# Medications & Choices

## The Perspective of Families and Youth

morning pills

## What Parents and Children Tell Us about Psychiatric Medications

June 4, 2008

Parent/Professional Advocacy League (PAL)

Institute for Community Health (ICH)

This family-driven research study, ***Medications and Choices: The Perspective of Families and Youth***, provides new and compelling information which clarifies how families decide upon the use of psychotropic medication for their child. We hope that by illuminating the difficult and complicated process that parents experience, we can change the perceptions of some as well as influence policy and practice so that the well-being of children with mental health needs and their families is enhanced.

***Parent/Professional Advocacy League (PAL)*** is the leading public voice for families whose children have emotional, behavioral and mental health needs in Massachusetts. PAL is the state organization of the National Federation of Families and is dedicated to promoting change that will improve the children's mental health system statewide.

***The Institute for Community Health (ICH)*** is a unique collaboration of three Massachusetts health care systems; the Cambridge Health Alliance, the Mount Auburn Hospital of CareGroup, and the Massachusetts General Hospital of Partners HealthCare. ICH is an organization dedicated to health improvement through community-based research, assessment, dissemination and educational activities. The ICH stimulates the creation of innovative programs and health policies through a community-based approach that will promote long term healthy lifestyles.

This project was funded by a grant from the Deborah Munroe Noonan Memorial Fund

*About the cover photograph:*
In 2000, Charlotte Sullivan designed a book entitled *Fragments: Pieces of My Sister's Life*. By combining photographs of her sister as well as her sister's own words, Charlotte hoped to present bipolar disorder (her sister's diagnosis) as being a vital portion of her life, as opposed to completely defining it. *Morning Pills* is a poignant image from that book.

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# *Medications & Choices*

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**What Parents and Children Tell Us about Psychiatric Medications**


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# *Forward*

"*Medications and Choices: The Perspective of Families and Youth*" is an important contribution to a complex and often confusing set of issues. Much is unknown but some things are certain. Emotional and mental health difficulties, so severe as to challenge a youth's capacity to function, are increasingly common. Yet only a fraction of afflicted youth are able to access care. We are now just beginning to scientifically understand the developmental, mental health and substance abuse disorders that can appear in childhood and adolescence. For some of these, effective treatments have emerged, including: stimulant medication for attention deficit hyperactivity disorder; applied behavioral analysis (ABA) for skill acquisition and reduction of self-harm in autism; and cognitive behavioral therapy (CBT) in combination with selective serotonin re-uptake inhibitors ("SSRI antidepressants") in moderate to severe obsessive compulsive disorder and in depression. For many other conditions the current treatment options are not yet as well proven.

Obtaining the right treatment for one's child is not an easy task. It requires that pediatricians and teachers join parents in recognizing a child's distress, finding an accurate diagnosis, matching that unique child's strengths and needs to a specific set of services and care, and accessing evidence-based treatments—when they are known and available. This often makes for a hard journey fraught with delays, changing or multiple diagnoses, and repeated attempts before finding a treatment that works well for one's child, relieves their distress and enables them to better participate in the things they enjoy.

Amidst these hurdles, there are many reasons for parents and youth to be proud and optimistic. You have demonstrated a heroic determination to find answers and to trust the best available options – and these options keep improving. Disorders once thought to occur only in adults are now more accurately recognized in our youths, and are more precisely understood and diagnosed. More clinicians are being trained in increasingly well proven therapies and medication treatments. Breakthroughs in other medical specialties are showing us that what we have thought of as single disorders often turns out to be sets of distinct disorders – each with its own unique genetic and biochemical hallmarks. When these features are identified, treatment becomes targeted, works effectively with less trial and error, and side effects can be markedly reduced and avoided.

This survey powerfully reminds us that prescribing physicians must partner with parents and youth to craft and evolve treatment plans and must always remember to fully explain what we now know, what we don't yet know, and what choices that gives us. It is an honor to participate in any PAL project, especially this one.

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# *Thanks & Acknowledgements*

Over the past several years, there has been both interest and scrutiny in the rising use of psychotropic medications to treat children and adolescents. Some of the media coverage has produced mixed reactions in many parents, who have felt their experiences were not accurately reported. This project grew out of their desire to be heard and our thanks go to them for making this project possible.

The Deborah Monroe Noonan Memorial Fund recognized the value in this study at the onset. Our thanks for their generous support and belief in this project, which allowed us to provide a vehicle for parents and youth to articulate their experiences.

We are also grateful to the following people for helping us to focus our attention and questions to come up with a survey tool that touched on the pertinent topics: John Anderson, Representative Ruth Balser, Alison Bauer, Elizabeth Childs, MD, David DeMaso, MD, Chief Justice Martha Grace, Katherine Grimes, MD, Walter Harrison, MD, Gordon Harper, MD, Representative Kay Khan, Arnold Kirschner, MD, Senator Richard Moore, Barry Sarvet, MD, Ron Steingard, MD, Marylou Sudders, Isa Woldeguioguis, Lynda Young, MD

We also appreciate the efforts of Matieu Bermingham, MD and Joseph Gold, MD for their constructive guidance in the reviewing process.

We are greatly indebted to Elaine Slaton and Shannon Crossbear at the Federation of Families for Children's Mental Health for their guidance in developing family-driven research methods which ensured that the values and experiences of families shaped this effort.

# Introduction

The use of psychotropic medications as a treatment for emotional, behavioral and mental health needs in children and teens has become commonplace. It has also become a far more controversial topic than the use of medication to treat other childhood illnesses. The rising number of children taking medications has been widely discussed in the media, by doctors, by school professionals and even by policy makers. Yet, the experience of the primary decision makers – families — has been missing from this conversation.

For many families, medication has dramatically improved daily life for their child and for their family. However, the process of finding out which medications are helpful and which side effects are tolerable is countered by the ambivalence many parents feel. Decisions around medications are often arrived at through a lengthy and difficult process. Both policy makers and clinicians should have an understanding of that process so that both policy and practice result in the most beneficial outcomes for children and adolescents with mental health disorders.

While each parent's decisions are personal, based on their own and their child's experiences, they share several common characteristics. All parents seek information that is reliable and easy to access. Most consider options besides medications. They are concerned about the financial costs and whether their insurance coverage will be adequate. And they are very aware of prevailing public opinion about children and psychotropic medications. After all, they are members of the same society that holds those opinions.

> *"I do not think parents casually consider the pros and cons when choosing to medicate their children. We have found medications, even with their side effects, to outweigh the risks and help my son to be fairly stable and remain living at home."*
>
> — Observation of a parent whose child takes psychotropic medication.

Parent/Professional Advocacy League (PAL) is an organization of Massachusetts families whose children have emotional, behavioral and mental health needs. This study was conducted by PAL in collaboration with the Institute for Community Health (ICH), an organization dedicated to health improvement through community-based research, assessment, dissemination and educational activities. This project was created to add the perspective of families and youth to the continuing discussion of the pros and cons of using psychotropic medications. As policy makers, clinicians and others debate these issues and their solutions, an important stakeholder in the discussion has gone unheard. It's crucial that we listen to parents and hear the insight that can only be provided by the families of children taking these medications.

# *Executive Summary*

Parents of children taking psychotropic medications decide whether their children take specific medications, whether they try new ones if the previous medications don't work and if they are pleased with the results. Yet this decision making process almost never occurs in a neutral, stress-free environment. Parents, grandparents and other caregivers receive conflicting messages from their children, their extended families, medical professionals and society at large. And each of these messages can influence those important decisions.

PAL and the Institute for Community Health conducted a survey with members (parents and caregivers) of the PAL network in 2006. The survey was also distributed through additional parent organizations. Over 300 parents responded to the survey answering questions about one of their children who was currently taking psychiatric medications. Analysis was conducted on 274 completed surveys. Information supplied by many parents indicated their child had significant mental health needs. In addition, children whose parents responded to the adult survey were also invited to take an online youth survey. Eighty-six youth responded and analysis was conducted on 66 surveys.

Parents expressed strong satisfaction with medications for their children simply because they work. However, although most parents wrote of their satisfaction, they also related their ambivalence. Many felt caught between their desire and sense of responsibility to find an effective treatment for their child and strong public messages that psychotropic medications for children are risky and stigmatizing.

The majority of youth (80%) expressed satisfaction with their medications, noting that medications made a positive difference in their lives. Youth focused on specific ways that medications helped and expressed less ambivalence than their parents. However, most youth felt the desire for privacy around both their diagnosis and prescription medications.

Several shared experiences, common elements and key values emerged from the myriad experiences of families.

*Parents reported high levels of satisfaction* with the use of psychotropic medications simply because they work more effectively than anything else available to them.

- 90% of parents reported that their child's medications helped him/her deal more effectively with his/her problems and 74% said they are satisfied with the medications.
- 86% reported that they would recommend that a friend consider psychotropic medica tions if their child needed help.
- 86% of the children taking psychotropic medications were also receiving psychotherapy

*The majority of families tried alternative forms of treatment* for their children, often before and then in combination with psychiatric medication. Parents wrote of the need for more choices in the range of available treatments.

- 50% of families tried alternative and complementary treatments before beginning psychotropic medications. These included behavioral plans, restricted diets, yoga and herbal remedies.
- Almost half (44%) rated the alternative treatments they tried as somewhat effective for their child.
- Less than 5% of families said that they themselves suggested beginning medications.

*Many parents worried about side effects* and were frustrated with trying a succession of medications.

- Almost half of the families stated that their child had tried 5 or more medications and an additional 45% had had trials of 2 to 4 different medications.
- Parents frequently mentioned their concerns about side effects and worried about long term effects.
- Youth shared their parent's worries about side effects, but were strongly focused on the impact on their bodies today.

*Parents stressed their need for good communication* with their child's prescriber. When these relationships were strong, they were highly valued by families. Both parents and youth were clear that a strong working relationship must include a role for the parent (and often the child) so that there is an exchange of information.

- Families relied strongly on the professional prescribing their child's medications for in formation and guidance. Nearly one-half (48%) viewed their child's psychiatrist as the most reliable source of information.
- The majority of parents (84%) reported that they were included in decisions about medications. However, nearly one-third (29%) felt that their child's prescriber was not as available to speak with them as often as they needed him or her to be.
- While parents rely strongly on the profes sional prescribing medications for important information, many youth (62%) rely on their parents. It is important that information from the prescriber to the parent be clear and complete.

*The majority of families sought out several avenues to gather information* about medications. Neither parents nor youth were influenced by advertisements by pharmaceutical companies. They were, however, influenced by the experience of other family members.

- Most families sought out 2 to 5 sources of information about psychotropic medications.
- Less than one-fifth (18%) consulted advertisements and less than 1% considered them a reliable source.

- Not one youth reported using advertisements as a source of information.

- The majority of parents (58%) said they were aware of the FDA "black box" warnings and were not influenced by them.

- However, if another family member was taking psychotropic medications, most of those families (56%) reported that they felt this impacted their decision making.

*A significant cohort of children were 4 years or younger when they first began taking medications.*

- 16% of families reported that their child began taking medication when he or she was 4 years or younger

- Many of the children were diagnosed at young ages with 26% receiving an intial di agnosis at age 4 or younger.

*Parents reported that their health insurance was more likely to cover medication than therapy for their child.*

- When asked if their insurance covered all of the medication visits their child needed, an overwhelming majority (76%) of the families said that it did.

- However, when parents were asked whether their insurance also covered all of the psychotherapy visits their child needed, far fewer reported that it did (53%).

Parents are the experts on their children and their families. They often go through a common process of seeking multiple sources of information and trying alternative treatments before agreeing to begin medications for their child. Once their children are on medication, parents struggle to reconcile negative messages about the use of psychotropic medications for children (by everyone from their extended family to the media) with their own positive experience of that same medication's effectiveness. In the end, people they know and trust, from their child's doctor to a family member taking medication, have more influence over their decisions than government bodies or pharmaceutical companies.

Parents were clear that this was more than just a medical decision. In more than half the completed surveys, parents wrote comments and shared stories by writing in the margins, next to their answers as well as in the section reserved for their observations. They were clear that this was a complicated decision and that the process was often difficult. They spoke of the need to persevere and the relief and satisfaction they felt when the treatment with psychotropic medications was successful.

# Background

The trend in prescribing psychiatric medications as a front line treatment for children and adolescents over the past decade has been well documented.[1] Increasingly, medications have been prescribed for younger children as well as children with a range of moderate and severe psychiatric illnesses. More children are being prescribed two or more psychotropic medications routinely. Until recently, managed care companies had few restrictions around access to medications or medication visits as contrasted by greater management around access to mental health therapy. Few barriers to accessing medications have existed.

Over the past few years, the public perception has changed regarding children taking psychotropic medications. A study published by Julie Magno Zito, PhD noted a three to five fold increase in antidepressant use[2] as well as the fact that 72% of youth received their prescriptions from primary care providers. The reaction of state and federal policy makers as well as the general public has been one of concern and an increasing belief that risks may outweigh benefits.

There has also been a marked trend in questioning whether parents, together with practitioners, can make optimal choices about medications based solely on clinical considerations. Outside factors such as advertising, internet-based advice and availability have been cited as influencing the decisions of parents. In some instances, parental decision-making has come under attack, as if parents had not carefully considered the decision to use medication, or had even been cavalier in their dismissal of potential risks involved. Little, if any, research has been done to capture the factors, decision-making paths, or experiences of families who have chosen, agreed to, or decided against the use of psychotropic medications to treat their child's mental health disorder.

Until recently, few, if any, medication trials included children and adolescents. Physicians, teachers and parents have reported the efficacy of some psychotropic medications for children, but there is a growing perception that many medications are more risky for children and teens. In October 2004, the FDA required that all antidepressants must carry a "black box" warning around increased risks for children and adolescents.[3]

Additionally, there is a growing list of insurance barriers to accessing psychotropic medications for many families. These can include three tier pharmacy co-pays, prior authorizations, the use of reference drugs, limits on the number of prescriptions per patient and other measures. Justifications range from controlling costs to evidence based clinical standards. The impact of these measures on parental decision making is seldom fully considered.

Parents also struggle to understand the im-

plications of the diagnoses being given to children. Over the last several years, several studies have shown a marked increase in the application of "major" psychiatric diagnoses to children. A September 2007 study, funded in part by the National Institute of Health, reported a 40 fold increase in the diagnosis of bipolar disorder in adolescents and children.[4] Parents are torn between feeling alarmed upon hearing multiple and often serious psychiatric diagnoses and relieved to find out that their child's constellation of behaviors has a name and can be treated. Often the recommended treatment includes medication.

## *Methodology*

This research project was designed to capture the perspective of families and youth relative to their decision-making process in choosing to use psychotropic medication as treatment. In order to accomplish this, the project used a parent[5] survey, parent focus groups, an online youth survey and youth focus groups. (See youth survey results in "Taking Medications: What Do Youth Say?") Approval for each phase of the project was obtained from the Cambridge Health Alliance Institutional Review Board through the Institute for Community Health.

A 53 question survey was developed with input from both families of children with mental health disorders and professionals working in the children's mental health delivery system. A draft survey was developed by PAL and ICH and sent to a group of 10 clinicians for comment. The survey was piloted with a group of five families in Lynn, Massachusetts who represented a cross section of parents in terms of socio-economic status and cultural backgrounds. Their children were diagnosed with a range of mental health disorders. Both clinical and family comments were integrated into the survey.

> *"I realize that I was not supposed to complete the survey due to my daughter's age. However, I very much wanted to complete the survey and contribute in some way. It would be terrific if you could glean something from my answers…*

The final survey, printed in English and Spanish, consisted of 52 structured questions and one open ended question. A list of medications was included with the survey for reference. The survey asked families about their experiences related to diagnosis, number of medications used, age at which medication was begun, sources of information about medication, family attitudes, cost and insurance factors, use of alternative treatments and satisfaction levels. There were four qualifying questions to ensure that respondents resided in Massachusetts; were involved with decision making around their child's medications; that their child was 19 or younger; and had been taking medications in the past twelve months. Parents with more than one child were asked to focus on one qualifying child in their

family and provide answers based on their experiences with this child. Only one survey was filled out per family.

The survey was distributed through the PAL network, a variety of other parent-run organizations and posted on several list serves. The survey was also posted on the PAL website (www.ppal.net) so that families could download and print out a copy.

Drawing on discussions from the survey development process, a focus group guide was developed. The focus groups were intended to explore more thoroughly some of the areas outlined in the survey and provide information that would link various topics. Five parent leaders were trained by a research team from the Institute for Community Health as focus group moderators. They then arranged and conducted focus groups in their communities (Amherst, Brighton, Leominster, Lynn, and Plymouth). A member of both the ICH and PAL research teams were also present at each focus group. Each focus group was two hours in length. A total of 34 families participated in the focus groups.

Of the 1059 surveys distributed to families between April 2006 and October 2006, 302 surveys were returned. This represents a response rate of 29%. Twenty-eight surveys did not meet criteria for the study (e.g., children over 19, parent not involved in decision making) and were excluded from analysis. A number of parents returned surveys knowing that their child did not meet the criteria (e.g., over the age of 19). As with many respondents, they wanted their experiences to make a difference by providing information on what decision making for families is really like.

## Demographics

Of the 274 families whose surveys were analyzed, 90% were parents, 5.5% were grandparents, 2.2% were foster parents and others were guardians or step-parents. The majority (93%) spoke English at home while 5.3% spoke Spanish with a smattering of other languages reported. The socio-economic status of the respondents was spread across all income brackets with approximately a third (34.4%) reporting that they made less than $29,000, another third (34.3%) saying they had incomes between $30,000 to $69,000 while an additional third earned more than $70,000.

When asked to identify their child's health insurance, 62.4% identified the insurer as a commercial carrier while 52.2% had MassHealth[6] and another 3.3% had supplemental insurance such as CommonHealth or free or reduced care. While the majority (79.6%) had a single type of health insurance, some families reported that they had more than one type of coverage.

Parents taking part in this study were asked several questions about their children. The ages of the children were between 5 and 19, with a mean age of 13.4 years. While the majority of the children were teens, 38.3% were 12 or younger. Seventy percent of the children were male; 30% were female. The racial/ethnic characteristics of the children were similar to the data from the 2000 Massachusetts census[7]. Of the respondents' children, 76.4% were Caucasian, 5.7% were African American, 1.5% were Asian, 11.8% were Hispanic Latino and 3% were multiracial.

The children reported on had moderate to significant mental health needs. About two-thirds were receiving services from a state agency (Department of Mental Health, Department of Social Services, Department of Youth Services, Department of Mental Retardation, Department of Public Health or the Massachusetts Rehabilitation Commission). Eighty-six percent of the children were receiving psychotherapy as well as medications.

The majority of the children were also receiving some form of educational services. These ranged from Title 1 services to an out-of-district placement. 81% were receiving services through an Individualized Education Program (IEP), while an additional 12.8% were receiving services through a 504 plan[8]. About one-quarter of the children attended a collaborative school or day school and 10% were in residential settings. Less than 1% were home schooled.

## *Diagnosis*

Often, one of the keys to open the door to treatment is a clear diagnosis. Many families find that, without a diagnosis, their access to necessary services for their son or daughter through their insurer or at school is difficult at best. Formally diagnosing children and adolescents seems to be trending upward. In a 2004 study[9] of children under age 18 who were receiving outpatient mental health services, the authors noted that there was a dramatic increase in the proportion of children diagnosed with autism and bipolar disorder, with an additional increase in diagnosing anxiety, ADHD and depression.

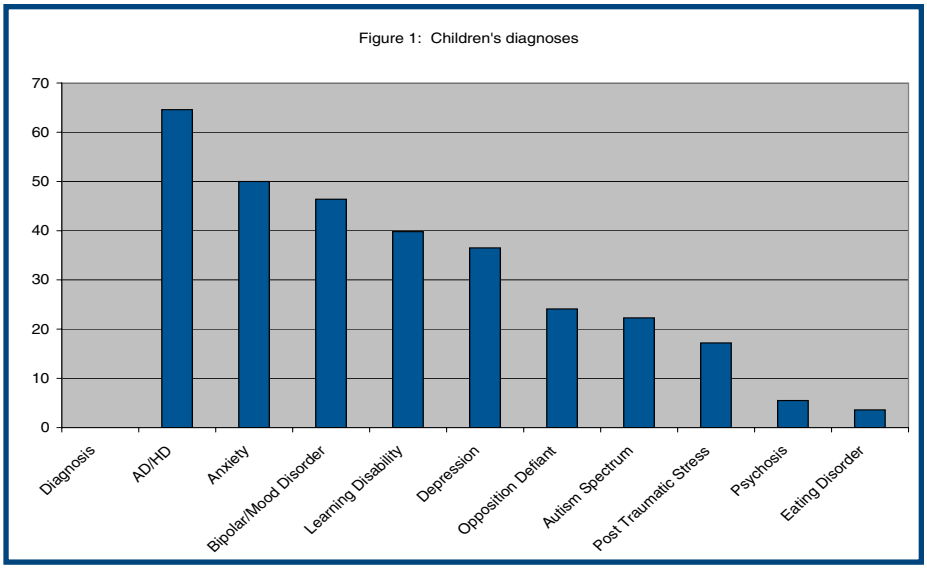
Criteria for psychiatric diagnoses from Anxiety Disorder to Bipolar Disorder are being more clearly delineated for use in children and adolescents. While some of these guidelines are intended for physicians and mental health professionals, many are accessible through books and the internet. Most parents responding to our survey displayed a familiarity with diagnostic language.

The majority of children had more than one mental health diagnoses. The largest number had two diagnoses, closely followed by children carrying three and four separate di-

agnoses. An additional 16% had five or more psychiatric diagnoses. The mean number of diagnoses was 3.1. Many families find that good information and communication is essential when their child's diagnostic picture is complicated. One parent commented, "Given the complexity of our son's diagnoses…requires an ongoing relationship with a psychiatrist that is *accessible*. We have been very fortunate in this respect."

A wide range of diagnostic categories were reported by families. The most commonly reported diagnoses were ADD/ADHD (64.6%), Anxiety Disorder/OCD (50%), Bipolar Disorder (46.4%), Learning Disability (39.8%), Depression (36.5%) and Oppositional Defiant Disorder (24.1%). Less commonly cited were Autism Spectrum Disorder (including Asperger's), Post Traumatic Stress Disorder, psychosis, eating disorders and substance abuse as shown in Figure 1.

Many of the children were diagnosed at young ages with about a quarter (26.4%) receiving an initial diagnosis at age 4 or younger, and half (49.8%) were diagnosed at ages 5-8. Another 16.6% was given their first diagnosis between ages 9-12 and an additional 7.2% were diagnosed at 13 or older. In a study investigating access to children's mental heath care in 2002[10], 48% of Massachusetts parents whose children had mental health needs reported that their child showed signs of a mental health problem by age 4. Because many of the children had moderate to serious mental health needs, their symptoms (often concerning behaviors) may have manifested at an earlier age.



## *Alternatives to Medication*

Throughout their comments, families spoke of their wish for more choices in treating their children. Therefore, it was unsurprising that the majority of families (82%) tried complementary and alternative treatments. According to the American Academy of Pediatrics (AAP), complementary and alternative medicine (CAM) is a group of diverse medical and health care systems, practices and products that are not presently considered to be part of conventional medicine.[11] Complementary medicine is used together with conventional medicine while alternative medicine is used in place of conventional medicine. Parents reported doing both.

> *"We very effectively treated sleep difficulties with melatonin. Six months later when his aggression increased we reluctantly began our trial of meds."*

The demand for complementary and alternative treatments for children has increased tremendously in recent years. The AAP estimates that approximately 20% to 40% of families whose children are "healthy" use these therapies while more than 50% of parents whose children have "chronic, recurrent and incurable conditions" use complementary medicines, usually in conjunction with mainstream care[12].

In alignment with this trend, approximately 50% of parents in this study reported using alternative treatments before beginning medications and a large number tried more than one either sequen-

## Taking Medications: What Do Youth Say?

*Lisa Lambert and Shira Goldenholz*

*Parent/Professional Advocacy League*

### *Introduction*

Youth who take psychotropic medications as a part of their treatment regimen can do so willingly, resist mightily or act somewhere in between. For the most part, their behavior has been chalked up to expected teen behavior or a product of their diagnosis. The reality, however, is more complicated.

In order for medications to work, they must be taken consistently. While parents struggle with their own ambivalence and need for better information, their sons and daughters go through a parallel process. They receive society's messages about psychotropic medications and weigh that against their own experience. They look for information, primarily from those they trust, and value being part of the decision making process. And most of all, they want to know if psychotropic medication is going to work in the immediate future.

Yet, many of the conversations about medications take place between the parent or guardian and the prescriber. Youth are key players in the process and often display an expertise about their bodies and their lives that is essential. Their perspective, focus and wisdom deserves attention as part of these important decisions.

tially or in a combination. Of those that tried a form of treatment or intervention other than medications, the overwhelming majority (90.9%) tried behavioral plans. Other popular trials included restricted diets (25.6%), exercise or yoga (23.7%), herbal remedies (18.3%) and visualization (15.5%). A smaller number of parents tried alternative or complementary therapies that were more unusual including chiropractic, massage therapy and acupuncture. Some have continued to use these interventions along with medications.

In a 2003 study, parents of children referred for evaluation for Attention Deficit Hyperactivity Disorder, were surveyed about their use of alternative and complementary therapies[13]. Overall, 54% reported using these therapies and most commonly reported using expressive therapies, vitamins and restricted diets. When asked to rate their reasons for choosing complementary and alternative treatments, parents reported that "natural therapy" and "having more control over treatments" were the top reasons. Although the reasons parents choose alternative treatments was not investigated in our study, parent comments in focus groups and in the open ended question show that they hold similar values. One commented, "I wish we had a place to go to consider alternatives to these medications."

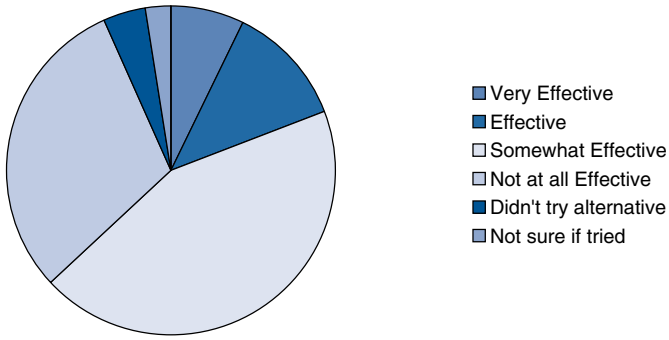
While the use of behavioral charts and diet restrictions can be designed and implemented at home, some of the other interventions (e.g., yoga, acupuncture) are more

## *Methodology*

This research project was designed to capture the perspective of youth as they took part in the decision-making process in choosing to use psychotropic medication as treatment. In order to accomplish this, the project used an online youth survey and youth focus groups. Approval for each phase of the project was obtained from the Cambridge Health Alliance Institutional Review Board through the Institute for Community Health.

Based on parent focus group comments about their children's experiences, a draft youth survey was developed. The survey was piloted with three youth from the Framingham area. Comments from the youth were incorporated into the survey and the final survey was posted online using SurveyMonkey, an online software tool. Upon request, paper copies of the survey were mailed to parents to give to their children. The final survey consisted of 19 structured questions and one open ended question. Questions focused on diagnosis, types of medications, quality and type of information/support around medication use and comfort level in discussing medication use. Information about this survey was disseminated to parents through a process similar to the adult survey. Parents then passed the online URL to their teen.

**Figure 2: Effectiveness of Alternative Treatment**




Most families found alternative treatments at least modestly effective. While few said that they were highly effective, almost half (44%) rated alternatives as somewhat effective for their child. An additional 19% rated the alternative treatments they tried as either very effective or effective. Another 30% were more discouraged, however, and felt the treatments they had tried were not at all effective. See Figure 2.

difficult to find for children and require out-of-pocket payment. The families who located and obtained these services were motivated and resourceful. Their desire to find a greater range of choices is evident in their comments. Less than 4% of all families reported trying no alternative treatments.

However, many parents were willing to try alternative treatments again. Although nearly a third (30.8%) said they would be open to trying these treatments on their own another time, more than half (51.7%) said that they would only do so in conjunction with medications. Another 11.7% said they were unwilling to give these treatments another try.

A focus group guide to explore the understanding, comfort level, access to information and satisfaction of teens was developed for the youth focus groups. Three focus groups were held with youth ranging in age from 10 to 21. The focus groups lasted from one and a half to two hours each and were held in Lynn, Plymouth and Worcester. Two members of the PAL research team were present at each group. A total of 13 youth participated.

For the youth survey, 86 youth responded with a final sample size of 66 respondents. Fifteen respondents did not meet the inclusion criteria (residence in Massachusetts, an age of 19 or younger and the youth must have taken psychotropic medications within the last 12 months); five respondents answered only the first three questions, leaving the rest of the survey blank.

## *Characteristics*

More than half (54%) of those who answered the survey were male, while another 29% were female and 3 did not answer the question. The majority of respondents (84.4%) were Caucasian, with smaller numbers of African-American, Asian, Hispanic/Latino and

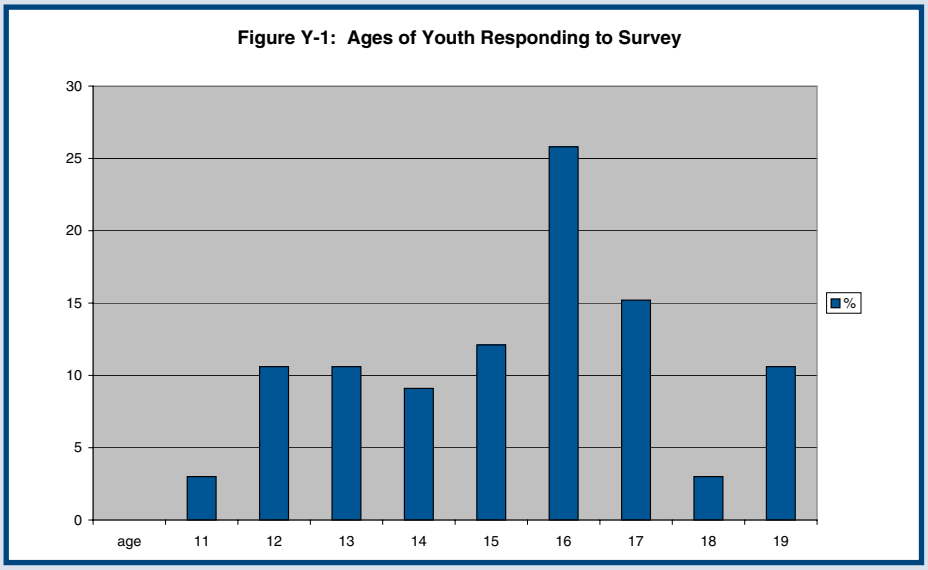
Parents of children with mental health needs reflect the general interest of the public in complementary and alternative treatments. They are also often motivated to explore as large a number of options as possible for treatment for their children. An additional factor may be that many parents are aware of the stigma associated with mental health treatment and are worried about the long-term effects of psychotropic medication. One mother wrote, "I do look forward to the day when we have other choices and my daughter can find her place in this world where people do not condemn, criticize, make fun of and otherwise stigmatize her."

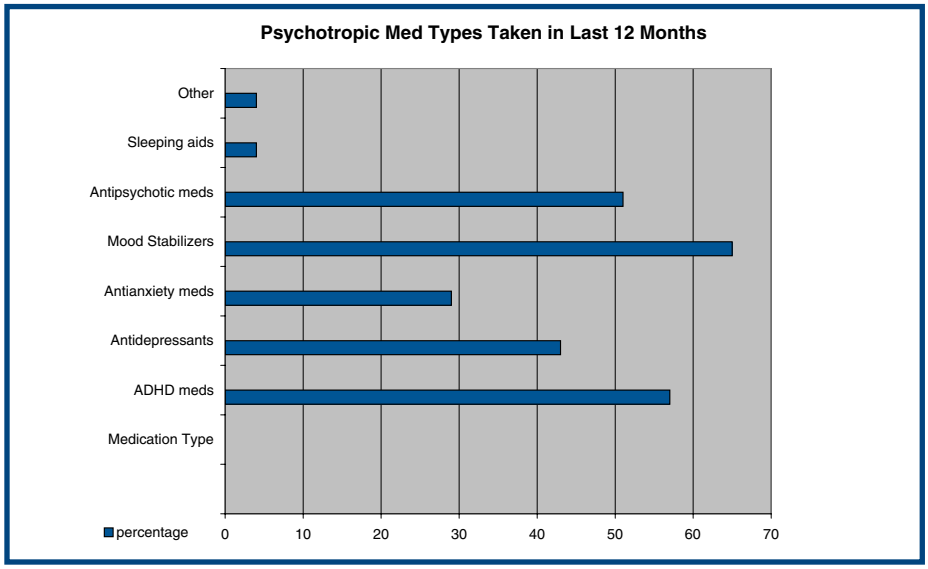
## *Starting Medication*

Contrary to popular perception, only 4.5% of families said that they themselves were the ones to suggest starting medications. Doctors and other mental health professionals were most likely to recommend medications. The majority of families reported that their children were in elementary or middle school when they began medications: 51.7% reported their child was 5-8 years old and another 23% said their child was 9-12 years old. One mother remarked, "My son was only 9 years old when he first went on meds. It took us 2 weeks after we filled the prescription before we could actually give it to him." An additional 8.6% said their child was an adolescent between 13 and 17 years.

mixed race youth responding. Youth responding lived in all parts of the state.
A small number (3%) of respondents indicated that they were 11 years old or younger. The remaining youth ranged in age from 12 to 19 years old. The mean age of youth taking the survey was 15.3 years.

**Figure Y-1: Ages of Youth Responding to Survey**






A significant cohort of children (16.1%) were 4 years or younger when they first began taking medications. For parents of very young children, the choices for treatment are often extremely limited. They find it difficult to access expertise around emotional and behavioral disturbances and to find the tools for dealing with their child's mental health issues. Given the paucity of options, medication may be seen as the only available option for families facing these challenges. One mother complained, "I feel the resources available for children are very few and far between, inconsistent and lack true understanding of the child."

Although most parents reported trying alternatives to medications, the period of time between receiving a diagnosis and beginning medications was relatively short, averaging a little less than 11 months. Some families, however, reported waiting years before beginning medications. The longest reported interval was 9 years. In very few instances, medications were begun before the child had been given a diagnosis.

Most families (83.5%) reported that their child had received a mental health assessment be-

## *Medications*

Most of the teens reported being on multiple medications with 21% taking 2 medications, 25% said they took 3 medications, 22% reported taking 4 or 5 medications and 13% took 6 or more medications. Only 9% were on just one medication. Five percent reported that they were unsure how many medications they were on and another 5% were not on any medications at the time they were taking the survey. Most of the youth responding to the survey disliked being on multiple medications. One said, "It is too bad one pill can't do it all." Another remarked, "Taking so many medications is really annoying."

Youth reported, just as their parents did, that the most common medication they took was mood stabilizers (59%). Other commonly prescribed medications included antidepressants (46%), ADHD medications (38%) and antipsychotic medications (35%). The majority of youth knew the names and types of the medications they were taking. Many of them identified the medications in their comments and in the focus groups and they seemed to know which medications caused side effects and which ones were especially helpful. One teen commented, "I have been on many different medications since I was diagnosed with

fore beginning medications. In 12% of the families, parents reported that their child had received more than one assessment before the first medication trial. Psychiatrists (62.8%) were most likely to provide these assessments, followed by psychologists (23%). In some instances, parents reported that pediatricians or school based or other mental health professionals provided the assessment. One parent commented, "Our pediatrician is wonderful but she is the first to say that dispensing psych meds is beyond her expertise. She referred us to one of only two child psychiatrists in our area. The wait was extremely long – even with the referral. Luckily the psychiatrist is wonderful – taking the time to really assess the situation and pay attention to the family history before prescribing."

When asked about the medications themselves, the majority (53%) of families reported that their child took between 2 and 3 medications at the time of the survey. More than one-quarter said that their child was taking 4 or more medications to treat their behavioral health needs. The most common medications were mood stabilizers (64.6%) followed by ADHD medications (56.9%), antipsychotics (51.5%) and antidepressants (43.4%). Many families involved in the focus groups noted that their children were on multiple medications at the same time.

bipolar disorder, depression and anxiety disorder. It seems that I have finally found the right doctor, after switching around many times. I am also on the right medications and they definitely help with my mood swings and other problems."

## *Side Effects, Stigma and Other Worries*

> *"People without the need for medications and emotional support don't understand those with the support. I feel I am looked down upon by those who don't need that support."*

Youth also reported that although their medications helped them overall, they are concerned about side effects. When asked whether the side effects made them want to stop taking medications, 53% said they wanted to stop and 46% said they did not. When asked more specifically if they worried about the effects the medication might have on their bodies, 61% said that they certainly did. One young man remarked, "No one told me about the bad acne and weight gain."

# *Medication Trials*

The single issue that generated the most comments from parents was medication trials. Trying various medications in an effort to find one that worked was nearly a universal experience. Only 5% of all parents reported that the first medication they tried was the one that worked for their child. 23.5% of the families stated that they had tried 1 or 2 medications, while another 22% told us that their children had tried up to 4 medications. An additional 17.2% had had medication trials of 5-6 medications and another 18 described trying 7 or more different medications. Some parents (14.6%) reported that their child was still trying different medications. See Figure 3. One mother remarked, "My experience with my daughter taking medications was trial and error. It was a constant battle for a while to find the perfect combination." Another's advice was short and to the point: "Keep trying until you get the right mix."

> *"Some medications work, then don't. It's frustrating we have had to try so many different medications but we have found some helpful meds in the long run."*

But for many families, finding an effective medication (or combination) includes stopping medications that don't work or produce troublesome side effects. Nearly 57% of parents reported that their son or daughter had stopped at least one medication during the previous year.

The most commonly reported reason for stopping a medication was the side effects.

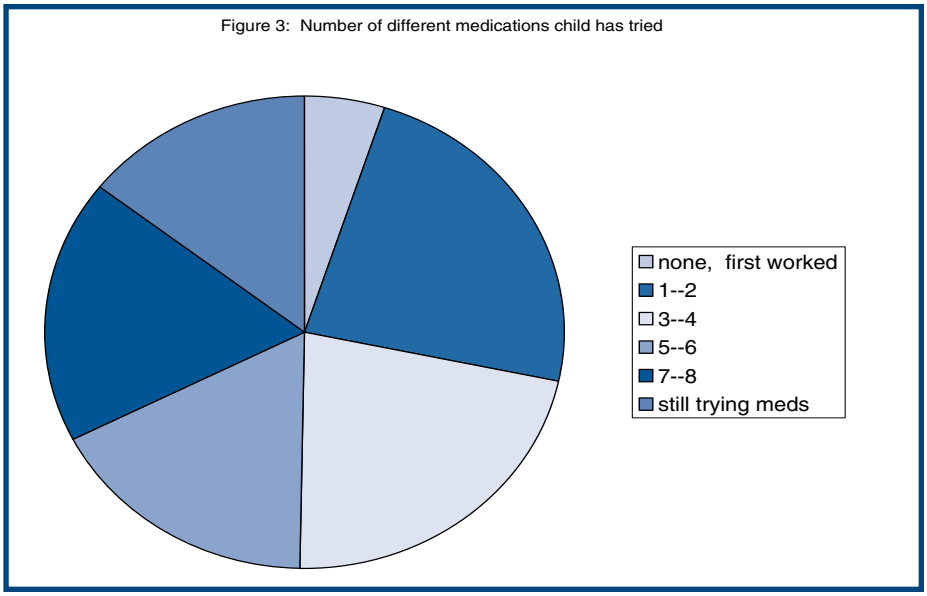
Although adults often focus on long term effects, youth in this study were primarily concerned with side effects that interfered with their day to day life. Dry mouth, sleepiness in school, weight gain and feeling "hyper" were mentioned most often. One teen asserted, "Sometimes the side effects seem bad enough that they are not worth the benefit of what I'm taking."

Many teens felt that taking medications left them open to the judgment of others about their psychiatric condition as well as about the medication itself. One explained, "It sometimes feels like I am not normal. I feel different from other kids. I wish I could control my mood swings and stop myself from crying better." Another remarked, "My experience has been that when people find out about my illness I get treated differently, so I don't tell a lot of people about it."

However, most young people's comfort level increased when they were sharing information about their medications with a close friend. In focus groups, youth made a clear distinction between sharing information with close friends as opposed to a larger peer group.

One parent said, "The side effects for my daughter have been incredibly difficult. I worry about long term side effects on her body and I also worry about the use of more medication to control the side effects of the current medications. I worry that a "side effect" may be a new symptom and vice versa." Other reasons for stopping medication included that the medication wasn't effective (45%), the doctor suggested discontinuing the medication (28%) or the child (19%) or parents (15%) wanted to halt the use of that medication. One family felt that the side effects far outweighed any benefits that they gained: "If we could do it all over, my son would have *never* taken any medication. It helped in elementary school, but once he entered high school all hell broke loose: tremendous weight gain, awful acne, unpredictable and erratic behaviors, including drugs and alcohol, to the point of total chaos in our household." Yet another parent summed it up by saying, "It is a constant battle of side effects vs. containment of symptoms."

Figure 3: Number of different medications child has tried




When asked if they were comfortable having friends know they took psychotropic medications, the respondents were evenly divided. About half (49%) were comfortable sharing this information, and the other half (51%) were not. One teen explained, "Basically, I am very open with it." Another took a different stance, "I don't like people knowing. If you can't tell I have ADHD, the meds are working and I don't need to tell."

## *Getting information*

Nearly all youth who responded knew the type of medication they took (a short list was provided for consultation). The majority of youth reported getting information about their medications from their doctor (82%), but this was followed closely by their parents or other close adult (62%). Even though teens are often very familiar with the Internet, only 5% reported using it to find out information about their medications.

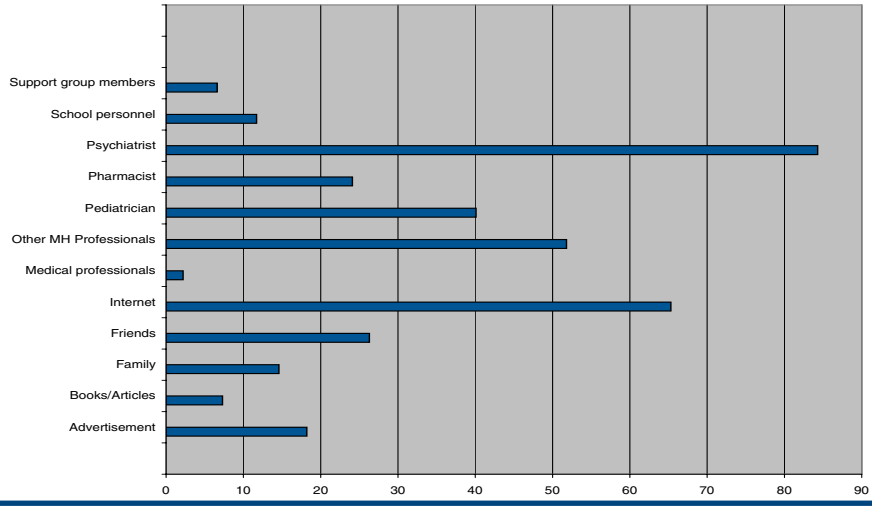
Most teens (70%) reported that they had the opportunity to ask their prescriber questions at medication visits. When asked if they were included in decisions about the psychiatric medications they take, half agreed that they were included in the decision making. An-

# *Finding Information*

Access to reliable and easily understood information is essential for parents who are making decisions about their children's medications. One parent noted that, "It is difficult to find information on these drugs and their effects on children *anywhere*." For most parents, accessing information, especially information about medications that apply to children, requires effort and persistence.

Yet despite the effort required, most families responding to the survey consulted two to five sources of information about medications to initially learn about medications as well as to increase their knowledge. Very few were willing to rely on a single source. While families consulted a variety of resources, for most, the prescriber was a key source of information. The overwhelming majority (84.3%) went to their child's psychiatrist to gain information and knowledge about psychiatric medications. Another large group (65.3%) consulted the Internet, other mental health professionals (51.8%) and their pediatrician (40.1%). Smaller numbers said they spoke to

**Figure 4: Sources of Information Used**




other 25% checked "neutral" and only 24% disagreed.

Youth responding to the survey expressed strong concerns about side effects and interactions and they characterized their communication with their prescriber on these subjects as not meeting their needs. When asked if the doctor or nurse prescribing their medications clearly explained any side effects, 47% agreed that they got the information they needed. Another 22% checked "neutral" and almost one third (31%) did not believe they got clear information about side effects. Several teens remarked that they knew about side effects but had little idea about potential interactions. One young man said, "I know not to take certain meds, but not what would happen if I did." Only 31% agreed that their prescriber clearly explained what would happen if they took their medications and used illegal drugs or alcohol. Half (50%) of the teens believed that their prescriber did not give them this information and 19% checked "neutral."

Other teens reported that they relied on their parent(s) to ask questions and would listen or jump in only if something was unclear. A number pointed out that there was

friends, family members or their pharmacist (see Figure 4).

Very few parents (18%) consulted magazine or television advertisements to gather information and fewer still (<1%) found these ads to be a good source of knowledge. A small number of parents (7%) consulted books or written articles for information.

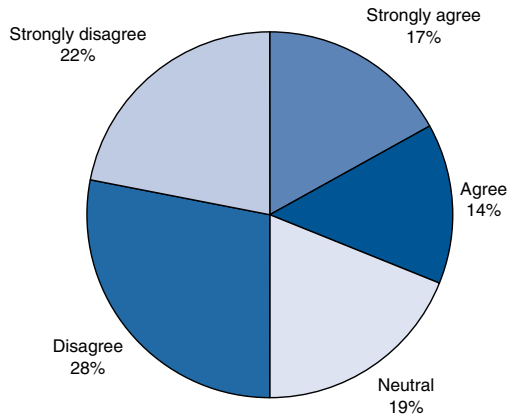
Although families consulted many sources, they tended to rely heavily on one or two. The majority (48.5%) found their child's psychiatrist to be the single best source of information about psychotropic medications. One parent commented, "Our experiences have luckily been guided by a knowledgeable, informative therapist who is a psychopharmacologist. Yeah, I know we are among the lucky few who found the best care." Another 23% found information on the Internet to be the source they relied upon the most.

*It is critical for an adult family member to be very well educated on what drugs are available to treat a particular disorder. I spend at least 2 to 3 hours collecting data on my son's psych meds through internet sites, discussions with parents and teachers, informational sessions with clinicians and the latest workshops in psychopharmacology. As a very well educated consumer, your decisions regarding medications for your child are based on the best possible information available, as opposed to just your prescribing doctor.*

information on the bottle after the prescription was filled.

Many teens said that their parent(s) had originally filled them in on why medication was needed and what it was for. One remarked, "I know the medications help me think more clearly and I don't think I would be as far as I am right now if I didn't take them. My mom and dad helped me to understand about them when I was younger." In addition, 62% felt their prescriber had clearly explained why they were taking psychotropic medications and 58% felt they had been told how the specific medication they were taking was going to benefit them. Nevertheless, even youth who felt that their doctors were available to give them information relied strongly on their mother or father to fill in the details.

**Figure Y-2: The doctor or nurse clearly explains what would happen if I took my medication with drugs or alcohol**



# *Other Influences*

A great deal has been written about the FDA "black box" warning[14] and its impact on the decision making of parents when agreeing to medications. Media stories commonly assert that families worry about this warning and are strongly affected by it. Parents who responded to the survey were aware of the warning yet the majority (58%) said it did not influence them. While an additional group (42%) felt that the warning had influenced their decision making, the degree of impact varied. Most parents in this group (58%) felt they were impacted to only some extent, while slightly more than a third (36%) said they were influenced to a great extent.

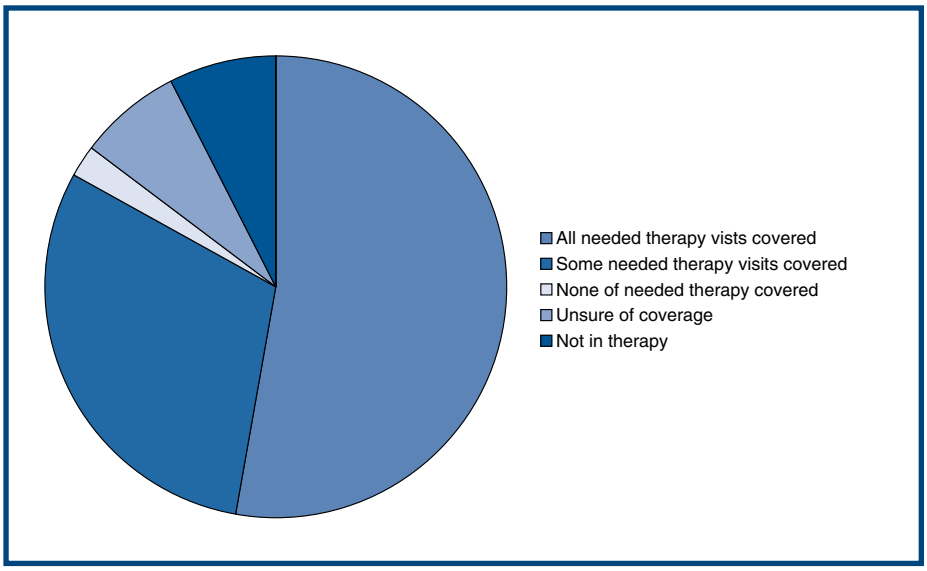
However, if another family member (spouse, another child or self) was taking psychotropic medications, most of those families reported (56.3%) that this was an influence on their decision making, at least to some extent. And a large number of parents (69%) reported that someone else in their family was taking medicationst the time they answered the survey. It was unclear, however, whether the other family member began taking the medications before or after the child.

Cost and insurance coverage are also factors that influence families. While the majority of families (62%) reported that their child had private insurance, 55% also reported that their child received MassHealth, CommonHealth or another form of publicly funded coverage. (A significant number of families (18%) reported that their children had more than one type of insurance coverage.) When asked if their insurance covered all of the medication visits their child needed, an overwhelming majority (76%) of the families said

Several made the distinction between information about a specific medication, which they preferred to receive from their doctor, and general information about psychotropic medications, which they received from their family. One young man commented, "My mom is a walking encyclopedia." It is important to note that parents depend strongly upon their child's prescriber for information and youth in turn depend on their parents. When the communication of information to parent is inadequate, the child may not receive the information he or she needs.

Not one respondent reported using advertisements for medications as a source of information. During focus group discussions, most teens said they had not seen (or noticed) ads for psychotropic medications although some remembered seeing them for physical conditions such as asthma. In one focus group, the teens were somewhat offended by the ads they had seen, feeling that the message was to make viewers feel the pharmaceutical company cared, when "the point is to sell specific meds."

that it did. However, when parents were asked whether their insurance also covered all of the psychotherapy visits their child needed, far fewer reported that it did (52.8%). Most of families who responded (85.6%), reported that a psychiatrist is prescribing medications for their child.



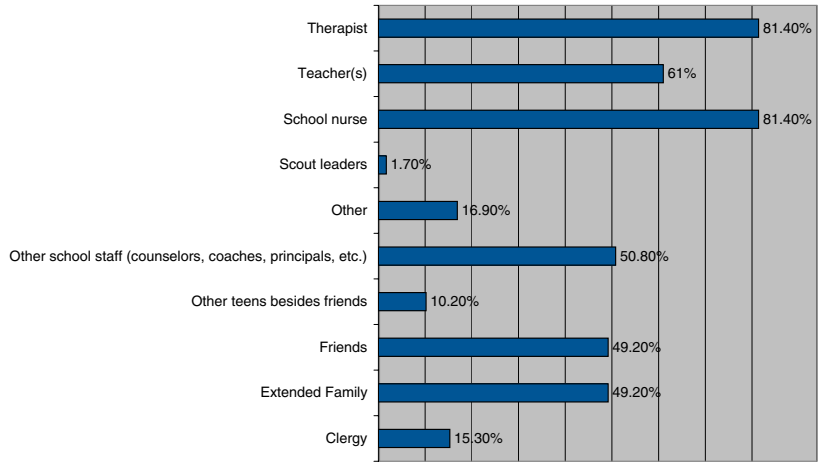

Yet even with access to medication visits, some families struggled to get the medications when needed due to constraints such as prior authorization and restricted drug lists. As one parent noted, "There have been many instances this year where the child's meds are delayed due to the insurance company newly requesting prior authorization and has delayed the pharmacy from filling our prescription."

Other families lamented the impact of co-payments for medications. One mother wrote, "Our biggest roadblock however, is the *cost* of meds. Our costs for all of our meds monthly can range $300-$400, depending on needs. We are a family of five, four with mental health needs." Another was

## *Medications and schools*

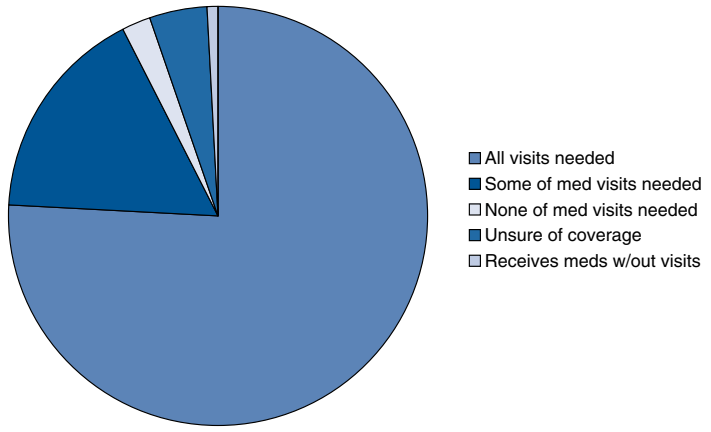
Youth responding to the survey had a higher comfort level sharing information about their medications with the school nurse than with anyone else in their life except their therapist or immediate family. An overwhelming majority (81%) were comfortable talking to the school nurse and an additional 61% were comfortable letting their teacher know about their medications. Other school staff such as counselors, coaches and principals were deemed acceptable to share information with by 50% of the youth, while 49% felt it was okay to let friends or extended family have information about their medications.

**Figure Y-3: People that youth are comfortable letting know that they take psychotropic medication(s)**




However, most teens strongly preferred taking their medications at home instead

**Figure 6: Insurance Coverage of Medication Visits**




very direct about the impact of costs on her decision making. She wrote, "Medication prices, availability and co-pays make a difference when deciding to change or add a med."

## *Communication Between Prescriber and Parent*

Families found that they relied strongly upon the professional who was prescribing their child's medication for information about their child's medications, dosage instructions, expected benefits and possible side effects. The majority of children (85%) had had a single person prescribing psychotropic medications in the previous year. While communication was strong around dosage and the reasons a child was taking medications, many parents felt they were poorly informed about possible side effects and potential interactions with other medicines.

Most parents were satisfied with the communication between the person prescribing their

of at school. The reasons varied but privacy played a consistent part. One focus group participant said, "I prefer taking my meds at home because it's easier. One time I forgot to go to the nurse and she came looking for me. My friends saw and it was uncomfortable." Another commented, "I like taking meds at home because it keeps it private."

### *Satisfaction:*

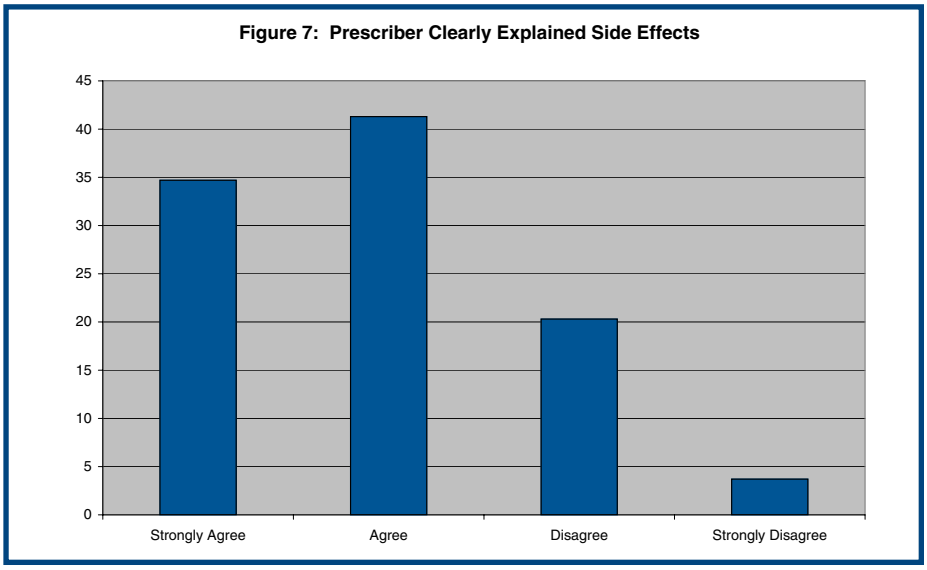
When asked if their medication(s) made a positive difference, 80% of the youth responded that it did. Unlike their parents, they didn't speak of the impact in global terms. Instead they noted the specific ways in which psychotropic medications helped them. One wrote, "I like it when my night time pill kicks in so that I can sleep. It was pretty hard to get to sleep before." Another noticed, "Some meds help you concentrate and focus at school."

Even youth who disliked medications didn't dispute that they could be effective. One said, "Personally, I think meds suck and I wish I could live without them or at least

child's medication and themselves when the discussion concerned the need for the medication and how to administer it. The vast majority of families (91%) reported that their child's prescriber clearly explained why their child was being prescribed the medication(s) and how often (96%) and what amount of medication (97%) should be given to their child.

However, when asked whether the person prescribing those medications clearly explained the side effects of that medication, fewer parents (76%) agreed (see Figure 7). Almost a quarter of the families (24%) responded that they disagreed or strongly disagreed that their child's prescriber had been clear when explaining side effects. And when asked whether that prescriber had clearly explained the potential interactions with other medications to them, more than a third (36%) responded negatively. (An additional 64% agreed that the prescriber had been clear when explaining potential interactions.)

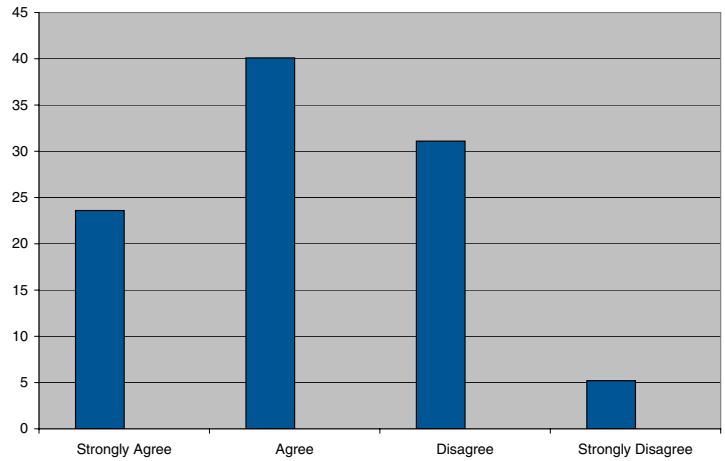
**Figure 7: Prescriber Clearly Explained Side Effects**




These responses are clearly concerning. Parents reported that they rely on their

go one week without taking meds and see how I do…If my meds worked I wouldn't want to die right now, so I guess my meds aren't working." Others asserted that being part of the decision making was an important element to them. One said, "Having a say in what you take is one of the most important things. Your opinion is important." Although teens emphasized their desire for privacy with regard to their medication use, they didn't wrestle with the issue in the same way their parents did. One said, "It's just not a big deal. I don't talk about meds with my friends, I have more interesting things to discuss. I rarely forget my meds, and when I do, it's only for a day – and all I get is a headache. I TAKE the pills but as far as I can tell, all they do is stop me from getting depressed in wintertime. It's a good thing, but it also doesn't have a major effect on my life in terms of other things. I swallow and get on with my day."

**Figure 8: Prescriber Clearly Explained Potential Interactions**




child's prescriber as the foremost source of information, yet a substantial number felt that they were not receiving sufficient information about side effects and interactions. As one parent commented, "One thing that made me change providers was when the doctor prescribed an antidepressant to my 14 year old son who was diagnosed with depression. I called her after 3 days of mania that I had never seen before. She said to me, '…If an antidepressant makes a child manic, he may get a bipolar diagnosis.' She needed to WARN me that I could have been observing this. I was furious."

Parent comments throughout the survey focused heavily on their experiences with medication trials, side effects and their relationship with their child's prescriber. These were seen as key elements to a successful outcome with medications. One parent remarked, "Choosing the doctor is the most important part of getting the correct medication."

While families understood the constraints that short medication visits place on communication, nearly one-third (29%) still felt that their child's prescriber was not as available to

## *Conclusions*

Children and adolescents who take psychotropic medications have more straightforward feelings, and less ambivalence, about those medications than their parents. They are pleased when medications help them, worry about their privacy and express frustrations with ineffective medications and side effects. Many of them have struggled to keep their attention focused, their mood on an even keel or their behaviors controlled on their own. A sizeable number have experienced difficulties at school or at home. They know why they take medications and clearly expressed their viewpoint about them.

Like most adolescents, the teens who responded to our survey are looking for a way to be part of important decisions that impact their lives and want information about medications in order to do just that. Many struggled to find a balance between their dislike of "having" to take medication and the knowledge that it often made a difference. They were focused on the impact of medications in their lives today and didn't worry much about long term effects. And most of them were realistic enough to

speak with them as they needed him or her to be. The majority (84%) reported that they were included in decisions about the psychotropic medications their child takes. And parents appreciate and value of being included as a part of their child's team. One observed, "We have experienced many bad psychiatrists that do not explain to us or listen to us when it comes to meds. We finally found a great child psychiatrist. I will do everything in my power to stay with this psychiatrist because I know that there are long waiting lists everywhere and the doctors are few and far between."

## Schools

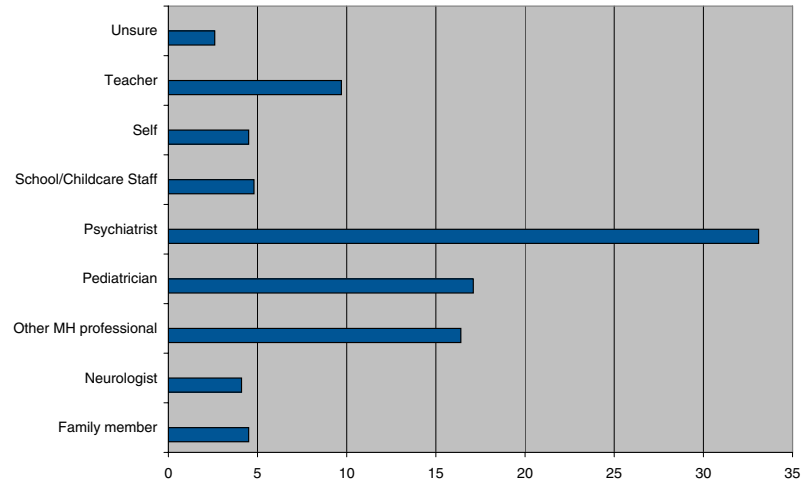
The majority of children and adolescents in Massachusetts spend six or more hours a day in public school. Teachers often observe emotional and behavioral difficulties that impact a student's day to day performance. School nurses frequently see students who are agitated, depressed, unable to concentrate or who may even harm themselves.

It is a popular conception that teachers or other school staff often recommend that a parent consider whether their child needs to be prescribed medications. Yet, when asked who first suggested that psychotropic medication might be helpful, less than 10% of families reported that their child's teacher made this suggestion (see Figure 9). Even fewer (4.8%) reported that another school professional or child care staff made this recommendation.

understand that their medications were only part of the answer. As one commented, "I think it's good when you need it, but I don't want to take meds my whole life. It helps stabilize things, but it doesn't do everything."

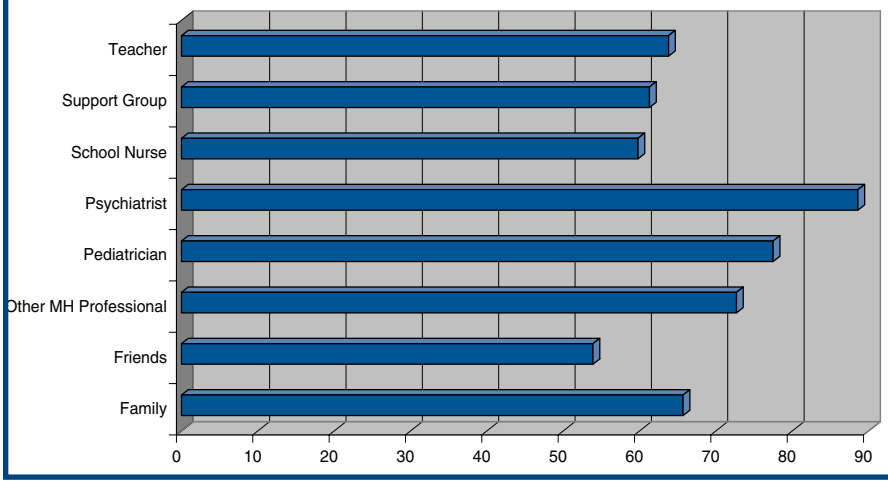
Youth taking psychotropic medications are seldom asked for their opinions and their experiences. They have strong feelings and are surprisingly well informed. They were glad to be asked for their perspective and thoughts about the medications they take and what impact those medications have. Nearly half of the teens who took the survey wrote comments and a number of those comments included their thanks for the chance to talk about medications.

**Figure 9: Person who suggested medications would be helpful**




As mentioned earlier, the majority of families reported that their children were in elementary or middle school when they began medications: 51.7% reported their child was 5-8 and another 23% said their child was 9-12 years old. However, at the time their parents participated in the study, the majority of children were in middle school or high school. A large number of families felt comfortable sharing information about their child's psychotropic medications with both teachers and school nurses. In fact, many families felt nearly as comfortable sharing this information with trusted school personnel as they did with family members. However, 81% of the children were receiving special education services and most parents reported that the special education staff understood their child's mental health needs better than earlier teachers who had had no training.

**Figure 10: People with Whom Parents Are Comfortable Sharing Specifics about Child's Medication**




Many parents find themselves in the role of supplying information about their child's medications, including the positive impact and possible side effects to school staff. One mother noted, "I feel as if I am constantly needing to educate the staff." It is troubling that nearly one-fourth of the parents did not feel they understood the side effects of their child's medications given that parents are often required to relay this information to school staff.

Some parents related how difficult it was to adequately explain their child's mental health needs to school personnel and to relay what are reasonable expectations for any improvements with or without psychotropic medications. One parent expressed frustration in her statement: "One of the biggest hurdles has been getting school personnel to understand that a child with a mood disorder will continue to have difficulties at school even with the best medicines and treatments in place *outside* of school, if educators do not receive training in the appropriate care of mentally ill children."

## Impact on the Family

Little research has been done on the impact of a child's psychiatric illness on the rest of the family. All parents must manage a number of responsibilities for their family including finances, child-care, sibling relationships, overseeing their child's education and medical needs. Studies on the effect of chronic childhood illness on parents reveals an increase in distress, increased financial burden, time constraints and higher marital stress. Patricia Sloper, PhD notes that there are high levels of distress for parents at 6 and 18 months after a child receives a diagnosis of cancer with little change over time[15]. She concludes that there is a significant need for family support on an ongoing basis when childhood chronic illness is present. This is also true for families whose children have mental health disorders.

Another study, conducted at the University of Queensland,[16] found that mothers of children with autism had significantly more family stress than mothers of children with a physical disorder or mothers whose children had no physical or psychological disorders. Families responding to our survey confirmed this. One parent wrote, "This illness has a tremendous impact on the rest of the family. We consider ourselves fortunate that we have managed to stay intact as a family unit."

> *"When they work, it's a beautiful thing; when they don't, the whole family suffers."*

The impact of medication trials on families was also highlighted. As noted, almost half of the children had tried five or more medications and an additional 45% had had trials of two to four different medications. About 15% reported that their child was still trying different medications (see Figure 3). Parents noted that this "trial" process can have an impact in and of itself. One mother explained, "They have helped him, but it's been (and continues to be) a long and challenging process to find the "right" med, dose, etc. I often wonder, Is this the "right" one, is there another one that is "better," is this the right dose?"

## Satisfaction

Throughout the survey, parents expressed great satisfaction with medications simply because they work. Arriving at a point where one or several medications addressed their child's symptoms outweighed their frustration with medication trials and the challenges they faced. As one parent noted, "After years of struggle we finally found medications that actually help my child, which is a great relief." Numerous parents recounted the struggles they went through and the pain their child and family

experienced. Many pinned their hopes on medications that would treat their child's psychiatric illness and kept their focus on that goal.

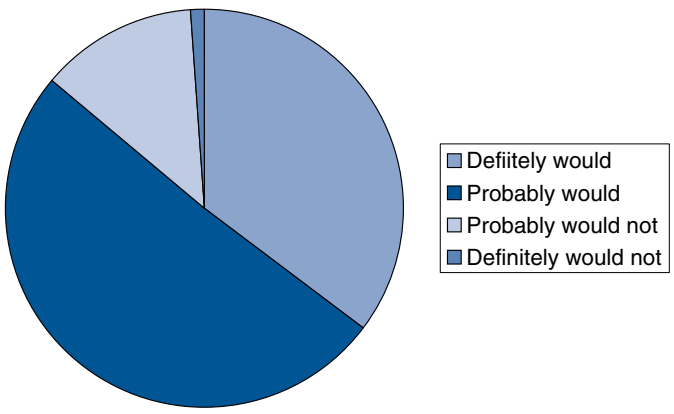
The survey posed three separate questions about satisfaction with medications. When asked if the medications helped their child deal more effectively with his or her problems, 89.8% of parents agreed that they did. "My child is stable and functioning well at home, school and in the community, I believe, in part, due to his use of appropriate psychiatric medications," one mother reported. And a grandparent responded, "My grandchild has been much better taking psychiatric medications."

*If my son was not taking psychiatric meds, he would not be able to function in life. He would not make it through one day.*

Another 86% of parents said they would recommend medications as an option to a friend whose child needed help with an emotional, behavioral or mental health disorder. And finally, 74.2% of parents said they are satisfied with the medications their child takes. These satisfaction levels are far greater than those given for alternative treatments. One parent stated, "I wish we had started meds at the onset instead of trying to work without them."

Satisfaction levels were affected by several different factors. Families who had family members currently taking medications were 1.9 times more likely to be satisfied with child's psychotropic medications compared with those who didn't have family members taking medications. One mother wrote, "Having experienced severe depression, I understood what a mood disorder feels like and I feel no small child should experience it when there is medication available." And if families had tried alternatives to medications, they were also slightly more satisfied than if they had not.

**Figure 11: If a friend's child needed help, would you recommend they consider psychiatric medications?**




Latino families were 3.2 times more likely to be dissatisfied with their child's psychotropic medications compared with Caucasian families. Families whose children were currently in psychotherapy were 4.2 times more likely to be dissatisfied with their child's psychotropic medications than those whose children were not currently in psychotherapy.

Although parents expressed satisfaction, they also wrote of their ambivalence. One parent noted, "I don't feel this questionnaire gets to the extreme ambivalence I have about psychiatric meds and the extreme pressure to use them. I found I checked off that I am basically satisfied with the medications and how they're helping, but that doesn't capture how I *feel* about this." Some parents wrote of the need to destigmatize medication. Others noted that they would be seen differently if they were giving their children medications for diabetes or asthma. One said, "The general public does not understand psychiatric meds and families are often criticized for using them."

Parents are often caught between dueling expectations when agreeing to medications for their child. On the one hand they feel a responsibility to find a treatment that helps their child and on the other they are told that medicating children is risky and somehow repugnant. Most try complementary and alternative treatments. Others may delay until making a choice becomes urgent. One mother captured the sentiments of many: "We began these meds with reluctance and hope to not have to use these or any similar meds again. Yet, we do appreciate that perhaps they helped heal something within. When we seemed without hope, they offered some."

In more than half the completed surveys, parents wrote comments in the margins, next to their answers as well as in the section designed for their observations. They were clear that this was a complicated decision and that the path to finding effective medications was often arduous. They spoke of the need to persevere, their search for information and how much they valued a strong relationship with their child's prescriber.

They were clear that this was more than a medical decision. It impacted other family members. Dealing with multiple medication trials and side effects created stress and sometimes had a financial impact. Because prevailing public opinion is often negative, many parents felt isolated.

When the right medication, or combination of medications, works, parents write not just of their child's symptoms being alleviated, but of a far larger impact. One mother said, "After trying many meds, some with awful side effects, we found one that has allowed my son to relax and focus. My son now says, 'It feels good to be me for once.'" Another put it even more succinctly, saying, "With these meds, he is able to have a life."

# Best Practices

*Through responses to the survey and participation in the focus groups, several parents identified programs that have helped them or their child. We are pleased to provide information about those programs here.*

### Medication Education Group at Hunt Center, Beverly Hospital, Danvers, Massachusetts

The Hunt Center runs a medication education group for children who are receiving inpatient services. The nursing staff provides education to the children in order for them to be part of their treatment planning and to better understand the role medications can have on behavioral health. Diagnosis, symptoms, and medications are discussed as well as side effects and compliance.

Various instructional tools are used such as posters, word searches, handouts and pictures. In order for the children to feel more comfortable about asking questions and to respect their privacy, one of the nurses has them write down their questions and put them in a paper bag. At the question and answer portion of the group, the nurse takes out the questions and answers them. The nurses are creative in their presentations and each has their own style of engaging with the children. They understand group dynamics and keep in mind the child as an individual who brings various experiences and backgrounds to the group.

### Medication Workbook at Providence Behavioral Health Hospital, Holyoke, Massachusetts

The nursing staff at Providence Hospital created a workbook for latency age children to help them understand their medications. The workbook includes stickers and other tools to help children illustrate each page. Subjects include understanding how medications make them feel, how they affect their bodies, how they help and what side effects they might experience. Each child's workbook is unique to them and is brought home as a continuing tool to help remember all they learned about their medications.

## Massachusetts Child Psychiatry Access Project

The Massachusetts Child Psychiatry Access Project increases the access of child psychiatry services for primary care providers in Massachusetts. This program is funded by the Department of Mental Health and designed and implemented by the Massachusetts Behavioral Health Partnership. MCPAP is available to all children and families, regardless of their insurance status and operates through six teams, each with a child psychiatrist, a social worker, and a care coordinator, providing psychiatric telephone consultation to PCPs, often immediately, but at least within 30 minutes.

The consultation will result in one of the following outcomes, depending upon the needs of the child and family:

An answer to the PCP's question
Referral to the team care coordinator to assist the family in accessing routine, local behavioral health services, with the understanding that there may be a 4 – 6 week wait
Referral to the team social worker to provide transitional face-to-face care or telephonic support to the Member and family until the family can access routine, local behavioral health services
Referral to team child psychiatrist for an acute psychopharmacologic or diagnostic consultation

For more information, please visit the following website: www.MCPAP.org

# Footnotes

[1] "NASMHPD Medical Directors" Technical Report on Psychiatric Polypharmacy," September 2001.

[2] "Trend in the News," Psychiatric Times, June 2002, Volume XIX, Issue 6.

[3] Press Release, Food and Drug Administration, "FDA Launches a Multi-Pronged Strategy to Strengthen Safeguards for Children Treated with Antidepressant Medications," October 15, 2004.

[4] Moreno C, Laje G, Blanco C, Jiang H, Schmidt AB, Olfson M. National trends in the outpatient diagnosis an treatment of bipolar disorder in youth. Arch Gen Psychiatry, 2007 September.

[5] The terms "parent" and "family" include parents, grandparents, foster parents and others who identified themselves as primary caregivers.

[6] Some respondents indicated that their children had more than one type of insurance.

[7] US Census Data 2000 shows that racial/ethnic data for Massachusetts children shows 79% while, 7% African American, 4% Asian, 11% Latino, 4% multiracial and 6% other.

[8] An education program falling under the guidelines of Section 504 of the Rehabilitation Act of 1973

[9] "Changes in Outpatient Psychiatric Diagnosis in Privately Insured Children and Adolescents from 1995 to 2000", Ilan Harpaz-Rotem and Robert A. Rosenheck, Child Psychiatry and Human Development, Volume 34, Number 4, June 2004

[10] "Speak Out for Access," Health Care for All and Parent/Professional Advocacy League, 2002

[11] American Academy of Pediatrics, "Children's Health Topics." www.aap.org/healthtopics/complementarymedicine.cfm

[12] Ibid.

[13] Eugenia Chan, M.D., MPH, Leonard A. Rappaport, M.D. and Kathi J. Kemper, M.D., "The Role of Complementary and Alternative Medicine in Attention-Deficit Hyperactivity Disorder." *Journal of Developmental & Behavioral Pediatrics*, 24(1), February 2003.

[14] In October 2004, the U.S. Food and Drug Administration directed manufacturers of antidepressant medication to put a "black box" warning on labels to describe the risk to children and adolescents. See FDA letter, October 15, 2004, "FDA Launches a Multi-Pronged Strategy to Strengthen Safeguards for Children Treated With Antidepressant Medications"

[15] Patricia Sloper, PhD, "Predictors of Distress in Parents of Children with Cancer: A Prospective Study," *Journal of Pediatric Psychology*,Vol.25, No. 2, 2000.

[16] Ruth Bouma and Dr. Robert Schweitzer, "The impact of chronic childhood illness on family stress: A comparison between autism and cystic fibrosis," *Journal of Clinical Psychology*, Vol 46, Issue 6, 1990.

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