

# Families on the Brink: The Impact of Ignoring Children with Serious Mental Illness

Results of a National Survey of Parents and Other Caregivers

The National Alliance for the Mentally Ill  
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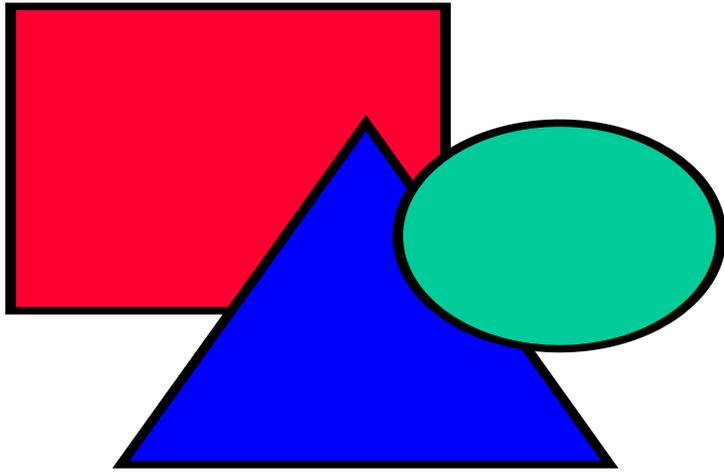
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## Families on the Brink: Message from NAMI's Executive Director, Laurie M. Flynn

The tragedies of school violence around the nation have alerted all of us to the risks our children face. While national consciousness of the pressures our kids confront has been raised, I worry that the enormous difficulties that children with serious mental illnesses and their families confront day in and day out, year in and year out, are being overlooked. The results of this survey of families with youngsters with disabling mental disorders show without question the barriers these families face just to obtain basic and necessary medical treatment. NAMI's survey reveals the struggles these families must endure to get essential education for their children and much-needed supports for the whole family. As the title rightly states, so many of these families are on the brink of survival. The suffering that this report gives voice to deeply saddens and outrages me, not only because these are the voices of mothers and fathers who must try to comprehend why their loved one, their child, has a brain disorder, but because they find themselves all too often having to fight for every shred of medical attention, school system support, and acceptance from their neighbors and friends. In the face of this struggle, they confront the unimaginable but all-too-real risks of family dissolution, financial bankruptcy, wrongful imprisonment of their child, and even the prospect of having to give up custody of their child just to get him or her treatment.

We cannot, as a nation, permit this tragedy to persist. And we need not permit it. We can invest in research so that we better understand serious mental illness in children and its effective treatment. We can make sure that every insurance policy, be it employer- or publicly funded, offers parity for mental disorders. We can fight for a healthcare system that provides comprehensive, high-quality, humane care for those with the most serious illnesses. We can end policies that require the relinquishment of custody as a means to a child's treatment. We can work to educate our healthcare and school professionals so that they truly understand serious mental illnesses and provide the kinds of services that are effective for children with these brain disorders. And we can all just say no to the parent-bashing stigma and prejudice that weigh down these families as they confront a horrible illness in their precious youth.

As we struggle to make the lives of all our children better in the wake of unthinkable school violence, we must not forget our children who have serious mental illnesses and their families who love them. Brain disorders can and do strike our most vulnerable members of society-our children. But we know much about how to help these kids, these families. Surely, it is our obligation as a just society to do so.

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## Families on the Brink: Executive Summary

Serious mental illness is very real for millions of our nation's children and adolescents. It is estimated that nearly half of the nation's 7.5 million children with a mental disorder have a condition producing serious disability. One of the most tragic manifestations of this national tragedy is the high and climbing rate of suicide among our nation's youth, with suicide being the third-leading cause of death among young people between the ages of 15 and 19 years—rates that have tripled since 1960. Behind these statistics are families struggling to best help their son or daughter with a serious brain disorder, families who are largely invisible to the public at large.

NAMI, the nation's largest organization for families facing serious mental illness, commissioned and helped conduct a national survey of families with children who have such a brain disorder. Developed using focus groups with such family members, the survey asked about the health status of the child or adolescent, treatment experience, and issues of treatment and service access, stigma, and family pressures. Families in all 50 states provided 903 responses.

Respondents clearly reflected the experience of a serious mental illness in a child or adolescent, with the vast majority of respondents reporting serious functional disturbances in their children, serious diagnoses, prolonged duration of illness, and intensive treatment and service use.

Major survey domains included: healthcare-provider experiences, health insurance and managed care, the fall-out of inaccessible treatment and services, school-system experiences, abuse of children and adolescents in various systems, and the toll on families. While some families reported some positive experiences in each domain, the overall picture is one of major barriers to care with devastating results for the children and the families. For example:

- Only 34 percent of respondents reported that their primary care physicians routinely evaluated mental, emotional, and behavioral issues and development; 56 percent of the responding parents stated that their children's primary care physician did not recognize their serious mental illnesses.
- Sixty-six percent of responding parents reported a lack of health insurance parity, with nearly half—49 percent—saying lack of parity impeded needed care.
- Nearly half of the respondents, again 49 percent, indicated that managed care organizations limited or denied access to needed treatment for their children to the detriment of their children's health.
- Twenty-three percent of respondents reported having been told that they will have to relinquish custody of their children to get needed services; 20 percent said that they did so to get care.
- Fifty percent of the responding parents reported agreeing or strongly agreeing with the statement, "I worry that my child will not get needed treatment and will become physically aggressive or violent."
- More than one-third of the parents who responded to the survey—36 percent—reported that their children were placed in juvenile justice because needed services were not available.
- Nearly half of the responding parents—46 percent—felt that schools resisted identifying children with serious mental illnesses; 68 percent said that their children must fail before services are put in place in schools. Only seven percent of respondents said that school professionals are adequately trained and prepared to deal with serious mental illness in children and adolescents.
- Thirteen percent to 15 percent of the family respondents said their children were physically or sexually abused during their stays in a hospital, residential treatment center, or jail. 22 percent

said that the use of seclusion or restraints on their children in a hospital put the children at physical risk.

The data above translated into an enormous toll on families. Nearly half of our survey respondents felt shunned by neighbors and friends because of their children's illnesses-and half said they were blamed for their children's conditions. In more than half the families, 55 percent, one of the parents had to change jobs or quit to take care of the ailing offspring. Fifty-nine percent said they felt like they were pushed to the breaking point. Seventy percent reported that their marriages had been severely stressed by the experience of caring for a sick child; and in 80 percent of the responding families, siblings were negatively affected.

These results paint a dire picture of what families with a child or adolescent with a serious mental illness contend with today. We must, as a nation, work to alleviate the gaps in illness recognition and treatment, remove unethical barriers to needed care and services, and end unthinkable requirements to relinquish custody to gain access to treatment. We must stop the stigma and inhumane conditions that too often surround serious mental illness in children and adolescents. NAMI calls for:

- increased research on the prevalence, nature, and effective treatment of serious mental illness in children and adolescents to better guide clinical care and public policy;
- a campaign to educate health and school professionals about serious mental illness in children and adolescents so we can improve early detection of these brain disorders and provide proper care and services and supports for children and their families;
- an end to health insurance discrimination against serious mental illnesses in children and adults at the national level;
- the passage of national requirements to improve access to and quality of care in managed care systems-passage of a managed care bill of rights;
- an end to the requirement that caring families relinquish custody of their children with serious mental illnesses solely to gain access to needed care;
- needed training of juvenile justice officials about the screening for and appropriate treatment of youth with serious mental illnesses who enter this system;
- high standards for the application of restraint and seclusion to children in the treatment system to eliminate the risk of harm to these young people with serious mental illnesses while they are in the hospital or residential treatment facilities; and
- a national campaign focused on ending the stigma and discrimination that surrounds serious mental illness in children.

NAMI plans to take a direct and leading role in aspects of provider and school-system education. We will also work vigorously to advocate for appropriate federal-, state-, and community-level actions to effect these goals. Our report targets specific federal actions that are timely as well. We must work together to end the neglect and discrimination that is assailing families facing a serious mental illness in their children.

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## Families on the Brink: Introduction

*The biggest issue we faced during the time our daughter began to manifest problems (when she was five years old) was to convince the "professionals" that she did indeed have a disease that was biologically based and not caused by alleged child abuse, bad parenting, or being Black, middle-class people living in a situation that was primarily middle-class Caucasian. All these things were used against us when we were trying to help our daughter. Thousands of dollars were wasted on "counseling" that didn't work and residential placements where the child controlled the agenda and the parents took the blame and paid the bills. The paternal history of schizophrenia (father's mother, grandfather, and possibly two uncles) was never taken into consideration in determining what might have been causing the illness in the child. It was parent-bashing at its worst.*

*Eventually, a 20-year marriage was destroyed because of the way the family was treated, and it is taking time for my daughter and me to repair our relationship. We both were cheated out of a normal mother-daughter relationship. She lost her adolescence and all the wonderful things that go with that (a first date, the high school prom, high school itself). That is the time we'll never get back.*

*Never allow the state to "take custody" of your child for treatment! We did and it destroyed a marriage, two adults, and a child!*

Disturbing events, such as the carnage that occurred at Columbine High School in Colorado, have deeply alarmed Americans, making them increasingly concerned about, among other things, their children's mental health and the availability of treatments and services should their children need mental health assistance. While every school and youth crisis does not necessarily directly implicate an underlying mental illness, certainly there are a number of children and adolescents who, along with their families, struggle with a serious mental illness or brain disorder. Data on the prevalence of mental disorders in the United States are not yet as well developed for children as for adults (National Advisory Mental Health Council, 1993). Nonetheless, a national 1989 report found that at least 12 percent of children under the age of 18 (approximately 7.5 million children) suffered from a mental disorder, and nearly half of them had a seriously disabling mental illness (IOM, 1989). It is not likely over the ten years since that study that these prevalence rates have gone down. The National Institute of Mental Health (NIMH) reports that one in ten children and adolescents suffers from a mental illness severe enough to cause impairment (NIMH, 1999). Suicide rates among young people have, tragically, sky-rocketed: the most recent statistics available show suicide to be the third-leading cause of death among youth aged 15 to 19 years and the second-leading cause of death among youth 19 to 24 years of age (NIMH, 1999). These rates have tripled since 1960.

While there is no question that much more research is needed to help us better understand the prevalence, nature, and effective treatment of serious mental illnesses in children and adolescents, existing research has pointed to some useful screening tools as well as helpful treatments and interventions. For example, studies have shown that both medications and behavioral therapy can be very helpful in treating children with attention deficit/hyperactivity disorder (ADHD), which is estimated to afflict three to five percent of school-age children (NIMH, 1999). Some treatments for childhood depression have also been shown to be effective. Screening tools are now available that can help reliably diagnose mental disorders in children and adolescents. Despite our growing awareness of both the serious mental illnesses that children and adolescents face and the available helpful

interventions, data show that access to treatment can be elusive. NIMH reports that only one in five children with disabling mental illnesses receive treatment (NIMH, 1999).

We know very little about the experiences of families confronting a serious mental illness in a child or adolescent. Most research has focused on the experience of parents with adult children with a severe mental illness, which is one of high financial cost, heavy care-giving burden, and considerable emotional strain (Hatfield, 1983; Hatfield, et al., 1996; Solomon, Beck & Gordon, 1988; Thompson & Doll, 1982). In the few studies of families who have children and adolescents with serious mental illnesses, researchers have found that such families perceive services to be less than optimal. They do not view professionals as supportive of families, and they encounter a variety of obstacles to care, including being required to relinquish custody of their child to obtain services (Baker, 2000; Collins & Collins, 1990; Fine & Friesen, 1988; Tarico, Low, Trupin & Forsythe-Stevens, 1989).

Families on the Brink: The Impact of Ignoring Children with Serious Mental Illness was commissioned by the National Alliance for the Mentally Ill (NAMI) to direct attention to the needs of families of children and adolescents with serious mental illnesses. The study examined family views of the availability of treatment and services as well as the difficulties encountered when caring for a child with such a disorder.<sup>1</sup> The survey results are described in the following pages, and quotations from responding parents are blocked throughout the text. The data show that while some families have had positive experiences obtaining needed treatment and services, many barriers exist that have devastating effects on the children and the families. The survey results paint a dark picture in which our public policies, our schools, and our treatment systems all but ignore children with serious mental illnesses and push families to the brink. The conclusion of this paper offers recommendations for research, treatment systems, and public policy to make sure that children with serious mental illnesses and their families receive appropriate care and support.

<sup>1</sup> Clinician, researchers, public policy makers and families themselves often use different terms to describe serious mental disorders in children, including "serious emotional disturbances, brain disorders, and neurobiological disorders." For the purposes of this paper, however, we will generally use the term "serious mental illness."

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## Families on the Brink: Methodology

### **Sample and Procedures: Focus Groups**

To develop the questionnaire to be used in the national survey, focus groups were part of the preliminary process for determining families' concerns. The focus groups were conducted in Bethesda, Maryland; Oklahoma City and Tulsa, Oklahoma; and Portland and Eugene, Oregon, sites selected to provide geographic variation in the sample. NAMI state coordinators and local coordinators solicited participants from their local communities and made arrangements for each group. Participants were families and family members who identified themselves as having a child (or children) with a serious mental illness. Conducted between May 12 and May 28, 1998, five two-hour focus groups were facilitated by experienced focus-group leaders. All group sessions were audiotaped, and an independent observer took notes. The tapes were transcribed and transcripts were analyzed for themes and general content by two co-investigators and an independent observer. Questions for the focus groups were based on hypothesized areas of difficulty for families. NAMI requested that focus group questions center on issues related to families' access to intervention and treatment services. The focus group participants were 37 family members representing 29 families in Maryland, Oklahoma, and Oregon. Most parents (72 percent) were married an average of 19 years, and most had only one child (51 percent). The average ages of the parents were 47 years (fathers) and 45 years (mothers). The participants were primarily Caucasian (89 percent) with an average household income of \$50,000. In most households both parents were employed full-time, and fifty-five percent of the fathers held a graduate or professional degree. In comparison, approximately 35 percent of the mothers held a graduate or professional degree, most mothers (37 percent) completed college; and some (21 percent) attended college or trade school.

### **Sample and Procedures: National Survey**

Content areas and specific survey questions were derived from the information from the focus groups, and the survey instrument was developed in conjunction with NAMI. Survey questions queried family, caregiver, and child demographics, including current and past behaviors, intervention and treatment services, and medications. Parents were asked to rate 42 statements about services for youths on a 1-to-7 Likert scale (1 = strongly agree; 7 = strongly disagree). Families were given the option to circle 'not applicable.' Affiliate members and friends of both NAMI and the Federation of Families completed surveys for Children's Mental Health.

Surveys were first distributed to the Federation of Families for Children's Mental Health National Conference in October 1998 in Washington, D.C. A questionnaire was included in each individual or family registration packet. Packets of ten questionnaires also were sent to each of the Federation's 150 state affiliates for distribution and completion. A total of 155 surveys were returned from individuals or families associated with the Federation of Families for Children's Mental Health.

In November 1998 survey questionnaires were also mailed to 3,093 individuals and organizations on a NAMI mailing list of individuals or organizations that had previously expressed interest in issues related to children and teens with a serious mental illness. Many organizations requested additional surveys for distribution in their areas. Follow-up mail was sent to approximately 1500 addresses that did not respond to the initial mailing. Finally, NAMI posted the survey questionnaire on its Web site

for approximately two months in January and February 1999, and 177 e-mail responses were received from this brief exposure. Approximately 83 percent of returned surveys were from the NAMI-related mailings and postings; however, only 39 percent of respondents identified themselves as a NAMI member of NAMI, while 24 percent identified themselves as a member of the Federation of Families for Children's Mental Health. Some respondents (5.6 percent) did identify themselves as a member of AMICAN (5.6 percent) or of the National Mental Health Association (5.7 percent).

Overall, information on 903 children or teens was returned from both NAMI and the Federation distributions. Twenty-four percent (219/903) of those families had more than one child or teen with a serious mental illness. Family members were asked to complete the questionnaire for each child in their household with a serious mental illness. Of the 903, 147 questionnaires were received in which the child was over age 21. Thus, for the purposes of the results described below, only data on children 21 years of age and younger were used (N=756).

While the study results give voice to the views of families facing quite disabling mental illness in a child, it is important to note that the sample is fairly homogeneous in terms of ethnicity, education, and age. Similarly, the youths reported on were similar in terms of ethnicity, diagnosis, and special education classification(s). Thus, the sample may not be as representative of the number and experiences as would a more heterogeneous sample of families who have a child (or children) with a serious mental illness. A second limitation was that the response rate was relatively low. Overall, only approximately 25 percent of surveys sent out were returned. Finally, respondents that returned the questionnaire may be different from those who did not return the survey. This respondent bias may have affected the results.

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## Demographic and Health Characteristics

Demographic characteristics of the sample are listed in Table 1 and summarized as here. The majority of the survey respondents reported that they were the child's mothers, and the mean age of the respondents was 43 years. The majority of the respondents were Caucasian, and they (72 percent) reported that there was at least one other adult living in the home. Most respondents (70 percent) had only one child diagnosed with a serious mental illness, although 30 percent of the families had two or more children with serious mental illnesses living at home. Approximately half of the respondents in the sample (56 percent) worked full-time, were college graduates or had a professional or graduate degree, and had total family incomes of \$40,000 or more. There were respondents from each of the 50 states. Primarily, families had private healthcare coverage provided by an employer (69 percent). While a large minority (37 percent) of the sample had Medicaid coverage for their children, four percent had no healthcare coverage. Finally, 67 percent of all respondents with healthcare coverage reported that their health benefit was managed.

Two-thirds (67 percent) of the children/teens reported on were male, and one-third (32 percent) were female, with their mean age was 13 years (the range was one year to 21 years old). The majority of the youths (80 percent) were Caucasian, while five percent were African-American and four percent were Hispanic. Most children (85 percent) were living at home setting. The mean grade level for the youths was 8th grade, and the majority of the children (70 percent) were receiving special education services from their schools. While all 15 special education labels were represented in the sample, the four most commonly reported classifications were emotional disturbance (55 percent), developmental delay (12 percent), other health impaired (16 percent), and specific learning disability (27 percent). While 23 percent had only one classification, 37 percent had two or more special education classifications.

Many caregivers acknowledged that their child or teen with a serious mental illness was currently exhibiting many disturbing or maladaptive behaviors (within the past 12 months). Most commonly reported were violence or physical aggression (65 percent), suicidal thoughts (45 percent), hyperactivity (64 percent), mood swings (83 percent), and withdrawal from family or friends (46 percent). Among the most commonly identified diagnoses for respondents' children were attention disorders, bipolar disorder, and obsessive-compulsive disorder. Although childhood schizophrenia is very rare, approximately two percent of respondents reported this diagnosis.

*From 15 years old to 17 years old...[our daughter] had ten hospitalizations and ten different diagnoses....[T]hey...kept passing her from facility to facility.*

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## Reports of Treatment and Services Received

Parents were asked to report on treatment and services their child (or children) were currently receiving and had received in the past. They were also asked to provide a value rating (i.e., some, considerable or no value) for each of the services received or experienced. The value ratings allowed parents to express their perspective about the usefulness of the intervention or treatment provided.

Over half of the children were currently receiving medication (53 percent), and 85 percent of the parents reported feeling that medication was of some or considerable value in treating their child's serious mental illness. The most commonly reported medications used to treat children and teens with a serious mental illness included mood stabilizers (e.g., Depakote, Lithium); impulse-control medications (e.g., Ritalin, Adderall); antidepressants (e.g., Zoloft); and Risperdal, Clonidine, and Biperiden. Of note is that 20 percent of the youths in the sample were taking no medication, while approximately one-third (32 percent) were taking three or more medications as part of their medication regimen.

Fifty-six percent of respondents reported that their child had received individual therapy, and 91 percent of these respondents indicated that the treatment was of some or considerable value. Fewer respondents reported that they were involved in family therapy (38 percent) or group therapy (20 percent), although both of these treatment modalities were perceived as beneficial. Ninety percent of respondents reported that family therapy was of some or considerable value and 76 percent perceived group therapy to be of comparable value. Only 10 percent of respondents had children enrolled in day treatment/partial hospitalization, and three-quarters of these families perceived this service to be of some or considerable value. A significant number of respondents (42 percent) reported that their child had in the past been treated in an acute-care psychiatric in-patient unit, and 82 percent of these respondents thought this treatment had been of some or considerable value for their child. While only 11 percent of respondents reported that their child was currently in a residential treatment center, 23 percent reported that their child had previously been in a residential center. Eighty percent of respondents whose children had received residential services perceived them to be of some or considerable value.

Although 46 percent of families who received early intervention in the past felt it was of considerable value, 75 percent of families reported they never received early intervention services. Family support and home interventions were highly valued by families (e.g., respite, in-home therapy, wrap-around services<sup>2</sup>). For example, even though 83 percent of families were not receiving wrap-around services, of the families that were receiving these services, 59 percent felt they were of considerable value. In-home therapy (home-based therapy) services were currently received by only 14 percent of the sample, but more than 73 percent of those families felt in-home therapy was of some or considerable value. Similarly, even though fewer than 25 percent of the families received in-home services, two-thirds of the parents thought the service was of some or considerable value. Twenty-three percent of the respondents stated that they used family support services, and 81 percent of those respondents who used these services found them to be of some or considerable value. Respite is another type of family-support service that families found to be of considerable value (63 percent); however, only 16 percent of families in the current sample were currently receiving such a service.

Overall, it is clear that in many cases children and teens are not receiving potentially beneficial interventions and services, yet these same services, when given, are highly valued by families. Thus, it appears to be common for there to be a gap between the services provided and those valued by families

and for very few flexible treatment options to be available to families who have a child with a serious mental illness.

<sup>2</sup> These services are designed to enable children with serious mental illness who might otherwise be placed in an inpatient or residential setting to remain in their own homes or another home-like setting. Respite care provides families with a substitute caregiver for a brief period of time to relieve parents or other caregivers from the responsibility of caring for their child. Respite care can be delivered in the child's home or in another setting and may be offered for several hours' duration or for an extended period of time, such as overnight or for a weekend. In-home services range from crisis care to prevent the child from having to be placed in a hospital setting to a longer term array of support services including psychological, social, educational, and economic counseling that assist families in maintaining a stable home environment.

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## Healthcare Providers: Potential Partners in Improving Access

*She was able to get an accurate diagnosis and recommendations for treatment because...she had a treatment team that consisted of a child psychiatrist, an MSW, and a psychiatric nurse...The people there knew what they were doing. They were competent. They saw her. Her child psychiatrist saw her everyday, and they spoke with her family for four hours before they made any diagnosis. They brought in her records from everywhere. They did a thorough evaluation on this child. We had filled out histories in the past that no one reads-you can tell by the way they talk to you. The team approach nailed it cold. They said, "Basically, this isn't a dysfunctional family. We have a child who is very dysfunctional creating problems within the family."*

Nine of the 42 survey questions were devoted to family perceptions of healthcare provider knowledge and accessibility (see Table 2). Survey responses signaled considerable support of healthcare providers by families. In general, respondents believed that professionals listened to their concerns (64 percent), although only 20 percent agreed or strongly agreed that their cultural differences were recognized and considered by professionals. Also in line with this view is the fact that 42 percent of respondents disagreed or strongly disagreed with the statement that "most of our health professionals have been more willing to label my child as 'naughty' than as having a serious mental illness." In other words, the family members felt that healthcare professionals took seriously the symptoms of mental disorders in their children. Fifty-eight percent of respondents expressed the view that professionals had included their families in treatment planning.

Most family respondents (51 percent) believed that their child's primary care physician did not require repeated visits or requests for referral for a specialist. But routine evaluation of emotional and behavioral concerns were not the norm either: Only 34 percent of respondents agreed that pediatricians and primary care physicians ask in routine visits about those issues; 39 percent strongly disagreed that routine evaluation occurred. In line with these data is the view of the majority of responding parents-56 percent-that their child's pediatrician or primary care physician did not recognize their child's serious mental illness. And although 39 percent of the respondents felt that their primary care physician appropriately prescribed medication for their child, 37 percent did not, even though most respondents-53 percent-did believe that their child's physician (weather a primary care doctor or psychiatrist) adequately informed them of potential side-effects of medications. Perhaps most surprising is the fact that 37 percent of family respondents did not think mental healthcare providers were well informed about the latest advances in the treatment of serious mental illnesses in children.

*I know that with my son I constantly went back to the pediatrician saying he's having trouble sleeping, with his behavior, connecting to other children-all of those things. He kept examining him physically and then he ran every possible test and said "He's fine. He's healthy." And I said, "Then, what?" And he would say, "I don't know." He gave me the names of some psychiatrists and psychologists after I pressed for them. I took [my son] to a psychiatrist who was an older man....He said if we, the parents, stopped fighting with each other,[my son] would be fine. It was our fault."*

Altogether, these responses suggest that most families with a child with a serious mental illness do trust and turn to their doctors and healthcare providers. Unfortunately, families have raised questions about the awareness of healthcare professionals, both specialists and primary care providers, of the early symptoms and scientific advances relevant to childhood mental illnesses.

*Wrap-around services are the comprehensive range of services and supports needed to maintain a child with a serious mental illness in a community setting. Many of these intense services were formerly offered by residential treatment programs, but are now individually tailored to the child's and family's needs to make it possible for children with serious mental illnesses to receive intensive services while remaining in their homes and communities.*

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## Insurance and Managed Care: Barriers to Needed Treatment

*I think if you have a mild or short-term problem there are plenty of services, but for long-term, serious problems or crises, there's nothing.*

Eight questions in the survey focused on access to necessary care and services, and they covered issues ranging from the availability of providers and services to health insurance and managed care coverage of needed care (see Table 3).

The overwhelming picture painted by our survey responses is one of enormous barriers to necessary care:

- Most respondents faced health insurance discrimination, which impeded necessary treatment for their children. Sixty-six percent reported the lack of health insurance parity for the treatment of a mental illness, which 49 percent said impeded needed care.
- Managed care, families' report, is a significant barrier to needed treatment for everything but medications. While 55 percent of the respondents thought their managed care organization approved needed medications, 48 percent said that accessing inpatient care in a crisis was difficult in managed care, and 49 percent said that their own children have been limited or denied access to service by their managed care plan, to the detriment of their child's health.
- Money matters as well. Fifty-five percent of respondents believe that their child's treatment and service options are limited by their family's income.
- In some instances the services are just not there. While 48 percent of respondents believed they had easy access to a child psychiatrist, 64 percent said their family does not receive routine support such as respite care, family support, and transportation. And 43 percent said the types of treatments most helpful to their children are not available.

*We are the parents of three little boys-one of whom has a severe mental illness. His last stay in the hospital was for 22 days-a stay actually cut short because our insurance carrier refused further payment. This wasn't the first time our son was in the hospital-nor will it be the last. It actually was his fifth inpatient experience over the course of 20 months.*

*Watching a loved one struggle is absolute hell. I know this one quite well as my own father was diagnosed with schizophrenia when I was just six. As a family, we have tried every possible course of therapeutic intervention: special education school placements, active participation in behavior management programs, family therapy, in-patient and partial hospitalization programs. We've done it all. I even took a one-year leave of absence from my place of employment-even though it devastated us financially-because there was no other way to manage John's illness, or the doctors' appointments, or the daily trips to the hospital. His illness literally took over our life, and almost destroyed us as a family.*

These findings portray door after door slamming in the face of families with a sick child-doors closing to appropriate treatment and services that are essential to the child's health and to avoiding the most horrendous results of the illnesses.

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## Living in Fear: When Treatment is Not Accessible

*We're trying. We will live on bread and water so our child can have decent care. If I choose to relinquish my parental rights to the state and put [my son] in the system for treatment, that, to me, is choosing my husband over my child. Or if I choose to get a divorce, I choose my child over my husband. I shouldn't be put in that position. I agonize over that daily. I'm wrestling with the guilt I have either way. People shouldn't have to break up their families to get their children care.*

Parents face tremendous fears for their children, fears too often realized when treatment is not available for a serious mental illness in a child or adolescent. Several questions in our survey focused on issues of child custody, violence, and the criminalization of young people with these serious mental illnesses (see Table 4).

Perhaps most heinous in the survey results was the finding that families continue to face the specter of losing custody of their children to get treatment. Twenty-three percent of the respondents reported having been told that they will have to relinquish custody of their children to get services; 20 percent said they did so to get care.

Violence is another worry of parents with children with a serious mental illness. Fifty percent agree/strongly agree with the statement, "I worry that my child will not get needed treatment and will become physically aggressive or violent."

Parents worry that, without treatment, wrongful imprisonment in the juvenile justice system will be the result of their children's mental illnesses. Thirty-six percent of our respondents reported that their children were placed in juvenile justice facilities because needed services were not available.

The neglect of children with a serious mental illness clearly has dreadful consequences for the children and their families. No family with a child with an illness should have to give up custody to receive care or live in fear of violence or the imprisonment of their youngster.

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## A School System in Denial

*There seems to be a resistance from the public school, passed down through the board of education, not to identify these children because they are too costly to the school. They think, "If you can just ignore them, maybe they'll go away." ...Some of these kids aren't even in school.*

Access to a good education is important for all children and their families. Children with serious mental illnesses and their families are no different. Unfortunately, our data imply that schools often avoid provision of the proper supports needed to help these ill children learn and prepare for their future.

Eight of our survey questions focused on school-related issues (see Table 5). The data show that only 22 percent of the families surveyed felt the school system had been very supportive of their children's needs. Only 30 percent said that individualized education plans-required by federal law-are prepared to really meet the needs of their children. Forty-six percent felt that schools resisted identifying children with serious mental illnesses; indeed, the evidence shows that parents have to fight for appropriate educational support:

- Only 16 percent believed the school system quickly evaluated their children and placed them in an appropriate special education class. A full 30 percent of respondents said the school rejected their request for such a placement, and 16 percent had to file a lawsuit to get assistance from the school system.
- The large majority of respondents-68 percent-said that their child must fail before additional services are put into place in schools.
- Only 7 percent of respondents said that school professionals are adequately trained and prepared to deal with serious mental illness in children and adolescents.
- 

*We need people to go out and talk to teachers. I know my son is not the only one at that school with mental illness. They don't recognize it. They don't know how to deal with it.*

Clearly, school systems in general are turning their backs on children with serious mental illnesses, an attitude that does not serve kids with mental illnesses, their families, or the larger community well. School systems will have to improve their knowledge and application of that knowledge to better serve children with these special educational needs.

*The only way to get services in is to hire a good lawyer-bottom line. If you can only access service through the school system because you're not eligible for community mental health services or your child is not a juvenile delinquent, then you've got to have money to hire a lawyer because that is the only way you are going to get an appropriate placement for your child.*

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## The Unthinkable Risks

What is perhaps most horrible to face when considering a child suffering from a serious mental illness is the vulnerability of that child when placed in the care of the treatment system or dumped into the juvenile justice system. We asked a few questions in our survey about perceived risks and experiences of abuse in the hospital, residential treatment center, or jail (see Table 6). Even though most respondents did not report knowledge of abuse, a sizeable minority did.

- Fifteen percent of our family respondents said that their child was physically or sexually abused during their stay in a hospital or residential treatment center.
- Thirteen percent said physical or sexual abuse happened to their child in jail.
- And 22 percent said that the use of seclusion or restraints on their child in a hospital put the child at physical risk.
- 

*Juvenile hall told me, "You have to have him arrested all the time." ...I want to press charges, but he's not a street-wise, cool kid. I don't want him slammed up in juvenile hall with gang-busters. Is that the right thing to do?"*

We must achieve a level of zero tolerance for abuse of these vulnerable children. No child should be abused while in the custody of a treatment system or jail; no family should have to worry about such treatment.

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## The Toll on Families

*"I think that a lot of people expect us to have friends with normal kids. It's painful to see my friends with normal kids. It's rubbing my face in what we don't have. I love seeing my friends with their normal kids, but it's incredibly painful. Because our kids have invisible disabilities, it's very hard. People don't understand. We're not typical. We can't do typical things. We don't have typical children.*

Given the many barriers that families face when seeking appropriate care for their young ones with a serious brain disorder, the lack of services, support, insurance coverage, supportive school systems, as well as the behavioral manifestations of these illnesses, it comes as no surprise that families are terribly strained. In fact, the strongest concerns expressed by our respondents centered on questions about stress and burden within the family (see Table 7). Dealing with a child with a serious mental illness affects the well-being of the whole family.

*My daughter, who's 19 years old, just came home from college. We were just talking about the effects of [her sister with] bipolar on her. Now that she's been away from us, she's had post-traumatic stress syndrome from living with us. Those were her words about it. Isn't that sad?*

Serious mental illness in a child appears to be an isolating experience. Forty-six percent of the respondents said that they feel shunned by friends and neighbors because of the illness. Fully 50 percent said that they felt that others blamed them for their children's conditions. Fifty-five percent of the respondents reported that they or their partners had to change jobs (and some had to take a lower paying job) or quit work altogether to care for the ailing offspring. No wonder that 59 percent of the respondents said that caring for their sick children often feels as if its pushing them to the breaking point. It is not just the caregiving parent who is suffering. Fifty-six percent of the respondents said that stigma and prejudice were exacting a serious, negative impact on their families and their children. Marriages are strained. Seventy percent reported that their marriages had been severely stressed by the experience of caring for a sick child. And siblings are negatively affected; 64 percent of the respondents felt that they could not care for their other children as they wanted because of the caregiving demands required by their child with a serious mental illness. Eighty percent said that the experience of a sister or brother with a serious mental illness has been extremely stressful for siblings.

In short, the challenges of caring for a child with a serious mental illness are falling largely on the shoulders of caregiving parents and families-with an enormous toll for all. Support for these caregivers, which the families view as inadequate, could do much to help assuage their burden and strengthen families confronting these illnesses. But we also must end the stigma and isolation that a diagnosis of serious mental illness so often translates into.

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## Conclusions and Recommendations

Parent's perceptions, comments, and ratings appeared consistent in both the focus groups and the national survey, and it is heartening that there were some positive findings. First and overall, the services offered and treatments available to patients, including collaboration with families, appear to have improved over the past 20 to 30 years, which proves that advocacy for policy changes and legislation can make a significant difference. Second, families that received or are receiving early intervention services for their children are able to note the differences and are pleased with the improved level of functioning of their children. Finally, when conducting the focus groups, it was evident to us that families who lived in states with mental health parity were pleased with the greater access to and availability of services for their child or (children) with serious mental illnesses. Thus, it appears that parity is making a difference in service accessibility and in the continuum of care.

It appeared, however, that at the individual level parents often felt blamed, frustrated, and unsupported by family, friends, professionals, and schools. Parents reported needing services like respite, wrap-around services, and family support services. It was extremely difficult for parents to feel continually blamed by professionals for their child's difficulties, the lack of treatment success, or their child's academic failure. Parents would like to be treated as competent, capable adults and would like to feel their ideas, thoughts, and concerns are respected and valued.

Similarly, while some families thought that professionals are well-informed and empathic, most caregivers felt the professionals involved in the evaluation, treatment, and medication management of their children were misinformed or lacked sufficient training or expertise to understand their children's disorder or treatment needs. Parents perceived that most professionals and services were not up to date with the latest research or treatment information and used outdated theories and approaches. Parents wanted more early intervention services and greater educational efforts directed at primary care physicians, teachers, educators and mental health professionals about the nature of serious mental illness in children and adolescents. Parents often had good experiences with multidisciplinary teams that respected them and their children and that included them in planning for their children.

At the policy level, caregivers did not feel the system was family friendly. The lack of insurance parity and the inequality of third-party payment for mental illness treatment led many parents to significant financial hardship and personal strain. Some parents felt penalized by the system for having a middle-class lifestyle and income and were not able to get the services needed for their children. The mental health system as it currently operates does not consider the treatment and intervention needs of youths with serious mental illness. In other words, the services offered by the system are meant to address more acute or short-term treatment needs for children. The mental health system is not yet able to accommodate youths who need intensive treatment and who have a chronic and serious mental illness. As a result, children and teens are often placed in systems that are unable to address their many needs. Parents would like parity for behavioral health insurance coverage so that they could access more services for their children. Caregivers also perceived that education and mental health agencies often protect their own vested interests rather than those of children with serious mental illnesses. Parents tended to view the child-services system as fragmented, which makes it difficult to obtain comprehensive, appropriate services for their children.

In addition to these failures of the very systems meant to serve those with serious mental illness, the survey results reveal some frightening and ethically unacceptable practices and outcomes. Too many families—more than 20 percent of the survey respondents—still face the unbearable decision of relinquishing custody of a child to obtain essential treatment or going without it. This is a decision no

parent should have to make. More than 10 percent of our respondents confessed that their children were physically or sexually abused while in the custody of hospitals, residential treatment centers, or juvenile justice facilities. More than 20 percent spoke of the physical risk their children faced while in seclusion or restraint. Surely parents should not have to worry that their children will be abused in the very facilities they entrust them to for care. We must end such tyranny for our most vulnerable young people.

Finally, the vast majority of respondents gave voice to the terrible toll on families-caretaking parents, spouses, siblings-caused by inadequate treatment and services for children with serious mental illnesses, the prevalence of stigma, and the injustice of outright parent-blaming. Inadequate information and services, in the face of social stigma, leave these families devastated-on the very brink of survival.

Given the dark picture painted by our survey respondents, we believe there are several actions that can be taken by federal, state, and local governments; by professionals; and by advocates. We offer recommendations that actually outline a complete agenda for ensuring that children and adolescents with serious mental illnesses receive the treatment and services they need so that they can enjoy their best health outcomes, achieve appropriate developmental gains, and experience true recovery. The outline below includes specific recommendations that address current legislative and federal activities that could help move us toward this goal.

**1. Research:** Clearly we need a significant investment in research that better reveals the prevalence, nature, and effective treatment of serious mental illnesses in children. With so many children receiving medication-53 percent of those represented in this survey-we need data to guide the appropriate use of these medications. We also need more comprehensive studies of the experiences and needs of families with children with serious mental illnesses, who are obviously in the frontline of dealing with these illnesses and their associated problems. NAMI calls on the NIMH to prioritize research on children's serious mental illnesses and develop a complete portfolio of basic, clinical, and services/policy research on this issue, informed by the experiences and priorities of families with children with these brain disorders.

**2. Professional education:** While our survey respondents signaled strong potential for partnership with professionals involved in the treatment of children with serious mental illnesses, there is clearly a need for both primary care and mental health providers to become better informed about current research findings and to work with families when treating ill children. It is crucial that primary care providers, especially, apply screening and early recognition tools so that serious mental illness is diagnosed as early as possible to prevent prolonged delays in appropriate treatment. A year lost to a child is a year that cannot be recouped. NIMH, along with the Center for Mental Health Services and professional societies, should focus some of its translation efforts on improving professional continuing education and practice and on disseminating tools for early identification and best treatment practices. In the coming year, NAMI is planning a major effort to disseminate to providers a scientifically documented screening tool to assist in this important area.

**3. Insurance parity:** We need to complete the job of ensuring that all health insurance policies offer complete parity in coverage for serious mental illnesses, including those in children. NAMI strongly urges Congress to pass Senate bill S. 796. It would require full parity for the serious and prevalent brain disorders in children and adolescents, including major depression, obsessive-compulsive disorder, and ADHD.

**4. Quality in managed care:** While the need for comprehensive and long-term care for children with the most severe and disabling forms of mental illness is a general problem needing attention, with the prevalence of managed care we need to address this form of care management. Managed care systems must make sure that children with the most serious and disabling mental illnesses receive the full complement of care required by their disabling illnesses. Specifically, NAMI calls on Congress to include in any patients' bill of rights legislation a) a requirement for all health plans to allow for children diagnosed with a serious brain disorder a "standing referral" to a child and adolescent psychiatrist; b) a requirement that plans allow child and adolescent psychiatrists to serve as primary care coordinators for children with these brain disorders; and c) a requirement for plans to allow families independent, third-party review of treatment denials.

**5. Responsive school systems:** Education of school-system professionals is also desperately needed so that they are better able to recognize serious mental illnesses in youth and provide appropriate services for them. Schools also need to reform from a "fail first" mind-set; our children cannot afford the loss of essential years of education. To this end, NAMI recommends that Congress amend the Elementary and Secondary Education Act (ESEA) to allow funding for training of regular classroom teachers in early identification of the symptoms of serious mental illness and the necessity of early intervention. NAMI further recommends that Congress reject efforts to a) repeal the current due-process protections in the IDEA law for families or b) grant school districts increased authority to pursue "cessation of services." The 1997 amendments to IDEA struck a careful balance between the rights of families and the need to give school officials greater control over student discipline procedures. Congress should respect this careful balance.

**6. Appropriate services in juvenile justice systems:** With so many children with serious mental illnesses ending up in our juvenile justice system, it is crucial that we ensure the appropriate recognition of these illnesses and their treatment in such settings. Therefore, NAMI urges Congress to support legislation to enact a new Juvenile Delinquency Prevention Block Grant and to allow states to use the funds for mental illness health assessments, screening, and treatment for youth that enter the juvenile justice system. States and communities should also be encouraged to use such funds to train juvenile justice system personnel on appropriate access to mental health and substance abuse programs. Congress should also use any new Juvenile Delinquency Prevention Block Grant program to encourage "inter-system collaboration" between local juvenile justice and mental health systems to enhance services for at-risk youth.

**7. Safe and appropriate use of restraint and seclusion:** A difficult decision of all families is the placement of their child into a hospital or longer term facility, such as a residential treatment center (RTC). Unfortunately, experiences documented by this survey documents the not infrequent and sometimes life threatening use of restraint. Why do injuries and sometimes even deaths occur? They occur because there is no evidence-based peer researched foundation for the use of restraint and seclusion. They are resorted to by inadequately trained and understaffed facility aides based on common use. They are resorted to because there are no national standards governing their use. Residential treatment centers, in particular, have no national uniform standards around clinical care, abuse and neglect avoidance, and restraint and seclusion. Given these circumstances, NAMI has called for the immediate enactment of national legislation, pending before the U.S. Congress as S. 736, S. 750, and H.R. 1313, which would: (1) specify that restraints may only be used for emergency safety situations as ordered by a physician and (2) mandate the reporting of all deaths and serious injuries to a third party investigative agency.

**8. Elimination of stigma attached to serious mental illnesses in children and adolescents:** There is an obvious and continuing need for our nation to end the hurtful myths about serious mental illnesses in children and adolescents. Unfortunately, young people, like adults, can get brain disorders, which are no-fault, biologically based brain illnesses. We must get that message out to our communities so that families living with these conditions are not left fighting the prejudice and hurtful attitudes that are so damaging to them. NAMI plans to develop materials for families to help them understand current scientific advances and to avoid being ashamed about their children having a brain disorder. NAMI also calls on the White House, in the wake of the historic and tremendously successful Mental Health Conference, to devote its anti-stigma campaign to correcting the misinformation about serious mental illness in children and adolescents and to acknowledging that these illnesses are brain disorders requiring medical treatment and support just as any other chronic and disabling conditions do.

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**Table 1--Demographics**

Sample	Number of Respondents	Percent of Respondents
<b>Respondent's relation to the child</b>		
Mother	527	75.8%
Father	44	5.8%
Stepmother	15	2.0%
Stepfather	4	.5%
Foster mother	21	2.8%
Foster father	4	.5%
<b>Ethnicity of Respondents</b>		
Caucasian	668	88.4%
African-American	37	4.9%
Hispanic	19	2.5%
Asian	3	.4%
<b>Education of Respondents</b>		
High school not completed	16	2.1%
High school/GED completed	69	9.1%
Some college/trade school	263	34.8%
Four year college degree	181	23.9%
Graduate/professional degree	179	23.7%
<b>Employment status of Respondents</b>		
Not employed	211	27.9%
Employed part time	169	22.4%
Employed full time	366	48.4%
<b>Family Income</b>		
\$0-\$14,999	78	10.3%
\$15,000-\$24,999	93	12.3%
\$25,000-\$39,999	151	20.0%
\$40,000-\$74,999	257	34.0%
\$75,000 - more	164	21.7%
<i>N=756</i>		

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## Table 2—Health Care Providers

Likert responses for individual questions	Percentages							Total
	Strongly Agree	Agree	Partially Agree	Neither	Partially Disagree	Disagree	Strongly Disagree	
1. Most of our health professionals have been more willing to label my child as "naughty" rather than as having a brain disorder/serious emotional disturbance.	15	11	16	9	7	25	17	711
2. My child's pediatrician/primary care physician has prescribed medication appropriate for treating my child's brain disorder/serious emotional disturbance.	17	22	12	8	4	16	21	565
3. Our family has usually been included by professionals in our child's treatment or treatment planning.	21	37	19	5	7	4	7	700
4. My child's pediatrician/primary care physician did not recognize and diagnose my child's brain disorder/serious emotional disturbance.	31	25	11	7	4	11	11	646
5. My child's pediatrician/primary care physician asks about emotional and behavioral concerns during routine visits and checkups.	13	21	17	5	4	18	21	681
6. Most mental health practitioners I encountered were not well informed about the latest advances in the treatment of brain disorder/serious emotional disturbance in children.	22	15	19	12	6	16	11	711
7. My child's pediatrician/primary care physician referred me to mental health professionals only after repeated visits or phone calls.	16	10	8	11	5	23	28	509
8. Professionals (doctors, teachers, therapists) listen to me and my concerns.	11	20	33	6	13	7	10	734
9. Our family's cultural differences have been recognized and considered by professionals when designing our child's treatment plan.	8	11	12	32	7	13	16	407
10. My child's physician adequately informed me about the potential side effects of my child's medication.	24	29	14	4	7	13	9	683

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**Table 3—Health Insurance and Managed Care**

Likert responses for individual questions	Percentages							Total
	Strongly Agree	Agree	Partially Agree	Neither	Partially Disagree	Disagree	Strongly Disagree	
1. The lack of equal insurance coverage has impeded necessary mental health treatment for my child.	32	16	15	10	3	15	10	621
2. The types of treatment(s) most helpful to my child are readily available in my community	9	15	19	3	11	17	26	728
3. My family receives routine support (such as respite care, transportation, family support) from the service delivery system in our community.	4	10	9	5	7	21	43	601
4. In my area, I do not have easy access to a child psychiatrist.	17	10	12	5	7	22	26	712
5. My HMO/managed care plan makes it difficult for us to get access to inpatient care when my child needs inpatient care or is experiencing a crisis.	35	13	13	14	4	13	7	443
6. Access to services for my child has been limited or denied by my HMO/insurance company/managed care plan to the detriment of my child's health.	32	17	13	12	4	12	10	555
7. My insurance policy provides equal benefits for mental and other health needs.	7	10	5	8	4	19	47	666
8. My child's treatment and service options are limited by our family's income.	32	22	13	7	2	14	10	675

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## Table 4—Custody and Juvenile Justice

Likert responses for individual questions	Percentages							
	Strongly Agree	Agree	Partially Agree	Neither	Partially Disagree	Disagree	Strongly Disagree	Total
1. I have been told I will have to relinquish custody of my child in order to receive services.	14	9	8	6	2	17	44	505
2. In my opinion, my child has been wrongly placed in the juvenile justice because the needed services were not available.	28	8	7	16	3	13	24	242
3. I worry that my child will not get needed treatment and will become physically aggressive or violent.	30	20	20	9	4	9	9	646
4. I have relinquished custody of my child in order to receive services.	14	3	3	7	--	21	53	293

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## Table 5—School Systems

Likert responses for individual questions	Percentages							Total
	Strongly Agree	Agree	Partially Agree	Neither	Partially Disagree	Disagree	Strongly Disagree	
1. In my school system, individualized education plans and other services are individualized to meet my child's educational needs given his/her brain disorder/SED.	10	20	22	6	7	15	20	664
2. The school system has been very supportive of my child's needs and me.	8	14	25	5	10	11	27	719
3. I have had to file a lawsuit to get assistance from the school system.	11	5	6	10	2	25	40	420
4. My child's school system is resistant to identifying children with serious emotional disturbances/brain disorders.	29	17	16	11	7	13	8	683
5. School professionals are adequately trained and prepared as to how to deal with our child's brain disorder/serious emotional disturbance.	3	4	10	2	11	21	49	730
6. It has been my experience (in our school setting) that my child must "fail" first, before additional services may be requested or put into place.	51	17	10	4	2	7	8	698
7. The school system quickly evaluated my child and placed him/her in an appropriate special education class.	7	9	8	3	7	16	49	670
8. The school system rejected my request to place my child in a special education class.	21	9	11	11	6	23	20	561

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**Table 6—Risks of Abuse**

Likert responses for individual questions	Percentages							
	Strongly Agree	Agree	Partially Agree	Neither	Partially Disagree	Disagree	Strongly Disagree	Total
1. My child has been physically or sexually abused in a mental health or residential treatment facility or hospital.	10	5	4	10	2	17	51	357
2. My child has been physically or sexually abused in the juvenile justice system.	8	5	5	15	--	20	49	212
3. The use of seclusion or restraints on my child while in the hospital or residential treatment facility put him or her at physical risk.	12	10	7	23	4	20	25	329

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## Table 7—Family Toll

Likert responses for individual questions	Percentages							Total
	Strongly Agree	Agree	Partially Agree	Neither	Partially Disagree	Disagree	Strongly Disagree	
1. My marriage/partner/relationship has been severely stressed by the experience of caring for a child with this type of problem.	48	22	16	5	3	2	4	664
2. Stigma and prejudice have had a serious negative impact on my child's or my family's well-being.	36	20	20	10	4	6	3	701
3. My partner or I have had to change jobs, take lower paying jobs or quit in order to have more time to take care of our child.	39	15	15	5	3	11	12	593
4. I often feel shunned by friends/neighbors/extended family because we have a child with a brain disorder/serious emotional disturbance.	30	16	22	9	5	11	8	721
5. I am unable to be as attentive to my other children as I would like to be because of the demands of caring for my child with a serious emotional disturbance/brain disorder.	42	22	19	6	3	5	3	609
6. I often feel that others blame me for my child's condition.	29	21	20	8	4	10	8	707
7. I often feel the experience of caring for my child with a serious emotional disturbance/brain disorder is pushing me to the breaking point.	40	19	20	7	3	6	5	734

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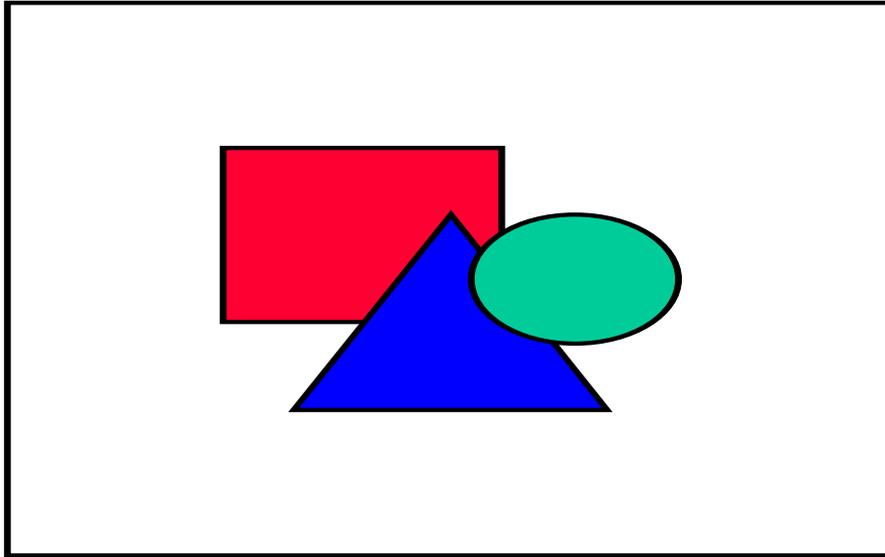
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## Families on the Brink:



[NAMI Prepares for New Administration](#)

[Hellish Lives for Children with Severe Mental Illnesses and Their Families, Landmark National Survey Finds](#)

[Families on the Brink: The Impact of Ignoring Children with Serious Mental Illness](#)

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