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. Every family spoke of the hurdles they had to overcome trying to find 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***.

Maryland Coalition of Families for Children's Mental Health

Acknowledgments

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

◆

Authors
Karen Friedman, Ph.D., Principal Investigator
Jane A. Walker LCSW

◆

The full report is available on the Coalition's website
www.mdcoalition.org

or contact

Maryland Coalition of Families for Children's Mental Health
10632 Little Patuxent Parkway, Suite 119
Columbia MD 21044
410.730.8267
410.730.8331 Fax
info@mdcoalition.org

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[1] 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.[2] 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.[3] In 2000, Bazelon followed with a monograph titled, **Relinquishing Custody, The Tragic Result of Failure to Meet Children's Mental Health Needs**.[4] 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

[1]*Focal Point*, Spring/Summer 1990 Portland State University, Research and Training Center on Family Support and Children's Mental Health.

[2]*Families on the Brink: The Impact of Ignoring Children with Serious Mental Illness,* NAMI Newsletter, The Advocate, *1999.*

[3]*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.

[4]*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. More than two 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 that 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.

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.

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.**

- 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.

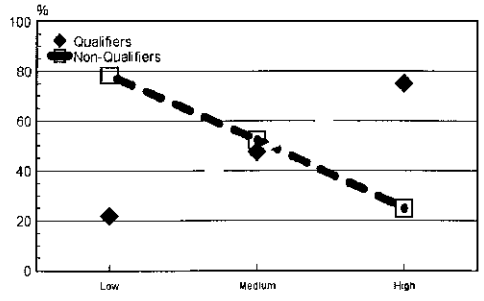
- Non-birth families, adoptive families in particular, were more likely to be confronted with custody issues.

- 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.

Frequency of Hospitalizations for Qualifiers and Non-Qualifiers

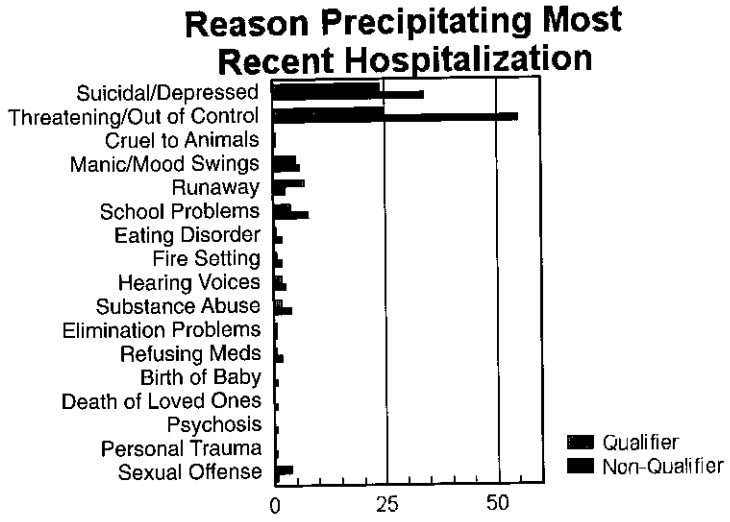


Frequency of Hospitalizations

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.



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

- 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 11 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) Expanding state resources for children's mental health services and expanding 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
in an act of desperation.

*Note from page 8: *Behavior Problems and Mental Health Contacts in Adopted, Foster, and Nonadopted Children*; A.E. Brand and P.M. Brinich, University of North Carolina at Chapel Hill, 1999.

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.

Maryland
Coalition of
Families for
Children's
Mental Health