

# Relinquishing Custody - ***AN ACT OF DESPERATION***

A Study Conducted  
by  
**The Maryland Coalition of Families  
for Children's Mental Health**

**September 2002**



Caring for a child with complex mental health needs requires dedication, stamina, persistence, courage and love. It also can require access to mental health services ranging from inexpensive community supports to more costly residential care, services that often cannot be obtained under insurance or under Medical Assistance. This is what one hundred eighty-three (183) families who participated in this study revealed to us through their experiences. Not a single family spoke of anything less than finding the most appropriate services for their child. As the issue of custody was raised in the survey, or during telephone interviews or focus groups, families responded to the mere thought of losing custody with words of pain and anguish at having to legally sever their parental role and relationship with their child. Truly each family came to the issue of custody relinquishment or losing custody as a last resort – ***an act of desperation.***



## **Acknowledgements**

Special thanks to all of the families who participated in the study



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The full report is available on the Coalition's website  
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## Defining the Issue

The custody issue is complex and is often defined in different ways. For the purposes of this study the issue of custody refers to either:

**1) Relinquishing or giving up custody of a child to the state**

Families may be advised to relinquish custody of their child to the state so that the child qualifies for Medicaid in order to pay for intensive, costly mental health services, including residential care. This situation occurs particularly when the child has private insurance that does not cover intensive mental health services.

**2) Losing custody as a result of being unable or unwilling to care for the child at home**

Responsible and involved families who can no longer care for their child at home feel they have no other option than to refuse to bring their child home from the hospital or other out-of-home placement when they are informed that the child is being discharged. In this instance families are told they will be charged with abandonment. Court proceedings then transfer custody of the child from the family to the Department of Social Services.

While there are differences in these situations, there are more similarities. In each instance the family cannot manage the child at home and they believe the child needs intensive services in the home and community, or more typically out-of-home residential services in settings such as a residential treatment center (RTC) or group home. Secondly, in each situation the family has no means to access or to pay for the services their child needs. And third, the end result is the same – a child is separated from their family. For these reasons, the study did not differentiate between relinquishing or losing custody of a child with mental health needs. Throughout this report the term “custody issues” will refer to both types of situations.



### Legal Definitions

**Custody** means the “right and obligation, unless otherwise determined by the court, to provide ordinary care for a child and determine placement.”

Md. Code Ann. Courts and Judicial Proceedings (CJ) § 3-801(k)

**Guardianship** means “an award by a court...of the authority to make ordinary and emergency decisions as to the child’s care, welfare, education, physical and mental health and the right to pursue support.”

Md. Code Ann. CJ § 3-801(n)

## Background

### "Stuck Kids"

The term used by State officials to refer to children whose families are unwilling or unable to take their children home from the hospital or other out-of-home placement such as an RTC.

### A National Perspective

The issue of custody relinquishment is not new or unique to Maryland. In 1989 the Research and Training Center on Family Support and Children's Mental Health<sup>1</sup> conducted a survey of 966 families. Twenty-five percent (25%) of the families responded that it had been suggested that they give up custody as a means to access appropriate, and often costly, mental health services for their child. Ten years later, in 1999, the National Alliance for the Mentally Ill surveyed families of young children with mental health needs and found that twenty-three percent (23%) of the families had been told to relinquish custody.<sup>2</sup> In 1999, the Bazelon Center for Mental Health Law published **Staying Together**, an analysis of state policies and legislation around the country pertaining to custody relinquishment.<sup>3</sup> In 2000, Bazelon followed with a monograph titled, **Relinquishing Custody, The Tragic Result of Failure to Meet Children's Mental Health Needs**.<sup>4</sup> Most recently the State of Missouri received national attention for enacting legislation in 2002 that allows families to obtain mental health treatment for their children without relinquishing custody. The Missouri Family Services Division estimated that 500 children – or 20% of the children in the agency's special foster care and RTC facilities – were in its custody solely because families could not otherwise access the appropriate level of mental health care.

### Maryland's Efforts

In 1996, the Maryland Disability Law Center (MDLC) brought to the state's attention the issue of children remaining in psychiatric facilities beyond their recommended discharge date. Families felt they were unable to safely care for their children at home and thus were told to relinquish custody, or, if they did not bring their child home from the hospital, risk being charged with abandonment and losing custody. MDLC's effort resulted in a series of responses by state agencies over a period of years:

- In December 1999, the Subcabinet for Children Youth and Families adopted a policy "to assist in assuring that minors who are receiving inpatient care for mental illness do not remain hospitalized past a recommended discharge date and are discharged to an appropriate setting."
- In March and October 2000, the Subcabinet adopted two different protocols for "Facilitating Discharge of Certain Minors from Inpatient Facilities."
- At the direction of the Office for Children Youth and Families, a "Stuck Kids" Steering Committee of state and local agencies and advocacy organizations was convened in Spring 2000 to develop a protocol for addressing situations *when families are "unable or unwilling" to bring their child home from the hospital.*
- The Department of Human Resources issued a memorandum in October 2000 to the local Departments of Social Services clarifying that the legal definition of Child in Need of Assistance (CINA) includes children who are "mentally handicapped" and that voluntary placement may be an option in these situations.

- The Mental Hygiene Administration committed \$2 million for one year from June 2000 – August 2001 to help fund service plans for youth who were hospitalized in psychiatric units and whose families were unable to have their child return home. During this time, placements for approximately 50 children were funded in short-term programs on the grounds of three psychiatric hospitals. These programs were referred to as “respite programs.”
- In December 2000 the Office of Children Youth and Families filed a report with the Chairs of the Senate Budget and Taxation Committee and the House Appropriations Committee on the efficacy of the 1999 interagency policy.
- The Mental Hygiene Administration also received a grant in 2000 from the Center for Mental Health Services to receive technical assistance from the Bazelon Mental Health Law Center on policy and funding strategies.
- In March 2002, the Department of Human Resources issued a “Roundtable Report on ‘Stuck Kids’, Closing the Gap on Inappropriate Placements.” The report presented a picture of increasing numbers of children with intensive mental health needs coming into foster care. The report also documents that the problem of custody also affects families caring for a child with developmental disabilities as well as families caring for a child with mental health needs.

Throughout the State’s ongoing efforts to address the issue of custody relinquishment, advocacy groups reported to the state and to the legislature that the related problems of “stuck kids” and custody relinquishment persisted. The Coalition also observed this through its involvement with several families who lost custody of their children. These real experiences brought the issue of custody from the level of a theoretical policy discussion to a tragic and very personal level. The experiences of these families prompted the Coalition to conduct a formal study on the issue of custody seeking direct input from families. The study, ***Relinquishing Custody - An Act of Desperation***, was initiated in Fall 2001 and completed in Spring 2002.



## Notes

<sup>1</sup>*Focal Point*, Spring/Summer 1990 Portland State University, Research and Training Center on Family Support and Children’s Mental Health.

<sup>2</sup>*Families on the Brink: The Impact of Ignoring Children with Serious Mental Illness*, NAMI Newsletter, The Advocate, 1999.

<sup>3</sup>*Staying Together: Preventing Custody Relinquishment for Children’s Access to Mental Health Services*, Bazelon Center for Mental Health Law and Federation of Families for Children’s Mental Health, 1999.

<sup>4</sup>*Relinquishing Custody, The Tragic Result of Failure to Meet Children’s Mental Health Needs*, Bazelon Center for Mental Health Law, 2000.

## **Methodology**

### **Goal**

The goal of the study was to provide empirical data to gain a better understanding of:

- ❖ The prevalence of families being advised to give up custody or losing custody of their child as a result of their child's mental health condition
- ❖ Factors that may predict or influence custody becoming an issue for a family
- ❖ Experiences of families who were faced with custody relinquishment

### **Protocol**

The study consisted of three methods: a) 25-question survey mailed to families; b) telephone interviews with a sub-group of families who responded to the survey; c) focus groups with families who were faced with loss of custody.

Criteria for inclusion in the study were: The family must be caring for a child who has been hospitalized for mental health treatment in the past two years for:

1. One episode of seven consecutive days, or
2. Two or more episodes.

Surveys were distributed through Core Service Agencies, Local Management Boards, Local Coordinating Councils and advocacy organizations. Notices were placed in local newspapers and the survey was posted on the Coalition's website. With approval of the Department of Health and Mental Hygiene Institutional Review Board, the Mental Hygiene Administration mailed surveys to families in the public mental health system who met the criteria. Families were paid a \$10 stipend for completing the survey. To protect confidentiality, surveys were not signed and families could separately submit a form to receive their stipend. Families could also elect to participate in a telephone interview. Approximately 1200 surveys were distributed throughout the state. One hundred seventy-six (176) surveys were returned. This represents a 14% return which is higher than the 10% return expected for mailed surveys.

Following the completion of the surveys, two focus groups were held with seven additional families who had confronted custody issues in the past year. These families are not included in the statistical analysis but their experiences are represented in the conclusions and recommendations.

### **Measure/ Instrument**

The primary measure used was the "Listening & Learning from Families Survey." Focus groups conducted by the Coalition along with indicators from the literature were used to identify relevant dimensions for this survey. A checklist of items designed to reflect these dimensions were developed and tested for reliability and clinical relevance. This survey provided information on hospital length of stay, type and intensity of services delivered, prescreening living arrangement, placement stability, demographics, and diagnosis. Survey variables were selected for their clinical relevance, low frequency of missing data, and likely impact on the model based on a priori examination.

### **Limitations**

It is recognized that the study has limitations for several reasons. Because the bulk of the surveys was mailed to families whose children qualified for Medical Assistance, the sample is

somewhat skewed. Such families would have access to a wider array of mental health services than families with private insurance and might be at less risk of being forced to relinquish custody. It is also possible that families who have given up custody may be reluctant to come forward and share their painful experience. Additionally, there are gaps in some of the data as families may not have completed every question. The survey represents just a moment in time for the child and family. A longitudinal study would perhaps provide a fuller picture of the risk of custody over time.

The study is noteworthy, however, because it is the first time the issue of custody has been studied in an empirical manner and the results have corroborated significant factors and raised questions about previously held assumptions.

### **Sample**

It is estimated that through various means of distribution, approximately 1200 surveys were distributed. One hundred eighty (180) or 14% of the surveys were returned. Four surveys were not included in the study because they did not meet the established criteria bringing the total sample to one hundred seventy-six (176). The following summarizes the characteristics of the parents of the children who were hospitalized:

- 38% were female
- 62% were male
- Average age 12.8 years (SD = 3.4)
- 57% white
- 42% African-American
- 2% Hispanic, Native American and bi-racial
- 76% Medicaid
- 11% Private Insurance
- 11% Medicaid and Private Insurance
- 2% Uninsured or Grey Zone

### **Qualifiers vs. Non-Qualifiers**

The survey was designed to identify those families who had been faced with the issue of custody. This was done by using responses to three specific questions:

- Custody question:

*“I was told that if I gave up custody of my child I could get services for my child.”*

- Abuse question:

*“I was told I could be charged with abuse and neglect if I did not bring my child home from the hospital.”*

- Abandonment question:

*“I was told I would be charged with abandonment if I did not bring my child home from the hospital.”*

Any family answering "yes" to one or more of these 3 questions was considered a "qualifier" for the study, and this term will be used to describe this group in all further analyses. A total of 48 (27%) families within the total sample met this criterion. The remaining 128 (73%) families made up the non-qualifying group.



## RESULTS

### Demographic Information

A series of chi-square analyses were computed to determine which demographic variables were related to whether families were told they could receive services if they relinquished custody or whether families who had been told they could be charged with abuse, neglect, or abandonment.

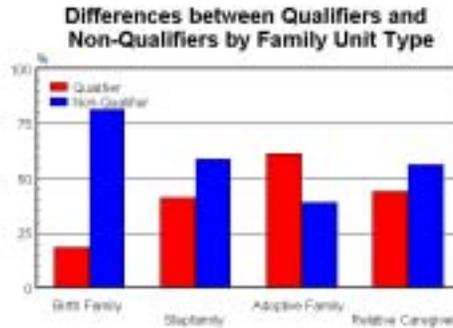
### Family Unit

Of the 176 responses, 118 or just over 2/3rds of the families were birth families. The remaining families were stepfamilies, adoptive families, foster families, relative caregivers, emancipated youth, and other caregivers. Three groups were dropped from the analyses because there were too few responses (foster family, other caregiver, and emancipated youth).

- There was a significant difference in the proportion of qualifiers dependent upon family unit,  $\chi^2=4.47$ ,  $p<.05$ . Further analyses indicated that the proportion of qualifiers from birth families were less likely to be qualifiers than any of the other groups. Less than 25% of the birth families were in the qualifier group, while approximately 50% of caretakers within non-birth groups were qualifiers. There were more adoptive families in the qualifier than the non-qualifier group.

Birth families were less likely to be in the qualifier group than non-birth families.

The chart below shows the differences in the proportion of qualifiers by family type.



Further analyses revealed that non birth-parent caretakers showed a significantly higher proportion of “yes” responses on the Abuse ( $\chi^2=16.07$ ,  $p<.05$ ) and Abandonment ( $\chi^2=18.61$ ,  $p<.01$ ) items, but not on the Custody item ( $\chi^2=7.30$ ,  $p>.05$ ). Therefore, they were placed in the qualifier group because of being told they would be charged if they refused to take their children from the hospital rather than being told to relinquish custody to access services.

The relatively large proportion of non-birth parents in the qualifier group was due to families being told they would lose custody and be charged with neglect, abuse, or abandonment rather than relinquishing of custody for services.

The finding for adoptive parents was interesting. There were 18 adoptive families within the sample, with 11 in the qualifier and 7 in the non-qualifier group.

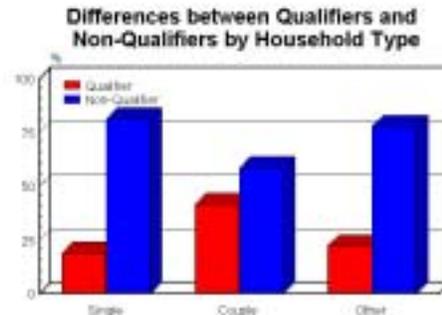
In contrast to other family types, Adoptive Families were more likely to be found in the qualifier than the non-qualifier group.

**Household**

Participants were asked to describe their household in terms of single, couple or other. The largest group (57.7%) indicated that they were a single parent. Thirty-seven percent described themselves as a couple. The remaining respondents (5.1%) checked off the “other” category. “Other” was most often a mother raising the child with another relative such as a grandmother or aunt.

More than half of the caretakers within this sample described themselves as single parent caretakers.

The chi-square analysis indicated that a much greater proportion of couples were more likely to be qualifiers ( $\chi^2=10.2$ ,  $p<.01$ ). More than 40% of the Couples group were qualifiers, while approximately 20% of the Singles and Other groups were qualifiers.



On all three of the dependent variable items (Custody, Abuse, and Abandonment) there were a significantly greater number of "yes" responses from couples than from single parent households. This was the only demographic variable where the Custody variable was a factor in discriminating between families.

Couples were more likely to be told to relinquish custody to access services than either single parents or other caretakers.

### **Demographic Information Other**

No other demographic information differentiated qualifiers and non-qualifiers. Custody issues cut across race, ethnicity, number of children, age of child, gender of child, and whether or not the child had another disability.

### **Race**

Within the sample the breakdown of the parents race was as follows: 41% African-American, 57% White, 1% Hispanic, and 1% Native American. The breakdown of the children's ethnicity was similar, except 4% were biracial. Neither the race of the caretaker or that of the child was a factor in determining the percentage of qualifiers.

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### Number of Children

This question was divided into sub-questions indicating how many children were in the family including those living away from home, and how many were living in the home. Total number of children ranged from 1-15 with more than ¾ having four or fewer children. Number of children still living at home ranged from 0-9 with over ¾ having three or less. Neither the total number of children or the number of children living at home was a factor in determining the percentage of qualifiers.

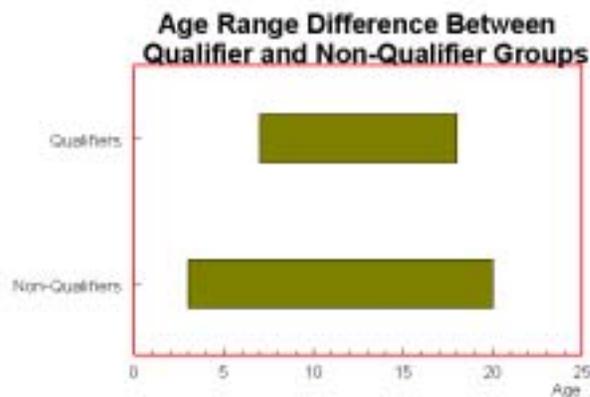
Neither the total number of children nor the number of children living at home was a factor in determining the percentage of qualifiers.

### Age of Child

The age of the child who had been hospitalized ranged from 3 to 20 years with the mean age being 12.8 years. The mean age for qualifiers was 13.5 and for non-qualifiers was 12.6. The t-test computed to determine whether the age difference between these groups was not significant ( $t=1.79$ ,  $df=111$ ,  $p>.05$ ).

There was no significant difference in the mean ages of children in the qualifier and non-qualifier groups. However, the range of ages in the qualifier group was smaller than in the non-qualifier group.

The age range for qualifiers was 7 to 18 years and for non-qualifiers was 3 to 20 years. The variances for these 2 groups were significantly different (Levene's  $F=7.54$ ,  $p<.01$ ). It is interesting to note that none of the families with younger or older children was included in the qualifier group. Custody is less of an issue for families with preschooler child or children past the age of majority.



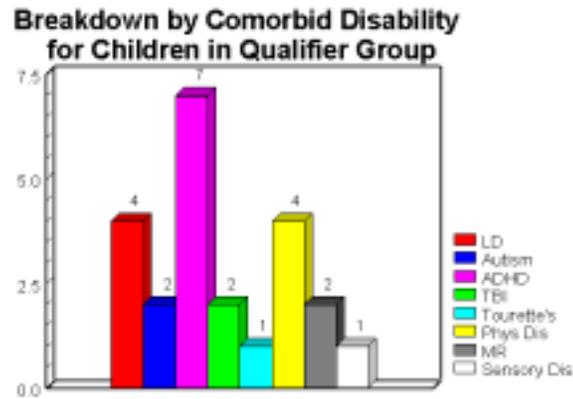
## Gender

Within the sample, approximately ¼ of the males and females were in the qualifier group. There were no significant differences in the proportions in the qualifier group by gender of the child.

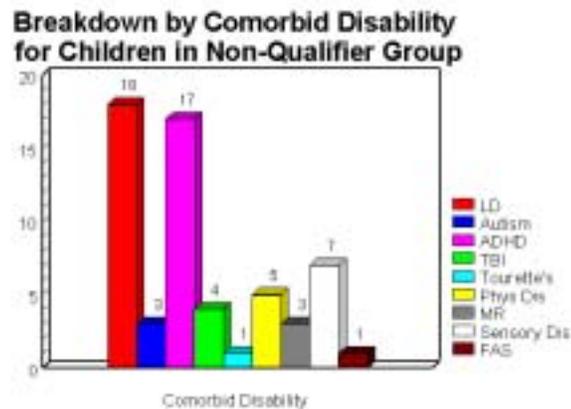
There were no significant differences in the proportions in the qualifier group by gender of the child.

## Other Disabilities

Breakdowns of the co-morbid disabilities of children within the qualifier and non-qualifier groups are shown in the charts below. The 3 largest disability categories for children within the qualifier group were attention deficit hyperactivity disorder (ADHD) (7), learning disabilities (5), and physical disabilities (4).



The breakdown for the children in the non-qualifier group is similar. This time, learning disabilities is the most frequently occurring co-morbid disability (18), followed by ADHD (17), sensory disabilities (7) and physical disabilities (5). The only difference is between the two groups seems to be in the sensory disability category, with more in the non-qualifying group.



There were no significant differences in proportions within the qualifier group by any of the specified co-morbid disabilities.

### **Involvement with Public Agencies**

Families whose children have complex mental health issues were frequently involved with multiple public agencies. The respondents were asked to check all public agencies they had been in contact with over time.

A larger proportion of qualifiers were involved with 5 of the 9 specific agencies.

A series of chi-square analyses were computed to determine whether there were differences in the proportion of qualifiers and non-qualifiers for those checking each public agency. There were significant results for 5 of the 9 agencies that were specified. In each of the significant results there was a larger proportion of qualifiers if the family was involved with the specific agency.

<b>Table 1.</b>					
<b>Breakdown of Qualifiers and Non-Qualifiers by Contact with Specific Agencies</b>					
	Had Contact With Agency		Did Not Have Contact With Agency		
<b>Agency</b>	<b>Qualifier</b>	<b>Non-Qualifier</b>	<b>Qualifier</b>	<b>Non-Qualifier</b>	$\chi^2$
Special Education	40	80	7	48	8.15**
Juvenile Justice	18	38	29	89	1.10
Core Service Agency	16	13	31	115	14.19**
Social Services	35	56	12	72	13.00**
Develop Disabilities	12	21	35	107	1.87
Local Management Bd	9	10	38	118	4.56*
Loc Coordinating Council	20	21	27	107	13.10**
Health Dept	13	36	33	92	0.00
Substance Abuse	4	17	43	111	0.74

\*\*p<.01 \*p<.05

As shown in Table 1, there was a significantly higher proportion of qualifiers for those families who had contact with Special Education, Core Service Agencies, Department of Social Services, Local Management Boards, and Local Coordinating Councils. Results were not significant for three agencies: the Department of Juvenile Justice, Developmental Disabilities, and the Health Department. In both DJJ and DDA there was a higher proportion of qualifiers where families had contact, but the results were not significant.

There was not a larger proportion of qualifiers if the family was involved with the Department of Juvenile Justice.

The results for specific agencies were consistent across all 3 questions defining the qualifier group. That is, when participants who were in contact with specific agencies indicated a high proportion of being told they may be charged with abuse, neglect, or abandonment, they also reported more suggestions of relinquishing custody for access to services.

### **Hospitalizations**

Respondents were asked several questions with respect to hospitalizations for their child within the last 2 years. These included frequency and duration of hospitalization, symptoms prior to the most recent hospitalization, services received prior to hospitalization, and readiness for discharge.

Using the chi-square analyses, several of these hospitalization questions showed significant differences between the qualifier and non-qualifier groups.

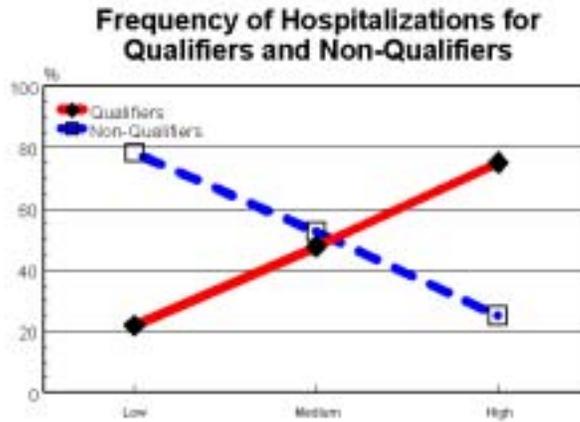
### **Frequency of Hospitalizations**

Within the sample, the range of number of hospitalizations within the last 2 years was from 1-15. If a respondent indicated that their child was not hospitalized within the last 2 years they were not included in this sample. Because of some small frequencies the responses were combined into 3 groups: Low (1-3 visits), Middle (4-6 visits), High (7-15 visits). As expected, most of children within the sample were in the Low group (83%) with 12% in the Middle group and 5% in the High group.

The families who qualified for the study had significantly more visits in the previous 2 years ( $\chi^2=15.82, p<.01$ ). For families in the Low group only 22% qualified, in the middle group 48% qualified, and for the high group 75% qualified. The data would indicate that families whose children required frequent hospitalizations were not receiving services needed to keep their children at home. Consequently, they were more likely to be told that to relinquish custody of their child in order to access a higher level of care. They were also being told they would be charged with abandonment more when they refuse to take their children home.

For families in the low group, only 22% qualified; in the middle group, 48% qualified; and for the high group, 75% qualified.

The pattern for all three qualifying questions was the same. The largest proportion answering “yes” to each question were among families whose children had the most hospital visits. On the Custody question, 62.5% of the families in this group were told to relinquish custody. The percentage of “yes” responses declined when children had less frequent visits to the hospital.



### Length of Hospitalizations

The length of hospitalizations for each stay ranged from two days to more than a year. There did not seem to be any relationship between length of stay and whether or not a family qualified for this study. However, the data were difficult to interpret because parents appeared to be confusing hospitalizations and stays in residential treatment centers.

There was no relationship between length of hospital stay and whether or not a family was in the qualifier group.

### Symptoms Prior to Hospitalization

The survey provided families with a list of 27 possible symptoms that a child might have exhibited prior to the most recent hospitalization. There was also an opportunity for the respondent to specify a symptom that was not on the list. Of these 28 categories, seven of the symptoms showed a significant difference in the proportions within the qualifier and non-qualifier groups.

There were seven symptoms that differed for the two groups. These included running away from home, stealing, reported history of being physically or sexually abused, reported history of physically or sexually abusing others, and inappropriate sexual activity, all of which involve issues of safety for the child or for others. In addition, being afraid others were out to get them and being manic were significantly different for the two groups. The table below shows the data and results for the significant Symptoms.

<b>Table 2</b>					
<b>Breakdown of Qualifiers and Non-Qualifiers by Significant Symptoms</b>					
	Exhibited Symptom		Did Not Exhibit Symptom		
<b>Disability</b>	<b>Qualifier</b>	<b>Non-Qualifier</b>	<b>Qualifier</b>	<b>Non-Qualifier</b>	$\chi^2$
Runaway	24	40	24	87	5.14*
Stealing	28	44	20	84	8.29**
Abused	21	35	26	91	4.47*
Abusive	12	8	36	118	11.89**
Inapprop Sex Act	18	23	30	104	7.30**
Manic	27	44	20	82	7.18**
Paranoid	25	37	23	90	8.02**

\*\*p<.01 \*p<.05

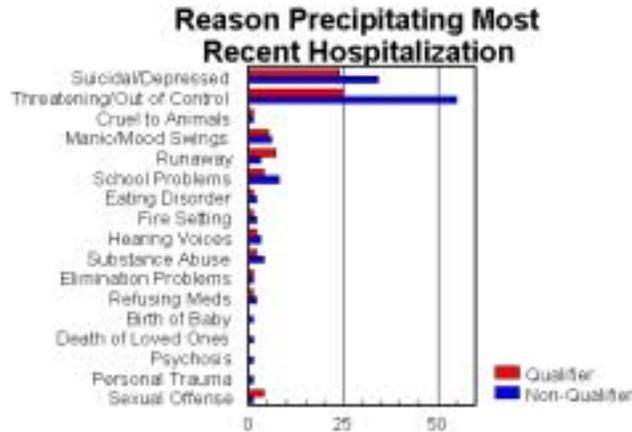
For each of the significant symptoms, there was a greater proportion of qualifiers when the symptom is exhibited. In fact, for one category, reported history of physically or sexually abusing others (Abusive) 60% of these families were in the qualifier group.

For one symptom, reported history of physically or sexually abusing others (Abusive), 60% of these families were in the qualifier group.

Some of the categories that one might have expected to differentiate between the two groups are not included in Table 2. These include: involvement with drugs or alcohol; threatening family members; suicidal threats or attempts, out of control behavior such as throwing things, fighting, misconduct in school, obsession with weapons, cruelty to animals, and anxiety, among others.

### Reason or Event for Most Recent Hospitalization

Families were asked to select one reason or event that precipitated their child's most recent hospitalization. Even though the question asked for the major reason, some parents provided more than one reason. The results from this open ended question were tabulated and shown in the graph below:



The two most frequent reasons children were hospitalized involved safety issues: depression and suicide attempts or threatening and out of control behaviors. In addition, the 48 families in the qualifier group responded to this question with 78 symptoms precipitating the most recent hospitalization while the 128 families in the non-qualifier group responded with only 125 symptoms. It then follows that children in the qualifier group might be exhibiting more symptoms requiring hospitalization.

Caretakers in the qualifier group indicated their children exhibited significantly more symptoms requiring hospitalization.

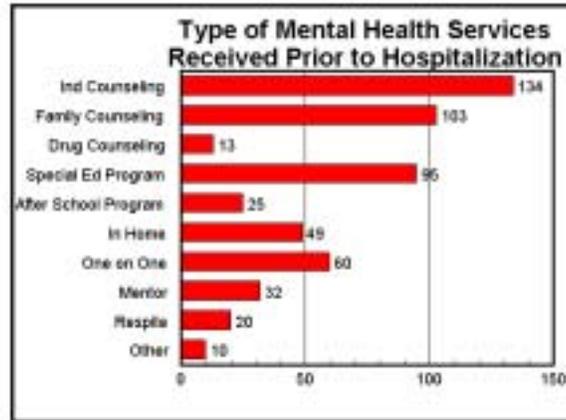
### Prior Mental Health Services

Families were asked if their children were receiving mental health services prior to the most recent hospitalization and if so, what services were they receiving. There were significant differences between the two groups receiving mental health services ( $\chi^2=6.83, p<.01$ ). Thirteen percent of all the children in the study were not receiving mental health services prior to their most recent hospitalization. However, only 2% of the children in the qualifier group were not receiving mental health services, while 17% of the children in the non-qualifier group were not receiving any mental health services.

A significantly greater proportion of children within the qualifier group were receiving mental health services prior to their most recent hospitalization.

### **Type of Prior Mental Health Services**

Of the 10 types of mental health services listed on the questionnaire only one type showed significant differences between the qualifier and non-qualifier groups (Special Education Program During School,  $\chi^2=5.30$ ,  $p<.05$ ). There were no differences in individual counseling, family counseling, drug or alcohol counseling, after school programs, in-home support services, one-on-one behavioral support, mentoring, or respite.



Of the 10 types of mental health services listed on the questionnaire, only Special Education Program During School showed significant differences between the qualifier and non-qualifier groups.

One would think that the children receiving certain types of services might be more represented in the qualifying group. The results of these analyses indicated that this was not the case. The one exception is that the children in the qualifier group were more likely to receive mental health services within a special education program during school hours. Perhaps the qualifying children were in a higher intensity level at school.

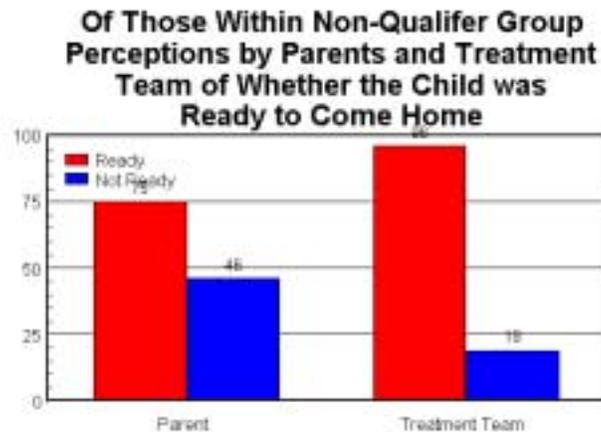
### **Readiness for Hospital Discharge**

Families were asked three questions about their child's readiness to be discharged from their most recent hospitalization. The first question involved the parent's perception of readiness of the child's hospital discharge. Two additional questions pertain to the treatment team within the hospital. Almost 90% of the families were aware that their child had a treatment team while the child was in the hospital. These parents knew that doctors, nurses, social workers, psychologists, therapists, and other hospital staff were on the team. Fewer than 10% of the families considered themselves to be part of the child's treatment team. The same percentage reported that someone representing their child's education was on the team. Two teams had behavioral specialists, two teams had dieticians, and two teams had DSS workers. Other members on one or two teams included a neurologist, a physical therapist, an occupational therapist, a case manager, a representative from the LCC, a representative from the CSA, a pre-adoptive parent, and one parent reported that the child was on her treatment team. This treatment team had input into the decision regarding the child's readiness for discharge. Families reported that 90% of the teams for the non-qualifier group and 80% of the teams for the qualifier group thought the children were ready to come home.

Families within the qualifier group were less likely to think that their child was ready to come home.

There was a significant difference in proportion of qualifiers based on parent perception of whether the child was ready to come home ( $\chi^2=20.71$ ,  $p<.01$ ). Families in the qualifier group were less likely to think that their child was ready to come home. However, there was no significant difference in the proportion of qualifiers based on the perceptions of the treatment team ( $\chi^2=5.59$ ,  $p>.05$ ). This dramatic difference was shown in the significant chi-square result when relating parent and treatment team perceptions to proportions within the qualifier group ( $\chi^2=24.48$ ,  $p<.01$ ) as well as the following graph. When parents perceived that the child was ready to leave they were not likely to end up in the qualifier group. Conversely, if the treatment team felt that the child was ready to leave the family was very likely to end up in the qualifier group.

When parents perceived that the child was ready to be discharged, they were not likely to end up in the qualifier group. Conversely, if the family did not feel the child was ready to be discharged, the family was more likely to end up in the qualifier group.



Further, this crossover effect was not evident within the non-qualifier group. A family was more likely to end up in the non-qualifier group if either the parent or the treatment team perceived that the child is ready to leave the hospital.

### After Discharge

A multi-part question was asked to determine what happened when a family was told that their child was ready to be discharged. As shown in Table 3 below, chi-square analyses revealed that all of these discharge options were significantly related to placement in the qualifier group.

**Table 3**

#### **Breakdown of Qualifiers and Non-Qualifiers by Response to Discharge Questions**

Upon Discharge:	Answered Yes		Answered No		$\chi^2$
	Qualifier	Non-Qualifier	Qualifier	Non-Qualifier	
Brought child home from hospital	37	123	10	4	15.24**
Given discharge plan with services	31	100	16	25	4.03*
Refused to pick up child at hospital	9	0	36	127	26.80**
Told staff child was not ready	35	24	12	103	47.27**
Told staff can't care for child at home	18	5	29	119	34.38**
Told I could get in home help	25	32	20	92	13.07**
Told child needed long term care in RTC	21	13	25	113	26.53**
Told to take child home while awaiting RTC	21	13	25	113	26.53**
Told to leave child while awaiting RTC	6	5	41	122	4.52*
Child transferred while awaiting RTC	6	5	40	122	4.70*
Told about voluntary placement	13	0	34	122	36.56**

\*\*p<.01 \*p<.05

For all of these questions except for one ("told I could get in-home help") the results were in the expected direction. Qualifiers were:

- Less likely to bring their child home or to be given a discharge plan with services.
- More likely to refuse to pick up their child,
- More likely to tell staff that their child was not ready to come home
- More likely to state that they could not care for their child at home
- More likely to be told by staff that their child needed long term care in an RTC
- More likely told they should either leave their child or take their child home while awaiting a placement in an RTC.

These children were also more likely to be transferred to another hospital program while awaiting an opening in an RTC.

Qualifiers were more likely to refuse to pick up their child, tell staff their child was not ready to come home, state they could not care for their child at home and be told that their child needed an RTC.

An interesting result was observed on the final question about voluntary placement. It is important to note that Maryland law permits voluntarily placements in foster care without relinquishing custody. However, only 13 of the families in this sample (7.7%) were informed about voluntary placement.

Only 7% of the families were informed about voluntary foster care placement, and all were included in the qualifier group.

### **Told to Give Up Custody to Access Services**

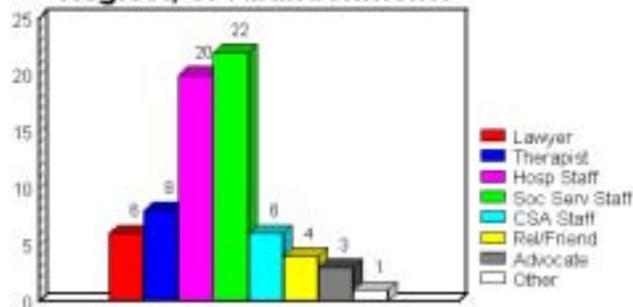
A significant item within this survey was the question "I was told that if I gave up custody of my child I could get services for my child". There were 29 respondents who answered "yes" to this question.

16% of the families were told that they could access needed services by relinquishing custody of their children.

### **Who Told You To Give Up Custody**

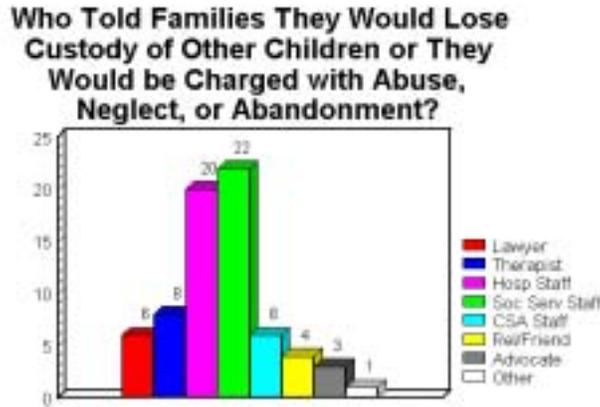
A total of thirty families within the sample reported that they were told that if they gave up custody they would get services. Fourteen of the families (45%) were told this from a relative or friend, 12 families (39%) were told this by social services staff, 8 families (26%) by a therapist, 8 by hospital staff (26%), 6 by an advocate (19%), 5 by CSA staff (16%), 2 by lawyers (6%), This breakdown is displayed in the following chart:

**Who Told Families They Would Lose Custody of Other Children or They Would be Charged with Abuse, Neglect, or Abandonment?**



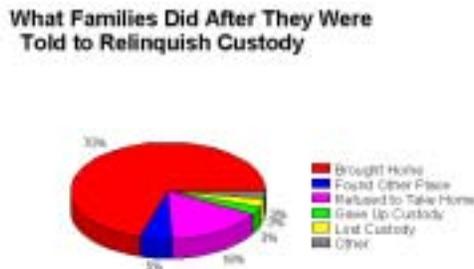
**Who Informed Families They Could be Charged with Abandonment?**

A breakdown of the people who told a caretaker that he/she would be charged with abuse, neglect, or abandonment is shown in the following chart. The majority of the threats were made by Social Service (31.4%) and hospital (28.6%) staff. The other listed persons made much smaller numbers of threats.



**What did Qualifier families do?**

The 48 families who were placed in the qualifier group were asked to specify what they did after they were told about relinquishing custody or told they would be charged with abuse, neglect or abandonment. While participants may have responded “yes” to more than one question, the results are shown in the chart below.



Within this group 26 participants brought their children home from the hospital, while only 6 refused to take their children home, and 2 found other living arrangements for their children. Two qualifiers gave up custody, 1 voluntarily. No qualifier indicated that they were actually charged with abandonment or abuse and neglect.

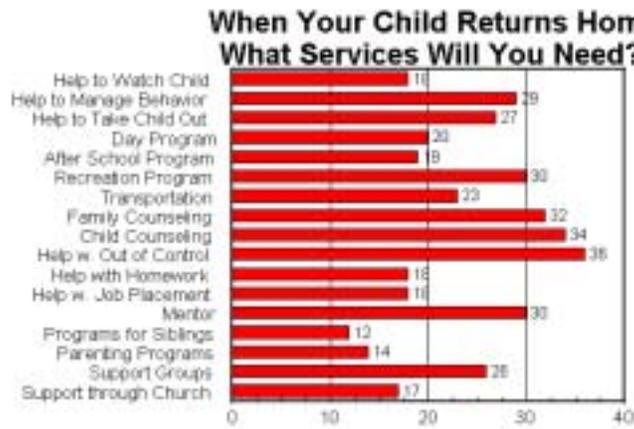
For families within the qualifier group, 26 participants brought their children home from the hospital while only 6 refused to take their children home. Two qualifiers gave up custody. No one reported that they were charged with abandonment.

While many caretakers were told to relinquish custody for services, few actually went that route. Similarly, despite the threats, none of the participants were actually charged with abandonment or abuse and neglect. There is a question of whether those who relinquish custody or were charged would be likely respond to this questionnaire or would respond accurately.

It is interesting to compare these results to those from the larger NAMI survey (1999), which reported that 20% of those who were told that they would have to relinquish custody to access services ultimately relinquished custody. Only 1 out of 30 respondents (.03%) followed that path in this study.

**Services Needed After Hospitalization**

For those families whose children were not living at home, respondents indicated their need for a variety of services after their child returns home. These needs are shown in the following chart.



The results in this chart are somewhat confusing. While only 30 families indicated that their child was living elsewhere, more than 30 families desired several categories of service needs. Some of the respondents misinterpreted the question, and answered even if their child was living at home. The most requested service needs, those checked by 30 or more families, were for someone to help the caregiver when the child gets out of control, counseling both for the child and for families, recreation programs for the child, and mentoring.

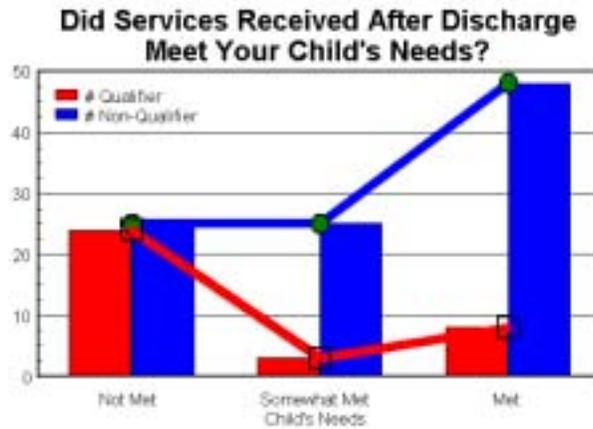
The most requested service needs after hospital discharge were for someone to help the caregiver when the child gets out of control, counseling both for the child and for families, recreation programs for the child, and mentoring.

### After Discharge, Did Services Meet Child's Needs?

In an open-ended question, families were asked if services received after discharge from the hospital or hospital program met their child's needs. The results showed 56 families reported that services received met their child's needs. Forty-nine families indicated that services had not met their child's needs. Twenty-eight families reported that services met their child's needs only to some degree or for some period of time.

If a family was in the qualifier group, they were significantly more likely to report that services had not met their child's needs.

There was a significant difference between the qualifiers and non-qualifiers with respect to needs being met. If the family was in the qualifier group, they were significantly more likely to report that services received had not met their child's needs ( $X^2=20.67, p<.01$ ).

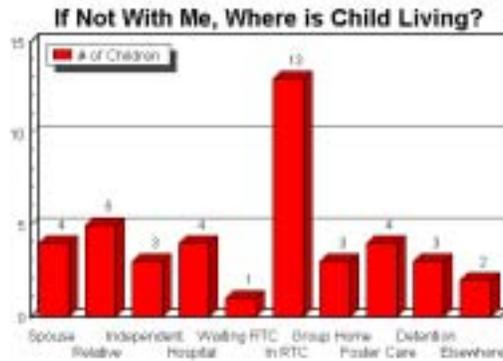


### Child's Current Status

#### Where is Child Living Now?

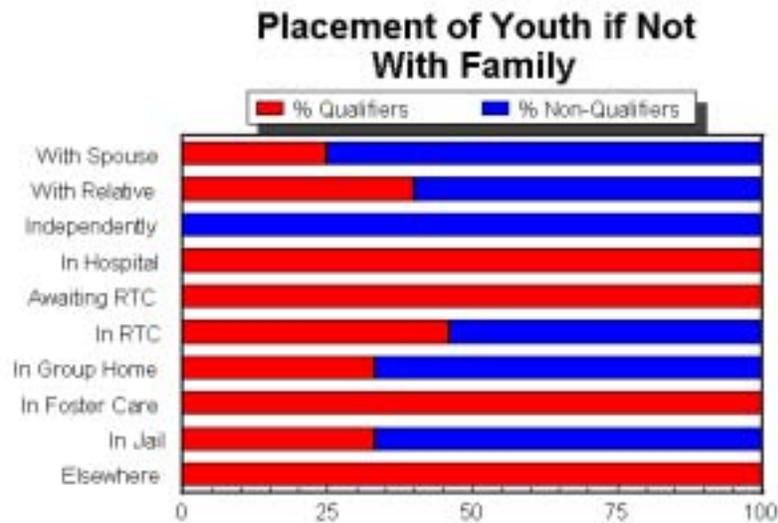
Families were asked to specify, from among 13 options, where their child was currently living. More than 80% of the families (142) responded that their child was living with them. Of the 30 families who specified that their child was living elsewhere, 13 were in an RTC and 4 more were living in a hospital. The remaining 13 families were spread out over the other categories as can be seen in the chart below.

More 4/5 of the families indicated that their child was living at home with them.



There were differences between qualifiers and non-qualifiers with regard to where the child lived. The chart below shows these differences when the child was not living at home. None of the children in the qualifier group were living independently. All of the children living in a hospital, waiting for an RTC, in foster care, and living elsewhere ended up in the qualifying group. The remaining living categories cut across qualifier and non-qualifier groups. It was interesting to note that this was true for those in a detention center/jail as well as being in a group home, in an RTC, and being with spouses or relatives.

All of the children living in a hospital, waiting for an RTC, in foster care, and living elsewhere ended up in the qualifier group; all living independently, in the non-qualifier group.

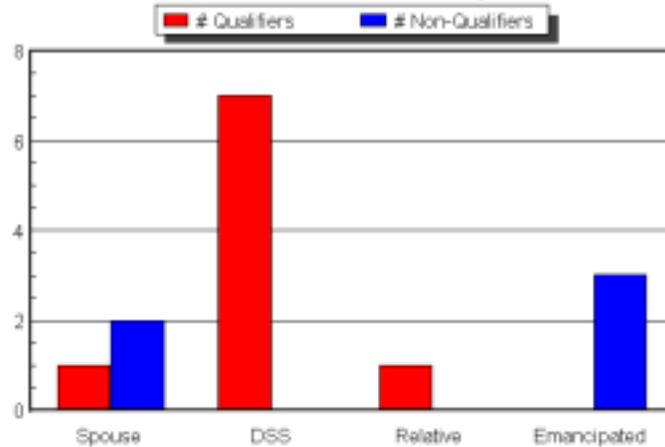


## Who has Custody of Child?

This question was designed to determine who had custody of the child at the time of survey completion. Within the sample, 158 respondents had custody of the child, and 14 did not. Of these 14 families half (7) were in the custody of DSS, spouses had custody for 3 children, a relative had custody for 1 child, and 3 were emancipated youth. As would be expected, all children in the custody of DSS or relatives were in the qualifier group, and none of the qualifiers were emancipated children. Where the parents or spouse had custody, the families were in both the qualifier and non-qualifier groups.

Of 14 families where the participant did not have child custody, half were in the custody of the Department of Social Services.

### If Not Me, Who Has Custody of Child?



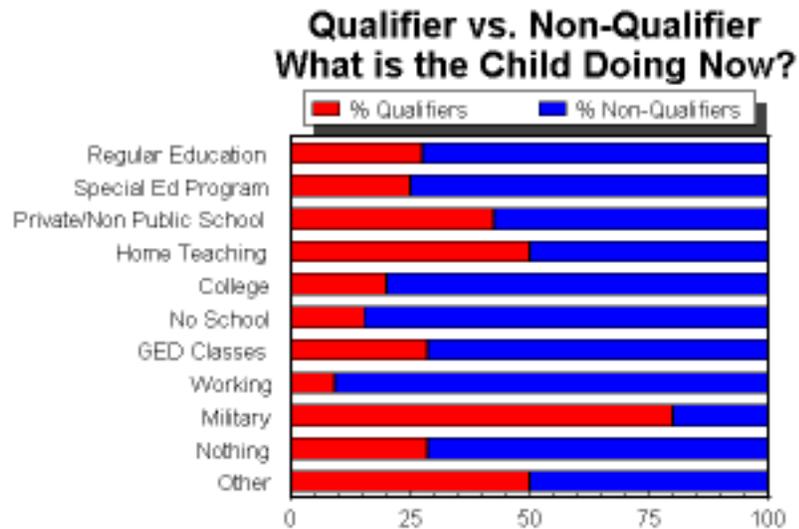
## What is Child Doing Now?

The vast majority of children within the sample were in school; 73 were attending regular public school, 52 were in special education programs, 40 were attending a private, non-public school, four were receiving home teaching, and 5 were attending college. Only 13 of the respondents indicated that their children were not attending school. The remaining 30 responses were divided into categories such as in the military, working, or doing nothing.

The vast majority of children within the sample were in some type of public or private school program.

What the child was doing did not seem to be related to their placement in the qualifier or non-qualifier group as shown in the chart below. However, those who were working tended not to be in the qualifier group and those in the military were included in the qualifier group. Perhaps caretakers viewed the military as an alternative to giving up custody to receive appropriate services.

What the child was doing did not seem to be related to their placement in the qualifier and non-qualifier group.



**Insurance**

**Type of Medical Coverage**

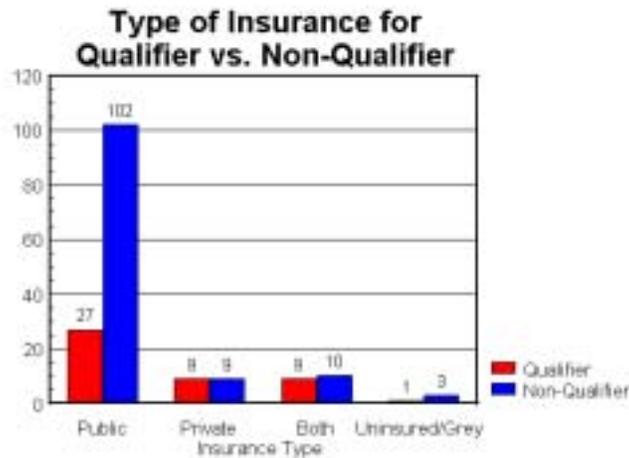
The types of medical coverage options were Public Assistance, (includes Medicaid, medical assistance, and Maryland Children’s Health Insurance Program), Private Insurance, Both, and Uninsured or Grey Zone. Within the sample 129 (76%) indicated Public Assistance, 18 (11%) had Private Insurance, 19 (11%) had both insurance types and 4 (2%) were Uninsured or in the Grey Zone.

Within the sample, more than 3/4 indicated they relied on Public Assistance for medical coverage.

Since more than 1000 of the approximately 1200 of these surveys were mailed out through Maryland Health Partners the large number of public assistance responses was probably not representative of the general population in Maryland. This selection factor must be taken in account when interpreting these analyses.

Despite the over-representation of families whose children receive Medical Assistance in the sample, there was overwhelming evidence that those who had private insurance either exclusively or together with public insurance were significantly more likely to be in the qualifier group ( $X^2=11.23$ ,  $p<.05$ ).

Families who had private insurance either exclusively or together with public insurance were significantly more likely to be in the qualifier group.



### Does Insurance Affect Care?

Families were asked whether they thought their insurance coverage affected their child's mental health care. Within the sample 71 (42%) respondents indicated that their insurance type did affect mental health care, while 99 (58%) said it did not.

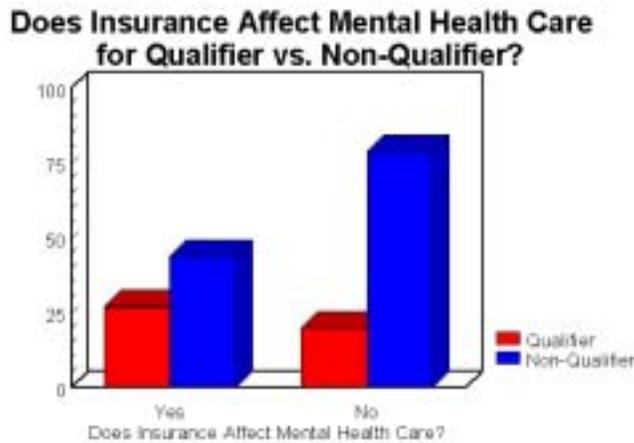
The majority of respondents indicated that their insurance type did not affect their mental health care.

This response was not consistent with the majority of literature and research, which points to the strong relationship between type of insurance and adequacy of mental health care.

The response to this question was significantly related to whether or not a family was in the qualifier group ( $X^2=6.57, p<.05$ ). As shown in the chart, a greater proportion of families who responded that insurance type affected care were in the qualifier group.

A greater proportion of families who responded that insurance type affects mental health care was in the qualifier group.

If a family has private insurance their coverage is less likely to pay for an array of mental health services, including community-based services and costly out-of-home residential placements. Therefore, they were more likely to be told to relinquish custody, which would provide the child with Medical Assistance. In addition, they were less likely to have a variety of services such as respite care or in-home services offered to them, which might enable them to keep their child at home.



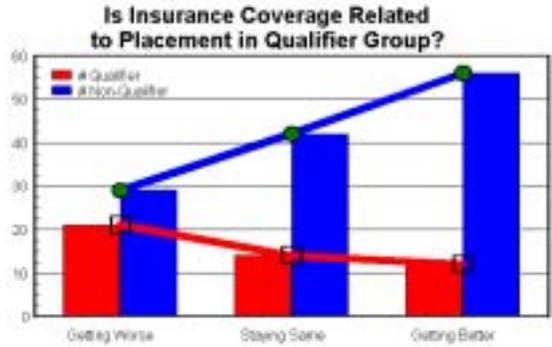
### Status of Child’s Mental Health

Families were asked to evaluate the change in their child’s mental health status over the past 2 years. Within the sample, 68 (39%) indicated that their child’s mental health improved, 50 (29%) said their child’s health deteriorated, and 56 (32%) felt that their status remained the same.

Significant differences between the qualifier and non-qualifier groups were shown to be dependent on the family’s response about the child’s mental health status ( $X^2=8.84, p<.05$ ).

Families within the qualifier group were more likely to feel that their child’s mental health condition was getting worse.

It is not surprising that families within the qualifier group were more likely to feel that their children were deteriorating. The proportion breakdown into qualifier and non-qualifier groups was similar for families who believed their children were staying the same or getting better. These trends are evident in the chart below:



There have been many lawsuits filed against private insurance companies for denying medically necessary health care treatment recommended by physicians for children and young adults suffering from mental illness. These private insurance companies routinely attempt to sidestep their coverage obligations by inappropriately shifting the cost of caring for such children to taxpayers and/or families. Private health insurance plans often limit the number of hospitalizations and therapy visits they cover. Many don't cover intensive home-based services or residential treatment centers at all.

It is, therefore, not surprising that a relatively large percentage of families within the qualifier group had private insurance and also believed that their children were losing ground over the past 2 years for lack of needed services.

Medical assistance covers a much wider array of services than any of the private insurance companies. The one main complaint is that there is no way to access residential treatment care if the child doesn't have medical assistance and the parent cannot pay afford to pay thousands of dollars out of pocket. Children with medical assistance also have access to many other support services such as respite, intensive in-home services, and mentoring that would help a family care for their child at home.

### **Logistic Regression**

A stepwise logistic regression was used to develop a model of whether or not a family would be included in the qualifier group, using demographic, clinical, and insurance variables derived from the Listening & Learning From Families Survey. The predictor variables were selected for their clinical relevance, low frequency of missing data, and likely impact on the equation based on the preceding chi-square analyses.

There were 11 predictor variables included in the design:

FAMUNIT – Family unit (birth, stepfamily, adoptive, relative, other)

HOUSE – Household description (single parent, couple, other)

OTHERDIS - Comorbid disability (yes/no)

- HOSP# - Number of hospitalizations
- MHSPRIOR - Prior medical health services (yes/no)
- READYHOM - Caretaker perception of child's readiness to come home (yes/no)
- TEAM - Was there a hospital treatment team (yes/no)
- TEAMREAD - Hospital teams perception of child's readiness to come home (yes/no)
- INSURANC - Type of medical coverage (public, private, both, none)
- AFFECT - Did type of medical coverage affect mental health care (yes/no)
- IMPROVED - Treatment progress (better, worse, same)

The results of the logistic regression to predict qualifiers from these clinical variables are shown in Tables 5. From the original 11 predictors, 4 were selected to be included in the model. Based on these 4 predictors the logistic regression generated a statistically significant model of the family likely to be included in the qualifier group (model  $X^2 = 50.68$ ,  $df = 11$ ,  $p < .001$ ), suggesting that the predictors classify better than the base rate. The overall accuracy of the model was 83.33%. Those in the non-qualifier group were predicted with higher accuracy than those in the qualifier group, at 94.0% and 55.26%, respectively. The positive predictive value (the odds of a family qualifying after that was predicted) was 48.8%. The negative predictive value (the odds of a family not qualifying after that was predicted) was 78.7%.

**Table 4**

**Classification Table to Predict Qualifiers vs. Non-Qualifiers from a Logistic Regression**

The Cut Value is .50

Observed	Predicted		Percent Correct
	.00	1.00	
.00	94	6	94.00%
1.00	17	21	55.26%
Overall			83.33%

The four variables that constitute the model are presented in Table 5. Each partial logistic coefficient represents the change in the log-odds of threaten versus non-threaten associated with a change in a given predictor, holding other predictors constant. Survey variables of READYHOM and HOSP# contributed the most to the prediction equation, while INSURANC and FAMUNIT played a moderate role in the equation.

**Table 5****Final Model Based on Stepwise Logistic Regression Equation**

Variable	B	S.E.	Wald	df	Sig	R	Exp(B)
HOSP#	.3437	.1336	6.6158	1	.0101	.1686	1.4101
READYHOM			9.5188	2	.0086	.1843	
READYHOM(1)	6.4640	47.2227	.0187	1	.8911	.0000	641.6015
READYHOM(2)	8.0520	47.2218	.0291	1	.8646	.0000	3140.0095
INSURANC			6.5824	3	.0865	.0599	
INSURANC(1)	-2.0120	1.3949	2.0805	1	.1492	-.0223	.1337
INSURANC(2)	-.3054	1.4398	.0450	1	.8320	.0000	.7368
INSURANC(3)	-9.0276	33.1184	.0743	1	.7852	.0000	.0001
FAMUNIT			12.5931	5	.0275	.1263	
FAMUNIT(1)	6.1322	99.6321	.0038	1	.9509	.0000	460.4454
FAMUNIT(2)	6.7864	99.6350	.0046	1	.9457	.0000	885.7255
FAMUNIT(3)	8.4881	99.6334	.0073	1	.9321	.0000	4856.5090
FAMUNIT(4)	-.3437	140.8989	.0000	1	.9981	.0000	.7092
FAMUNIT(5)	7.6963	99.6338	.0060	1	.9384	.0000	2200.2106
Constant	-13.9984	110.2657	.0161	1	.8990		

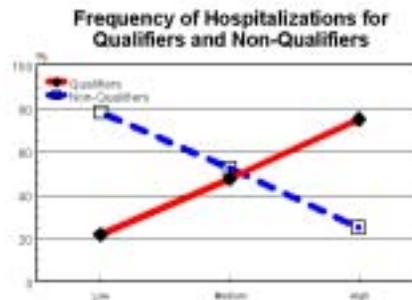
The equation derived from these analyses, using the standardized [Beta] weights in Table 6, will be replicated on an entirely new sample of surveys now being collected.

### **Summary of Findings**

The following bullets highlight the findings from data analysis of the responses from one hundred seventy-six (176) completed surveys. The full report with detailed analysis can be found on the Coalition's website, [www.mdcoalition.org](http://www.mdcoalition.org).

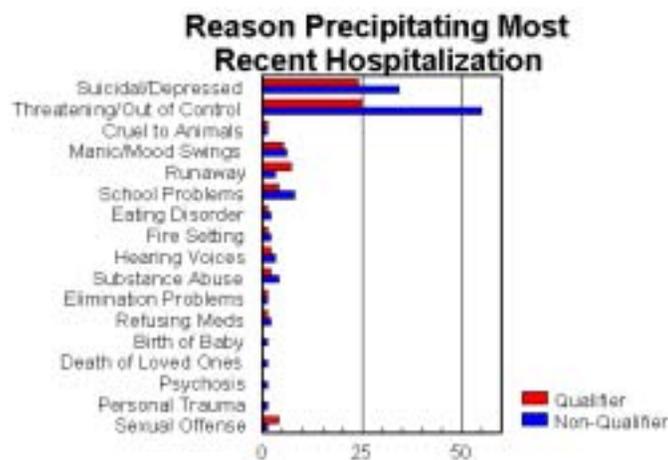
- 48 families (27%) reported that they were advised to relinquish custody or refused to bring their child home from the hospital and risked losing custody. This number is consistent with data from national surveys conducted in 1989 and 1999.
- Of the families who were faced with custody issues:
  - 13 families (7%) were told that they could access needed services for their child by relinquishing custody.
  - 13 families (7%) were told they would be charged with abuse or neglect if they did not pick up their child from the hospital.
  - 17 families (10%) responded that they were advised both to relinquish custody and also informed they could be charged with abandonment.
  - 5 families (3%) lost custody of their child
- Issues of custody cut across race, ethnicity, number of children in the family, gender of the child and whether the child has any other disability.
- Non-birth families, adoptive families in particular, were more likely to be confronted with custody issues.
- Only 7% of the families were told about voluntary foster care placements.

- Families were involved with multiple agencies - most frequently Special Education, Core Service Agencies, Department of Social Services, Local Management Boards and Local Coordinating Councils. Fewer families had contact with Juvenile Justice, Developmental Disabilities or Health Departments.
- As the number of hospitalizations for a child increased, the likelihood that families would confront custody issues increased. There was no relationship between the length of hospitalizations and issues of custody.



Qualifier = Family confronted with custody issue  
 Non-Qualifier = Family not confronted with custody issue

- A history of the child physically or sexually abusing others or being abused increased the likelihood of families considering custody issues.
- Safety issues, for the child or for the family, were the most frequently reported symptoms requiring hospitalizations.



- When families were informed that their child was being discharged from the hospital and families felt their child was not ready to come home or that they could not care for their child at home, the family was more likely to be confronted with the custody issue.

- The aftercare services families requested most often were: someone to help when their child gets out of control, counseling for the child and their family, recreation programs for the child and mentoring programs.
- Families who reported that aftercare services did not meet their child's needs were also more likely to have confronted custody issues.
- Families who had private insurance exclusively or together with Medical Assistance were significantly more likely to be confronted with custody issues.
- When asked if their child's condition had improved or deteriorated over the past two years, families confronted with custody issues were more likely to report their child's condition was getting worse.

## **Conclusions**

The following conclusions are drawn from the empirical data and also from written comments on the surveys, telephone interviews and focus groups with families confronted with custody issues.

- 1. Custody relinquishment and the underlying inability of families to obtain necessary mental health services for their children are major policy issues affecting the well being of children and families and straining public agencies, providers and public resources. The issues warrant the highest priority of public policymakers.**  
Because of the intensive needs of these children and the budget constraints of agencies, responsibility for children with complex mental health needs and multi-agency involvement is shifted from agency to agency until courts become involved.
- 2. Families do not want to give up custody of their child.**  
While 27% of the families who participated in the study were advised to relinquish custody, few (3%) reported actually losing custody. Most of the families in the study could not bring themselves to give up custody. Instead they brought their children home under pressure and threat of losing custody.
- 3. Children had lengthy histories of serious, chronic mental health disorders.**  
Families had serious concerns about their child by the time they entered school. In telephone interviews, families reported taking their children to pediatricians, mental health professionals, Child Find, and school personnel. They were often told the child would "outgrow" the behaviors. In spite of a variety of services and numerous hospitalizations, their child's behavior progressively deteriorated.
- 4. Families were persistent and sought help everywhere they could.**  
Families demonstrated incredible perseverance and reported going to five or more agencies seeking assistance. Several families contacted advocacy organizations and elected officials including Councilmen, Congressmen, Senators and even the Governor.

**5. Safety for the child and family was the bottom line.**

Families tolerated many years of emotional turbulence in their homes. When families began to fear for the safety of their child, other children or their personal safety, families reached the breaking point. Many described situations where they were attacked or threatened by their child. Safety in the home and protection of siblings were the key reasons families stated their child could not return home and they risked charges of abandonment for refusing to pick up their child from the hospital.

**6. Families were most likely to consider custody relinquishment when one or more of the following factors were present:**

- a) Repeated hospitalizations
- b) Children were being cared for by non-birth families including adoptive families
- c) The family felt the child was not ready for discharge from the hospital
- d) Private insurance

With the addition of each factor, there is a greater likelihood that custody relinquishment will be considered.

**7. The impact on families was financially devastating.**

Families frequently reported that caring for their child had a significant financial impact. Many caregivers lost jobs or could only work part time as a direct result of their child's intensive needs and repeated crisis. Families also reported enormous medical costs they incurred in order to pay for services for their child. Families reported taking out second mortgages or going into debt to pay for intensive services they could not otherwise access. When they were no longer able to pay for services they were forced to consider relinquishing custody.

**8. Every member of the family felt the strain.**

In addition to financial burdens, families expressed exhaustion, depression and hopelessness for themselves. They had grave concerns for the well being of their other children who were less demanding and consequently received less of their parent's time, energy and family resources. Families often felt they were asked to make choices and take time and resources away from the other children because of their child with mental health needs. The strain was also reflected in demands families were required to meet such as weekly family therapy sessions and constant crisis calls from the child's school.

**9. Private insurance posed a major hurdle in accessing intensive services.**

Families felt they were at the mercy of their private insurance companies. They had limited choices of therapists, limits on the number of hospital days covered, costly co-payments for medication and for treatment, especially when therapy was required several times a week. The frustration most frequently expressed was the inability to access residential treatment for a child with private insurance regardless of the severity of the child's illness or the recommendation of the child's treating professionals.

**10. Advising families to relinquish custody or leave their child in the hospital or residential facility is a common practice.**

Since the data from the study was compiled, the Coalition and other advocacy groups have been contacted by increasing numbers of families who have been confronted with relinquishing or losing custody of their children. This leads to the possibility that families who have lost custody are reluctant to discuss these issues and came forward after recent media attention highlighted the issues and portrayed their ordeal compassionately. It is alarming to hear from families that they are advised that it is "routine" to relinquish custody in order to access services for their child. We, therefore, believe that the study's findings on the percentage of families who have been advised to give up custody or who have given up custody underestimates the actual number of families faced with loss of custody.

**11. Custody issues for adoptive families in the study are not representative of adoptive families as a whole.**

Research comparing emotional or behavioral problems between adopted and non-adopted children indicates, "Significant differences disappear when a small group of influential cases were removed. This suggests that the differences seen between groups reflect a small number of cases and are not representative of the groups of adoptees as a whole." \*Note: Page 12 We believe the same is true regarding custody. A few significant cases do not represent the many adoptive families who never have to confront these issues.

## **Recommendations**

**The Coalition believes that no family should lose custody of their child in order to access needed mental health services. To this end, the Coalition recommends:**

- 1) Enacting state legislation that prohibits transfer of custody in order to access needed mental health services such as the "Missouri law," a state law that gives courts the right to order mental health care for children without families relinquishing custody.
- 2) Expand state resources for mental health services for children and expand the use of existing funds by:
  - a. Pooling interagency funds for children with intensive needs who do not qualify for Medicaid
  - b. Developing a program for families caring for children who have special needs to buy into Medicaid on a sliding fee scale such as the model contained in the Family Opportunity Act
  - c. Developing capitation programs for children with intensive needs similar to the capitation programs for adults.
  - d. Applying to the Center for Medicaid and Medicare Services New Freedom Initiatives 10-year demonstration projects for
    - i. Community-Based Alternatives to Psychiatric Residential Treatment Facilities for Children and
    - ii. Respite Services for Caregivers of Children

- 3) Clarifying the roles and responsibilities of the respective state agencies, the Department of Health and Mental Hygiene's Mental Hygiene Administration and Developmental Disabilities Administration, the Department of Juvenile Justice, and the Department of Human Resources with regard to "Children in Need of Assistance" (CINA).
- 4) Until legislation is enacted to prohibit loss of custody:
  - a. Expanding the use of voluntary placements in situations where children with mental health needs cannot be cared for in their home or have private insurance that does not cover intensive services. The state's ability to obtain Medicaid reimbursement and Title IV-E reimbursement from the federal government for children in out-of-home placements does not require that the state be given custody of the child.
  - b. Preserving "guardianship" so that families retain full parental rights and the parent-child relationship is preserved while the child is living in an out-of-home placement. Families should retain the right to make decisions regarding the child's education, physical and mental health.
  - c. When a local Department of Social Services has custody of a child, requiring the Department to inform families verbally and in writing what rights they have and how a family can petition the court if they perceive their guardianship rights are being infringed upon.
  - d. Strengthening the family and child relationship while the child is living in an out-of-home placement by fostering ongoing communication and visits with assistance for transportation if needed. This will facilitate the child's smooth transition home at the earliest appropriate time.
- 5) Prohibiting the practices of:
  - a. Threatening or charging families with abandonment when they refuse to pick up their child from a hospital or other facility out of fear for the safety of their family and the child
  - b. Placing families on the Central Registry of Abuse and Neglect of Children in Maryland because they refuse to take a child with mental health needs home from a facility.
- 6) Expanding co-commitment of children with mental health needs to the Department of Health and Mental Hygiene and the local Department of Social Services, and if appropriate, the Department of Juvenile Justice, so that the court has the resources and expertise of all agencies. Children should remain the primary responsibility of the Department of Health and Mental Hygiene to ensure they receive the most appropriate mental health services.
- 7) Creating mental health units within local Departments of Social Services so that situations involving children with complex mental health needs are handled appropriately and distinguished from abuse or neglect situations.
- 8) Expanding the mental health system for children including:
  - a. "Wraparound" services that support families caring for their child at home, such as respite care, in-home support, case management and 24-hour crisis intervention services
  - b. A system of care that encompasses all developmental stages from early childhood to transition age services

- c. A continuum of services that includes community step-down services to support children as they return from residential programs
  - d. Targeted case management services that follow a child after discharge from the hospital and prevent repeat hospitalizations
  - e. A statewide system of care so children and families in every jurisdiction in Maryland have equal access to care
- 9) Developing and disseminating statewide policies and procedures on admissions to residential treatment centers for those children on medical assistance and those covered by private insurance.
- 10) Improving communication about and access to the mental health services that Medicaid covers by:
- a. Complying with the duty to inform under Early and Periodic Screening, Diagnosis and Treatment (EPSDT) requirements so that families of children under 21 years, case managers, Core Service Agencies and providers are aware of the covered services, such as behavioral aides and residential treatment care, and how to access them
  - b. Enacting legislation to ensure that the local education agency does not impede access to residential treatment care for a child with a legal entitlement
  - c. Enforcing existing laws that guarantee residential treatment care and other covered services shall be provided with reasonable promptness where medically necessary
- 11) Developing training programs for:
- a. Police, Juvenile Judges and Juvenile Masters on mental health issues and resources for children
  - b. Department of Health and Mental Hygiene, Department of Human Resources, hospital and emergency room staff on protocols and policies related to children with intensive mental health needs
  - c. Community-based providers on evidence-based practices for children
- 12) Enacting legislation that mandates private insurance policies issued in Maryland to:
- a. Cover critical mental health services for children such as respite care, in-home and wrap-around supports as well as residential treatment centers that can prevent more costly cycles of hospitalization
  - b. Extend hospital coverage to the date when a child potentially becomes eligible for Medical Assistance
- 13) Increasing support for families to ensure:
- a. The safety of all family members
  - b. Assistance to prevent job loss due to the demands of caring for a child with intensive needs
  - c. Additional financial support and services for grandparents and kinship caregivers
  - d. Adoptive families have full and complete disclosure on health and mental health histories of birth families and access to adoptive subsidies and Medical Assistance available to the family regardless of the age at which the child is diagnosed
  - e. Stepfamilies and blended families have access to specialized mental health services
  - f. All families have information and access to family support and advocacy organizations



### **Dedication**

**To all families  
faced with losing custody of their child  
in order to access needed services.**

**May this report become a catalyst for change  
so that no family will be faced with losing custody  
as an act of desperation.**

## Voices of Families



"I'm a ward of the state now." - A 16 Year Old Child in Foster Care  
After her Mother Gave up Custody to Access Services for her Daughter

"They said it was a phase." - A Parent

"The other children are afraid of him." - A Parent

"I'm weary, I've aged and I'm mentally drained." - A Grandmother

"The system let me down. They took the U out of US and tried to  
destroy my family! They did not succeed." - A Single Mother

"I do want to state that I am an educated professional who was familiar with the 'system.' I went through many difficult times trying to get services for him. I feel sorry for families who do not have the resources and background that I had to bring us where we are today."  
- A Grandfather

"I feel like I'm living in a straight jacket" - A Parent

"I know that my daughter is just a number to the state of Maryland, but my heart is broken because I have a troubled child who is confused and depressed about her condition and because I don't understand it...I can't help my baby girl!!!! And that breaks my heart MOST OF ALL!!!!"  
- A Mother

"If he didn't have private insurance, he'd already be in an RTC." - A Mother

"I refuse to take him home and I get a few more days. I take him home and he's back within 2 weeks. I can't leave him alone. How do I get an RTC?" - A Parent

"If his private insurance and MA had agreed that he needed a higher level of care, he could of gotten the help a lot earlier and he wouldn't of hurt me, his brother, father and school staff." - A Mother

"I refused to take her home and the court talked her mother into taking her home, even though she felt at danger too (previous threats and assault)." - A Father

"I have had to fight to get him what he needs. He currently is in respite care and I'm looking at a \$100,000 bill. I have been fighting the county for months to get him help. No one wants to be the lead agency. He continues to go downhill." - A Parent

"I have not been working for over a year since my son's diagnosis because he needs adult supervision at all times." - A Parent

"I personally would like to hold my family together and have more respite care. It is our desire to keep our child at home with us. United as a family." - A Parent

## MARYLAND COALITION OF FAMILIES FOR CHILDREN'S MENTAL HEALTH

### **Our Coalition is a grassroots coalition of family and advocacy organizations dedicated to:**

- ◆ Improving services for children with mental health needs and their families, and
- ◆ Building a network of information and support for families across Maryland.

The Coalition represents families across the state of Maryland who are caring for a child with mental health needs. Many of the children have been in psychiatric hospitals, residential treatment centers, juvenile justice facilities or special education programs.

Each family struggles 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 mental health needs, families have many strengths and want to be full partners with professionals in planning their child's care.



### **WE BELIEVE**

- ◆ Children with mental health needs have potential and require specialized services to achieve their full potential.
- ◆ Families are the constant in a child's life and are equal partners in planning, implementation and evaluation of services for their child.
- ◆ Services should be provided for children and families from a strength-based approach and consider the whole child and entire family.
- ◆ Communities should develop a coordinated system of care that is available to all children with mental health needs and their families.