emergency department. For safety reasons, some families thought law enforcement should be the ones to transport the children. Conversely, several families had experienced their children being handcuffed when transported by law enforcement (11 out of 16). All agreed this was traumatizing to the children and for this reason some families hesitated to call law enforcement for assistance.

The majority of families did not have a positive experience in emergency departments. Long waits (sometimes for days), being treated judgmentally and not being listened to were the primary areas of concern.

"The ER needs to be more educated and caring. They lack severely in empathy. They stigmatize people a lot. If a child is going through a crisis it is not the parent's fault."

"I wanted the ER to listen to me since I am the parent and know my child best….You know your child better than anyone…and everyone is quick to judge."

"One time we were in the ER at least 24 hours - longer than the admission. She was not able to get her current meds or her birth control."

Almost all families expressed frustration about the lengthy wait in the emergency department. Six to eight hours was the norm. The wait was not always because it took that long to evaluate the children, but because children lingered for days until a bed in an inpatient facility was found for their children.

"We were there three days waiting for a bed."

"Children end up in the hospital 24 to 36 hours until a bed opens.

"I sat in the emergency room three nights and three days with him before they found a bed for him."

Many hospitals have a policy that a family member cannot leave their children who is there for psychiatric evaluation or treatment unattended in the emergency room. This creates a tremendous burden to families, particularly single parent families who may have other children to care for. Families reported that their children were served meals, watched TV and had a bed to rest in while the families could not even leave the room to get something to eat or to take a break.

"She has had 16 hospital admissions. I'm usually there over 24 hours….I'm not even allowed to leave the room. Because I'm the parent I have to remain in the room."

Despite the difficulties with using the emergency department, clearly many families felt that their children needed an inpatient hospitalization and the emergency department was the only way to access admission to the hospital. Families that had experience with emergency department admissions spoke of learning the ropes to get their children admitted to the hospital.

"Had to use key words to get help - threatening to commit suicide, a danger to others."

"Once you get past the gargoyles at the gate the care was wonderful."

Although families reported poor experiences with emergency departments, some felt that, regardless, the emergency department had been helpful in dealing with the crisis. Thirteen families (41%) reported that it had been helpful while 19 (58%)[iii] of families reported that it had not been helpful. Ironically, many families reported that their children calmed down upon entering the emergency department. They failed to display the aggressive or threatening behavior that created the crisis in the first place. This was extremely frustrating to families, as professionals conducting the evaluation often did not appear to believe the behaviors the family described before going to the emergency department. Families sometimes felt they had gone through hours or days of sitting at the emergency department for nothing - especially if their children were not admitted and they ended up taking their children back home without receiving any additional treatment, resources or support.

Mobile Crisis Teams

Mobile crisis is defined as: "a team of trained mental health clinicians (i.e. social workers, psychologists) that you can call to come to your house or wherever the crisis is occurring, to help you manage the crisis while it's happening and provide follow-up support."[iv]

"I called mobile crisis once. They came out to the house. I had a pretty good experience."

When asked if they were aware of whether or not their community had mobile crisis teams, 19 (46%) of the 41 families that answered this question reported "yes," seven (17%) reported "no," and 15 (37%) families replied that they did not know. None of the Spanish-speaking families in Montgomery County were aware of mobile crisis teams. After further probing, it turned out that even those families who indicated they were aware of mobile crisis were often referring to other programs such as wraparound/care management entities or family preservation. Additionally, families may have indicated that they used B-CARS (Baltimore Child and Adolescent Response System) and later responded that they were not aware of mobile crisis teams in Baltimore City. Because of this confusion about mobile crisis, it is somewhat difficult to draw specific conclusions about the use or benefits of mobile crisis.

With these caveats in mind, the data regarding the use of mobile crisis teams does shed some light on the use of crisis services. Sixteen of the 19 families who reported that mobile crisis teams were available in their community said that they had used mobile crisis services (including wraparound and family preservation). If available, mobile crisis was a service that was pursued quite frequently.

Of the 16 families who had used mobile crisis teams, 69% were disappointed by the limited help that was offered. A number of families noted that although they called the mobile crisis team, it never came out. Other families felt frustrated by the response, or lack of response they received from mobile crisis.

"I haven't heard anybody around here who's said good things about mobile crisis.

"They call it mobile crisis but they don't come out."

"I called the mobile crisis team. They told me to take her to the hospital."

"We have yet to ever have the mobile crisis team show up. We just went the ER route."

"Mobile Crisis team takes hours to come - ended up having to call 911 because they never got there."

"My child was out of control and the mobile crisis team told me to put him on the phone. When my son took the phone, mobile crisis said he was fine. My son went on to terrorize the neighborhood for two more hours."

The survey asked if there were any additional follow-up contacts with the mobile crisis team in the weeks following the crisis. Ten families reported that there had been no follow-up from the mobile crisis team.

"They never followed through. Never followed up to see how she was doing."

Five families (31%) reported that the mobile crisis team had been helpful – one specifically referred to B-CARS, which was also named twice as one of the mobile crisis teams that provided follow-up services. Undoubtedly, some of the poor experiences with mobile crisis teams may have to do with the limited hours that many teams operate, or the distance they must travel. This may indicate that even when a jurisdiction has a mobile crisis team, it may not be accessible to families when needed.

Crisis Hotlines and Online Resources

Crisis hotlines have been around for over 40 years and are a universal crisis service available to families. Maryland has a network of five centers around the state and all utilize the same toll-free crisis number. The number can be called from anywhere in Maryland and the caller is connected to the hotline center in their region. All centers operate 24-hours a day, 7-days a week, 365 days a year.

Given this long history and the statewide availability of the hotlines, it should be noted that only thirteen of the 43 families that answered the question (30%) reported that it was available in their communities. Eleven (26%) of families reported using a crisis hotline or online resource. Only six of those eight felt that it had been useful.

"I called (the hotline) when in crisis –they don't give me good answers. Told me to call the police."

When asked if their child had ever used a crisis hotline or online resource, only three families reported yes. It is possible, however, that some youth had used a crisis hotline or online resource and their families were not aware of this.

"My son used a teen hotline. They talked to her for like half an hour. She was much better afterwards."

In a sign of the changing times, one father commented that he had not seen his daughter speak into her phone for two years as she only used the phone for texting. While amusing, it is also revealing and suggests that crisis hotlines may need to adapt their technology to current times. Maryland Youth Crisis Hotline now has an online chat room available Monday through Friday from 4 pm – 9pm. There is also a national suicide prevention online chat room that is available from 2PM-2AM EST (http://suicidepreventionlifeline.org/GetHelp/LifelineChat.aspx).

Additional Types of Crisis Services

In both the survey and focus groups, questions were asked about a number of other types of crisis services. Few of these services are available and they are limited to a small number of jurisdictions. The majority of families reported either that the service was not available in their community, or they did not know whether or not the service was available in their community. These services included:

1. **Mental Health Urgent Care Services** – Mental Health Urgent Care is defined as "a walk-in clinic where you can take your child when in crisis to see licensed mental health clinicians for support, evaluation, and referrals without an appointment."[v] Eight families from Baltimore, Howard and Harford Counties reported using Sheppard Pratt Urgent Care. In six of the eight cases, Urgent Care resulted in an inpatient hospitalization.

2. **Emergency Respite** – Emergency Respite is defined as "a safe environment (such as a residential or group home) you can take your child while in crisis. Its purpose is to provide an unplanned, temporary break (up to two weeks) for you when you are overwhelmed." Only three families reported using Emergency Respite services, and with little satisfaction.

3. **Emergency Department Diversion-** Emergency Department Diversion is defined as "a service in which a licensed mental health clinician is available to you when you visit a hospital's emergency room to address your child's crisis and help you decide whether your child should be admitted to the hospital." Sixteen (36%) of the 45 families that answered the question stated that the service was available in their jurisdiction; 15 families stated that they had used the service. Most stated that they had learned about the service through the emergency department or their doctor. It was a service that consistently was credited with being helpful to the family and resulted in inpatient hospitalization for the child. In these instances, it was not a hospital diversion as the service is intended to do, but rather expediting an inpatient hospitalization.

4. **Care Coordination and Stabilization -** Care Coordination and Stabilization is defined as "longer-term community-based support that continues to help your family after the crisis has occurred, with the goal of preventing future crises." Thirteen families replied that Care Coordination and Stabilization services were available in their communities. Nine families reported using Care Coordination and Stabilization: significantly, eight said that it had been helpful; one mother said that it had not been helpful due to the long waiting list. This is likely a reference to the 1915 (c)(RTC) waiver. Other sources listed for care coordination services included services provided by the local departments of social services (DSS) and wraparound care coordination provided by Maryland's Care Management Entities. The high percentage of families who found the

service helpful indicates that intensive community-based services are welcomed by families as an alternative to inpatient hospitalization.

Table 2. Responses to Family Survey on Crisis Services

Type of Crisis Services	# of Families Responding	Do You Know if This Service is Available in Your Community?	Have You Ever Used This Service for Your Child?	Was it Helpful?
Crisis Hotlines/ Online Resources	43	13	11	6
Police	39	39	28	16
Mobile Crisis Team	41	19	16	5
Emergency Department	39	39	33	13
Mental Health Urgent Care	47	12	8	4
Emergency Respite	47	9	3	0
ED Diversion	45	16	15	10
Care Coordination and Stabilization	43	13	9	8

What Would Help?

In both the surveys and the focus groups, families were asked what crisis services they would find most helpful. In the survey, they were asked to rank on a scale of one to seven (1 = most helpful and 7 = least helpful) the list of crisis services indicated on the survey. Twenty-six families answered/or answered correctly the question. When totaled, most services fell fairly close together, with one exception, Mental Health Urgent Care. Table 3 shows the ranking of most helpful crisis services given by families.

Table 3. Ranking of Most Helpful Crisis Services
(Ranking – lowest score = most helpful and highest score = least helpful)

Type of Crisis Service	Score
Mental Health Urgent Care	65
Mobile Crisis Teams	100
Emergency Respite	108
Emergency Department Diversion	116
Care Coordination and Stabilization	117
Crisis Hotlines/Online Resources	123
Crisis Beds	137

When asked to comment at the end of the survey what services they would find to be most helpful, Mental Health Urgent Care was specifically mentioned six times. Other answers

included: "not having to go to the ER to be evaluated;" "routes and alternatives to hospitalization;" "more support from Mobile Crisis Teams;" and "wraparound."
In the focus groups, families spoke of more personalized crisis services as being helpful – working with someone they knew.

"While he was on RTC waiver for two years we had a crisis team available to assist him at any time – he had no hospitalizations."

"We have Maryland Choices with a crisis team. So we called the family support partner and the support team member. She calmly walked me through the crisis. That to me is the most important first step in any crisis – someone I already had a relationship with."

Similarly, a few families mentioned how helpful it would be if they could access the child's therapist during the crisis, so that someone who is familiar with the child is responding during the crisis.

Conclusions

The surveys and focus groups provide rich information regarding families' positive and negative experiences with crisis services in Maryland. Two critical factors must be taken into consideration before drawing any conclusions from the surveys and focus groups. First, there is the obvious fact that the availability of crisis services for children differs vastly across the state. A second and perhaps less obvious fact is that what may be a crisis for one family may not be a crisis for another family – or in the eye of the crisis service provider. One example is the family who called crisis services when their child refused to go to school. While this does not represent the majority of calls, it does point to the wide range of crisis calls.

1. **Families want alternatives to the Emergency Department.**
   Perhaps the most significant conclusion is that families do not want to use the emergency department, although it was the service accessed most often. The long list of the negative aspects of using the emergency department and families' overall dissatisfaction with emergency departments make this quite clear. Families continued to use the emergency department because it was the only way in which they could access acute inpatient hospitalization, which they believed their children needed. Inpatient hospitalization is usually the only intensive mental health service available to most families. The dissatisfaction with emergency departments undoubtedly accounts for the very high prioritization given to the implementation of Mental Health Urgent Care centers. Families clearly wanted a pathway to hospitalization other than emergency departments.

   "I would like to see mobile crisis teams be able to do assessment right there, and then they can take them to the acute hospital."

   "Need a streamlined system, especially if your child has already been diagnosed, so that you're not sitting there from 24 to 48 hours."

This also is probably why Emergency Department Diversion, as families understood the service, was given such a high rating. Of the 14 families who stated that they had used the service, 11 felt that it been helpful and 10 children had been hospitalized. There was a strong correspondence between families who thought the service had been helpful and those whose child had been hospitalized.

2. **Law enforcement officers are the front line for crisis.**
   Many families called law enforcement agencies (city, county or state police, or sheriffs), in the hopes that the law enforcement officers could talk their children out of a crisis, or get their child to realize the severity of their actions. These families were not seeking access to acute inpatient treatment. They saw law enforcement as a resource that could help them to de-escalate the immediate crisis situation. Although many families had favorable things to say about the law enforcement, there was a widespread consensus that more law enforcement officers needed more training on mental health issues, especially with regard to children.

3. **Families with limited English proficiency faced additional challenges and fewer options in a crisis.**
   The surveys and focus groups yielded some unique information about Spanish-speaking families that can be generalized to families with limited English proficiency. On the survey, the Spanish-speaking families prioritized as a service Crisis Hotlines/Online Resources, which ranked low among other families. One family asked for "a Spanish speaking hotline where you can find information and just talk to someone." Another said "It would be a great idea to have a Spanish speaking hotline for all kinds of questions." Another said that the most helpful service would be a support group. Three families had used the Montgomery County Crisis Center, where there was always someone who spoke Spanish.

   Of note is the fact that only one family spoke of using law enforcement (and that was to report that her child had run away and was missing for over 24 hours). There was a clear reluctance to call the police whereas, in other focus groups, law enforcement was most often the first number called. Likewise, only one family member mentioned that she had taken her child to the emergency room.

4. **Maryland's mental health crisis system is underfunded and lacking in services.**
   The dearth of effective crisis services in Maryland is evident. The over reliance on emergency rooms, law enforcement, and inpatient hospitalizations is the result of a lack of alternatives. Families who stated they had care coordination through wraparound, a wraparound team, and a crisis plan in place were much more likely to be satisfied with the service than other services. One family member explicitly stated that in the two years her child was in wraparound, they were able to avoid any hospitalizations.

Recommendations

1. **All treatment providers should develop a crisis plan with the family.**
   The positive experiences families reported with wraparound and with family preservation are an indicator that the most critical components of crisis response for a family are: 1) a crisis plan in place and 2) someone who can respond quickly and 3) preferably someone who knows the child, and 4) follow-up to make sure the situation is stable. The State can plan a critical role in providing training to providers on developing crisis plans.

2. **Provide more widespread mental health training for law enforcement officers about responding to children's mental health crises**.
   Law enforcement officers are on the front line and the second most frequently used crisis service. While many jurisdictions have implemented mental health training for law enforcement, there continues to be a need to expand training across state, county and city law enforcement agencies and to include specific training on children's mental health.

3. **Expand Mental Health Urgent Care Clinics.**
   The Emergency Department bottleneck can be eased by providing walk-in Mental Health Urgent Care Centers with extended hours. These centers should be able to provide families with evaluation, information and support. With appropriately trained professionals, Urgent Care Centers could serve as a place for crises to de-escalate, as now frequently happens in the emergency rooms.

4. **Increase the number of 24/7 Mobile Crisis Teams across the state.**
   A crisis is defined by the urgency of the situation. To be effective, a Mobile Crisis Team must be able to respond in a matter of time. More Mobile Crisis Teams are needed throughout the state, and all Mobile Crisis Teams should have extended hours.

5. **Expand Maryland's Emergency Department Diversion Program.**
   Families would prefer not to go to the Emergency Department. If alternatives were available they would welcome them. This, however, must be accompanied by the provision of alternative intensive services and follow-up in the community.

6. **Work with Maryland State Department of Education to Provide Youth Mental Health First Aid Training to Schools Across the State.**
   Because many crises occur within school hours and the school building and classroom, it is imperative that all school personnel receive Youth Mental Health First Aid training to better understand, anticipate and respond to a child in crisis.

7. **Expand the Array of Intensive Community-based Services.**
   Families took their child to the emergency room because there were not alternatives. If more intensive community-based services were available, such as care coordination and wraparound teams, families would not feel that inpatient hospitalizations were the only option for their child.

8. **Increase Public Awareness of Crisis Services**
   From Western Maryland to the Eastern Shore, there was a lack of information about crisis services where available and how to access them. A concerted effort should be made to increase public awareness of crisis services in each jurisdiction.

The Voices of Families

This report could not begin to capture all the experiences and comments that families shared during the focus groups and on the survey responses. However, MCF wants to ensure that these families' voices are heard and so we have included additional quotes from families that convey their frustrations, fears and recommendations.

Crises involving out-of-control behavior

"Very violent"

"Child destroying the room (cussing and acting wildly). Out of control.

"Altercation with peers in the neighborhood involving some destruction of property."

"Taking fire extinguisher, running around campus, destroying the house and furniture, breaking windows, going down the steps backwards in a chair."

"Child became agitated, increasingly aggressive…broke a window, destroyed a room, etc."

"Aggressive – nasty – destroying things."

"Destruction of property. Hitting us."

"My child physically attacked me."

"Broke doors, very aggressive."

"He became very violent."

"He wanted to kill me."

"My child arrived home from school agitated and upset. The child proceeded to kick and punch everything and everyone they came in contact with".

Out-of-control behavior accompanied by self-injury or danger of self-injury

"Mental breakdowns, nonstop screaming, destroying property, shutting down behaviors, suicidal."

"Child presented danger to self or others."

"Self destructive and property destruction."

"Out of control behaviors. Attempted to destroy property, trying to injure brothers and mom and self."

Emergency Room Usage

"He has been taken to numerous psych units. Very lengthy waits."

"When I took my kid to the ER they acted like there was something wrong with me – what kind of parent are you?"

"Anti-stigma thing is what they would need in the ER."

"We've been to the ER more than half a dozen times. I've never been out of the ER in less than eight hours. We stopped using an ER."

"Some of the hospitals are not equipped to serve them with their needs. The doctors don't take the time to listen to what you have to say. You're the one who knows the child."

"They blame you. They completely take them out of your care."

"They don't always have a sitter to let you out of the room."

"We sat in the emergency room for six hours. We never spoke to anyone. At 2:00am a nurse came out and said that "we don't think he's a danger to himself or others.""

"We took him to the emergency room twice. I was at (the ED) 13 hours and they said there was nothing they could do and sent us home. I took him to (another ED) I sat there 19 hours. They didn't admit him."

"When we got to the hospital one of the nurses started…putting him down and putting me down for the situation."

"I wish there was a way that when they were in crisis that instead of going to the emergency room there was a choice."

"You don't speak English so you have to wait for a translator to come…discriminated against because we don't have insurance. When you don't speak English you are the last one to be seen."

"Because of the attitude, the insurance, the language, it makes you not ask for help."

"The hospital experience has been as traumatic as other experiences."

"During a manic episode…I took him to the hospital and he was admitted quickly. They gave him medication to calm him down and sent him home. The problem never really gets addressed, only the presenting symptoms of the crisis."

"He would know how to behave to seem ok and get sent home."

Emergency Department stays while waiting for an inpatient bed

"There was a 72 hour delay."

"The wait is ridiculous for a bed."

"Usually she has been taken to the ER by the police based on a 911 call. In ER waited one to three days."

Law Enforcement Response

"When the police came to myself themselves they were very helpful. They transported him to the hospital without handcuffing him."

"I had to call the cops 3 times…they threw (the child) down and tasered him."

"The police officer was good. Was not my experience in the past."

"The police did a good job."

"The police need mental health training. The police and ambulance drivers are judgmental of you."

Criminal justice and contacting law enforcement officers

"I deal with Baltimore city. The only thing the police do when they come out to my house is refer me to juvenile justice."

"A lot of it in my situation was the police. They will bring it back to your plate and say you need to control your child. We have had charges filed and went to court."

The police said that there was nothing they could do. Said we could press charges. They told us that we would have to take him to juvenile services and file charges."

Mobile Crisis Services

"DSS and Case Management at the Health Department has mobile crisis, but it is not mobile crisis. You call the crisis line and they say you could call the cops or you could take him to the hospital."

"Mobile crisis works when they're there. They give advice over the phone – they don't come out."

"They call it mobile crisis but it's more like PRP – targeted case management is more responsive than mobile crisis."
"Mobile Crisis doesn't have the money to operate 24/7."

"I called the crisis center – they sent the cops to my house."

"Mobile Crisis team takes hours to come. Ended up having to call 911 because they never got there."

"The women who came to my house (mobile crisis) seem unprepared to deal with a real crisis."

"If I call mobile crisis they tell me to call the police."

"I called the crisis center and they told me to call 911."

"I called mobile crisis about four times…when I called they didn't call me back for 24 hours. When they called they told me I needed to call 911. Really rude to me. Completely unhelpful."

"The schools don't even know to call the crisis people. They called the police, who called crisis services. He just came out and lectured the child. I don't know what their training is."

"If you call after 6:00 at night forget it. You just get the message to call 911."

"I've called mobile crisis and had to leave messages. They never returned my call."

"One time I called and they told me to bring her in. They would not come out to the house."

"Mobile crisis only talked to me over the phone."

"Last experience with mobile crisis was good. It took them an hour to get to there."

"During a manic episode, I called the crisis team and waited three hours, then I took him to the hospital and he was admitted quickly."

"I called mobile crisis response. By the time they arrived (2 ½ hours later), he had calmed down and gone to bed.

Appendix A. Demographics n=48

Family

Birth Family	35
Adoptive Family	4
Foster Family	1
Relative Caregiver	7
Guardian	1

Jurisdiction

Allegany	6	Dorchester	5
Anne Arundel	1	Harford	4
Baltimore County	8	Montgomery	7
Baltimore City	5	Queen Anne's	2
Caroline	2	Talbot	2
		Washington	1

Gender

Male	33
Female	15

Age

0-9	4
10-13	8
14-17	24
18-21	12

Health Insurance

Medicaid	35
Private Insurance	13
None	1
"Care for Kids"	2

Diagnoses

ADHD	33	PTSD	10
Anxiety D/O	24	Sleep D/O	9
Mood Disorder NOS	23	Conduct D/0	8
Depression	22	Self-injurious Behavior	8
Bipolar D/O	19	Trauma History	7
Oppositional Defiant D/O	19		

Medication Use

Yes	39
No	8

If Yes, Average Number of Medications

4.4

Agency Involvement

DSS or Foster Care	28	Substance Abuse Services	9
Special Education	39		
Juvenile Services	17		

Notes:

[i] As stated, the survey was 13 pages long. It proved cumbersome and somewhat confusing to some families. Of particular difficulty was responding to questions about a crisis when some families reported that they had experienced as many as 15 crises in the previous two years (the average was 3.73). Given time constraints, it was not possible to ask families to complete the survey for each crisis. Some families chose to report on just one crisis only; other families gave composite answers to the questions. For example, to the question, "Where did the crisis occur?" instead of checking one box, one family answered that two had occurred at home, two had occurred at school, and one had occurred in the community. Such inconsistency in the responses makes it difficult to conduct any meaningful data analysis.

Further problems arose with families differently interpreting the question than the survey had intended. For example, to the question if a family had used a mobile crisis team, a number of families replied that yes, they had, when from the conversations held in the focus groups it was clear that they were not referring to mobile crisis teams but to mobile treatment services available through family preservation services through DSS. Confusion also arose over the question about care-coordination and stabilization services. Some families reported that they had received this service, when in fact it was not available in their community. They interpreted the question to mean case management. It is extremely important to note that families interpreted various crisis services that the survey queried in a different manner than the survey intended. Families have their own unique understanding of crisis services.

For these reasons, the surveys cannot be broadly used for data analysis. The surveys are rich in information about families' use of crisis services, but they do not lend themselves to an overall data analysis.

[ii] All 48 families answered these questions.

[iii] One family did not answer this question.

[iv] The definitions given here regarding crisis services are taken from the definitions in the survey that was distributed to families.

[v] See above.