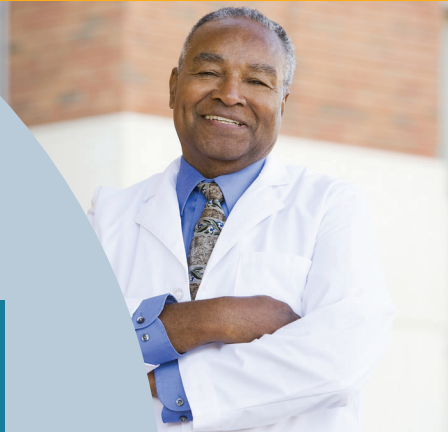


The Family Experience with Primary Care Physicians and Staff

A Report by the National Alliance on Mental Illness

May 2011



Find Help. Find Hope.



National Alliance on Mental Illness

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The Family Experience with Primary Care Physicians and Staff

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The National Alliance on Mental Illness (NAMI) is the nation's largest grassroots mental health organization dedicated to building better lives for the millions of Americans affected by mental illness. NAMI has more than 1,100 NAMI State Organizations and NAMI Affiliates across the country that engage in advocacy, research, support and education. Members are families, friends and people living with mental illness such as major depression, schizophrenia, bipolar disorder, obsessive compulsive disorder (OCD), panic disorder, posttraumatic stress disorder (PTSD) and borderline personality disorder.

INTRODUCTION

The data included in this report is based on information received by NAMI in response to a web-based survey, conducted from June 1 to July 1, 2009. NAMI received 554 survey responses. Responses to the 23 survey questions came from parents and caregivers of children and adolescents living with mental illness. Parents and caregivers answered a variety of questions related to their experiences discussing mental health concerns about their child with primary care physicians and staff. The survey took approximately 30 minutes to complete. NAMI also asked colleague mental health advocacy organizations to send the survey out through their networks.

The survey included the following sections:

- demographics;
- background information;
- primary care setting;
- initiating communication;
- effective communication and dialogue;
- action steps; and
- additional recommendations and comments.

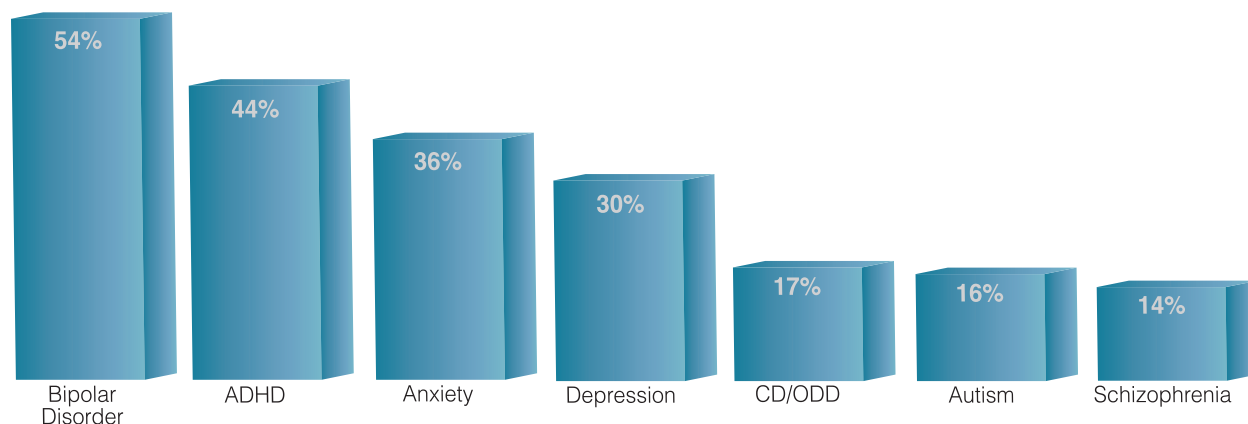
DEMOGRAPHICS

The families who completed the survey represent a diverse geographic area, with 40 states represented. Their children also represent a racially diverse population, with the majority being identified as Caucasian (73 percent), however, responses were also received from families with children who are African American (10 percent), multiracial (6 percent), Latino (5 percent), Native American (3 percent) and Asian American (3 percent).

BACKGROUND INFORMATION

Type of Illness

When asked about their child's primary diagnosis or diagnoses, families provided the following responses. Respondents could check more than one diagnosis.



Age of Onset

When asked at what age their child first exhibited behavioral or emotional problems that gave them concern, families responded as follows:

- 37 percent reported at 1 to 3 years old;
- 26 percent reported at 4 to 7 years old;
- 14 percent reported at 8 to 11 years old;
- 13 percent reported at 12 to 15 years old; and
- 10 percent reported at 16 to 18 years old.

PRIMARY CARE SETTING

Making Families Feel Comfortable

Families were asked if there are any aspects of a primary care office that would make them feel more comfortable talking about their child's mental health. They provided a wide array of responses to this open-ended question. Table 1 outlines the five most common responses provided and the explanations respondents offered.

Table 1. Top five ways to make families feel more comfortable

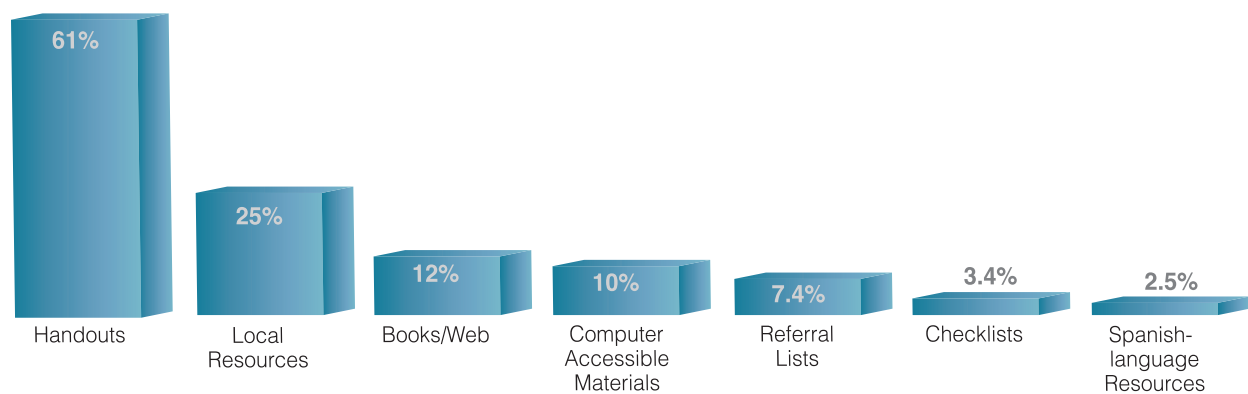
1	<p>Resources. Include mental health resources in the waiting and exam rooms to help families feel more comfortable raising mental health concerns about their child. Families shared the following rationales.</p> <ul style="list-style-type: none">• Resources show that the practice is receptive to the topic of mental illness, is aware of mental health issues and cares about children's mental health.• Visible resources make raising mental health concerns less scary and gives families more confidence in raising their concerns.• Resources help trigger questions families may have about their child's mental health.• Resources help normalize mental health issues.• Resources help parents feel less alone and isolated.• Resources connect families to information early and, ideally, before a crisis occurs.
2	<p>Private area. Families stressed the importance of a private area within the primary care office to discuss mental health concerns, with the option of not having their child present, for the following reasons.</p> <ul style="list-style-type: none">• It decreases concerns families have related to others hearing about their child's mental health or behavioral issues.• It helps parents and children feel more comfortable and less nervous about discussing mental health.

Table 1. Top five ways to make families feel more comfortable (continued)

3	More knowledgeable staff. Families felt that primary care pediatricians and staff with a strong knowledge about mental health and community resources for families would make them feel more comfortable.
4	Supportive, nonjudgmental staff. Families expressed the need to have primary care physicians and staff be more supportive and nonjudgmental about mental health concerns, which includes: <ul style="list-style-type: none"> • actively listening; • using positive language and having a positive attitude; and • providing prompts to discuss mental health concerns.
5	Screening/questionnaire/checklists. Families emphasized that having a primary care pediatrician ask about developmental, emotional and behavioral issues during well-child visits was important and would help normalize mental health issues. It also helps to make families feel more comfortable discussing these issues. They also stressed the importance of having primary care pediatricians use mental health screening tools, questionnaires and checklists as part of routine clinical practice.

Requested Resources

When asked an open-ended question about the kinds of resources that they would like available in a primary care setting, an overwhelming majority of families requested more handouts, including fact sheets, family guides, pamphlets and brochures about mental health issues. Families provided the following responses about the resources they would like in primary care offices. Respondents could check more than one resource.



Families also indicated the need for youth-friendly resources and for all resources provided to include crisis hotline numbers. Respondents also expressed disinterest in resources published by pharmaceutical companies.

Topics Families Want Addressed

Families were asked what topics they would like to see covered if mental health resources were made available in primary care offices. Table 2 outlines the five most common topics families requested information about.

Table 2. Top five topics families want addressed in resources	
1	<p>Mental illness. Include mental health resources in the waiting and exam rooms that describe the early warning signs, behaviors and symptoms of mental illness. Families noted that there are often attention-deficit/hyperactivity disorder resources available but no resources on other mental health conditions.</p>
2	<p>Action steps. Families emphasized the need for resources that include information on what to expect and do after a child has been diagnosed with a mental illness and how to effectively cope with the situation. They also requested materials on how mental illness affects family members and the steps that can be taken to ensure the health and well-being of every family member.</p>
3	<p>Services and supports. Families expressed the need for a resource binder that outlined the various services and supports available in their community. They shared the need for the following information to be included in the binder:</p> <ul style="list-style-type: none"> • support groups for families and children, family education programs and skills training classes; • payment options for community-based services and supports (<i>i.e.</i>, insurance, social security and grants); • family advocacy organizations (see the list at the end of this survey report); and • tips on how to navigate through community-based services and supports.
4	<p>Referrals. Families expressed concern that primary care offices often lack a comprehensive referral system for mental health care providers. Families shared that they would like referrals to the following providers to be available in primary care offices:</p> <ul style="list-style-type: none"> • child and adolescent psychiatrists and psychologists; • mental health counselors and therapists; • sleep specialists; and • other local experts. <p>Additionally, families emphasized the need for referrals to mental health providers who accept private insurance and public insurance and to low-cost providers. Families also wanted primary care physicians to be honest about the shortage of mental health care providers, which may cause long waiting times.</p>
5	<p>Behavioral interventions. Families expressed a need for information on behavioral interventions and strategies they can use to address challenging behaviors their child engages in as a result of his or her mental illness.</p>

Availability of Helpful and Informative Resources

Families were asked whether they found resources that have been available in the primary care setting relevant, helpful and informative. Respondents provided the following responses:

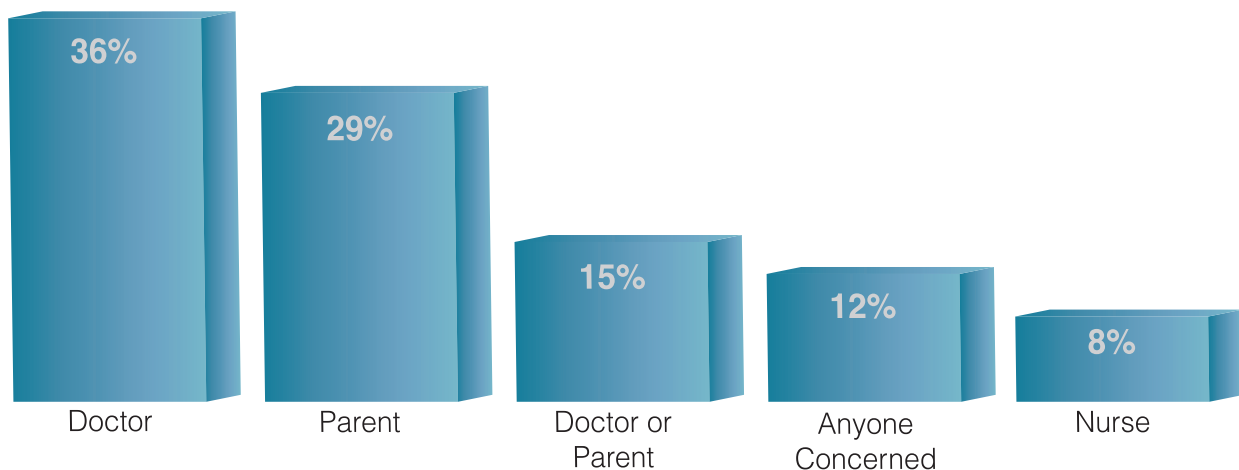
- 46 percent replied that no resources have ever been available in the primary care setting;
- 30 percent replied that available resources were relevant, helpful and informative; and
- 24 percent replied that available resources were not relevant, helpful and informative.

Respondents also shared that oftentimes when resources were available, it was “too little, too late,” so the information provided was irrelevant.

INITIATING COMMUNICATION

Starting the Conversation

When asked who should start a conversation about their child’s mental health during a primary care visit, families replied as follows:



When asked whether they have discussed mental health concerns with primary care physicians, families replied as follows:

- 90 percent said yes; and
- 10 percent said no.

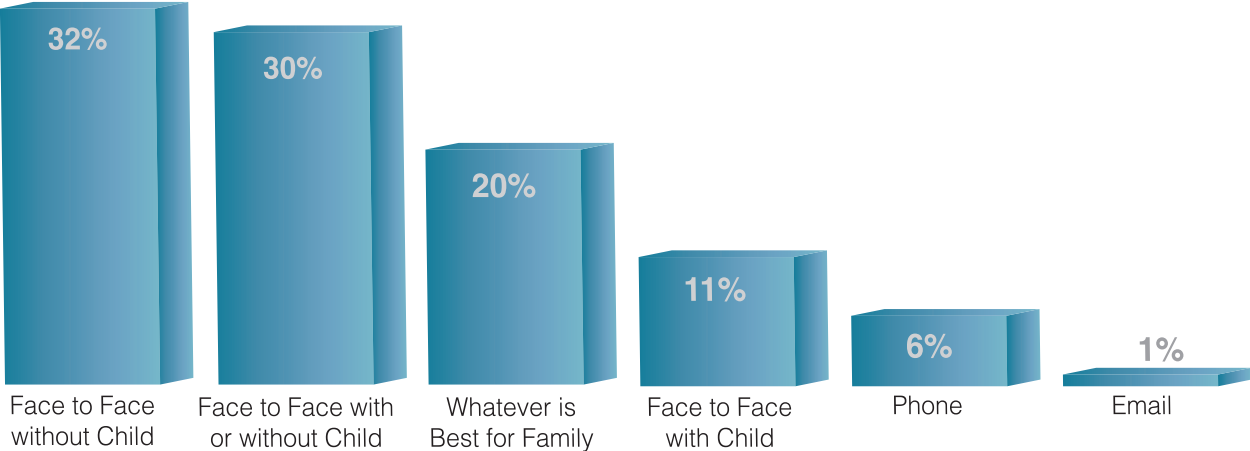
When to Discuss Mental Health

When asked about when mental health related topics should be discussed during a visit to the primary care office, families provided the following responses.

- 45 percent of families replied during the appointment;
- 23 percent of families replied before the appointment;
- 20 percent of families replied after the appointment; and
- 12 percent of families replied any time.

How to Discuss Mental Health

When asked about how mental health related concerns should be discussed, families provided the following responses.



Importance of Mental Health Discussion

Families provided the following responses when asked whether they think it is important for primary care physicians to discuss their child’s mental health if no one has any concerns:

- 83 percent replied yes;
- 12 percent replied no; and
- 5 percent replied not sure.

EFFECTIVE COMMUNICATION AND DIALOGUE

Communicating with Families

When asked what primary care physicians can say or do to make families feel comfortable talking about mental health concerns, families provided practical suggestions on effective communication. Table 3 lists their most common suggestions.

Table 3. Suggestions for effective communication
<ul style="list-style-type: none">• Educate themselves about early onset mental illness and local resources for families so they are comfortable talking with families about these issues.• Have mental health screening tools, including checklists and questionnaires, available for parents and youth to fill out before, during or after appointments to help start conversations about mental health. Families suggested also having an auto email that provides families with a mental health screening tool to complete before a child’s appointment.

Table 3. Suggestions for effective communication (continued)

- Emphasize that mental health is as important as physical health and is a critical part of a child’s overall health. This will encourage families to open up.
- Share personal stories and connections to mental health conditions.
- Make questions about mental health a routine part of every well-child visit and physical exam. Discussing mental health—even when there are no immediate concerns—helps open the lines of communication should a future problem arise. Begin the conversation with, “At this age, certain health issues can emerge, so I would like to ask a few general questions like...”
 - Do you have any concerns about your child’s mental health?
 - How is your child behaving in school, at home and with peers?
 - Do you feel you need any extra support for your child’s behavior?
 - How are your child’s moods? Are there any emotions that concern you?
 - Is your child sleeping and eating well?
 - Do you have a family history of mental illness?
- Listen to families’ concerns without judgment.
- Ensure privacy and confidentiality. Talk with both parents and children alone and create a safe place to express concerns.

Helpful Comments

When asked about the most helpful comments anyone has ever made about their child’s mental health, families provided a wide range of responses. Table 4 includes the most common responses from families.

Table 4. Top five most helpful comments

1	There is hope. Families shared that they want primary care physicians to be hopeful, encouraging and positive by saying things like “There is always hope. We will do whatever it takes to help your child.”
2	You are not alone. Families want to know that they are not alone in having a child living with mental illness. They felt statements like, “You are not alone,” “This is more common than you realize” and “Here is contact information for a local support group for you to meet other families who are going through the same thing,” were extremely helpful.

Table 4. Top five most helpful comments (continued)

3	It's not your fault. Families emphasized how helpful it was when primary care physicians did not blame them for their child's mental illness. They greatly valued hearing the following, "It's not your fault. There is a lot you can do to help your child, your family and yourself to get through this."
4	I understand. Families shared that comments that acknowledged their pain and showed empathy, compassion and understanding were helpful. They shared the following comments as examples. <ul style="list-style-type: none">• I know this is a difficult time for your family, how can I help?• You will get through this. Here are some local resources to help you get through this challenging time.• If you continue to have concerns about your child, please contact me. I am here to help.
5	Your child has many strengths. Families greatly valued primary care physicians who focused on their child's strengths. They felt starting a conversation by saying, "Your child is wonderful and here are some examples of how your child is special..." set a positive tone for a conversation about mental health.

Discouraging Comments

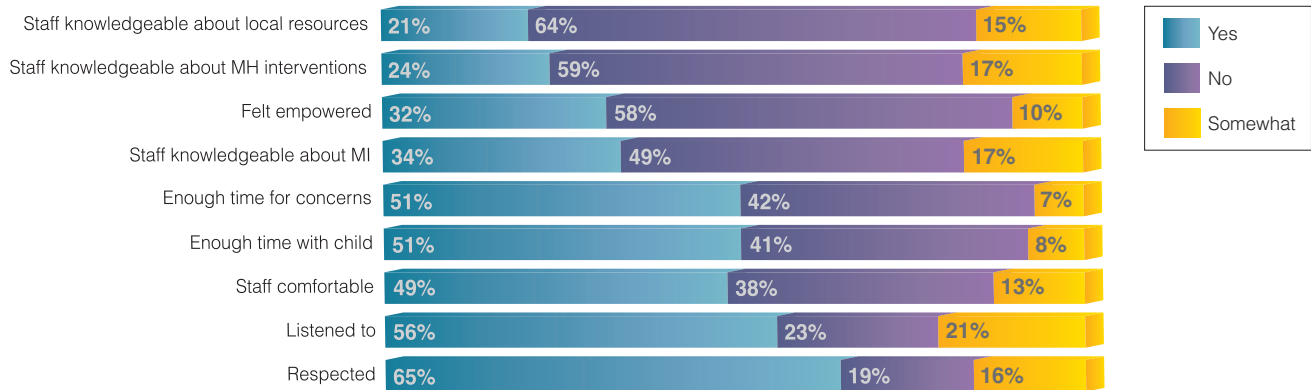
Families were also asked about the most discouraging comments anyone had ever made about their child's mental health. Two main themes emerged from the responses shared by families as outlined in the following table.

Table 5. Top two discouraging comments

1	Dismissive comments. Families responded that they greatly value being respected, listened to and validated. They shared that dismissive comments about their concerns were extremely discouraging. They found the following comments unhelpful. <ul style="list-style-type: none">• "Nothing is wrong. It is all in your head."• "Your child just needs discipline and limits."• "Your child will grow out of it."• "You are being an overprotective parent."• "You are overreacting."
2	Blaming comments. Families shared that comments that directly or indirectly questioned their parenting or implied they caused their child's mental illness were extremely discouraging. They felt that automatically blaming families or assuming they were the problem only prevents them from talking openly with health care providers about mental illness.

Follow-up Questions

Families that answered yes when asked if they have discussed mental health concerns about their child with primary care physicians were redirected to follow-up questions about how they felt after discussing mental health concerns with primary care physicians.



ACTION STEPS

Ideal Action Steps

Families were asked if, after discussing mental health concerns about their child, whether the primary care physicians took any action steps (e.g., provided mental health screening, provided counseling, gave referrals or shared information and/or resources). Family responses to this were varied, with some responding that no action steps were taken while others felt their primary care physicians were extremely supportive and helpful. Many families felt it was up to them to take action, including finding referrals and community-based services and supports—many shared that they wished primary care staff could have helped more with information seeking.

Families were also asked what action steps they would like primary care physicians to take. The following table outlines the action steps families would like primary care physicians to take when mental health concerns are expressed.

Table 6. Ideal action steps

1	Listen. Families shared that they want primary care physicians and staff to first respectfully listen to their mental health concerns about their child without judgment and without rushing the appointment.
2	Ask questions. Once concerns are shared, families shared that they would like primary care physicians to ask follow up questions to have an interactive discussion about the concerns.
3	Screen. Families emphasized mental health screening as a useful tool in identifying mental health concerns within primary care offices.
4	Evaluate. Families shared that before a mental health diagnosis is made, they want primary care physicians to rule out other physical conditions that can mimic mental illness.
5	Refer. Once a mental illness is suspected, families shared that they want primary care physicians to refer them to mental health providers for further evaluation and treatment and to community-based services and supports (including support groups, family education programs, complementary and alternative treatments and related services).
6	Follow up. Families emphasized that they really want primary care physicians to follow up with any referrals they provide to ensure that they received help. Even better, families would like primary care physicians to make any necessary appointments for them. Oftentimes, having primary care physicians make the call helps families get seen more quickly by mental health specialists.
7	Provide treatment. If no mental health specialists are available, families responded that they would like primary care physicians to provide follow up care, including psychotherapy, counseling, skills training and medications if they are properly trained to do so. Families insisted that they did not just want to be prescribed medication by primary care physicians; they want to be educated on other treatment options, including alternative and complementary treatments.
8	Encourage. Families felt that primary care physicians were in a key position to emphasize the importance of mental health and to encourage families to seek treatment and have their child remain in treatment.

Follow-up Care

Families were asked what role primary care physicians have had in their child's mental health care once a diagnosis was made. Responses to this question were varied with some primary care physicians taking the primary role in treating a child's mental illness, others taking a more

limited role of monitoring side effects of medications and some not playing any role in a child's treatment.

The following table summarizes the recommendations families shared about the role they would like primary care physicians to play once a mental health diagnosis is made.

Table 7. Ideal follow-up care

- Develop a coordinated and collaborative care plan with other health care providers involved in the child's treatment to increase and improve communication among the providers.
- Participate in a treatment team with the other health care providers and family.
- Ensure the "whole" child is treated. Provide a more rounded picture of the child to other health care providers involved with the child's treatment.
- Maintain all of the child's medical records. Be a gatekeeper for these records.
- Be the point of contact for all the care the child is receiving.
- Ensure families are involved in the treatment team for the child.
- Communicate regularly with any mental health care providers to remain up-to-date on the treatment the child is receiving and medications being prescribed.
- Manage and monitor side effects of medications, including weight gain.
- Prescribe medications when psychiatrists are unavailable. Be knowledgeable about any medications the child is prescribed and regularly communicate with psychiatrists about these medications.
- Work with school professionals to ensure the child receives appropriate school-based mental health services and supports. Advocate on behalf of the child if these services and supports are not provided.
- Respond to any ongoing concerns families have, provide resources and regularly ask families if any other services or supports are needed. Families responded that they appreciate when primary care physicians have an ongoing interest and concern about their child's mental health and well-being.
- Empower youth with the confidence, education and resources they need to cope with their mental illness.

ADDITIONAL RECOMMENDATIONS AND COMMENTS

Families were asked to provide one recommendation they have for primary care physicians that they believed would make a difference in identifying youth living with mental illness earlier and linking them with effective mental health services and supports. Families often recommended the following as important factors in the early identification and intervention of mental illness:

- routine mental health screening;
- co-location of primary care physicians and mental health care providers;
- education of primary care physicians on mental illness and the lived experience of mental illness; and
- enough time to understand families and their concerns.

This survey report summarizes the responses NAMI received from families about their experiences in primary care. The following also includes a representative sample of thoughtful comments that families provided in the survey.

Early Identification and Effective Communication

- “Primary care physicians who can help diagnose potential mental illness can save a child and parents years of pain.”
- “Just ask the child, ‘Is anything bothering you today?’ Sometimes all it takes is the question of concern and they open up like a book.”
- “Screen all children, listen to parents concerns, alleviate stigma attached to mental health issues in children.”
- “Learn how to ask a parent, even if not prompted, about a child’s behavior, any changes, things that may be of concern to the parent and, if possible, observe the child. Know the signs to look for and if anything looks remotely of concern or the parent is concerned, refer for mental health screening. Give out NAMI information no matter what.”
- “It would be great if doctors let parents know early in the relationship that they are concerned about both physical and mental health. Let parents know they should feel free to bring up any questions or problems during pediatric visits.”
- “Make discussion of mental health concerns a part of every well-child visit with both child and parent separately.”
- “Understand the red flag symptoms of mental illness to look for, listen to parents/caregivers concerns and point them in the direction of mental health specialists and resources. Have pamphlets on mental health diagnoses available in the waiting and exam rooms just like you do for physical symptoms. Have resources and phone numbers for parents to walk out the office door with.”

- “Spend as much time with your families as possible and ask (and listen) to parents about their challenges and needs. Empower someone in your office to become a professional in working with families who have children living with mental illness.”
- “Take additional education on recognizing and diagnosing mental illness so that you can become an advocate for these children. Develop a checklist or standard list of questions to make sure you are at least broaching the subject with parents.”
- “Treat mental illness like the flu or chicken pox; look for the warning signs.”
- “Trust parents’ intuition.”
- “This is a real issue for families and shouldn’t be ignored because it is uncomfortable. The earlier it is treated, the greater chance of recovery.”
- “Do not abandon the topic of mental illness just because we see a psychiatrist.”
- “Talk with parents alone at every physical.”

Resources and Referrals

- “In most cases medication was prescribed, but referrals and resources would have been great.”
- “Involve the child in his or her care. Educate the child along with the family about what to expect, including all aspects of medication side effects. Offer alternative methods of dealing with mental illness. For many, this is a lifetime challenge and help with taking charge as much as possible is empowering.”
- “After an initial referral, the next time you see the patient ask how the referral worked. If it didn’t work, give them another. Check to see if they are even going to the referrals.”
- “Please be prepared to provide resources for those with and without insurance. It is a scary time for the patient and family member and they are looking to you for leadership. When the physician is not well-equipped to handle the situation it makes it that much more frightening for everyone involved.”
- “Make sure the patient and family follow up with referrals and other services recommended. Follow up with them on this.”
- “When treatment is recommended, make sure it is actually available for the child.”
- “Medications are not the only answer. Counseling, family training and information about services and supports in the community are important.”

Collaboration and Co-location

- “I wish we could have been a team that helped my child instead of me having to find the answers on my own.”
- “Create a safe zone. Take time, care and tact with families.”
- “It is important for primary care staff to realize that a diagnosis of mental illness is as devastating as any other chronic illness and is still surrounded by significant stigma. These folks need support and understanding!”
- “Mental illness affects the entire family. A holistic, family approach is needed for families to not just survive but to be successful and flourish.”
- “An ideal situation would be for the psychiatrists to be located in offices with primary care doctors. Together they can monitor physical side effects that medications might have on the rest of the body.”
- “I wish they had an in-house child psychiatrist who accepted my insurance and could write the prescriptions when needed.”

Primary care physicians play a key role in the lives of children with emerging mental illness. This survey report summarizes the experiences families from across the country have had with primary care physicians and staff. It also provides recommendations on how to strengthen the interactions between families and primary care physicians and staff.

NAMI greatly appreciates the contributions of families who participated in this survey and hopes that it will help lead to positive change. NAMI also appreciates the commitment that primary care physicians and staff make to children and their families every day.

To learn more about the resources that NAMI has developed for primary care physicians and staff, please visit www.nami.org/primarycare.

Family Advocacy Organizations

National Alliance on Mental Illness (NAMI)

www.nami.org

Child and Adolescent Bipolar Foundation (CABF)

www.bpkids.org

National Federation of Families for Children’s Mental Health (FFCMH)

www.ffcmh.org

Mental Health America (MHA)

www.nmha.org



National Alliance on Mental Illness

Find Help. Find Hope.

www.nami.org

NAMI HelpLine: 1 (800) 950-NAMI (6264)

Twitter: [NAMICommunicate](https://twitter.com/NAMICommunicate)

Facebook: www.facebook.com/officialNAMI