

Speak Out for Access



The Experiences of Massachusetts Families in Obtaining Mental Health Care for their Children

Health Care For All and Parent/Professional Advocacy League

**Written by:
Ariel Frank, Josh Greenberg and Lisa Lambert**

October 2002

Speak Out for Access

The Experiences of Massachusetts Families in Obtaining Mental Health Care for their Children

October 2002

**Written by:
Ariel Frank, Josh Greenberg and Lisa Lambert**

Parent/Professional Advocacy League
59 Temple Place, Suite 664
Boston, MA 02111
617.542.7860

Health Care For All
30 Winter Street, 10th Floor
Boston, MA 02108
617.350.7279

**Produced with funding support from the
Blue Cross Blue Shield Foundation of Massachusetts**

CONTENTS

Executive summary	1
Major findings	3
Background	5
Methods	6
Demographic data	7
Access to care	8
Parental involvement	11
School support	12
Care in a crisis	14
Medications	16
Conclusions and recommendations	17
Appendix A: Families' stories	19

ACKNOWLEDGEMENTS

We gratefully acknowledge the Blue Cross Blue Shield Foundation of Massachusetts for funding this project. The views expressed in this report are not those of the Foundation, and should not be construed as the Foundation's attempt to influence any political or legislative action.

We are also indebted to Children's Hospital Boston for donating the Spanish translation, and to the Boston Public Health Commission for covering some of the printing and postage costs. In addition, we would like to thank the Children's Museum, the Boston Breakers and the Boston Red Sox for donating raffle prizes.

Jon Delman, Emily Feinberg, Suzanne Fields, Amy Glass, Nicholas Herold, Denise Lau, Cathy Pineau, John and Carol Willett, and Drs. Karen Hacker, Joseph Restuccia, Joshua Sharfstein and Carole Upshur helped us tremendously by commenting on drafts of the survey and data. Davekumar Chandrasekaran provided painstaking administrative support.

Special thanks go to Tara Brownell, age 13, of New Bedford for the artwork that graces the cover.

Most importantly, we appreciate all of the parents who provided their valuable insights by participating in focus groups, responding to the survey and sharing their stories with us.

EXECUTIVE SUMMARY

The children's mental health system in Massachusetts and across the country is in crisis. Families are reporting major difficulties locating and accessing services for their children and adolescents. Often when one service is obtained, linkages to other services are few and far between. Additionally, families report limited success in finding supports when their children first begin displaying signs of mental health needs. However, there is very little data describing either the specific barriers families face or how often these obstacles delay treatment. Health Care For All and Parent/Professional Advocacy League have been working together for more than a year to survey parents* of children with mental health problems. Their responses clearly reflect the numerous barriers to access.

At the time of this writing, we have received 301 responses. The survey results describe significant problems with access to care, the sufficiency of information provided to families, and parents' involvement in treatment. Additional concerns identified by families included the lack of early identification and treatment and a lack of knowledge about mental health in the public schools.

Six recommendations are listed at the end of this report. Families described again and again the barriers to getting the services their children needed and often offered suggestions for how the mental health system, both private and public, can be improved.

First, access to an array of community-based services must be increased, with less reliance on crisis care. Several findings support this:

- 33 % of respondents waited more than a year before receiving treatment as often as needed, and.
- Almost 40 % experienced a delay in treatment because they couldn't get an appointment or the services they needed were too full.

* While the majority of those surveyed were parents, respondents include other direct caregivers including grandparents and foster parents.

- 42 % of the children had violent crises, 40 % were self-injuring during their most recent crisis and 26 % were suicidal.
- 43 % of the parents believe their child's crisis was at least somewhat preventable.

Second, parents should be included in the design of children's mental health programs from the initial planning stages.

- Almost half the parents were not at all satisfied or only somewhat satisfied with the amount of involvement they have in their child's care.
- Many parents wrote that professionals "pushed aside their concerns" and blamed them for their children's illnesses.

Third, a spectrum of services must be available, regardless of who is the payer.

- 60 % of respondents said they worry at least some of the time that their child will hurt him/herself or others because needed services are not available.
- 26 % stated that their insurance always or often won't cover services that their child needs.
- 52 % of children waited 1 to 12 hours for an admission to a hospital during a crisis while an additional 16 % of children waited 13 hours or more

Fourth, policies must be put in place to connect the points of entry, increase communication and reduce fragmentation.

- 76 % of respondents said providers were not at all helpful or only somewhat helpful at linking them to other resources about their child's diagnosis.
- 44 % said they were not at all satisfied or only somewhat satisfied with the amount of communication between the hospital and other mental health providers.

Fifth, public schools must be educated about mental health problems in children and adolescents.

- 50 % said that their interactions with the school system had not been satisfactory because "school system professionals do not understand mental health issues."
- 30 % of the parents related that their child's most recent mental health crisis had occurred at school.

Sixth, Massachusetts should pass legislation that mandates mental health screenings by age 4, either through the early education or primary care settings.

- Nearly half of the parents reported that their child first began to show signs of a mental health problem by age 4.
- Again, nearly half said that their child's primary health care provider never or rarely asks about mental health.

MAJOR FINDINGS

1. Complex Needs

- 48 % of the children reported on first began to show signs of a mental health problem by age 4.
- 32 % have siblings who also require mental health treatment.
- 23 % have other serious health problems, including substance abuse.

2. Getting help for the first time

- 76 % of respondents said providers were not at all helpful or only somewhat helpful at linking them to other resources about their child's diagnosis.
- 48 % said their child's primary health care provider never or rarely asks about mental health.
- 39 % experienced a delay in treatment because they couldn't get an appointment or the services they needed were too full.
- 32 % of parents were not able to access services because they didn't know how to find them.
- 33 % waited more than a year before receiving treatment as often as needed.

3. Access to ongoing care

- 60 % of respondents said they worry at least some of the time that their child will hurt him/herself or others because needed services are not available.
- 31 % said "Getting providers to understand my child's problems" often or always poses a problem in getting mental health care.
- 25 % said the provider's failure to accept their insurance often or always poses a problem in getting mental health care.
- 26 % stated that their insurance often or always wouldn't cover services that their child needs.

4. In-school supports

- 67 % of respondents said they were not at all satisfied or only somewhat satisfied with the amount of help they had received from public school professionals.
- 57 % said their children's IEPs or 504s were not at all or only somewhat meeting their needs.

- 50 % said their interactions with the school system had not been satisfactory because “school system professionals do not understand mental health issues.”
- 28 % said, “We agreed upon services, but the school has not provided them.”
- 30 % reported that their child’s most recent crisis happened at school.

5. Care in a crisis

- 49 % of respondents said their child’s main mental health care provider is not at all accessible or only somewhat accessible after regular office hours.
- 48 % said the care their child received during his/her most recent crisis was not at all helpful or only somewhat helpful.
- 42 % of the children had violent crises, 40 % described the most recent crisis as self-injuring and 26 % said their child had been suicidal.
- 36 % of the respondents said their child had been sent home or to a facility far from home at least once because there were no hospital beds available.
- 52 % of children for whom the question was applicable waited 1 to 12 hours for an admission to a hospital during a crisis, while an additional 16 % of children waited 13 hours or more.
- 29 % of respondents said their child’s last hospital stay was too short.
- 18 % were admitted to a general hospital or an adult unit, rather than a psychiatric facility for children.

6. Communication/parental involvement

- 49 % of respondents said they are not at all satisfied or only somewhat satisfied with the amount of involvement they have in their child’s care.
- 45 % said that their child’s mental health provider leaves them only somewhat or not at all hopeful that their child will get better.
- 44 % said they were not at all satisfied or only somewhat satisfied with the amount of communication between the hospital and other mental health providers after their child was discharged.
- 28 % did not receive a transition plan after their child’s last hospitalization or said the plan they received was not at all helpful.
- 7 % said they did not discuss medications and their possible side effects with their child’s mental health provider(s), and another 28 % said their discussions are not at all helpful or only somewhat helpful.

"Along the way, I would always think I was on the right road. I would get these referrals to these different social workers and I would come there with all of my notes, all of my medical papers, all of my journals, and I would think, 'This is going to be the right person who is going to fix this problem.' By second grade, he'd seen at least a dozen mental health professionals.

None of these doctors said, 'You've got to do this,' or I would have done it. I knew that things were worsening and I wasn't getting him the right help. When you have a physical disability, you get treatment. When you have a child born with a mental illness, you just stumble through this flawed system."

BACKGROUND

Stories such as the one above, from the mother of an 11-year-old boy, show the human toll of the children's mental health care crisis in Massachusetts and across the country. The state of the system is alarming because it is estimated that one in 10 children and adolescents suffers from mental illness severe enough to impair functioning, and that fewer than one in five of these children receives needed treatment in any given year.¹ The media has increasingly called attention to the situation in recent years, focusing mainly on the plight of "stuck kids" who are forced to remain in hospitals longer than medically necessary, because no community-based programs have openings for them.² But while it is known, mostly anecdotally, that children face numerous barriers to accessing mental health treatment, specific Massachusetts data is not readily available.

The purpose of the "Speak Out For Access" survey was to give Massachusetts families the opportunity to inform policy-makers and the public, and to advocate for more accessible, better quality children's mental health care. Health Care For All and Parent/Professional Advocacy League (PAL) spent more than a year developing and distributing a survey for parents of children with mental health needs. Through interviews, many parents have helped to add a human face to the statistics. The stories and quotations throughout this report are real, though the names have been changed to protect the families' privacy.

Both the survey results and the personal stories vividly illustrate the trauma many families are facing. The results put a familiar problem in new relief. They show just how difficult services are to obtain, and that once families find their way to care, the care is often less helpful than they had hoped. In the words of one parent who responded to the survey, "There's no point of entry to the so-called 'system,' and there is actually no system. It's up to the parents to find their way through the maze and piece together a program for their child. Even when they have the maze pretty much figured out, there are very few programs available."

¹ Website of the National Institute of Mental Health, "Brief Notes on the Mental Health of Children and Adolescents." Updated Nov. 8, 1999.

² See, for example, Knox RA, Dembner A. "Trapped in a mental ward: State lacks programs for troubled youths." Boston Globe. June 4, 2000. Also see Goldberg, C. "Children trapped by mental illness." New York Times. July 9, 2001.

METHODS

The primary goal of the “Speak Out for Access” survey was to focus attention on the experiences of families with children and adolescents who have mental health needs. To that end, three focus groups were held with parents in Greenfield, Arlington and Boston during the summer and fall of 2001. These locations ensured that participants throughout the state would bring a variety of experiences to shape the final questions on the survey. Parents in these groups reside in urban, suburban and rural settings, represent a variety of cultural perspectives, are insured by both public and private health plans and are raising children with an array of diagnoses and a large age range. About six parents attended each two-hour meeting, which was conducted during a regularly scheduled PAL support group meeting. Feedback on the survey was also solicited from several physicians and public health professionals.

The final survey consisted of 42 questions dealing with access to services, ongoing treatment, medication, crisis care, inpatient hospitalization, school interventions and demographics. Most of the questions asked respondents to choose among five or more choices, and one question was free response.

Beginning in November 2001, packets of surveys were mailed to 61 PAL parent coordinators, health advocates, hospital unit managers and other people who requested copies to circulate. In total, approximately 1,900 surveys were distributed this way and 387 of these were in Spanish. In January 2002, surveys were also mailed to approximately 2,100 households on PAL’s mailing list. In addition, surveys were sent to individuals who requested copies after learning about the project through fliers and websites. The survey was posted on the PAL (www.ppal.net) and Health Care For All (www.hcfama.org) websites beginning in January 2002. Approximately 10 responses were received from this exposure. Respondents were entered in a raffle as an incentive to complete the survey, and weekly reminder emails were sent to PAL family advocates and other individuals who had given us their addresses. In March, follow-up postcards were sent to all of the households on the PAL mailing list that had received the original mailing.

The project had one main limitation: An outreach effort beyond the scope of this project would have been necessary to reach families who were not already receiving some mental health services. By their own accounts, many of the respondents in our sample have benefited from support groups, educational advocates and, in some cases, attorneys. Thus, it is reasonable to assume that there are families in Massachusetts who are facing even greater barriers than the ones who mailed back the questionnaire. In other words, while the stories and statistics reveal many gaps in the system, it is very likely that the picture would be still more dismal if all of the parents of children with unmet mental health needs could have been reached.

DEMOGRAPHIC DATA

At the time of this writing, 301 responses have been received. Surveys were returned from every county in the state except Dukes County (Martha's Vineyard) and Nantucket County.

Household incomes were reported across a wide range:

- 30 % of the respondents reported household incomes of less than \$30,000 in 2000
- 26 % reported household incomes of at least \$70,000.

Families reported paying for health care through a variety of methods:

- 60 % of respondents said they paid for their child's mental health care at least partly through MassHealth (Medicaid) or another government program,
- 53 % said they paid at least partly through employer-based insurance,
- 7 % said they pay at least partly out-of-pocket.

More than one answer was possible for this question, and other types of insurance, such as military and union, were also represented among the responses.

70 % of the children reported on were male and 27 % were female (3 % of the respondents skipped this question. The largest number of children, 42 %, was between 15-19 years old. 34 % were between 10-14 years, 17 % were between 5-9 years old, while the rest were younger or their parents skipped the question. The majority of the children/teens were at least partly Caucasian (82 %), while 6 % were at least partly African-American and 7 % were at least partly Hispanic. 8 % were at least partly another race or ethnicity. (More than one answer was possible for this question.) 94 % of the respondents primarily spoke English at home, 3 % spoke Spanish, .3 % spoke other languages (including American Sign Language)³ and 2.7 % skipped the question.

Additional information about the children and adolescents showed that 23 % of the children have other serious health problems, including substance abuse. 32 % have siblings who also require mental health treatment. Accessing and coordinating medical care as well as mental health care, or arranging services for two or more children, multiplies the difficulties for families.

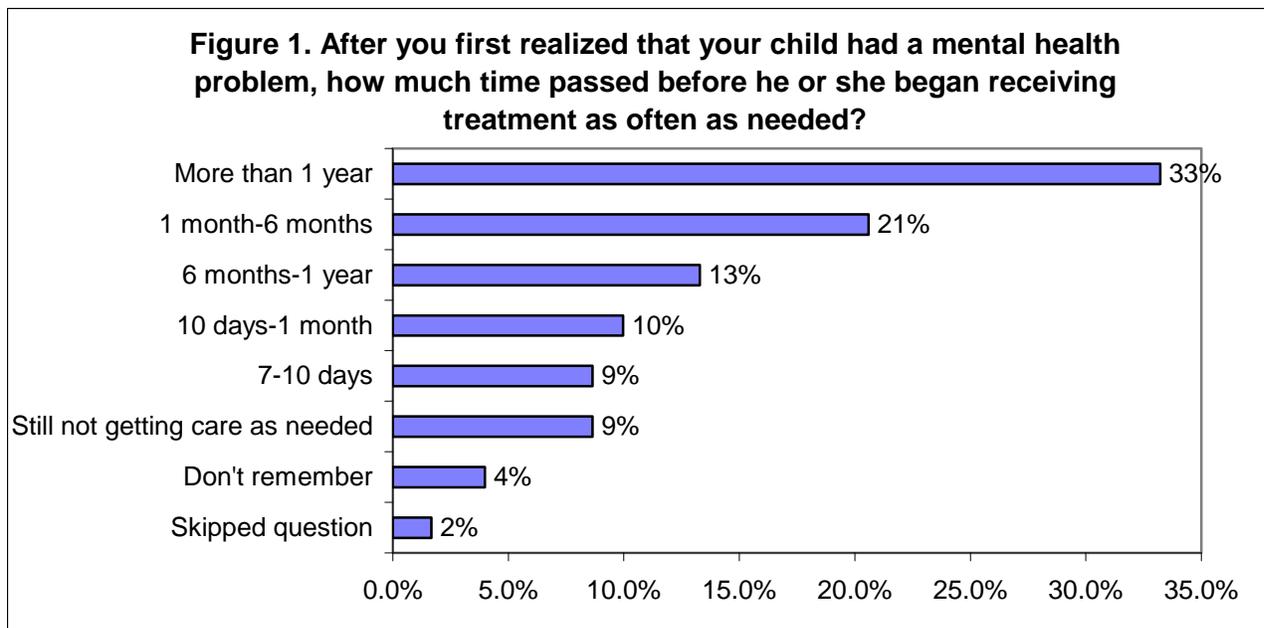
³ The demographics of our sample were almost identical to those of the Commonwealth as a whole. According to the 2000 U.S. Census data, 84.5 of the state's population is Caucasian, 5.4 % is African-American, 6.8 % is Hispanic and 7.7 % other. Thirty-six % of households have incomes over \$50,000 and 33 % have incomes under \$25,000.

ACCESS TO CARE

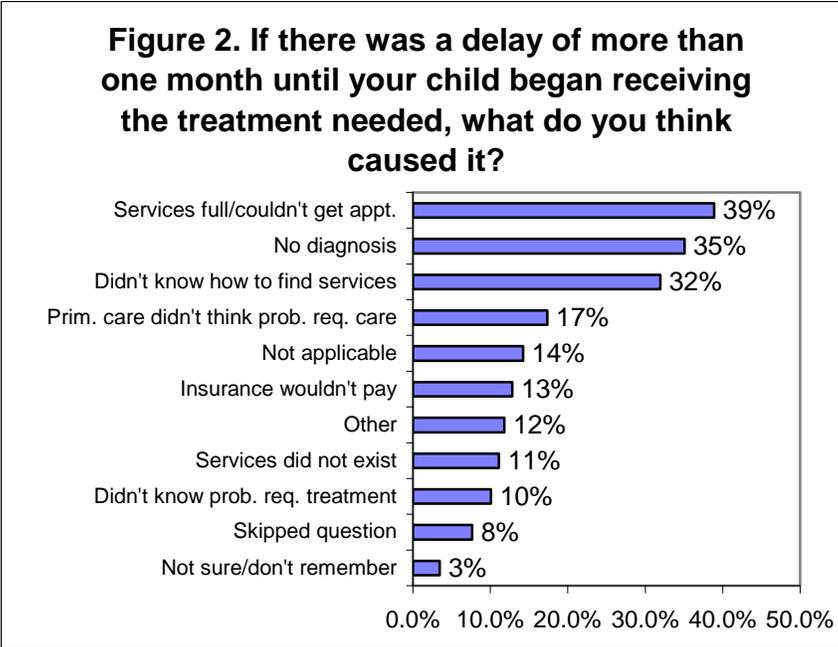
"We went from pediatrician to pediatrician. Nobody gave us any answers. Everybody said put her in time-out, set limits, do this, do that. No one said anything about maybe it has to do with her wiring."

"I was at the HMO one day with her. It might have been seeing some therapist who wasn't getting it yet. I remember saying, 'I've smacked her.' I needed to tell somebody. I said, 'I hit her.' It was a cry for help."

The first section of the survey asked parents to report on their family's very first encounters with the children's mental health care system. Parents were asked, "After you first realized that your child had a mental health problem, how much time passed before he or she began receiving treatment as often as needed?" (Figure 1) 19 % stated that it took a month or less. Another 21 % replied that it took from one to six months to get treatment. However, the largest percentage, 33 % of respondents, said their child waited at least one year before receiving treatment as often as needed. 9 % answered that their child was still not receiving care as often as needed. Referring back to the data on insurance coverage, 93 % of all the respondents reported that their child had health insurance. The lack of timely access to treatment does not appear to be due to lack of insurance.

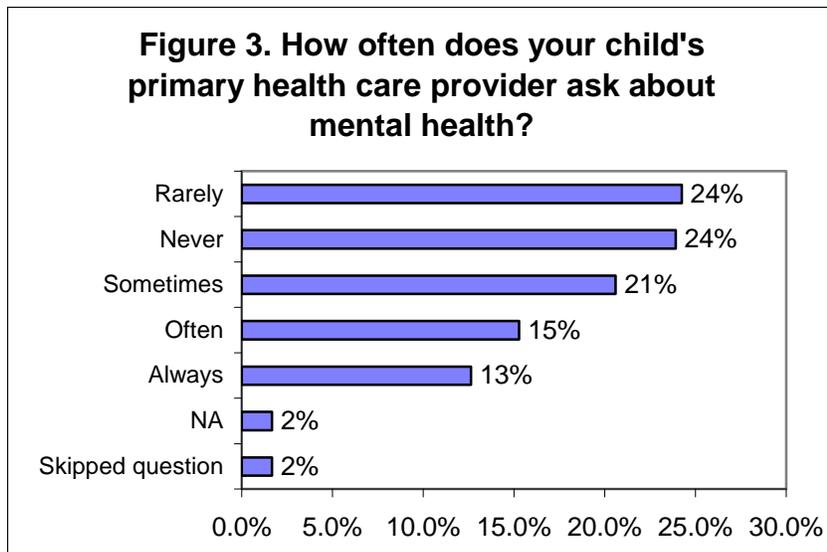


When asked what they thought caused the delay in their child’s care, the greatest number of respondents – 39 % – said the services were too full or that they couldn’t get an appointment (Figure 2). Another 35 % attributed the delay to the fact that their child did not have a diagnosis. 32 % replied that they didn’t know how to find services. Smaller numbers of parents cited other factors, such as “primary care provider didn’t think the problem required treatment” (17 %), “insurance wouldn’t pay” (13 %), “services did not exist” (11 %), and “I didn’t know the problem required treatment” (10 %). Most respondents cited more than one reason.



Overwhelmingly, the barriers to accessing services illustrate that services are difficult to find and often are not available when located. This is due to a variety of factors ranging from lack of openings to payment barriers. Interestingly, 62 % of respondents cited lack of diagnosis or an ignorance of the acuity of the problem by either the primary care doctor or the parent. Mental health problems in children and adolescents are often viewed as a passing concern or behavior not linked to mental health needs.

In response to another question, 48 % said their child’s primary health care provider never or rarely asked about mental health. An additional 28% responded that their child’s doctor often or always asked (Figure 3). This result is consistent with a survey of 300 parents and 201 pediatricians done by Columbia University’s Center for Advancement of Children’s Mental Health in 2000. 44 % of parents in that study said their child’s doctor never asks about mental health issues, yet 77 % of pediatricians said they ask about their patients’ mental health at least most of the time.⁴ This disparity suggests a substantial communication

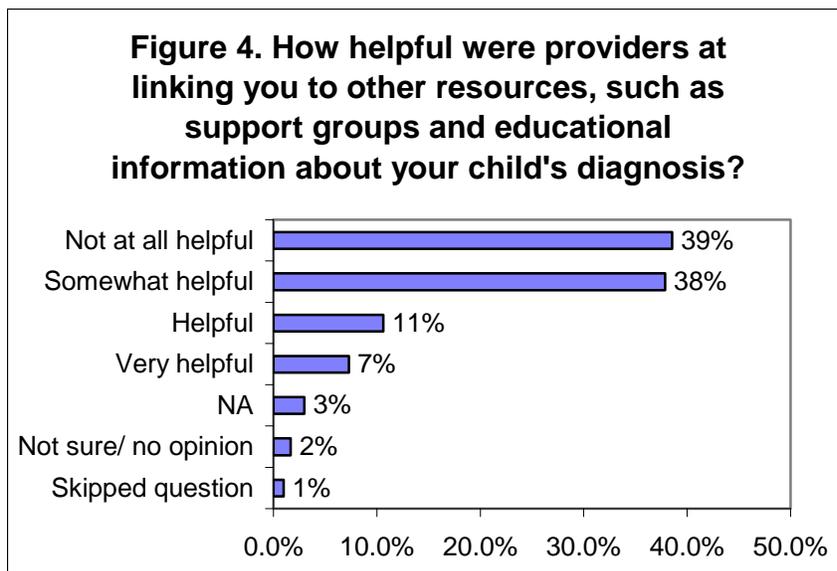


often or always asked (Figure 3). This result is consistent with a survey of 300 parents and 201 pediatricians done by Columbia University’s Center for Advancement of Children’s Mental Health in 2000. 44 % of parents in that study said their child’s doctor never asks about mental health issues, yet 77 % of pediatricians said they ask about their patients’ mental health at least most of the time.⁴ This disparity suggests a substantial communication

⁴ “New center seeks to improve results in children’s mental health,” *Mental Health Weekly*. May 22, 2000.

gap between parents and doctors, which can contribute to delays in both identification and treatment.

Approximately half of the respondents, 48 %, also said their child showed signs of a mental health problem by age four. Contrasting this response with the one discussed above raises important concerns. In the stories included with this report, many parents describe children who cannot soothe themselves as babies, who react to difficulties with prolonged tantrums and exaggerated fears or who may even express a wish to die at a shockingly young age. When children are very young, parents usually take their concerns to their child’s doctor. The opportunity for early identification and treatment is often lost for many children.



When families discussed ongoing care, several key issues emerged. 77 % of the respondents said providers were not at all helpful or only somewhat helpful at linking them to other resources (Figure 4). 36 % of the families also reported that their children see three or more mental health providers regularly. Yet after lengthy waits for treatment and difficulties accessing care, 31 % of the families report that “getting

the provider to understand my child’s problems” often or always poses a problem in getting mental health care.

“On our son’s first diagnosis, there was no one to tell us about available services, case managers, etc.,” one mother wrote. “We were lost and had to find our own way and learn on our own.”

Insurance coverage provided a different set of barriers. Payment for services emerged as a significant issue for many families. 25 % stated that the provider’s failure to accept their health insurance often or always posed a problem in getting mental health care. 26 % answered that getting their insurance to cover services that their child needs often or always poses a problem. An additional 17 % of respondents identified that their children’s symptoms were often or always not considered severe enough to obtain services, indicating that access was limited by a prohibitive standard of medical necessity.

PARENTAL INVOLVEMENT

"I go to meetings and they ask me how he is doing, but they do not care. Why do they bother to ask? Why do they bother to have me attend these meetings? They come prepared with the cost-saving plan they have created without my input, without knowledge of my son's current state of mental health. When I ask for changes or explain that I do not agree, I am told that nothing else is available."

One theme in particular ran throughout the respondents' written comments, the focus groups and interviews: Parents want to be consulted about their child's treatment plan, and their children tend to do better when they are. Yet 49 % of the respondents said they are not at all satisfied or only somewhat satisfied with the amount of involvement they have in their child's care. Many parents wrote that professionals "pushed aside their concerns," made them feel "disrespected," and blamed them for their children's illnesses.

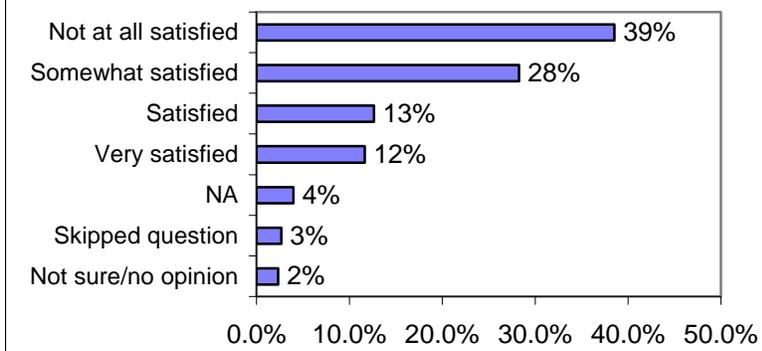
When asked, "How hopeful do your child's mental health providers leave you that he or she will get better?" parents' answers ranged across a wide spectrum. About 45 % of the parents said they were not hopeful or only somewhat hopeful. However, 34 % said that they felt hopeful or very hopeful.

Although parents expressed frustration with a system that is discouraging and often unresponsive, many parents still believe that positive outcomes are possible for their children.

Respondents expressed a need for more "wrap-around" programs that involve the whole family in the child's treatment plan. One mother wrote that her daughter had seen many therapists and had continued to decline until she was referred to such a program, Project Connect: "They understood exactly what we as a family needed to do to help our daughter and ourselves," the mother wrote. "Although they are only supposed to stay directly involved with a family for a certain length of time, we needed them longer and they were able to be flexible."

SCHOOL SUPPORT

Figure 5. How satisfied are you with the amount of help your child has received from public school system professionals?

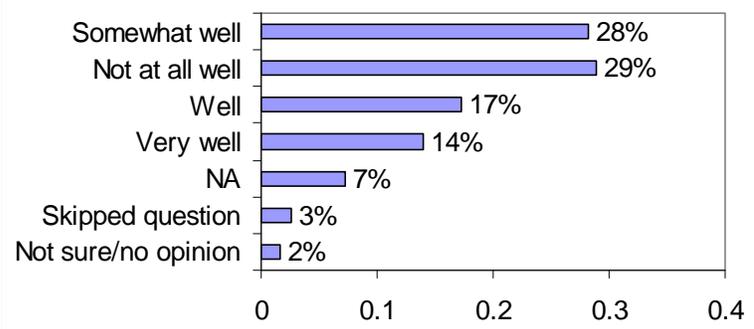


Parents also revealed frustration with the supports for students with mental health needs available through the public school system. 67 % said they were not at all satisfied or only somewhat satisfied with the amount of help they had received from public school professionals (Figure 5), while 57 % said their children’s IEPs (Individual Education Program) were not at all or only somewhat meeting their needs (Figure 6).

When parents were asked why their interactions with the school system had not been satisfactory (Figure 7), the most common response was “school system professionals do not understand mental health issues” (50 %). The next most common response was “we agreed upon services, but the school has not provided them” (28 %). Factors cited less frequently were “school system professionals disagree with my child’s other mental health providers” (20 %), and “school system professionals say my child is not eligible for mental health services” (9 %).

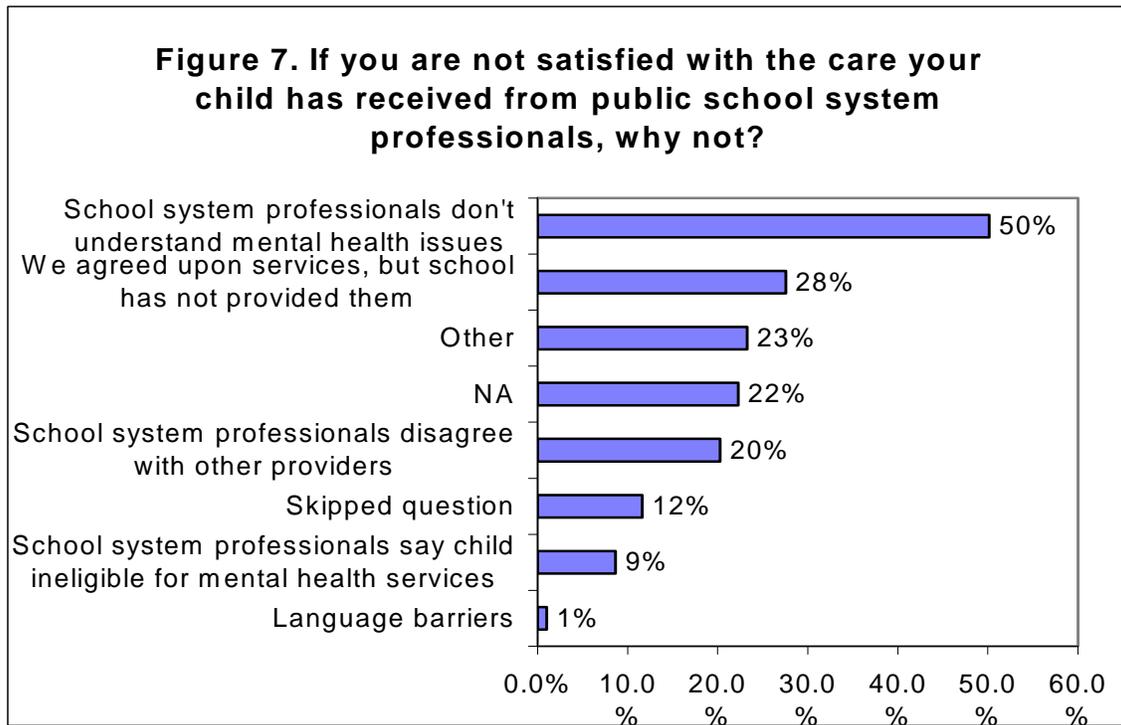
These results are similar to those of a nationwide study conducted by the National Alliance for the Mentally Ill in 1998. Nearly half of the responding parents in that survey – 46 % – felt that schools resisted identifying children with serious mental illnesses. 68 % said their children had to fail before services were put in place in schools. And only 7 % said that school professionals were adequately trained to deal with

Figure 6. If your child has an IEP or 504 plan, how well is it meeting his or her needs?



serious mental illness in children and adolescents.⁵

This is particularly disturbing when juxtaposed with the responses given when parents were asked where their child's most recent crisis occurred. Nearly one-third (30 %) responded that the latest crisis had occurred at school -- a setting where many parents feel the professionals do not understand mental health issues.



A mother from Pittsfield recalled in the “Speak Out For Access” survey what she had gone through to get her son mental health services through the schools: “When my child was young I tried to address his academic needs and was told boys learn slower. I tried to explain to teachers about post-traumatic stress disorder, as my son had witnessed domestic violence over a period of years. It felt like a struggle to offer a child supports to cope. When I involved the schools in an IEP I had to advocate strongly and get an attorney to have his education plan followed. My son left school at 16 with an eighth grade education. We both stopped fighting.”

⁵ National Alliance for the Mentally Ill. “Families on the Brink: The Impact of Ignoring Children with Serious Mental Illness.” July 1999.

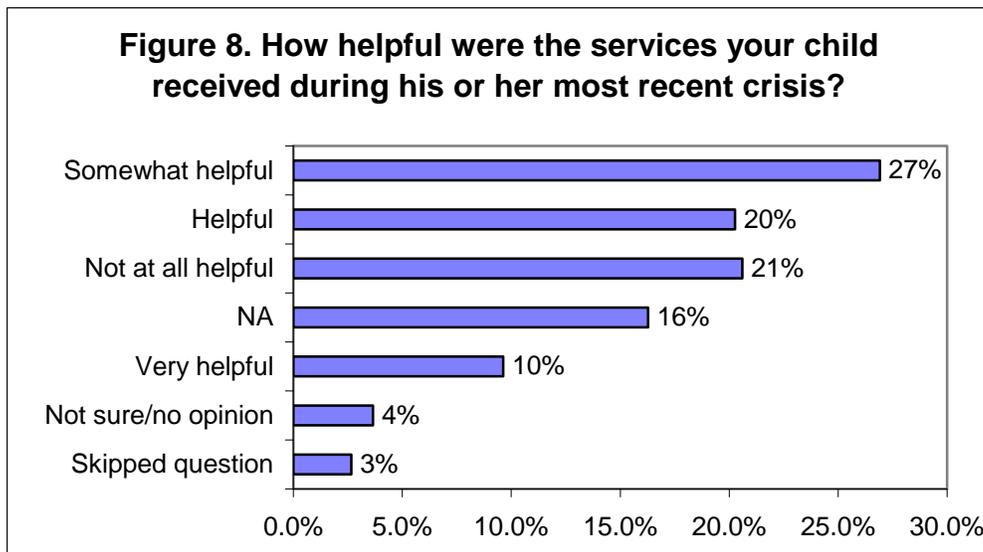
CARE IN A CRISIS

"We have gone to the crisis team three times and we have been denied services because of our insurance or they say there is nothing wrong with him. They told me to voluntarily give my son to DSS or they say it is my husband's and my fault..."

When my son rages now, we put him in his room where he is safe from hurting others and himself, and we wait it out. There is no help anywhere."

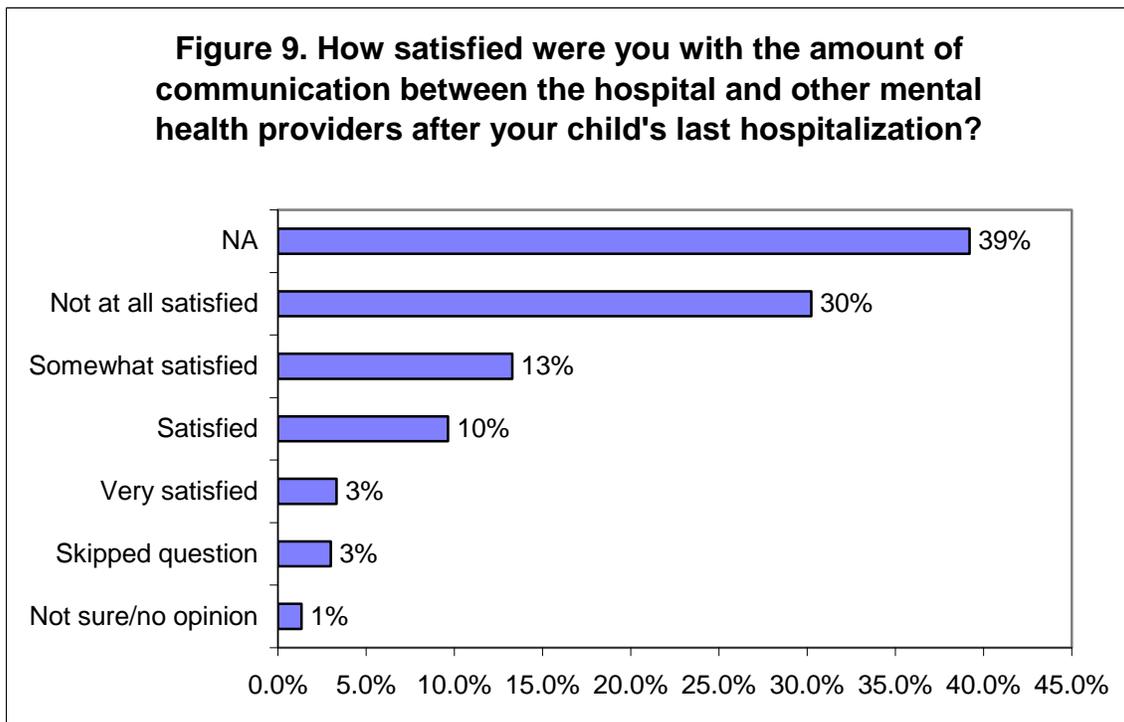
Even during a crisis, treatment was not readily obtainable or satisfactory for the children reported on. 49 % of respondents said their child's main mental health care provider was not at all accessible or only somewhat accessible after regular office hours. Another 48 % said the care their child received during his/her most recent crisis was not at all helpful or only somewhat helpful (Figure 8). This is of particular concern in light of the fact that 42 % of the children had crises their parents characterized as violent. Another 40 % identified their child's crisis as self-injuring and 26 % described the crisis as suicidal.

Given that many parents characterized crisis care as unhelpful, it is not surprising that 60 % of the parents said they worry at least some of the time that their child will hurt him/herself or others because needed services are not available. When asked how preventable they believed their child's most recent crisis to have been, 43 % said it was at least somewhat and in some cases, very preventable. Crisis services are both costly and often stressful to use, yet the wait for community-based treatments increases reliance on them.



When questioned about their experiences hospitalizing their children and adolescents, parents reported substantial barriers. 52% of children for whom the question was applicable waited 1 to 12 hours for admission to a hospital during a crisis, while another 34 % waited 13 hours or more. . Furthermore, 36 % of respondents said their child had been sent home or to a facility far from home at least once because there were no hospital beds available. When the children in our sample needed inpatient hospitalization, 18 % were admitted to a general hospital or adult unit, rather than a psychiatric facility for children, because no beds were available. And once children were admitted to the hospital, 29 % of the parents said their stays were too short.

Again, linkages between providers surfaced as an issue. About 43 % of the parents said they were not at all satisfied or only somewhat satisfied with the amount of communication between the hospital and other mental health providers after their child was discharged (Figure 9). 28 % of those surveyed said they were not given a transition plan after their child’s last hospitalization or that the plan they received was not at all helpful. By contrast, only 13 % said the plan they received was helpful or very helpful.



One mother said in an interview that even though doctors had determined that her 15-year-old son was “chronically suicidal,” a hospital sent him home after one week with a discharge plan that called for six hours per week in a drug rehabilitation program. He was to spend the rest of the time at home without supervision, since both of his parents worked full-time. While the mother fought to keep her son hospitalized for his own safety, she said hospital staff threatened to charge her with neglect if she didn’t remove him.

MEDICATIONS

The use of psychotropic medications for children and adolescents has become a controversial subject in recent years. For a variety of reasons, psychiatric medications are being used as a front line treatment for children and adolescents. Antidepressant use increased three- to five-fold from 1988 to 1994, according to a recent study published by Julie Magno Zito, PhD.⁶ The study also notes that 72 % of youth received their prescriptions from primary care providers. This would indicate that access is somewhat easier and waits for medication treatment may be shorter than with other forms of mental health treatment.

In the "Speak Out for Access" survey, parents responded more positively about access to medications, although there was still need for improvement. Almost half said they never have a problem paying for their child's psychiatric medications while 19 % said they had trouble at least some of the time. 7 % said they do not discuss medications and their possible side effects with their child's mental health provider(s), while 28 % said their discussions are not at all helpful or only somewhat helpful. 54 % said their discussions were helpful or very helpful.

In a separate section of the survey, parents were asked which services their child had received and were then asked to rate the helpfulness of those services. 48 % of families rated medication visits as "very helpful."

⁶ "Trend in the News," *Psychiatric Times*, June 2002, Volume XIX, Issue 6.

CONCLUSIONS & RECOMMENDATIONS

Overall, the parents who responded to our survey described a road filled with confusion, frustration and anguish. Waits for services are appallingly long or treatment is not available at all, leaving parents fearful for the safety of their child and family. Other major hurdles seem to be that there is no roadmap for parents to follow when a child needs mental health services, and that families often feel misunderstood or even ignored by providers. Furthermore, many different agencies provide mental health services for children, but their responsibilities are not clearly defined and services are frequently delayed because of funding disputes, insurance denials and waiting lists. Many parents said they thought it would be easier to obtain care if their children had physical illnesses rather than mental ones. Certainly, it is unimaginable that one in three children with cancer or diabetes would have to wait more than a year for treatment in Massachusetts.

Several recommendations emerged from the survey responses, interviews and focus groups:

1. Increase access to an array of services in the community, with less reliance on crisis care.

Parents repeatedly characterized crisis services as unsatisfactory and almost half believe that their child's crisis was at least somewhat preventable. Yet access to care in the community is fraught with barriers that include long waits, insurance denials and confusion about where to find services. Parents often feel as though their children must deteriorate before they can obtain services, and by then the only options are hospitals, residential facilities, therapeutic schools or even foster care or the juvenile justice system. It is crucial to allocate more resources and focus more on designing community-based programs that include the entire family in the treatment plan and use an interdisciplinary approach to care.

2. Parents must be included in program design and treatment planning up-front – not after all the major decisions have been made.

The parents who responded to our survey can clearly offer invaluable expertise about the services that would be most beneficial to their children. Parents often find themselves providing information about one part of the system to another and offering critical assessments to providers about what works and what does not. Yet this kind of involvement only creates change for one person instead of change for every family. When families are involved at all levels, their experience, insights and skills can help create a system that works better for those people who use it.

3. A spectrum of mental health services must be available to children and adolescents with mental health needs and their families, regardless of who is the payer.

Parents work very hard to find a service that will meet their child's treatment needs only to find that it is not available because of insurance denials or barriers to state agency eligibility. The state mental health parity law includes an expanded description of services that would help many children with mental health needs, yet these treatments are rarely paid for. Many services paid for by state agencies serving children are delivered by private providers yet they are unavailable to children not served by those agencies. Existing services need to be open for purchase by other payers and insurers must expand the benefit array offered to children and adolescents with mental health needs.

4. Policies should be made to connect the points of entry, improve communication and reduce fragmentation across the system.

Families waste precious weeks, months or even years knocking on door after door to access services that their children need. Currently, many children deteriorate while waiting for services to start, or languish in inappropriate treatment settings because of funding disputes, waiting lists and the lack of accountability in the mental health care system. Since children receive mental health services from many different agencies and providers, as well as the public school system, we should ensure that each of these arenas has a clearly defined set of responsibilities, that there is communication across them, that children have good case management and that treatment decisions are based on what is best for the child. It is also essential that providers of services have access to information about what services exist, how to access them and what is effective for each type of mental health need.

5. Public schools must be educated about mental health concerns in children and adolescents.

Since the one thing all children have in common is that they spend a good portion of their day in school, it is not surprising that educators find themselves dealing with incidents arising from the mental health problems of some students. Yet, public school teachers and administrators have very little training around what mental health diagnoses look like in children or how to deal effectively with them. As a result they are often unable to provide appropriate services until the student's problems require costly services.

6. Mental health screenings should be mandated by age 4.

Early identification and intervention is crucial, since nearly half of the respondents said their child showed signs of a mental health problem by age 4. Yet, according to the parents in our sample, primary care providers and school system professionals often do not ask about or recognize mental health problems until they are severe and debilitating. It is important that early identification and treatment be implemented to prevent delays in treatment. A year lost to a child is a year that cannot be regained. Massachusetts should pass legislation that would mandate mental health screenings by age 4, either in pediatricians' offices or early education settings.

Appendix 1: Families' Stories

Daniel's Story

(Names have been changed to protect privacy.)

Daniel Davis' childhood was marked by stark contrasts: One instant the wiry, wavy-haired boy would be calmly strumming his guitar or sleeping with his sheltie dog. He was bright and sought challenges: He liked to take his toys apart and use the parts to make "inventions," or stick with the hardest level of a new computer game until he won. But an instant later, his parents would discover him curled in a fetal position on the floor of a darkened room. He would be trembling, weeping, haunted by a flashback or a nightmarish vision of needles and knives.

Daniel's fears gripped him most powerfully at night, and as a result, his parents got little sleep. His mother, Barbara, would bolt out of bed, awakened by a sound or an ominous feeling. She would open Daniel's bedroom door and stand there looking at him, looking for the slow rise and fall of his chest. More than once, she found a broken razor in the trash and superficial cuts on his wrists. "I feel lonely," Daniel told her on one of those instances. "I just want it to stop."

The Davis' lacked health insurance when Daniel's problems began, though both worked. No one ever mentioned the Children's Medical Security Plan, a Massachusetts program that covers children who are ineligible for other free or reduced-cost care. When Barbara tried to buy insurance coverage for Daniel, she was told she would have to purchase a family plan and that she and her husband would need expensive physicals and lab tests first. Barbara, a nurse, had to reduce her hours at work so that she could be home with Daniel – and the family's debt soared.

Public school and special education settings had little to offer Daniel. The guidance counselors didn't seem to know enough about his diagnosis, post-traumatic stress disorder, and group therapy was not offered, though Barbara tried to get it. She says special education teachers did try to learn about her son's problems, but they were overwhelmed, underpaid and received no funding for professional development.

The Davis' most frightening and maddening experience with the children's mental health care system occurred when Daniel was 15. Though doctors had recently deemed him "chronically suicidal," a hospital sent him home after one week with a discharge plan that called for six hours per week in a drug rehabilitation program. The rest of the time, he was to spend at home – alone.

“If you will make yourself available to Daniel at all times, he will be safe,” the primary therapist told Barbara. While she fought to keep her son hospitalized for his own safety, she says hospital staff threatened to charge her with neglect if she didn’t remove him.

“I felt they were trying to kill my kid,” she says. “Any therapist who wrote a discharge plan that required one person to stay awake 24 hours a day to ensure the safety of a sick child would be liable to discipline from a number of regulatory agencies. I was so angry, because I knew how medically and legally inappropriate she was being.”

The hospital suggested Barbara file a Child in Need of Services petition to get her son the help he needed, but she refused because she was afraid of losing custody or traumatizing him further. During a CHINS hearing, which takes place in a courtroom, a judge may place a child in the state’s care or with another adult.

Adding to the family’s problems, the hospital could not find a nearby day treatment program for Daniel because all of them had long waiting lists. He was eventually placed at a facility in Needham, more than 20 miles away. Each day, Barbara drove from the family’s home in Woburn to the treatment program in Needham and then to her job in Methuen, 40 miles away. In the afternoons, she turned around and repeated the routine in reverse.

“My son was explosive and disintegrated rapidly and we still had to wait and go out of area for everything. It’s amazing I’m not dead because of all the stress we had to go through,” she says.

Now 20, Daniel is doing better, though he still has difficulty sleeping and making decisions about his future. He recently stopped going to community college and he quit taking his psychiatric drugs when his medication manager moved to another facility. Barbara has learned to advocate for him, by typing a family history for providers, documenting the day-to-day changes in his moods and behaviors, and writing letters to public officials. Still, she wonders how Daniel’s life would be different had he received appropriate care early and consistently.

“At every level, there is a lack,” she says. “The whole descent could have been stopped.”

A Lost Childhood

(Names have been changed to protect privacy.)

After ending a physically and verbally abusive relationship when her son and daughter were toddlers, Sharon Myers struggled to keep her children safe. It was a constant challenge for the single mother on welfare, in a filthy housing project where stabbings sometimes turned the hallways into crime scenes.

Melissa, the younger child, was petite but packed a lot of energy. “If there was something going on, you can almost guarantee that she’s the one who planned it,” Sharon recalls of her curly-haired, green-eyed daughter. “She used to like to draw and color and paint – that meant on the walls!” Brian, who as a baby had amazed his mother by walking and talking early, was growing up to be a handsome, shy and intelligent little boy. “We were fine for awhile, all three of us, by ourselves,” she says.

Then Sharon got a boyfriend.

But Melissa began to withdraw and to be terrified of staying with anyone other than her mother. She would act out in violent, unpredictable ways. “We’re talking someone all of 25 pounds tearing the house apart,” Sharon remembers. “Looking at her could set her off.”

Desperate to find out what was wrong with her child, Sharon didn’t know where to turn. She didn’t have many friends she could confide in, so she rifled through the phone book, begging therapists to help. Most were unwilling to accept a six-year-old patient. If they did agree to see Melissa, they’d find nothing the matter. “I had no clue what was wrong with my child and no idea where to get services,” Sharon says.

Two years later, Melissa jumped out of her bedroom window, screaming and threatening to stab anyone who came near. “I had to put her somewhere where she’d be safe,” Sharon says. “So I had her arrested for assault with a deadly weapon. I eventually had to turn over temporary custody of her to [the state]. It was the biggest mistake of my life.”

Melissa ended up in the hospital, with a range of diagnoses including oppositional defiant and post-traumatic stress disorders. Finally, after a flashback, she revealed that her mother’s boyfriend had molested her multiple times.

Sharon believes that some aspects of the children’s mental health care system harmed her daughter rather than helped her. When Melissa finally started seeing a therapist, for example, her treatment was discontinued several times because of staff turnover. Long waiting lists kept her from receiving the care she needed promptly. And Sharon says providers often blamed her for her daughter’s problems rather than listening to and working with the family. “I had to fight for more involvement in her treatment,” Sharon says.

Melissa has now been living away from home for nearly five years. In that time, she has stayed at various foster homes and residential treatment facilities. Her mother and brother spend

time with her at weekly family therapy sessions, and Sharon says the sessions are helping. The parent support group she attends has also been a “lifesaver,” she says. She just wishes she could have found the services earlier.

In March, if all goes as planned, Melissa is scheduled to come home permanently. Sharon believes the family would have been reunited sooner if she had known where to find help, and if providers and state agencies would have treated her as an equal partner. More parents need to be aware of their options, and that they are not alone, she says.

“I wish I could start an agency and say, ‘If you need help, come here.’ Or an 800 number, or just a place downtown somewhere,” she says. “You’ve got a child with problems, come here and we’ll help you.”

A Search for Answers

(Names have been changed to protect privacy.)

Sally Mahoney knew something was wrong with her daughter very early on. As a baby, Allison never settled down for a nap, she was a fussy feeder and she didn't smile. She seemed cranky all the time. "She cried and cried," Sally says. "I remember holding her and she just didn't respond."

Allison's responses to the bumps and bruises of childhood continued to go beyond the typical tantrum. When she scraped her knee as a toddler at a family reunion, she sat down in the middle of the road and wailed for an hour. A frightened neighbor came outside and tried to calm her with candy, but Allison wouldn't let anyone near her. On her first day of kindergarten, she ran from the classroom to the parking lot and locked herself in the family car.

"We went from therapist to therapist. Nobody gave us any answers," Sally says. Instead of asking about family history, doctors told the Mahoneys that Allison's problems had to do with their parenting. "Everybody said put her in time-out, set limits, do this, do that. No one said anything about maybe it has to do with her wiring." Meanwhile, at home, her mood swings continued and she talked of hating herself and wanting to die.

The Mahoneys went back to their HMO repeatedly for advice, and doctors tried prescribing a variety of medications to Allison. But she still had no diagnosis, case manager or treatment plan – and nothing was helping. She hated going to school because she couldn't concentrate on what the teacher was saying.

Nothing changed until Allison was in the fourth grade, and her mother admitted to having hit her in frustration.

"I was at the HMO one day with her, seeing some therapist who wasn't getting it yet. I remember saying, 'I've smacked her,'" Sally says. "I needed to tell somebody. It was a cry for help."

Only then did the HMO contact the state Department of Mental Health and begin an intense effort to link the family to services, Sally says. Allison went to a day treatment center for a complete psychiatric evaluation and was diagnosed with bipolar disorder, approximately eight years after her symptoms had begun. The doctor in charge of the facility prescribed Depakote, which finally stabilized her, and the family began receiving services from Project Connect, a program that designs, implements and monitors specialized treatment plans for children with severe emotional problems.

Project Connect is based on a model developed by the National Institute of Mental Health. It brings together a team composed of the family, all of the professionals working with the family – such as therapists, teachers, probation officers and social workers – and all of the significant people in the family's natural support network, such as clergy and friends. The team

members attend bi-weekly meetings in neutral settings, and make an individualized plan of services that build on the strengths of the child and family.

“Although they are only supposed to stay directly involved with a family for a certain length of time, we needed them longer and they were able to be flexible,” Sally says. “They understood exactly what we, as a family, needed to do to help our daughter and ourselves.”

But getting modifications for Allison at school was still a struggle, because school system professionals couldn't see evidence that her disease was the source of her inability to learn. Like many children with bipolar disorder, she would hold herself together at school and fall apart once she got at home. “Her days were still miserable and they were saying, ‘There's nothing we can do,’” Sally says. “They were absolutely rigid: ‘We will not do anything, she is absolutely fine in school, there is nothing we can see.’” Only after Allison had disintegrated to the point where she required hospitalization did her school set up an educational plan for her.

Allison is now in eighth grade and is doing better. The HMO covers 24 psychiatric visits a year with a \$10 co-pay, and she has had the same therapist and psychopharmacologist for the past three or four years. But when she hit puberty recently and her symptoms began to re-emerge, it was her mother who noticed that her medication levels had never been readjusted. “She's just been suffering for three months. Why wasn't there anyone who said it's time for her to have a meds check?” Sally asks. “If she had diabetes or a heart condition or cancer, I don't think that would have happened.”

At school, Allison attends a special education class once a day and is integrated into mainstream classes the rest of the time. Her course load and assignments are tailored for her as well. Last year, she joined the yearbook staff.

She still suffers because of the stigma of mental illness, however. When classmates call her “Red SPED,” a reference to her red hair, she complains to her mother that her brain “doesn't work.” “She feels alone,” Sally says. “It's not like you want other people's pity, but you want their understanding.”

Seven Years Gone

(Names have been changed to protect privacy.)

When 3-year-old Michael Brown told his mother he wanted to die, she was so shocked and frightened she didn't tell a soul. She was outside with him on a freezing day when Michael, who used sign language to compensate for speech difficulties, pointed to a patch of ice and signed, "Michael walks on ice, ice breaks, Michael falls in water. Michael wants to die."

Michael had been born with a cluster of birth defects known as VATER syndrome, and during the first two years of his life, he had endured a stream of medical procedures, including lengthy surgeries. When he was a toddler, his speech began to regress and he misbehaved a lot, but doctors said it was normal behavior for a child with his disabilities. They told his parents he would stop acting out when his ability to communicate through sign language improved.

But although Michael's speech improved, his behavior continued to decline. A year later, with him still throwing violent tantrums and emptying half-gallons of milk around the house, a child psychologist put him on psychiatric medication.

The Browns, who had had no trouble finding the help Michael needed for his physical problems, spent the next seven years navigating the mental health system.

"Along the way, I would always think I was on the right road," Michael's mother, Cheryl, says. "I would get these referrals to these different social workers and I would come there with all of my notes, all of my medical papers, all of my journals, and I would think, 'This is the right person who is going to fix this problem.'"

A few months would pass though, and the providers would lose interest, Cheryl says. It seemed like they would realize how complex Michael's problems were and that they weren't sure how to help. Suddenly, instead of recommending that he return in three weeks, they'd tell his parents to call in an emergency.

At school, Michael would stand on tables and uproot desks. He once wrapped twisted paper towels around a classmate's neck. By second grade, he had seen at least a dozen mental health professionals and had been placed in an out-of-district therapeutic school. By fourth grade, he was attending classes in a different building than his friends and eating lunch at a separate table. And last year, his specialized school expelled him because Michael was too much for even the on-site psychiatrist to handle.

Cheryl blames the delay in Michael's care on the time allotted to psychiatric visits, the fragmentation of the mental health system, and the lack of knowledge about pediatric mental illness – even among doctors and other professionals who treat sick children.

"You spend more time driving to the doctor's office and sitting with your kid, and you've just sat down and the appointment's over. You're in and out of there before there's any

treatment possible,” she says. “If heart surgery needs 18 hours, that’s the time you give it. If you need three hours of mental health help, that’s the time you should take.”

Michael finally began receiving the help that made a difference seven years after his problems began – and only then through chance. His social worker happened to be friends with a pediatric psychiatrist who had closed her practice but was willing to see Michael as a personal favor. The very first visit, she referred him to Bradley Hospital, a facility for children and adolescents with severe emotional, behavioral and developmental disorders in East Providence, Rhode Island. She even called the Browns on New Year’s Eve to see how Michael was doing. He spent 12 weeks at Bradley and was stabilized, before being transferred to a one-year residential school placement in Needham.

Now Cheryl asks why none of the experts Michael saw earlier in his life were able to provide the same level of care – especially since the hospital that could help him was only 45 minutes away. “I was running around with this child who was in such mental anguish and pain and so severely mentally ill, and I made no progress,” she says. “No one can take away the pain of how I feel, because I can’t give Michael back those seven years of his life.”