# how-to guide

The Parents' How-to Guide to

# Children's Mental Health Services

in Massachusetts

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# **Foreword**

n Massachusetts, many families with children in need of mental health services are finding that it is difficult to get the care their children need. Understanding our mental health care system is a challenge. Parents often end up trying to navigate through unfamiliar territory with limited tools—and the experience, while sometimes rewarding, can also be frustrating and discouraging.

This "How-To Guide" is intended to provide help for parents. Designed to be practical and easy to read, the Guide is a reference tool that will introduce you to the kinds of mental health services available for children in our state. You will also find information about how to get these services and how to pay for them. The advocacy tips sprinkled throughout the chapters offer additional guidance and words of wisdom about the potential obstacles you might encounter along the way.

The Guide began as a project undertaken by the Health Law Section of the Boston Bar Association (BBA) and its Social Action Committee, which identifies and pursues worthy social causes that advance the health of Massachusetts citizens. Since 1999, child mental health has been a focus of the Social Action Committee's community service efforts. The BBA's experience in this realm made it increasingly clear that families with children in need of mental health services face widespread problems of access to services, funding for services, and availability of care. These issues have defied resolution for decades. In response, the BBA has sought to improve the situation for these families through critical inquiry, coalition building, creative problem solving, and advocacy.

Several years ago, the BBA convened a Task Force comprising the key stakeholders in child mental health in Massachusetts—government agency heads,

legislative leaders, civic leaders, mental health advocates, and representatives of children, families, courts, schools, providers, payors, employers, and academia—as well as members of the Social Action Committee. In January of 2002, the Task Force issued a Report recommending that certain actions be taken to improve the status of children in Massachusetts with mental health problems. One recommendation was that this Guide should be developed to help parents recognize child mental health conditions and get access to mental health services for their children.

In preparing the Guide, we consulted with families and their advocates who have been through the Massachusetts mental health system, as well as with government agencies, mental health professionals, other providers, and payors who are part of the system. As a result, the Guide reflects the input of a wide variety of sources from multiple disciplines with differing points of view and experiences. We hope that it will become broadly available to parents through doctors' offices, schools, hospitals, public agencies, and human and social service providers.

At the same time, we realize that the Guide represents only one small step toward helping families gain access to the child mental health services they need. Broader systemic reform of the mental health system in Massachusetts is within reach—but it will take the sustained attention and effort of many people working together to improve the availability and quality of services for our children. By publishing this Guide, the BBA is proud to reaffirm its commitment to that continuing effort.

Editor-in-Chief and Co-Chair, Children's Mental Health Task Force

Michael L. Blau, Esq.

# **Problems your** child may have

#### **Overview**

ost parents find that their child or adolescent will behave in a problematic way at some point along the road to adulthood. Sometimes, the problematic behavior is brief or only occurs every now and then. Other times, the behavior may last for weeks or may occur frequently. In all cases, parents wonder what they should do. Should you ignore the problem and wait for the "phase" to pass? If you contact your child's school or a mental health professional, is this an overreaction? And how do you know if your child's behavior indicates a significant mental health concern?

If your child has behavioral or emotional problems, the problems may appear at home, or they may surface in other ways. Some children and adolescents have difficulties at school, while others may raise concerns because of the way they behave in the community or because they get into trouble with authority figures like the police. Remember that it can be useful to discuss your concerns with your spouse, a relative, or a trusted friend. In general, you should not be alarmed by moody teenager behavior that seems typical. However, if you simply dismiss your child's behavior as a "phase" without discussing it with anyone, you may end up overlooking a problem that is more serious.

In fact, it is important to identify a mental health concern early, so that your child can receive the proper care if he or she needs it. Many behavioral and

### emotional problems can be addressed with treatments that are safe and effective.

behavior occurs. Later on. As a parent, you will want to follow a twoit may be important to step approach if you are troubled by your child's behavior. First, you need to be able to recognize whether an ongoing problem exists that is affecting your child's life. Second, if such a mental health services that might help your child.

know exactly what happened and when. problem does exist, you need to know how and where to find the professional

The goal of this chapter is to assist you with the first step of the two-step approach described above: how to recognize whether your child's behavior should raise serious concerns. Here, you will find descriptions of some of the more common child behavioral and emotional problems that parents find troubling. This information can help you decide whether you should bring your concerns to your child's pediatrician, a parent support organization, the school health professionals, or a mental health professional, all of whom can provide insights into whether your child's behavior indicates a more serious underlying problem.

In some cases, a child may be suffering from more than one emotional or behavioral problem or may be diagnosed as having more than one mental health illness. This can make the situation more complex and confusing for everyone involved. By being aware of possible symptoms and problems early on, you may be able to help sort out your child's problem at a later stage.

# **Advocacy Tip**

If you are worried about

your child's behavior, start keeping notes about

specific moments when the

chapter one: problems your child may have

# Symptoms and possible diagnoses

#### 1. Overactivity and inattentiveness

#### General information

Many children of varying ages have difficulty paying attention, controlling their high energy levels, and/or doing what they have been told to do. This is entirely normal in most cases. In particular, if your child is young (ages 3 to 5), he or she may have a lot of energy and may sometimes seem inattentive and overactive. However, if your child's inattentiveness and overactivity persist over time and appear to interfere with his or her learning and social relationships, this may be cause for concern.

#### Checklist of symptoms and effects

Consider whether your child is behaving in any of the following ways:

#### Inattention

- often fails to give close attention to details or makes careless mistakes in schoolwork, work, or other activities
- often has difficulty staying focused on tasks or play activities, and is easily distracted
- often does not seem to listen when spoken to directly
- often does not follow through on instructions (even if he or she understands them) and fails to finish schoolwork, chores, or duties in the workplace
- often has difficulty organizing tasks and activities
- often avoids, dislikes, or is reluctant to engage in tasks that require a focused mental effort (such as schoolwork or homework)

- often loses things necessary for tasks or activities (such as toys, school assignments, pencils, books, or tools)
- often is forgetful in daily activities

#### Overactive

- often fidgets with hands or feet or squirms in seat
- often leaves seat in classroom or in other situations where children are expected to remain seated
- often runs about or climbs on things in situations where this is inappropriate
- often has difficulty playing quietly
- often is "on the go" or acting as if driven by a motor
- often talks excessively
- often blurts out answers before questions have been completed
- often has difficulty waiting for his or her turn
- often interrupts others during conversations or games

#### Possible diagnoses

Since many children—especially young ones—may behave like this, you should try and determine whether your child's behavior seems to occur too frequently and appears to be interfering with his or her ability to learn and form social connections. If the behavior is severe enough to trouble you, it is possible that your child may have a medical condition or a learning disorder, Attention Deficit Hyperactivity Disorder (ADHD), or an anxiety or mood disorder.

# **Advocacy Tip**

Be careful not to jump to conclusions about your child's behavior. A hasty diagnosis may be incorrect and can lead you in the wrong direction in terms of the treatment your child needs.

#### Medical condition and/or learning disorder

Your child may have a medical condition (such as bad eyesight or hearing) or a learning disorder. These can make children restless and impatient, particularly in a learning environment where they are having difficulty keeping up with other students.

#### Attention Deficit Hyperactivity Disorder (ADHD)

Your child may have ADHD, which is found in approximately 3 to 5 percent of school-age children. A child who has ADHD is unable to stay focused on tasks at home or at school and has problems with learning, making friends, and developing self-esteem.

#### Anxiety and/or mood disorder

Your child may have an anxiety or mood disorder that is making it hard for him or her to pay attention, sit still, and/or complete tasks. These disorders are discussed in Sections 2 and 3 of this chapter.

#### 2. Extreme anxiety or fear

#### General information

Almost every parent has had to comfort a child after a nightmare or an episode where a child is afraid of the dark, of monsters, or of everyday activities like speaking in front of his or her classmates. These anxieties are quite common during childhood and adolescence. As your child grows and develops, he or she is bound to have occasional fears and worries. However, if

these fears and worries seem excessive, and/or if they cause your child to feel extremely upset and to have trouble functioning on a daily basis, you may want to take a closer look at the problem.

#### Checklist of symptoms and effects

Consider whether your child is behaving in any of the following ways:

- often feels shaky, restless, or tired
- often experiences shortness of breath, a very rapid heart rate, and/or cold and sweaty hands
- often complains of stomach pain, headache, and/or dizziness
- often seems "edgy" or irritable, and has difficulty concentrating and/or falling asleep
- often worries too much, broods over things, and feels very nervous
- often feels as though every situation will end badly
- often speaks of feeling helpless or powerless
- often has trouble sleeping alone and experiences frequent nighttime fears and/or nightmares
- often resists going to school
- often argues with others and frequently stirs up conflict

# **Advocacy Tip**

You know how your child behaves at home—but you also need to know how he or she behaves at school, both in class and out. Talking with teachers, coaches, and administrators can be helpful.

## **Advocacy Tip**

It is important to try and encourage your child to talk with you about emotions and problems. As your child grows older, he or she may need help and support when coping with social situations.

#### Possible diagnoses

If your child or adolescent is behaving this way on a frequent basis, he or she could be suffering from a medical condition or a serious anxiety disorder. Although anxiety disorders are common and come in a variety of shapes and sizes, some are more serious than others. If your child is having a lot of trouble just getting through the day, this is cause for concern.

#### Medical condition

Your child may have a medical condition—such as hyperthyroidism or hypoglycemia (these terms are defined in the Glossary at the end of this Guide)—that produces symptoms similar to the symptoms of an anxiety disorder. Substance abuse also results in similar symptoms.

#### Anxiety disorder

Your child may have a serious anxiety disorder that is causing feelings of excessive fear (a phobia) or panic. A disorder like this can affect your child's self-esteem, social development, and academic performance.

#### 3. Extreme sadness and despair

#### General information

Most children, especially teenagers, go through ups and downs as they grow older. As a parent, you learn to expect these mood swings. However, if your child appears to feel sad and "low" for weeks at a time and has trouble

snapping out of it, the problem may be more than just a bad mood. You should pay close attention to this, because your child might be suffering from a very serious condition.

#### Checklist of symptoms and effects

Consider whether your child is behaving in any of the following ways:

- often seems downhearted, irritable, and/or bored
- often talks about feeling hopeless or sad
- has less interest in activities, even those he or she once enjoyed
- seems to have less energy and/or seems to be going through frequent severe mood swings
- seems to spend less time with friends and has less interest in relationships of any kind
- often has trouble communicating or is reluctant to talk
- seems to feel isolated, lonely, and self-critical
- often has trouble concentrating and is not performing well in school
- often seems hostile or angry and is very sensitive to rejection
- often complains of headaches or stomach pains
- makes a major change in eating or sleeping habits
- often throws temper tantrums, and the tantrums are increasing in length and intensity
- talks about running away from home and/or tries to do it
- mentions suicide and/or other self-destructive behavior

#### Possible diagnoses

If your child seems unable to break free from intense feelings of sadness and despair, and if these feelings persist for several weeks, he or she may be suffering from a serious depression or a bipolar disorder. It is important to determine this as soon as possible, to reduce the risk of harm to your child. Also, if your child's condition is identified and treated early, he or she is more likely to recover quickly.

#### Depression

Your child may be experiencing depression, which is a complex illness with many possible causes, including stress and biology (when it is a trait that runs in the family). Depression can lead to poor academic performance, social isolation, family problems, and—in extreme cases—suicide.

#### Bipolar disorder

Your child may have a bipolar disorder, which is a kind of depression. Children with this disorder go through periods of being very depressed followed by periods of being extremely irritable and are likely to have temper tantrums.

# **Advocacy Tip**

Once you receive a diagnosis from a qualified professional who has thoroughly examined your child, make sure you understand and agree with the opinion. Ask questions! Even doctors can be wrong.

#### 4. Problems with food or fear of being too fat

#### General information

In today's world, nearly everyone feels pressure to be thin, and this pressure is sometimes difficult for teenagers to handle. Your child may become very careful about what he or she eats, and may also become extremely interested in exercise. Most of the time, you do not need to worry about this. However, if your child seems overly obsessed with food and weight, if he or she frequently disappears after eating, or is becoming painfully thin, this is cause for concern. Your child's health may be in serious danger.

#### Checklist of symptoms and effects

Consider whether your child is behaving in any of the following ways:

- often expresses an intense fear of being fat
- feels fat even if he or she is underweight
- is not able to maintain a healthy weight for his or her height
- has stopped getting her period
- has a low sense of self-esteem
- often talks about feeling worthless because of his or her weight
- often eats and then vomits to get rid of the food
- often eats and then exercises much more than is typical
- seems to be increasingly isolated from friends and family
- often prepares food as if carrying out a ritual (may cut food up into tiny pieces, for example)

• often prepares food for others in a very careful way, but may not eat any of this food

#### Possible diagnoses

Many people are concerned about their bodies and their weight. In a small number of cases, this concern becomes extreme and may turn in to an eating disorder, which can be a very serious illness. If your child is behaving this way on a frequent basis, it is time to explore the problem. It is important to catch this illness as early as possible, because early treatment of an eating disorder usually leads to a faster recovery.

#### Eating disorders

There are four different types of eating disorders, and all of them are dangerous. You have probably heard of these two types: Anorexia Nervosa and Bulimia Nervosa. A child suffering from Anorexia will be terrified of gaining weight and may count every calorie, eat only tiny amounts, and even weigh his or her food. A child suffering from Bulimia will appear to eat normal or even large amounts of food but will secretly try to find ways to "purge" the food, such as by vomiting it back up. For more information about these eating disorders (and others), see the Glossary at the end of this Guide.

# **Advocacy Tip**

When you discuss these behaviors with your child, try to avoid using labels and medical terms. For example, "mood swings" is a less frightening term than "bipolar disorder."

Girls are more likely to develop eating disorders, but boys—especially competitive athletes—can develop them, too. If your child has an eating disorder, both you and your child may end up confused,

frustrated, and unhappy. More importantly, these disorders can lead to severe weight loss, various health problems, and even death.

#### 5. Problems that arise after a traumatic event

#### General information

When a child goes through a traumatic event, he or she is likely to have a reaction, and the reaction can lead to emotional and/or physical problems. This is a normal response. If your child has lived through a traumatic experience—such as a violent event in the home or the neighborhood, a painful medical procedure, a shooting or similar emergency at school, or sexual or physical abuse—it is important to help him or her deal with any problems that may follow. Support from family members and friends can make a big difference.

#### Checklist of symptoms and effects

Consider whether your child is behaving in any of the following ways:

#### Infants and toddlers up to age 2.5 years

- seems more irritable than usual
- seems more clingy than usual
- cries more often than usual

#### Children ages 3 to 5 years

- often seems to feel helpless and powerless
- often seems to feel that the world is not a safe place
- often has a hard time being away from you (the parent)
- has more nightmares than usual
- seems fearful and anxious
- talks about the traumatic event, telling the story over and over
- acts out the traumatic event

#### Children ages 6 to 12 years

- has more difficulty concentrating in school than usual
- has more difficulty sleeping than usual
- seems fearful and anxious
- talks about the traumatic event, telling the story frequently
- acts out the traumatic event and/or makes drawings of it
- complains of aches and pains when nothing is wrong

#### Children ages 13 to 18 years

- seems fearful and anxious
- connects the traumatic event to feelings of sadness, anger, guilt, and/or revenge
- seems to need to talk about the traumatic event
- seems more irritable than usual
- withdraws from family and friends
- has more difficulty focusing in school than usual
- has more trouble sleeping than usual

#### Possible diagnoses

These symptoms are usually a normal reaction to a stressful and/or traumatic event. In most cases, the reaction is only a short-term reaction, and (with some help from family and friends) the symptoms will go away over time. In some cases, the reaction is more severe. If your child's symptoms do not go away over time, he or she may have Post-Traumatic Stress Disorder.

#### Short-term reaction to trauma

If your child has experienced a stressful or upsetting event and shows some of the symptoms listed above, you can help by answering his or her questions, getting the family back into daily routines, and offering extra attention and affection.

#### Post-Traumatic Stress Disorder (PTSD)

A child with PTSD will show symptoms for longer than a month and will also start having more severe problems at home, in school, and with friends. He or she may express extreme fear, may begin avoiding people and places that are reminders of the event, and/or may become extremely withdrawn. If this is happening to your child, you will probably need to find help outside of the family.

## **Advocacy Tip**

Even a very young child can have a mental health illness. Instead of avoiding or ignoring a problem your young child may be having, try finding a way to discuss the problem with him or her.

#### 6. Extreme anger or defiance

#### General information

Most children begin to rebel a little against their parents, usually as they enter their teenage years. You may learn that your child has been caught shoplifting or has been fighting with a schoolmate. He or she may sometimes lie to you or refuse to do what you ask. In many cases, teenage rebellion is not cause for alarm. However, if your child is acting very aggressive on a frequent basis or is being destructive, you may have a more serious problem on your hands.

#### Checklist of symptoms and effects

Consider whether your child is behaving in any of the following ways:

- often loses his or her temper
- often gets into arguments with you or other adults
- refuses to follow the rules set by you or other adults
- seems interested in annoying people on purpose
- often blames others for his or her misbehavior
- is easily annoyed by other people
- often seems angry and resentful
- often seems full of bitterness and eager to lash out at someone
- has caused or seems likely to cause damage to property
- has caused or seems likely to cause physical harm to a person or animal

#### Possible diagnoses

Many children and teenagers get angry at adults, misbehave, and refuse to obey their parents. However, if your child's hostile behavior seems extreme to you, and if these behaviors continue for six months or longer, then you may want to explore the problem. Your child may have a developmental problem or a behavior disorder called Oppositional Defiant Disorder.

#### Developmental problems and/or family tension

It is possible that your child's behavior is the result of developmental problems or problems at home. A child who is having a hard time keeping up in school, or who has trouble expressing himself or herself, may feel more hostile than most children. A child who is enduring family problems may also feel hostile and act more aggressively.

#### Oppositional Defiant Disorder (mild)

A child with mild Oppositional Defiant Disorder may behave well at school, and may also behave well with friends, but will misbehave frequently while at home. If your child has this disorder, he or she may argue excessively with you, use offensive language, or refuse to obey your rules. He or she may be feeling unusually angry and resentful. It is important for you to try and understand why your child feels this way.

#### Oppositional Defiant Disorder (severe)

A child with severe Oppositional Defiant Disorder has the problems described above and is also likely to cause harm to people, property, and/or animals. He

# or she may become very destructive and may also start having problems at school. In extreme situations like these, your child may be dangerous to others and will

# **Advocacy Tip**

Whenever you have a gut feeling that your child may be having trouble of some kind. it's better to trust this feeling, even if your friends or family members don't share your concern.

#### 7. Tendency to use drugs or alcohol

probably need professional help.

#### General information

Some teenagers experiment with alcohol and drugs. In some cases, children begin using drugs or alcohol on a frequent basis. Often, a child who is using drugs or alcohol will try very hard to hide this from his or her parents. If you think your child might be developing a problem with drugs or alcohol, it is important to keep in mind that he or she may have an underlying emotional problem that is causing or contributing to the substance abuse. When you address the issue of substance abuse with your child, be sure also to try and address any mental health problems he or she may be having.

#### Checklist of symptoms and effects

Consider whether your child is behaving in any of the following ways:

- is very irritable and/or seems to be going through a change in personality
- often starts arguments and/or behaves irresponsibly (stays out late at night, for example, or breaks limits you have set)
- is missing school and/or neglecting schoolwork
- often shows poor judgment and a negative attitude

- often seems "out of it," sluggish, and not really aware of what's going on or seems unnaturally energetic and excited
- often has glazed eyes or reddened eyes
- often has trouble waking up
- often gets a bloody nose
- has stained fingers or visible needle marks (or "tracks")

#### Possible diagnoses

If your child is engaging in excessive use of substances such as drugs or alcohol, this may be evidence of an addiction—and addictions are generally treatable. However, a drug or alcohol addiction is frequently a sign that something else is wrong. Your child may be depressed or traumatized, for example. You may need to explore his or her state of mind and mental wellbeing in order to determine what steps to take next.

## **Advocacy Tip**

Remember to get involved and stay involved if you think your child needs help. Ask questions, write everything down, be organized, and be prepared to advocate for your child.

#### Summary and things to remember

You have now reviewed a variety of child behavioral and emotional symptoms—the symptoms that most often trouble parents (please see the chart on page 24). This is step one of the two-step approach described at the beginning of this chapter. With the information you find here, you will be able to make a more informed decision about whether your child's behavior indicates a serious problem. If you decide that your child might need professional help, Chapter 2 will be useful because it explores the question of where and how you can find services for your child.

Remember that nearly all children and teenagers go through rough spots as they mature, and most of them also get into unhappy conflicts with their parents. It is important to observe your child's behavior carefully and discuss it with people you trust before you jump to any conclusions. In the long run, your child may or may not need professional services—but he or she will always benefit from the love and understanding you can offer.

# Symptoms & possible diagnoses

Symptoms	Possible Diagnoses
Overactivity and inattentiveness	<ul> <li>Medical condition or learning disorder</li> <li>Attention Deficit Hyperactivity Disorder (ADHD)</li> <li>Anxiety or mood disorder</li> </ul>
Extreme anxiety or fear	<ul><li>Medical condition</li><li>Anxiety disorder</li></ul>
Extreme sadness and despair	<ul><li>Depression</li><li>Bipolar disorder</li></ul>
Problems with food or fear of being too fat	■ Eating disorder
Problems after a traumatic event	<ul><li>Short term reaction to trauma</li><li>Post-Traumatic Stress Disorder (PTSD)</li></ul>
Extreme anger or defiance	<ul><li>Developmental problems or family tension</li><li>Oppositional defiant disorder (mild or severe)</li></ul>

# First steps for getting help

#### **Overview**

f you have read through the information in Chapter 1, and if you are reasonably certain that you need some outside help for your child, the next question is: How can I find that help? Maybe your child's pediatrician can answer some important questions for you. Or perhaps the teachers, administrators, or health care professionals at your child's school will be helpful. Friends and/or members of your community—youth leaders, advisors in your church or other faithbased organization, caregivers at your local health services clinic—may also be valuable resources for you. Each one can offer helpful observations and information, and some can offer services as well.

However, each of these options opens up a different path for you and your child to follow. This means you may find yourself wondering: Where do I start? What questions should I ask? If the health services my child needs are available from both the school and our community health center, which one should I turn to? Will the school and the health center work together to help my child?

The goal of this chapter is to help you with those questions as you begin evaluating your options—and this is step two of the two-step process described in Chapter 1.



Remember that it is important to make some observations of your own about your child's behavior. Your observations will be useful to any service provider who wants to help your child. See the chart on the next page for people and/or organizations that can help. Before contacting someone for help, try to answer the following questions as best you can:

# **Advocacy Tip**

If your child has a mental health problem, he or she may not be able to control his or her behavior. This lack of control may be your first sign that something is wrong.

- Is your child's troubling behavior similar to the behavior of other children in his or her age group? (For example, it may be typical for a 3- or 4-year-old child to throw a temper tantrum because you have said "No ice cream before dinner!" But it is not typical for an 11-year-old child to throw a tantrum over the same issue.)
- How often does your child behave in a way that troubles you? (For example, does your child throw a tantrum once a week—or twice a day?)
- How severe or extreme does your child's behavior seem to you? (For example, if your child stamps his or her feet during a tantrum, this is less severe behavior than if he or she destroys something in your home during a tantrum.)
- How long does each episode of troubling behavior last? (For example, does the temper tantrum last for 10 minutes—or for an hour?)
- Where does your child's troubling behavior occur? (For example, has your child had discipline problems in school, in an after-school program, or with the coach of a sports team? Have any of your child's friends or the parents of those friends ever complained about your child's behavior?)



By answering these questions, you will be able to assist the health service providers as they try to understand your child's behavior. If your child needs treatment, the treatment plan will be designed to address his or her specific needs—and since you are the one who knows your child best, your input will be invaluable. Some parents may find it difficult to speak up, but it is important to be an active participant whenever someone is creating a treatment plan for your child.

#### Who can help

#### 1. A family member or trusted friend

#### When and/or why you should turn to a family member or friend

Many of us know somebody whose child has needed help because he or she was behaving in a troubling way. When this person is a family member or friend, you may feel more comfortable discussing the problem with him or her—and it will probably be helpful to sit down and learn about what happened in that person's situation. You will probably feel better and less alone once you talk about the problem with someone who has had to deal with something similar. It is reassuring to know that other parents have also had to figure out problems like this—and it might be a relief for you to share your concerns with someone who is sympathetic.

#### How the family member or friend might help

If the family member or friend has gone through something similar to the problem you are facing, he or she will probably have some good advice for you. That person may also know your child (and you) well enough to make

## **Advocacy Tip**

If you don't know any other parents whose situations are like yours, consider joining an online parent discussion group (see our Resource list for more information).

source list
ormation).

You might also be able to get some good ideas about where to look for help and what to expect during the process. If your family member or friend has found a health care provider that he or she likes, you might want to consider seeking help from the same provider. In almost every case, your family member or friend will also be a strong source of support for you as you begin trying to help your child.

#### What questions to ask

Consider whether it might be helpful for you to ask your family member or friend one or more of the following questions:

- What made you decide that your child might need help?
- Where did you go first? (Your child's school? The doctor?)
- How did you choose a doctor or therapist for your child?
- What kind of treatment has your child had, and has it worked?
- Where can I go to talk about my own feelings and concerns?

#### 2. Your child's pediatrician

#### When and/or why you should turn to a pediatrician

Your child's pediatrician is someone you can turn to with any questions about your child's health or behavior. Because the pediatrician is the person who knows the most about your child's health history, he or she has the knowledge and resources to help you try and determine whether your child's behavior is

the result of a medical condition or a mental health illness. Even more importantly, you may feel comfortable discussing your child's behavior with the family pediatrician—even if you don't feel comfortable discussing the problem with anyone else.

#### How the pediatrician might help

The pediatrician will listen to your concerns, and write notes about the problem in your child's medical record (this is called "taking a history").

If the pediatrician believes your child might benefit from mental health services, he or she will probably give you a list of health care professionals and health care service centers. Most pediatricians will recommend that you call several different providers on this list. You are more likely to get the services your child needs if you make several phone calls instead of just one. The pediatrician may also recommend that you speak with someone at your child's school. (The services provided by schools and health care centers are discussed in later sections of this chapter.)

If the pediatrician believes your child is a danger to himself or herself, or to other people, then the situation is considered an emergency and the pediatrician will probably try to get immediate help for your child. The pediatrician may send you and your child to the emergency room of a local hospital or may

## **Advocacy Tip**

When speaking with your child's pediatrician or any other medical professional, be sure that you don't minimize your concerns and/or downplay your child's symptoms.

locate an emergency services team that will evaluate your child at the pediatrician's office. In either case, your child's mental health will probably be evaluated by a social worker.

After evaluating your child and speaking with you about your child's behavior, the social worker will make recommendations for your child's treatment. These recommendations may include intensive mental health services and/or hospitalization. Keep in mind that the emergency room doctor—if he or she believes that your child is a danger to self or others—has the power to hospitalize your child without your consent.

#### What questions to ask

Consider whether it might be helpful for you to ask your child's pediatrician one or more of the following questions:

- Can you give me a list of mental health service providers in my area?
- What do you recommend I do for my child at this point?
- Have you been trained to diagnose or treat mental health problems?
- Should I get a second opinion?
- What have you recommended for other parents in my situation?
- How do I keep you involved in my child's treatment?

# **Advocacy Tip**

Some pediatricians have access to psychiatric experts who can help address your child's symptoms. Ask your child's pediatrician to arrange a consultation like this if possible.

#### 3. Your child's school teachers, administrators, or health care staff

#### When and/or why you should turn to your child's school

Your child's school can be a very good source of information and support. If you have noticed something in your child's behavior that is troubling, it is a good idea to contact the school to find out how your child is behaving at school. You may also want to find out if your child's schoolwork is suffering. Because your child spends much of his or her time at school, the information you can get from people at the school might be very important and sometimes even reassuring.

Even if you have not noticed a problem with your child at home, the school may contact you because someone has noticed a problem at school. If this happens, it is important to take the school's observations seriously. Your child may behave differently at school than at home. Also, you may have grown so accustomed to your child's behaviors that you may be

> overlooking a serious problem. Try not to feel panicked or insulted if the school calls you, because this is an opportunity to work with the school on your child's behalf.

# **Advocacy Tip**

It is important to pay attention to your child's troubling behavior at home, even if he or she has no problems at school. Troubling behavior usually shows up at home first.

#### How your child's school might help

The teachers, administrators, and health care staff at your child's school can provide you with valuable information about how your child behaves at school and about his or her academic performance.

With this information, you will be able to develop a more complete understanding of your child's behavior.

Your child's school can also put together an informal team of teachers and specialists who will observe your child's behavior in the classroom. This team can then work with your child's teachers to make changes in the classroom that will help your child improve his or her behavior. Some strategies that help your child in the classroom may also help your child at home.

# **Advocacy Tip**

You may need to be persistent with your child's school. In general, schools resist providing mental health services and—unfortunately—may try to downplay a child's emotional problems.

The school's mental health specialist—usually a social worker, therapist, or psychologist who works part-time or full-time with the school—can provide your child with short-term individual counseling. The mental health specialist may also want to meet with you to discuss your child's situation.

Special education services are available at your child's school for children with mental health problems and/or learning disabilities. If you request a formal evaluation from the school (or if a teacher, administrator, or health care professional requests one), the school is required to conduct a complete assessment to see if your child is eligible for special education services. This evaluation will become part of your child's school record. Getting special education services for your child can often be a complex process. Please see Chapter 5 of this Guide for more information about services that are provided in schools.

#### What questions to ask

Consider whether it might be helpful for you to ask your child's teacher, school administrator, or school health care specialist one or more of the following questions:

- Who works with the school to provide mental health services to the students?
- How do we develop an education plan for my child?
- How have you worked with other children who behave like my child?
- How can I stay involved in my child's education plan?
- How often will you update me on my child's progress?

#### 4. A psychiatrist, psychologist, or other mental health professional

#### When and/or why you should turn to a mental health professional

Many parents are reluctant to contact a mental health professional such as a psychiatrist or a psychologist. Some parents worry about what other people will think about them or their child. Other parents worry that they will have difficulty understanding the mental health professional's recommendations. Many also worry that they will lose control over their child's treatment and/or that the treatment will be very expensive.

However, a mental health professional is the person who is most qualified to help you if your child has a mental health problem. For example, your child's pediatrician may recommend that your child visit with a mental health professional. You may also get recommendations from family members or close friends. It is important to know that you can contact a mental health professional directly when seeking help for your child.

If you have medical insurance, the mental health services that are available to your child will depend on what is covered by the insurance and/or what services you can afford to pay for on your own. Please see Chapter 3 of this guide for more information about paying for your child's care.

## **Advocacy Tip**

If you are unable to get services for your child on your first try, don't give up! Keep knocking on doors!

It is helpful to know that psychiatrists, psychologists, social workers, and therapists also work through schools and other agencies to help children get the care they need. You may find that your child is eligible to receive services from a mental health professional at school.

## How a mental health professional might help

Mental health professionals are the experts on mental health, and they are trained to provide many different kinds of care. If your child is brought to an emergency room at the hospital because of an emotional problem, he or she will be evaluated by a mental health professional. Mental health professionals also provide services in many non-emergency situations.

For example, mental health professionals usually provide "talk therapy," which means they talk with your child one-on-one about his or her problems and try to help your child improve his or her behavior and/or mood. Sometimes, talk therapy also works for groups of children. Mental health professionals also provide other services for children, such as behavioral therapy and play therapy.

Therapy for children has become more common in recent years, and most families are willing to give it a try. However, many parents find it hard to accept the idea that their child might need more intensive treatment, such as medication or hospitalization. Keep in mind that your child's best interests need to come first. Mental health professionals provide a wide range of services, and you will want to consider as many options as possible, even if some of them make you feel uncomfortable.

If your child's emotional condition can be improved by medication, a mental health professional such as a psychiatrist or clinical nurse specialist can prescribe the medication. Sometimes, you will find that medication is suggested for your child early on during treatment. It is always a good idea to ask your child's mental health professional about other treatment options that might be helpful.

## **Advocacy Tip**

Medication raises many issues.
Make sure you understand
everything about your child's
medication—and make sure
your child continues to take
the proper dose.

If your child's emotional condition is only moderately severe, a mental health professional will work with your child while he or she continues living at home. This is called "outpatient treatment." In this case, you may find it fairly easy to stay involved with decisions about your child's treatment.

If your child has a more severe mental health condition, he or she may need to live for a while in a hospital or a residence for children or adolescents with mental health disorders. This is called "inpatient treatment" or "residential care." In this case, it may be more difficult for you to stay involved with decisions about your child's treatment. However, the

mental health professionals providing treatment for your child should be in contact with you on a regular basis. You will have a better chance of staying involved with your child's treatment if you actively seek information and answers from these professionals.

#### What questions to ask

Consider whether it might be helpful for you to ask the mental health professional one or more of the following questions:

- What is your specific background and training in child mental health?
- Have you treated children with problems similar to my child's problem?
- What are my child's treatment options?
- Which option do you recommend, and why?
- How long will it take for my child's mood or behavior to improve?
- How can I stay involved with my child's treatment?

You may also want to ask yourself the following questions:

- Has this mental health professional explained everything to me in a way that helps me understand my child's situation?
- Am I comfortable with this mental health professional?
- Does this mental health professional seem genuinely concerned and interested?

Remember that there are many different kinds of mental health professionals, and some of them are able to provide services that others cannot provide. For example, if your child needs medication, he or she will need to get treatment from a mental health professional who is able to prescribe the medication.

## **Advocacy Tip**

Before signing any consent forms for your child's treatment, be sure to ask questions, get the facts, and know the pros and cons. Be particularly careful when medication is involved.

Depending on what kind of care your child needs, it is important to try and figure out if the mental health professional is a good match with your child.

## 5. A community health center, youth agency, or social services agency

## When and/or why you should turn to a community agency

In most cases, parents turn to a community agency because someone has referred them to that agency. If your community has a health center, it may offer services that can help your child. Your child's pediatrician or school may also suggest that you explore other local agencies to see what services are available there.

Often, a parent finds a community agency helpful because it offers programs and services that are designed to meet the particular needs of the community and the community's children. The programs and services for children may be woven into the community in a way that helps build connections between the families in that community. Also, community agencies are sometimes able to offer specialized services that address your child's specific emotional needs. Many community agencies provide services like these by working together with hospitals and public agencies such as the Department of Mental Health and the Department of Social Services.

Different kinds of community agencies provide different kinds of services and programs. An "activity agency" like the YMCA or a Boys and Girls Club usually organizes after-school programs for children and teenagers in the community. If you are concerned about your child's behavior and you feel that he or she needs to be more active, you might send your child to such an agency. Organized physical activities can often help children develop friendships and can contribute to your child's physical and emotional health.

Your local faith-based organizations may also provide after-school programs and/or other services for children in the community. Again, programs like these can improve your child's general health and well-being.

However, if your child has a more serious
mental health condition, an activity agency or
faith-based organization is probably not
equipped to deal with it. In this case, you may
want to find out whether your community has a local
mental health and/or social services provider—such as the Massachusetts
Society for the Prevention of Cruelty to Children (MSPCC)—that is better
equipped to address a more troubling mental health problem.

### How a community agency might help

Most community agencies provide the same range of services your child might receive from a private mental health professional, but at a lower cost. Many

## **Advocacy Tip**

Some churches, synagogues, and other faith-based organizations have special needs classes which may provide support for children with behavioral or emotional issues. community agencies (including faith-based organizations) also organize support services for the families in the community. For example, the MSPCC has daycare and after-school programs, programs to educate and support parents, and programs to protect against child abuse or neglect, as well as mental health counseling. Some agencies provide individual and group therapy, medication therapy, and mental health testing services. Unlike mental health professionals who work in private practice, community agencies are often willing to provide services in a family's home.

#### What questions to ask

Consider whether it might be helpful for you to ask the community agency staff member one or more of the following questions:

- What kind of services can your agency provide for my child?
- Does my family need to meet certain eligibility requirements to qualify for services?
- Who provides mental health services through this agency, and what kind of training does he or she have?
- Does my child need services beyond the services that you can provide?

#### 6. A hospital emergency department

#### When and/or why you should turn to an emergency department

If you are very worried about your child's emotional condition, and if you don't have easy access to a therapist's services, you may want to bring your child to a hospital emergency department for immediate evaluation. Some parents feel that they should wait until their child behaves in a seriously desperate way before bringing him or her to an emergency department. However, you know your child well enough to know if he or she is behaving in a disturbing way, and you may need to trust your instincts.

If it is very clear that your child is having a severe emotional crisis, do not hesitate to bring him or her to the emergency department. Some children who are having a severe emotional crisis may behave violently and seem to be out of control, while others may seem completely paralyzed by serious depression. It is particularly important to bring your child to a hospital if he or she is threatening to harm other people, harm himself or herself, and/or commit suicide.

You can drive your child to the hospital yourself, call for a taxi that will take you there, have a friend or family member take you there or go along with you, or even call 911 if you believe your child needs to be transported in an ambulance with professional medical assistance. Try and choose the transportation option that makes the most sense in terms of your child's safety and your own safety.

Your community may have a local emergency services team (such as the Boston Emergency Services Team—or BEST Team—in Boston) that you can call. These teams are generally trained to provide emergency services including transportation to a hospital emergency department if necessary.

## **Advocacy Tip**

As a parent, you have the right to stay with your child in the emergency room—and it's always best if you stay.

#### How an emergency department might help

When you first arrive at the hospital, your child will be given a medical exam and a health care professional (such as an emergency department nurse) will ask you for information about your child's condition and situation. Your child will also be examined by a mental health specialist. In most cases, this specialist will talk with you and your child separately, then bring the family together to discuss recommendations for treatment.

If your child is in a crisis and/or may cause harm to himself or herself or others, the specialist may tell you that your child needs to be admitted to the hospital as an inpatient. If your child is not in a severe crisis, the mental health specialist may recommend that your child see a therapist. Other treatment recommendations include outpatient mental health services and/or intensive homebased services.

In each of these situations, you should expect the mental health specialist to explain everything to you clearly and help you understand your child's options. The emergency department staff should also help you plan the next steps for your child's treatment. In fact, this may be the most important part of an emergency visit. Be sure to work with the mental health specialist to plan what will happen when your child is released from the emergency department.

#### What questions to ask

Consider whether it might be helpful for you to ask the emergency department staff member or mental health specialist one or more of the following questions:

- Is my child stabilized?
- What specific treatment plan would you recommend for my child?
- Why are you recommending this particular treatment plan? How will it help my child?
- What other treatments did you consider?
- If my child needs to be hospitalized, how long will he or she stay in the hospital?
- Can I bring things for my child, like games or clothes or snacks?
- Can you help me figure out whether the services you recommend are covered by my insurance plan?

#### A special note about consent forms

In an emergency department setting, parents are often asked to sign forms consenting to treatment or the release of information. Although it is important to maintain an open line of communication between the hospital and your child's school, you will need to be very aware of what information is flowing back and forth. In order to maintain your child's privacy as much as possible, you will want to try and control the information exchange by only consenting to the release of certain information. Take care not to sign any "blanket" consent forms that place no limitations on the release of information.

#### 7. The police and the juvenile (criminal) justice system

#### When and/or why the police may get involved

If your child is charged with committing a crime, he or she will be taken into custody by the police. In very rare cases, the police may be called in by a

parent or family member who has been harmed or has reason to believe that he or she is in danger of being harmed by the child.

Once your child is in police custody, he or she will go through proceedings in the juvenile justice system. Only children who are involved with this system can receive services from the Department of Youth Services (DYS), which provides just a few basic mental health services. DYS can get involved if your child is being held on bail and is waiting for a trial or if he or she has been committed to DYS by the court. The court can only commit a child to DYS if he or she has been charged with having committed a crime while between the ages of 7 and 16, and he or she pleads guilty to the criminal charge, is found guilty after a trial, or violates the terms and conditions of probation.

## **Advocacy Tip**

More and more police departments are teaching their officers about child mental illness. Try and find out how prepared your local department is—but only call the police if you have no other options.

If your child is in trouble with the law and if you believe this has happened because he or she has a mental health disorder, you may want to advocate for mental health treatment while your child is being detained and/or instead of imprisonment.

to help address a child's mental health condition. If you are aware that your child might get into trouble with the law, it is important to try and get services for your child that might help keep him or her out of police custody. The juvenile justice system and DYS are absolutely the "last resort" in terms of mental health services and should be avoided if possible.

#### How the police or DYS might help

If a judge has placed your child in temporary DYS custody, your child will be seen by a social worker. If DYS is familiar with your child and knows that he or she has a severe mental health problem, a higher-level mental health professional may be called in to help. DYS offers additional mental health services for children who have been committed to DYS—but DYS commitment is generally not something that you would want for your child.

It is possible that DYS will make an effort to get other agencies—such as the Department of Mental Health or the Department of Social Services (DSS)—involved with your child's case if those agencies provide services that may help your child. Unfortunately, other agencies sometimes try to avoid working with children who have been detained by DYS because they think DYS cases are too complicated.

The DYS has one residential facility for children with mental health problems—but it is a very small facility and only accepts male children who have been committed to DYS custody and are in crisis.

Generally, if your child is in DYS custody, you will have little or no control over what happens or what services your child receives.

## **Advocacy Tip**

Very few children get appropriate mental health treatment while in DYS custody. The Resource list in this Guide has some legal and clinical advocates who might be able to help.

#### A special note about CHINS

If someone—your child's teacher, for example, or a police officer—suggests that you might want to file a CHINS (Child in Need of Services) petition to get services from DSS or DYS for your child, you should be extremely cautious. This is a time to think hard about the situation before acting. If you file a CHINS petition, you will be taking your child to court and filing charges against him or her, which could have a very negative effect on the relationship you have with your child. Also, it is difficult to predict what kind of services the judge will order for your child. The mental health services provided by DSS and DYS tend to be very limited.

Be sure to get as much information as you can from an attorney or advocate if you are considering filing a CHINS petition, and try to avoid filing a CHINS petition unless it is the last and only option for your child.

#### What questions to ask

Consider whether it might be helpful for you to ask the DYS staff member one or more of the following questions:

- Why is my child being detained by DYS?
- What services will you provide my child in detention?
- How can I have my child transferred to a hospital?

## **Advocacy Tip**

If your child has a serious mental illness, he or she may receive services from several different agencies. Always ask an agency about finding someone to help coordinate your child's care.

# Summary and things to remember

You have now been introduced to a number of different ways to seek mental health services for your child (please see the chart on page 48). Next, you will need to think about how to pay for these services. Schools provide some services for free, but mental health services in general can be expensive, especially if you have little or no health insurance. Chapter 3 will help you begin to learn more about health insurance and payment options, and how they may determine what kind of services are most easily available to you and your child.

As you go forward, it is important to remember that if your child has a mental health illness, you can expect that a variety of people will work together as a team to help your child. For example, you might first make contact with your child's pediatrician instead of your child's school, because you feel more comfortable with that approach. Even so, it is likely that the pediatrician and the school will end up working together to help your child.

This team approach allows the people working with you and your child to collect and discuss the widest possible variety of important information. This approach is also a way of providing your child with as many services as possible—within an agency, in his or her school, and/or at home. It is important that you work hard to keep people interested in and involved with your child's situation.

## Seeking help

Your child's situation	When to get help	Where to get help
<ul><li>Mild to moderate change in behavior</li><li>You are worried but not alarmed</li></ul>	Soon (a routine assessment)	<ul> <li>Pediatrician</li> <li>Mental health professional</li> <li>School</li> <li>Family/Friend</li> <li>Community agency</li> </ul>
<ul> <li>Major change in behavior</li> <li>Child seems unable to function without help</li> <li>You feel unable to cope or help</li> </ul>	48-72 hours (urgent)	<ul><li>Pediatrician</li><li>Mental health professional</li><li>School</li></ul>
<ul> <li>Severe, out-of-control behavior</li> <li>Chid may be a threat to self or others</li> <li>You are frightened</li> </ul>	Immediately (emergency)	<ul><li>Hospital emergency department</li><li>Police</li></ul>

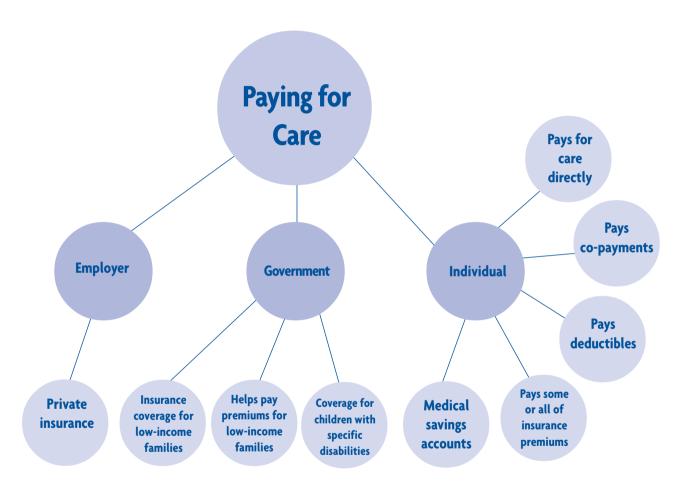
chapter three

## Paying for services

#### **Overview**

edical services in general—and mental health care services in particular—can be expensive. There are a variety of ways to pay for mental health care, including private health insurance plans, public health insurance programs, or your own personal funds (please see the chart on page 50). In many cases, you will find that you need to use two or even three of these sources to cover the cost of mental health care for your child.

For example, your employer may provide health insurance coverage but may require you to pay a portion of the monthly fee (or "premium") charged by the insurance company. In addition, the insurance plan will probably require you to pay an additional fee (called a "co-payment") whenever your child receives a health care service. In this case, you and your employer are sharing the costs of health care. Some public insurance programs can help you meet the costs of private employer-provided health insurance—and in that case, you would be using three different sources to cover your child's health care costs.



## **Advocacy Tip**

Even if you have insurance, you may still have trouble getting the services (or payment for the services) your child needs. Keep written records to help with requests.

This chapter is designed to help you make smart choices about how to provide your child with the best possible mental health care in an affordable way, through a private insurance plan, a public program, or both. The chapter will help you:

- gain a general understanding of the kind of private insurance plans and public programs that are available
- consider which insurance plan or program may be right for you and your child depending on need and/or eligibility

One way or another, it is very important for you to try and get some kind of health insurance coverage for your child. Most insurance plans will help you meet the costs of mental health care services such as therapy, medication, and testing and/or evaluation. In a few cases, more intensive services like acute residential treatment and day treatment are also covered. (Please see below for a more complete list of the kind of mental health services your child might need.) Without insurance coverage, you will face an uphill battle if you are unable to personally afford the services your child needs.

Note: If you have private insurance, emergency services for your child will always be covered. Medicaid—which must pay for any medically necessary service—will also cover emergency services.

It is important to remember that the information provided in this chapter is just the tip of the iceberg. With any insurance plan or program, you will need to follow through on your own to get more detailed information about mental health care coverage for your child.

## **Advocacy Tip**

In any emergency situation, a hospital is required to evaluate your child and provide stabilizing treatment if he or she has a mental health condition.

The chart [at right] describes the kind of services that may be provided to your child by mental health care professionals. All insurance plans and programs cover emergency services, but coverage of other services depends on the specific plan or program. These other services usually include intensive non-residential outpatient services, office-based outpatient services, and inpatient services.

Some of the terms used in the chart may look unfamiliar. The Glossary in the back of this Guide explains many of these terms in more detail.

Types of insurance plans and programs

## Group insurance through an employer

Most children in Massachusetts with employed parents or caretakers are covered by private health insurance. Private health insurance is either "group" or "non-group." If you have a group plan, you are buying insurance as a member of a larger group—employees at a company, for example. If you have a non-group insurance plan, you are buying insurance as an individual (or family). Non-group insurance can be very expensive. Most people with private health insurance have group coverage through an employer.

Group insurance plans usually fall into one of the following categories:

- Primary Care Physician (PCP) plan (where the primary doctor who cares for you
  or your child manages your health care and is the "gatekeeper" who authorizes
  specialized care)
- Preferred Provider Organization (PPO) plan (where you can keep your costs lower by seeking care for your family from providers who participate the PPO plan)

## A list of mental health services

## **Emergency services**

- Crisis intervention and screening
- Short-term crisis counseling
- Emergency medication management
- Crisis stabilization

## Intensive non-residential outpatient services

- Community services from support services to more intensive services
- Family stabilization services
- Observation / holding beds (partial hospitalization)
- Psychiatric day treatment
- Care during a transition from one level of care to another
- Substance abuse treatment

## Office-based outpatient services

- Diagnostic evaluation
- Individual and/or family therapy
- Group therapy
- Case consultation and/or multi-disciplinary team consultation
- Medication management
- Psychological testing
- Substance abuse assessment and services.

## **Inpatient services**

- Acute in-hospital treatment
- Short-term residential treatment
- Longer-term residential treatment

- Health Maintenance Organization (HMO) plan (where you and your child receive care from a specific group of health care providers who participate in the HMO)
- Fee-for-Service or Indemnity plan (where you pay a fee for each service you receive and for only those services)

#### Choosing a group insurance plan

If you are able to get insurance through your employer, you might find that you have several different choices of private health insurance plans. Each plan will charge you a monthly premium, and most will require you to also pay co-payments and/or deductibles for the services your child receives. Some plans provide

## **Advocacy Tip**

Incomplete records are the primary factor when insurers refuse to pay for a service. Remember to keep copies of all correspondence!

"better coverage" of a particular service, such as hospitalization, which means these plans pay a larger share of the costs of that service or pay for more days of treatment. Others may limit your choice of health care providers for your child (as discussed in the next chapter).

When choosing a plan, you will want to find the one that best fits your child's health needs. Be sure to learn the following details about the plan:

- which mental health and medical health services are covered
- whether your choice of providers is limited
- what your personal costs are likely to be for your child's services
- whether you can change to a different plan easily if you need to

There are several ways to learn about these details. You can:

- review the plan's written summary of benefits, which will explain what services are covered and what providers you can use
- discuss the plan with a staff member from your employer's human resources office
- talk to the provider(s) you prefer to find out which plans they participate in and/or which plans they think are better

## Insurance through a public program

Public insurance programs can provide assistance if you are unable to get private insurance through an employer or if you are unable to afford the employer-provided health insurance on your own. In order to receive assistance from a public program, you and/or your family must meet the specific eligibility requirements of that program.

Some public programs can serve as a supplement to private insurance. A program like MassHealth CommonHealth in Massachusetts can provide health benefits to families who have a disabled child. CommonHealth can serve as a backup (or "wrap-around") insurer if your private insurance doesn't pay for all needed mental health services.

A public insurance program may be a Primary Care Clinician (PCC) plan (similar to a private Primary Care Physician plan) or a Health Maintenance Organization (HMO) plan.

## **Advocacy Tip**

A mental health care advocate can help you sort out insurance details, select a plan, or locate an agency that will work with your child. See the Resource list at the back of this Guide.

#### Applying for a public insurance program

To apply for most public insurance programs in Massachusetts, you will need to fill out a Medical Benefit Request (MBR) form. The majority of the programs that apply to children are MassHealth plans. To participate in MassHealth, your child must qualify for assistance based on your family's income or on your child's disability. In Massachusetts, one out of every four children are covered by MassHealth.

The MBR form can be downloaded from the MassHealth website and is also available by calling a MassHealth Enrollment Center. Many health care providers have the forms and might help you fill out and submit your MBR form. A health care advocate can help, too. The state also encourages people to submit applications online.

## **Advocacy Tip**

When filling out a complicated form seeking assistance, getting someone to help you fill it out is much better than leaving some sections blank. Incomplete forms can cause delays.

#### When to define a child as "disabled"

The words "disabled" and "disability" may sound very negative to you. In fact, your child may not appear disabled and/or may not be disabled in your opinion. It is possible that he or she will nevertheless meet the standards for "disabled" as described by the laws that govern public health care programs in Massachusetts.

Note that your child's eligibility is based on his or her mental health disability or any other kind of disability (regardless of his or her mental health).

You may have concerns about your child being labeled "disabled." However, be sure to keep in mind that your child may fit the legal definition of "disabled" and may therefore be eligible for special services. As information

about disabilities becomes more widespread, more people with temporary or permanent disabilities are gaining recognition and learning about their rights.

After you have sent in your MassHealth MBR form (described above), the question of whether or not your child has a disability will be decided by MassHealth. All of the medical and non-medical information that you send will be reviewed.

## Types of public programs

After you send in your MBR form, it will be reviewed to see if you and your child are eligible for a MassHealth plan based on your family's income or on your child's disability.

Each MassHealth plan has its own eligibility rules. If you are eligible for one of these plans, the MassHealth administrators will place you in the plan that will give you and your family the most benefits based on the information you have provided. You will receive notification telling you which plan you and your child are eligible for, and how much of a premium (if any) you will pay. Once you have enrolled in a MassHealth plan, you and/or your child will receive a MassHealth card. If you are paying a premium, you will be billed monthly.

## **Advocacy Tip**

If you can't afford private health insurance but you think you don't qualify for a public program, don't give up! Eligibility is complicated, and your family may be eligible in ways you haven't considered.

If you and your child qualify for a MassHealth plan, the plan will either pay your health care providers directly or will pay part or all of your insurance premiums (if you have or can get private insurance). If you and your family are not eligible for a MassHealth plan, your MBR form will then be reviewed by the Office of Medicaid to determine if your child is eligible for services under the Children's Medical Security Plan (CMSP).

## **Advocacy Tip**

It's important to remember that if your child has any private insurance coverage. that insurance must be used before MassHealth coverage is used.

MassHealth is broken down into several different types of health insurance plans. The MassHealth plans and other public programs that children are eligible for are described below.

#### MassHealth Standard

This plan offers the most comprehensive set of MassHealth benefits, including inpatient and outpatient hospital services, medical services, and mental health and substance abuse services. It is available as a PCC plan, an HMO plan, or a Fee-for-Service plan. A child in a low-income family may qualify for this plan if he or she meets any one of the following conditions:

- is under the age of 19
- is in foster care
- is receiving Supplemental Security Income (SSI) due to a disability
- is a disabled adult child, at least age 18, who was formerly receiving SSI

#### MassHealth Family Assistance

This plan—also known as the "Children's Health Insurance Program"—covers low-income families whose level of income makes them ineligible for the MassHealth Standard plan. There is no disability requirement for this plan. Instead, your child may qualify for this plan in one of two ways:

## **Advocacy Tip**

Be sure to check with your child's doctors to make sure they are MassHealth providers. MassHealth only pays health care providers who participate in the program.

- If you are unable to get insurance from your employer, MassHealth Family Assistance provides direct benefit coverage for your child. You may be required to join a managed care plan.
- If you are paying private health insurance premiums to an employer-sponsored plan, Family Assistance will help pay for part of those premiums and will also pay some co-payments and deductibles for your child's well-baby and well-child visits

#### MassHealth CommonHealth

If your child is under the age of 19 and has a disability, and if your family income is high enough to make you ineligible for MassHealth Standard, your child may be able to enroll in this plan. There is no upper income limit for CommonHealth. People enrolled in CommonHealth pay a relatively low

monthly premium for services, and the premium is calculated on a sliding scale according to your income and

> the size of your family. This plan's benefits are similar to the benefits you and your child would receive under MassHealth Standard.

## **Advocacy Tip**

In the CommonHealth application process, you will receive a standard denial notice for the non-disabled members of your family. Only the second notice—the CommonHealth Decision Notice—applies to your child who may be disabled.

#### The Children's Medical Security Plan (CMSP)

Any child age 19 or younger who lives in Massachusetts is eligible for coverage under the Children's Medical Security Plan (CMSP) if he or she is currently uninsured for primary or preventive health care and is not eligible for MassHealth primary or preventive health care coverage. There are no citizenship or immigration rules for this program.

Each family with CMSP coverage pays a monthly health insurance premium that is based on the family's size and household income. For each visit to a provider, you will also pay a co-payment of less than \$10.00, depending on your family's size and income. Mental health care services covered by CMSP include outpatient services (up to 20 visits per year), substance abuse services, and medication.

#### Medical Security Plan (MSP)

This plan is available to individuals and families who are eligible for unemployment compensation benefits. When the Division of Employment and Training (DET) sends out an unemployment benefits package, this mailing will include information about MSP. If you have received a DET mailing about unemployment benefits, be sure not to overlook the MSP information and application.

MSP offers two health care options. It can help you pay private health insurance premiums if you are continuing to receive benefits under the Consolidated Omnibus Budget Reconciliation Act (COBRA) after a job loss. It can also cover health care costs for you and your child directly by providing a series of benefits for you and your family.

## **Advocacy Tip**

Be careful not to downplay your child's condition when explaining it in person or describing it on a form. Being open about his or her worst days is a better way to get the services your child needs.

#### Additional assistance

Paying for a child's mental health services can often place an extra burden on the family's financial situation. The programs listed below can help ease that burden. Your child may be eligible for one or more of these programs:

- Supplemental Security Income (SSI) due to a disability
- Emergency Aid to Elders, Disabled & Children (EAEDC), which is administered by the Division of Transitional Assistance and covers children who live with someone who is not a relative
- Temporary Assistance for Needy Families (TANF), a short-term program that covers children who live with a relative
- Food stamps

## **Advocacy Tip**

Always take extra care when reading or trying to interpret any notice from a public or private agency. If something isn't clear to you, get some help to be sure you understand the notice!

# Summary and things to remember

This chapter is designed to provide you with some very basic information about the ways you can pay for (or get help paying for) your child's mental health care services with an insurance plan or program. Insurance plans and programs—whether they are offered through a private insurer or through the state—are complicated, and you may find that it is challenging to get all of the services your child needs.

In fact, most people at one time or another find themselves trying to deal with an insurance plan or program—private or public—that does not cover or refuses to pay for the mental health services a child needs. Chapter 4 will explore insurance in greater depth, to explain how most insurance companies go about providing mental health services and how to appeal an insurance company's refusal to provide those services.

The most helpful thing you can do for you and your child whenever you become a member of an insurance plan or program is this: Get as much information as you can about your plan, including information about the services it covers, how it handles mental health benefits, and the procedures you should follow to get benefits and to appeal a denial of care. An insurance plan will only work well for you and your child if you understand what benefits it provides and how you can get the most out of them.

chapter four

## Navigating mental health networks

#### **Overview**

f your child needs mental health services, you can probably get these services as long as you can pay for them. But mental health services are very expensive—which means the more important question is whether you can get help paying for them.

Having insurance is only the first step toward getting services and getting assistance paying for services. As discussed in Chapter 3, there are a variety of different private insurance plans and public programs that can help you pay for your child's mental health services. To get the best possible coverage for these services, you will need to be very familiar with your plan's benefits and procedures, and you may have to overcome some obstacles along the way.

Most insurance plans limit your choice of health care providers by covering more (or all) of the costs of care from certain providers while covering less (or none) of the costs of care from other providers. For example, if you and your child get your health care services through a Health Maintenance Organization (HMO), the HMO will only pay for services provided by the specific care providers who participate in the HMO's "provider network."

A plan's provider network is made up of the health care professionals who have agreed to participate in the network and who will accept payment from that plan. In most cases, the plan's payment rates are low, which means only a limited number of providers are willing to participate. You are not required to bring your child to a provider who is in the network. However, in the case of some HMO's, if you choose to have your child visit an out-of-network provider, your child's health care costs may not be covered at all and you may have to pay all of the costs out of your own funds.

The provider network arrangement varies from plan to plan and is not always as simple as it is with an HMO plan. For example, a Preferred Provider Organization (PPO) plan also has a network of providers. This network may not be as large as an HMO plan's network, but PPO plans are generally less strict about out-of-network coverage. If your child receives health care from an out-of-network provider, you will have to pay more personally (out of pocket) for this care, but the PPO plan will pay at least part of the costs.

When it comes to mental health care in particular, many insurance plans complicate the situation further by hiring a second company to manage the mental health and substance abuse services offered by the plan. Your plan's network of mental health providers will be listed in your plan's provider directory and/or in a mental health provider directory available from this second company.

This chapter will provide you with some fundamental information about how to navigate a mental health provider network, obtain services for your child from an appropriate provider, and obtain payment for services. You will also find information in this chapter about how to fight back against (or "appeal") an insurance plan's decision not to pay for your child's services.

## **Advocacy Tip**

The insurance plan's summary plan description (SPD) is a crucial source of

information—so crucial, in fact, that you

**Getting** coverage for mental health services

## The summary of your plan's benefits

are entitled by law to receive it. A plan No matter which kind of plan you have, it can be fined if it doesn't make its SPD is a good idea to contact the plan directly available upon request. (or your employer's human resources office, if they have the information about your plan) to ask about the mental health benefits that are provided. You are entitled to a written summary of all the benefits provided by your plan. This summary will also explain how to get services (including services from an outof-network provider, if allowed by the plan) and how to file a grievance.

Be sure to carefully review the summary of benefits, also known as a "summary plan description" (SPD). Different plans offer different types of mental health benefits, and some plans pay for more services than others. Some plans may also pay more of the costs for services from out-of-network providers or may have smaller yearly deductibles. If you are familiar with the benefits your plan offers, you will be able to make better choices when you are trying to get services for your child.

#### Subcontracted mental health services

Some health insurance plans contract directly with mental health and substance abuse providers to furnish services directly. However, as mentioned earlier in this chapter, many private insurers in Massachusetts hire a second company to manage their mental health and substance abuse services. This process is often referred to as "carving out" services. The company handling the carved-out mental health and substance abuse services usually provides

these services through a separate network of licensed mental and behavioral health specialists.

In Massachusetts, some public insurance programs carve out mental health and substance abuse services, too. The management of these services is usually provided by an organization called the Massachusetts Behavioral Health Partnership (MBHP or "the Partnership"). The Partnership has its own network of mental health care and substance abuse care providers.

## **Advocacy Tip**

Finding a provider who participates in the MassHealth network can be very difficult!

The mental health care carve-out company manages care and handles claims for the primary insurance company—for a price. You may run into several problems when dealing with a carve-out company. For example, if the carve-out company denies benefits, it can be difficult to get the primary company to address this problem and take responsibility for it. Also, many carve-out companies are large and operate in several different states. When you call the carve-out company, your call may be answered at a large call center that isn't in Massachusetts—and the medical specialist who is supposed to answer your question or help you determine coverage may not know very much about the availability of health care services in your area.

In general, carve-out companies are more difficult to deal with than the primary insurance company and some have a reputation for denying claims. Many carve-out companies earn more money if they can justify denying more claims.

## **Advocacy Tip**

If you have a complaint or concern regarding your insurance plan, be sure to put it in writing—and keep a record of all correspondence.

#### The mental health network

If your insurance plan and/or carve-out company offers mental health and substance abuse benefits through a network of health care pro-

viders, this network determines how and where you will get the most coverage for your child's services. Generally, you can expect full coverage for mental health services that are included in the insurance plan and provided by a health care professional who is in the plan's mental health provider network. This is usually the easiest and least expensive way to obtain mental health services for your child.

If you are interested in getting services from a particular health care professional who is not a member of the plan's network, you will want to consider the following two questions:

- Does your plan provide any coverage for the particular service you want if the provider is not in the plan's network?
- If the plan does provide coverage for the service even with an out-of-network provider, how much coverage is provided and how much will you have to pay out of your own pocket?

Note that—regardless of whether you are seeking help for your child from an in-network provider or an out-of-network one—you will need to follow the plan's instructions about contacting a mental health provider, as discussed in the next section.

#### Prior approval and referrals

In addition to its rules about which mental health services are covered and whether services from an out-of-network provider are covered, an insurance plan also has procedures you should follow when trying to get mental health services for your child.

## **Advocacy Tip**

The providers participating in your plan's network will all be listed in your plan's provider directory. However, some providers in the directory will be unavailable because they aren't taking any new patients.

For example, when you want your child to receive a particular service in a non-emergency situation, you may need to get prior approval of that service from a primary care physician or from the carve-out company itself. Otherwise, your plan might not cover the cost of that service. In some cases, the plan requires you to get a referral to a particular provider from your child's pediatrician or primary care physician.

Note that the primary care physician's prior approval or referral must be formal and in writing. Usually, the doctor signs a form and then faxes or emails it to the insurance plan. If your primary care physician only gives you verbal approval of a service, this is not an official approval or referral, and your insurance plan will be free to disregard it. Be sure to ask your doctor to send the referral or prior approval in writing to the insurance company.

It is important to remember that some plans require prior approval or a referral even if you are bringing your child to a mental health care provider who is a member of the plan's provider network.

## **Problems** you might encounter

#### The "adequate access" problem

There are several types of problems that can occur when you are trying to get (or are getting) mental health services for your child under your particular insurance plan. First, you may have difficulty finding a provider for the particular service your child needs, even though your insurance plan covers the service. For example, there may be no providers of this service in your community or there may be too few of them, in which case you will be told that there is a long wait for services.

This is an "adequate access" problem. Most private insurance plans are required by law to make sure that you and your child have adequate access to mental health services (whether or not the services are managed by a carveout company). This adequate access requirement is only satisfied if the insurance plan meets these conditions:

- Its network of health care providers has all of the different provider types required by Massachusetts law
- The network providers offer the full range of mental health services required by the law (including specific treatments that are appropriate for children of different ages and with different kinds of conditions)
- The network has enough providers so that no patient has to wait an unreasonably long amount of time to get treatment for a severe condition
- Mental health care is delivered promptly and appropriately

## **Advocacy Tip**

Some insurance plans have very different procedures for dealing with in-network providers versus out-ofnetwork providers, especially in terms of prior approval. Learn about these procedures and follow them with care!

If you believe your insurance company is not meeting its legal obligation to provide adequate access to services, you can try to resolve the problem in one of the following ways:

- Ask the insurance company to provide you with a list of available providers
- Look for another type of mental health provider within the network who might provide the service your child needs
- Ask the insurance company to approve and pay for services from a mental health provider who is available but who is not in the network
- Switch to a different insurance plan
- File a complaint with the Massachusetts Division of Insurance (DOI)
- If all else fails: consult with a lawyer who is knowledgeable about mental health advocacy

## **Advocacy Tip**

If your plan refuses to cover a service, you are entitled to know why, and the plan should provide a detailed explanation.

Adequate access can come up as a problem when you have insurance through a public program as well. However, the standards for adequate access in the public sector are complex, and this makes them difficult to enforce. Be sure to get a list of available providers and explore your alternatives as much as you can. Unfortunately, litigation is often required in this situation.

#### Denial of eligibility for a public program

If you have filed a MassHealth Medical Benefit Request (MBR) form and if you have been notified that you are not eligible for any MassHealth or other public program, you can appeal this decision through the Fair Hearing Appeals

process. The best way to request a hearing is to fax your request to the Board of Hearings at the Office of Medicaid.

#### Denial of service

Another problem you might encounter is a "denial of service" or "denial of benefits," where the insurance plan tells you that a mental health service that your child needs is not covered and/or the plan refuses to pay for this service. If your child is denied benefits, you have the right to appeal the insurance plan's decision. Both public and private insurance plans are required by law to have a grievance or appeal process. The appeal process (and the rights you have) will vary depending on how the insurance plan is structured.

You may be able to obtain free legal help when appealing a denial of benefits. The list of legal resources at the end of this Guide may help you find free legal services in your area.

## **Advocacy Tip**

If you receive a bill charging you for services you believe are covered by your plan, be sure to check in with your plan. The bill may simply be a mistake or a copy for your records—not a denial of services.

The insurance plan is required to provide you with a written description of the appeals process and a phone number you can call for assistance. It is important to call the insurance plan and/or visit your employer's human resources department to get as much information as you can about the specific appeals process.

# Appealing a denial by a private insurance plan

In general, if you want to appeal a denial of service by a private insurance plan, the following guidelines will apply:

## **Advocacy Tip**

Insurance plans frequently base denials of payment on the claim that the services provided to a child are not "medically necessary."

- You will file a formal written complaint or "grievance" with the insurance plan, using its internal grievance procedure.
- A private insurance plan must acknowledge your grievance in writing within 15 days and resolve it within 30 days, also in writing. If your child needs urgent medical care and/or the situation is an emergency, the insurance plan must resolve the grievance much more quickly.
- If you go through the insurance plan's internal grievance procedure and your child is still denied benefits, you may request a review of the insurance plan's decision by the Department of Public Health's Office of Patient Protection (OPP).

Note that if your private insurance is a "self-insured" plan (which means your employer—usually a large company—pays directly for your health care services), then your right to appeal a denial of benefits is limited. The OPP process mentioned above will not be available to you. A self-insured plan is required to provide a grievance procedure, but your right to appeal under this type of plan is governed exclusively by federal law. For more information about self-insured plans, contact the

Employee Benefits Security Administration of the U.S. Department of Labor.

## **Advocacy Tip**

Only your insurance plan and not a provider has the authority to deny coverage.

#### Appealing a denial by a public program

In general, if you want to appeal a denial of benefits by a MassHealth plan, or a decision by the Office of Medicaid that you are required to enroll in a Managed Care Organization (MCO), the following guidelines will apply:

#### For an MCO grievance

- You must file an "internal grievance" with the plan within 30 days of the denial of benefits.
- If your child is receiving services and you file your grievance within 10 days of the denial, your child may continue receiving those services until the grievance is decided.
- If your child is receiving emergency services and has not been discharged yet, you can ask for an expedited grievance decision that will be handed down in 60 minutes (one hour).
- You can also ask for the 60-minute expedited decision if your child's life or health might be seriously endangered by a delay in the grievance procedure.
- Usually, outpatient grievances are decided within 5 business days. All other grievances are usually decided within 2 business days.

Note that your MCO can ask your health care provider for information relating to your appeal. If this request for information is made, the deadline for the decision about your appeal will be measured from the time when the MCO receives this information.

## **Advocacy Tip**

Make sure that your child's doctor will stand up for him or her if the insurance plan claims that services were not "medically necessary." The doctor's support is essential to challenge the denial of benefits.

#### For a PCC plan/Partnership grievance

- You can try calling and discussing your complaint with a Partnership staff member. If the complaint is not resolved, you can send a written grievance to the Partnership.
- The Partnership's Quality Management Department will review and resolve the grievance within 15 days and will send you a letter explaining how the Partnership will respond to your grievance.
- If you are not satisfied with the Quality Management Department's decision, you may appeal that decision by filing a written appeal (or by calling in and appealing by telephone) within 30 days of the date on the Quality Management Department's letter.
- If you are appealing a change in the services your child is already receiving, you must file your appeal (in writing or by telephone) within 10 days of the date on the letter in order to avoid an interruption of services.

#### Appealing a public program's final decision

If you file an internal appeal for a denial of benefits and the appeal is decided against you, you will receive a notice of denial containing specific information about why the request was denied. If you want to appeal further, you may request an appeal with the Office of Medicaid Board of Hearings.

## **Advocacy Tip**

The appeal process—although challenging—can lead to a positive result. For example, by clarifying the situation for your insurance plan, you may discover that additional coverage is available.

If you feel that your plan is not providing a service that your child needs, asking for that service in writing will improve the chances that the plan will honor your request.

- You will need to file a request in writing within 30 days of the date on the denial notice.
- If you are appealing a change in the services your child is already receiving, you must file your appeal within 10 days of the date on the denial notice in order to avoid an interruption of services.
- When filing an appeal, it will be helpful to the Board of Hearings if you attach a copy of the denial notice you received.

Statemandated benefits for children

#### The Mental Health Parity Law

Some private insurance plans—including most plans provided by employers are governed by the Mental Health Parity Law. Under this law, an insurer is required to provide children who have substantial functional impairments or biologically-based mental health conditions (such as bipolar disorder or schizophrenia) with certain "medically necessary" health care benefits. If you and your child have been denied benefits, you may want to call a health law attorney to find out whether the Mental Health Parity Law might help you.

#### Additional benefits

You and your child have a right to all of the specific services covered by your insurance company. Your insurance plan is a contract between you and the insurance company, and—under this contract—you have paid for the services and are entitled to receive them. A law known as the HMO Reform Act of 2000 also ensures that you and your child can receive the following benefits:

- **Emergency services:** If your child is experiencing a mental health emergency and you seek emergency services for him or her, your insurer or HMO must pay for these services. Generally, this is true even if the services are not pre-authorized and even if they are provided by a non-network provider.
- Continued coverage of disabled adult children: If you have private family coverage, your disabled child may be eligible to remain on your plan as an adult and receive payments after the insurance coverage would normally terminate for children.
- Provider is not a member of new plan: If your child has been seeing a mental health care provider, and you switch to an insured health plan with a network of providers that doesn't include your child's provider, your insurance plan will continue to pay for your child to see the old provider for up to 30 days. The provider must agree to comply with the terms of your new insurance plan.
- Referral for ongoing care: Many insurance plans require you to get a referral for specialist care (which includes virtually all mental health services) from your child's primary care provider. If your child is covered by an insured plan and has a mental health condition that requires ongoing care, the primary care provider may make a single "standing referral" (instead of providing a separate referral for each service) that allows you to receive payments for ongoing care from a participating mental health specialist.

Don't rely on information you get over the phone from your plan—unless you can get written confirmation. The information your plan provides in writing is the only information you can count on.

## Summary and things to remember

Sometimes, dealing with health insurance can be time-consuming, frustrating, and even infuriating. The health care system in our country is far from perfect—but on the other hand, insurance plans do help people obtain and pay for the health services their families need. If your child needs mental health care, having health insurance will probably—in the long run—be worth all of your effort and frustration.

It is important to keep in mind that health insurance plans are complicated organizations, and most of them employ people who have a genuine interest in helping you sort through the complications. You might find that your plan's employees are the key to understanding the plan's benefits, procedures, and method of handling mental health services.

However, it is equally important to remember that sometimes you need to have an ally on your side when dealing with an organization as complicated as a health insurance plan. The list of resources in the back of this guide can help you locate a mental health advocate in your area.

As mentioned in Chapter 2, there are some mental health care services that will be provided to your child without cost regardless of whether you and your child are covered by an insurance plan. These services are designed for very specific situations and will have some limitations. In the next chapter, you will find information about one of these specific situations: the mental health services that can be provided to your child by his or her school.

# Services in your child's school

#### **Overview**

hen you are seeking mental health services for your child, it is important to investigate every resource. As discussed in Chapter 3, these resources include your own private insurance and insurance plans offered by the government. The government offers another kind of resource as well: direct services, which are provided directly to you by the state through the public school system or state agencies. Generally, direct services are low-cost or free of charge and are available regardless of your insurance coverage if you and/or your child meet the program's eligibility requirements.

Local school districts, overseen by the Massachusetts Department of Education, play a central role in the provision of direct mental health services to families with children. This is because most children spend much of their time in school, where teachers and administrators are able to observe any learning or social problems that might be developing. As mentioned in Chapter 2, the school is equipped to provide feedback and information about your child's development. The school will have a nurse on staff, and most schools also have a school counselor, social worker, and/or psychologist. Generally, these health care professionals are trained to provide limited mental health services to the students.

The school is also required to provide special services for children with disabilities who would otherwise be unable to make progress in their

education. These services include special education services and services that are provided under Section 504 of the Rehabilitation Act (often referred to as "Section 504 services").

Although people sometimes assume that special education and Section 504 services are only for students who have physical, learning, and/or developmental disabilities, these services are also available to students with serious emotional problems and/or mental

health issues—conditions that can interfere with the learning process. However, it is important to keep in mind that a child with emotional problems is not necessarily considered disabled. In order to receive services designed for children with disabilities, he or she must meet the eligibility requirements spelled out by the laws.

This chapter will give you an overview of the mental health services that may be available at your child's school. You will also find information about eligibility rules that will help you decide whether your child's mental health concerns are serious enough to qualify him or her for these services.

Most children in Massachusetts attend public schools (including charter schools), and the information in this chapter is primarily about public schools.

## **Advocacy Tip**

It may be helpful to know that schools must provide educational services to any child who is hospitalized or who has to stay at home for a period of 14 school days or more.

If your child is very young (birth to age 3), you might be interested in the Early Intervention programs provided by the Department of Public Health (see Chapter 6).

If your child attends a private school, some of the rules discussed below may be slightly different at your child's school.

#### Services and eligibility

#### 1. Basic mental health care

As mentioned above, your child's school will have a designated mental health care professional on staff and/or on call. In a few cases, schools have a fulltime or part-time counselor, social worker, or psychologist in residence. These professionals are responsible for psychological testing in the schools. On occasion, they may also provide some limited short-term mental health care, such as one-on-one counseling or group counseling, for students in the school. They can also assist in emergency situations. If you believe your child could benefit from meeting with the school's mental health care professional. consider contacting the school to discuss the services that are available.

Basic mental health services in schools are available to students regardless of eligibility for special education or Section 504 services. Your child can get these services without following a specific process or plan. However, it is important to keep in mind that the mental health services available in schools can vary a great deal from school district to school district.

## 2. Special Education

#### Overview

Your child's public school system is governed by state and federal laws that require it to provide a "free appropriate public education" (FAPE) to students

Even if your child is enrolled in a private school, he or she (if disabled) is eligible to receive special education services from the public school system.

with disabilities. Special education services are designed to make this possible. The school is responsible for either providing or funding the special education services that its students need.

#### **Eligibility**

In order to be eligible for special education services, your child must be between the ages of 3 and 22 and must not have graduated from high school yet. He or she must also have a disability that significantly affects his or her ability to make progress in school and/or form good social relationships.

Eligibility is determined through a three-part test:

- Does your child have a disability?
- Does the disability prevent your child from making effective progress in his or her regular classes?
- Does your child require specialized services in order to benefit from the curriculum that is taught in the school?

According to the definition of "disability" in the laws governing your child's school, a child with an "an emotional impairment" may be disabled by an emotional and/or mental health problem if the condition is serious enough to meet these standards:

- The condition has been or will be present for a long period of time
- The condition is having or will have a serious negative effect on your child's performance in school

Additionally, at least one of the following must also be true:

- Your child is having trouble learning, and there is no other explanation for this difficulty
- Your child is unable to build or maintain good relationships with his or her classmates and teachers
- Your child's behavior and/or emotional response is often inappropriate
- Your child is generally depressed or unhappy
- Your child often develops physical symptoms and fears that are associated with problems at school and/or with other people

#### Requesting an evaluation

If you believe that your child may be disabled by a mental health condition, as described above, you may request that the school system evaluate your child to determine whether he or she is eligible for special education services. Your child's teacher or another professional (such as a pediatrician) may also make this request. Regardless of who

requests the evaluation, you will have to consent to it in writing before the evaluation can take place.

## **Advocacy Tip**

You may be able to get information about a school district's compliance with special education regulations through the Department of Education's Program Quality Assurance Services (PQA).

Once you request an evaluation, the school is required to perform it. The evaluation is carried out by mental health care professionals working with your child's school. It consists of a series of tests that will help these professionals learn about your child's abilities, behavior, and day-to-day functioning. Your

child's education history, medical history, and history of social and emotional development will also be reviewed.

This evaluation is supposed to take place within 30 school days of the day you gave your written consent. You may find that you need to encourage the school to pay attention to its deadlines.

#### The Individualized Education Plan (IEP)

Within 45 school days of the day you consented to the evaluation, the school is supposed to arrange a meeting with you, your child's teacher(s), and any other service providers who may be involved. Note that you can ask to receive a copy of your child's test results two days before this meeting, and the school should follow through with your request.

At the meeting, you will all discuss the results of the evaluation and reach a decision about whether your child is eligible for special education services. If—as a group—you determine that your child is eligible to receive special education services, you will all work together to create an Individualized Education Plan (IEP). This group of people then becomes your child's IEP team. If your child is 14 years old or older, he or she may also be a member of the IEP team.

However, being present at the meetings can make a child feel anxious, so you should consider the pros and cons before inviting your child to join the team

## **Advocacy Tip**

Experience shows that a school may resist paying for services as a child's needs intensify. Learning when to persist with the school—and when to back off—may help you get the services your child needs.

After discussing services and deciding which services your child needs, the IEP team will then discuss where your child will be placed to receive these services. In general, your child's school is required to provide special education services in the "least restrictive environment" (LRE), which

## **Advocacy Tip**

The goals and benchmarks described in your child's IEP should be very clear, concrete, and well-defined. You should be able to recognize when your child is making progress.

means that your child will spend as much time as possible learning in regular education classes with his or her classmates. If possible, the school will give your child the services he or she needs within the school setting. However, depending on the situation, the school may need to find a placement for your child in a private or residential school setting.

The IEP for your child must be completed within 45 days of the day you consented to the evaluation. In most cases, you will leave the meeting with an IEP in hand. If the actual plan is not completed at the meeting, the school should provide you with a written summary of the meeting's proceedings. You should then receive the IEP within three days of the meeting.

After the IEP is completed, you have up to 30 school days to consent to both the IEP and the placement that has been recommended for your child.

## Special education services

Public school systems are required to provide—or fund—the services and assistance a child needs to be successful in a regular education setting. These services may include:

- educational services, including residential services
- technologies to help disabled students
- counseling for students and/or their families
- transition services for students moving from one level of services to another level of services
- consultation services
- behavioral support
- home-based services
- after-school services
- summer services

Sometimes a child who has problems in school needs to be placed in a residential educational setting away from home. The school district is a major source of funding for children in residential settings, and a special educa-

tion program may be the right solution for a child whose difficulties are caused by a serious emotional and/or mental disability. However, keep in mind that the school district is only required to provide mental health services to children who demonstrate a related educational need.

The IEP team will identify the specific services your child needs and will create a list of these services to include in the IEP. In addition, the IEP team will discuss the hopes and dreams you and your child have for the future and will outline goals for your child to meet. These goals are also included in the IEP. Your child's school will measure his or her progress toward these goals, and will provide you with written progress reports.

## **Advocacy Tip**

Dealing with special education can be very stressful for parents, particularly when the school system drags its feet. Seek help! It's not easy to be both parent and advocate.

It's important to schedule next year's IEP meeting before leaving this year's meeting! Otherwise, you may have trouble finding a time when all team members can meet.

At least once a year, your child's IEP team will sit down together and review the IEP, making any changes that are necessary. Every three years, the school will conduct a re-evaluation of your child.

## Discipline by the school

If your child is eligible for special education and/or if your child's school is aware that he or she has a disability, there are limits to the school's ability to suspend or exclude your child from school. If the school wants to exclude your child for more than 10 days, the school must raise this question with your child's IEP team. The team must then decide whether your child's behavior is a result of a disability. If it is, then your child cannot be excluded from school unless you agree to the arrangement (or unless the situation is one involving a weapon or drugs). If your child's behavior is not a result of a disability, the school can exclude him or her for more than 10 days.

In addition, if your child is receiving services and is excluded from school for more than 10 days, the school district must continue to provide the services.

> The services may be provided in an alternative setting, such as an alternative school program or an at-home tutoring program.

## **Advocacy Tip**

Do your best to communicate with your child's school often (and document the communication). You can play a vital role in keeping the school informed and aware of your child's needs.

#### Resolving disagreements or disputes

When you are seeking special education services for your child, or when the school is providing these services, there are a number of problems that might come up. For example, you and your child's school may get into a dispute because you disagree about:

- the amount of time it takes for the school to respond to your request for an evaluation and/or complete other tasks
- the eligibility determination process or decision
- your child's IEP (part of it, or all of it)
- the way services are being delivered to your child
- any disciplinary actions being taken against your child
- any other matter relating to the education and/or placement of your child

Whenever you are able to solve a problem by sitting down with people from your child's school and/or school district and talking about it, this is probably

the easiest and least complicated solution. However, you have other options for resolving disagreements with your child's school.

## **Advocacy Tip**

You are almost always better off trying to work things out with your child's school informally before going forward with a formal procedure. Formal procedures are time-consuming and may be viewed negatively by the school.

#### Independent Educational Evaluation

If your child's school has completed an evaluation for special education services, and if you disagree with the school's results, you can request an Independent Educational Evaluation (IEE). You can pay for the IEE yourself or through private insurance, or you can ask the school to provide some or all of the funding. At this point, the school may request financial information from you, and may use a sliding scale to determine how much of the IEE costs will be paid by the school and how much will be paid by you.

#### The Bureau of Special Education Appeals

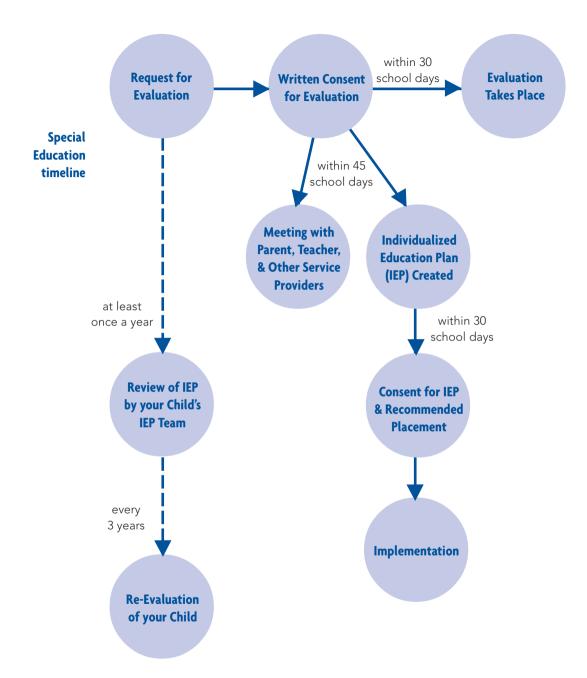
If you get into a dispute with your child's school, the Bureau of Special Education Appeals (BSEA) has the authority to hear the arguments and resolve the dispute. The BSEA will first offer you a chance to participate in a mediation process with the school. This is a less formal procedure that is worth considering if you are interesting in avoiding formal legal proceedings.

However, you can choose instead to take your dispute before the BSEA in a formal legal proceeding. Your child has the right to stay in his or her educational placement until the legal proceedings have come to an end.

## **Advocacy Tip**

Some school districts have developed procedures for resolving special education disputes at a local level. However, there are times when formal proceedings are unavoidable.

Because BSEA hearings are formal and usually require witnesses and documentation, the hearings often last for several days. Questions about rules and procedures are usually raised. You can choose to represent your child on your own at a BSEA hearing. However, families that have assistance from either a lawyer or an advocate generally fare much better in this process. See the Special Education timeline on the next page for more information.



#### 3. Section 504

#### Overview

Some students with disabilities are able to succeed in school without special education, as long as the school provides them with the support services they need. Under a law known as Section 504 (part of the Rehabilitation Act of 1973), schools are required to make the adjustments that are necessary to help these students learn.

#### Eligibility

Under Section 504, some students—including students with mental and/or emotional disabilities—who may not be eligible for special education can still get special assistance. For example, if a child who is hard of hearing wants to tape record a class, her school may have to consider allowing her to tape record the class even if it has a policy it. Similarly, a child who is challenged by emotional and/or mental health issues might need to take medication during school or might need to be given an opportunity to use other self-calming techniques during school. If the school does not try to accommodate a student in one of these situations, its actions may amount to discrimination against a person with disabilities. Section 504 protects against this kind of discrimination in education.

Any child who is eligible for special education services will also be protected under Section 504, but it is important to know that Section 504 covers a broader range of disabled students than the special education laws cover.

In order for your child to receive services under Section 504 in school, the following statements must be true:

- Your child has (or has a history of) a physical or mental impairment
- The impairment interferes with your child's learning in a significant way
- The school can help with this learning problem by making reasonable accommodations (such as allowing a student to tape record classes, in the previous example)

#### Requesting an evaluation

If you request a Section 504 evaluation and/or someone in your child's school requests one, the school may conduct an evaluation to see if your child meets the qualifications stated above. The school is not required to conduct this evaluation, but it is required to give you its reasons if it turns down your request.

The school must obtain your consent before performing a Section 504 evaluation of your child.

## **Advocacy Tip**

For help understanding the complications of special education and Section 504. try the Massachusetts Department of Education's excellent parents' guide on these topics (available on the DOE website).

#### Services provided under Section 504

As it does for students eligible for special education services, the school will put together a team of people—including you—that will decide whether your child is eligible for Section 504 services. If he or she is eligible, the team will then create a written plan that details which services are necessary (and/or if a

To find people who can provide advocacy assistance, contact the Federation for Children with Special Needs (FCSN) and ask about the Special Education Advocacy Network. (See the Resource list at the

specialized education placement is necessary) to help your child succeed in school.

This written plan is called a Section 504 back of this Guide.) Plan. Unlike the Special Education IEP, this plan does not have to follow the specified IEP format. However, the team developing the plan can use an IEP format if the team determines that this is in the child's best interests.

The school is required to offer Section 504 students a full range of services, which means it will provide or fund the services that are necessary for a Section 504 student to receive his or her "free appropriate public education" (FAPE) in the "least restrictive environment" (LRE). The services your child receives will depend on his or her particular needs.

Unlike what is required for special education, the school does not have to re-evaluate your child every three years. However, the school does have to perform re-evaluations on a regular basis and must reevaluate your child before making any significant changes to the services your child receives and/or to his or her placement.

## **Advocacy Tip**

Whenever your child's school commits to providing help for your child, be sure to write a letter of confirmation to the school. This letter may be useful if disagreements arise.

#### Resolving disagreements or disputes

#### Independent evaluations

Under Section 504, you do not have the right to seek funding from your child's school to help pay for an independent evaluation. You can still get an independent evaluation for your child if you are prepared to pay for it yourself or through private insurance.

#### The Bureau of Special Education

If you have a dispute with your child's school regarding the provision of a "free appropriate public education" under Section 504, the Bureau of Special Education has the authority to resolve this dispute.

#### 4. School-Based Health Centers

## Overview and eligibility

School-Based Health Centers (SBHCs) are located onsite at a limited number of elementary, middle, and high schools across the state. These Centers provide primary health care—including mental and behavioral health care—to school-aged children. SBHC staff are trained to recognize the warning signs of mental illness and are able to help parents find the appropriate services for their children. SBHC staff also work to educate school staff and administrators about child mental health warning signs and needs, as well as healthy emotional development. Each SBHC is operated by a private health care provider, and SBHC staff encourage partnerships between schools, health care providers, and families.

Any school-aged child is eligible to enroll for mental health care at a local SBHC, regardless of his or her insurance coverage or the family's ability to pay for services. Generally, a parent or guardian must give written consent to the child's treatment.

Keep in mind that school systems vary widely in the kinds of mental health services they provide. An SBHC may be a convenient and accessible resource, but it may also be limited. For example, services may not be available during the summer and other school vacations.

#### **Getting SBHC services**

An SBHC is usually open for patients whenever the school is in session. In many cases, students with emotional and/or mental health concerns receive services on a walk-in basis. Depending on the particular SBHC, mental health services may also be available by appointment.

If your child is enrolled at an SBHC, you will receive specific information about where to go for mental health care when the SBHC isn't open. Any SBHC that closes during school vacations and/or the summer vacation must transfer student health records to its associated health care provider. The provider is then able to provide care to the students while the SBHC is closed.

#### Types of services

The services available at SBHCs include:

- Student screening and comprehensive evaluations
- Referrals for special services
- Treatment planning and crisis plans
- Emergency interventions
- Assistance for students returning to school after hospitalization
- Updates for parents about their child's treatment and progress
- Communication with a child's primary care clinician as needed

## Paying for services

If your child is covered by private health insurance or MassHealth, the SBHC will collect the insurance information from your child and will try to recover some or all of the costs of mental health care. The SBHC will not turn students away or refuse to give services based on an inability to pay.

## **Summary** and things to remember

The public school system can be a key factor in your child's growth and development. If your child is enrolled in a public school, its teachers, administrators, and mental health professionals are responsible for your child's health and well-being as well as his or her education. They can offer observations and information that will help you understand your child's behavior. As discussed in this chapter, they can also provide crucial services that may have a profound effect on your child's ability to learn and make progress in his or her education.

If your child is eligible for special education services or Section 504 services from the school, you will have an opportunity to work with a team of people who have your child's best interests at heart. This team approach can be very useful. You will have the chance to hear different points of view and learn more about your child's situation. You may even find that some members of the team will help you gain a better understanding of other mental health services and options that might be available to your child.

The next chapter discusses additional direct services that may be available to you and your child through state agencies such as the Department of Public Health and the Department of Mental Health. It is important to remember that you may have to work hard to get the mental health services your child needs—and it is always helpful to have someone else working by your side. Any time you meet someone (such as one of your child's teachers) who might help you advocate for your child, try to make the most of the assistance they are offering. The more people you have on your side, the better off your child may be.

# Other state programs

#### **Overview**

or many families, the services available through the school district and/or through insurance are sufficient to address a child's mental health needs. For other families, these services are not enough. This may be because the child's mental health needs are very intense and/or because it is particularly difficult to manage his or her behaviors in certain settings. In these situations, a broader range of flexible and sometimes non-traditional mental health services is needed.

In Massachusetts, state agencies such as the Department of Mental Health and the Department of Public Health may be helpful. They offer certain mental health services—usually short-term—to families and children who meet eligibility requirements. These services are available through health care service providers (or "vendors") that contract with the state.

Vendors usually offer a range of services, some of which are funded with state dollars. For example, the Massachusetts Society for the Prevention of Cruelty to Children (MSPCC) offers a number of different privately-funded testing, counseling, and treatment programs for children as well as state programs like Early Intervention.

If your child has a mental health disorder, you may find that you have several different options in terms of how and where you can get state services for your child. At the same time, you may find it difficult to get state services for your child, due to eligibility requirements, long waiting lists, the location of vendors, and other obstacles. Difficulties may also arise if your child is receiving services from one agency and needs additional services from

without becoming discouraged.

remove an old one.

## **Advocacy Tip**

Be sure to ask an agency for a complete description of the full range of services it offers. This will help you figure out how best to meet your child's needs through that agency.

This chapter provides introductory information about the state agencies in Massachusetts that offer mental health services for children. You will also find information about some of the private agencies through which the state agencies operate. If you have access to the Internet, be sure to visit the websites of state agencies to get the most updated information on the services that are available. These services frequently undergo changes as laws and policies change. At times, the state may also add a new kind of service or

another, because state agencies have a tendency to act as though a child is entirely the responsibility of the agency that is already providing services. However, it is important to keep trying to get state services for your child

In this realm, there is no single best path for you to follow, and your child may end up receiving mental health services from several different agencies and/or

Try to pursue services even if you are unsure of your child's eligibility. Some state agencies will provide short term services for your child while you wait for an eligibility determination.

vendors. Although one state superagency—the Executive Office of Health and Human Services (EOHHS)—oversees all of the state agencies and departments offering mental health services, the coordination of care from these agencies and departments presents many challenges. EOHHS is aware of care coordination problems and is trying to address them, but you may need to take action in this situation and find some

#### **Department** of Mental Health

## 1. Overview and eligibility

The Department of Mental Health (DMH) provides direct services as well as services through private mental health care providers, public schools, and other government agencies. DMH also manages the MassHealth services provided by the Massachusetts Behavioral Health Partnership (discussed in Chapter 3). The overall goal of the DMH is to improve the quality of life for children with serious mental illnesses or severe emotional disturbances by providing a network of connected services and a DMH case manager to help organize each child's care.

help for yourself. If your child is receiving care from different agencies, it is important to try and find someone who has experience as a case manager and

who will help you coordinate the services and/or payment issues.

DMH services are available to applicants who meet specific criteria regarding their need for services. To be eligible, your child must have a serious mental

If your child's condition gets worse after you have applied for services and been placed on a waiting list, call the agency with an update. This may move your child up on the waiting list.

illness and must not have access to services elsewhere. Because of the demand for DMH services, your child's eligibility will also depend on the availability of services and a determination of your child's need for services compared to other applicants' need for services

Eligibility for DMH services also varies depending on the specific service. For example, only teenagers requiring long-term (three months or more) treatment in a secure residential facility will be admitted into a DMH intensive residential treatment program.

#### 2. Getting DMH mental health services

The DMH provides emergency and acute hospitalization services through a company called the Massachusetts Behavioral Health Partnership (MBHP or "the Partnership"). If your child is experiencing a mental health crisis, he or she can receive immediate evaluation and stabilization services from a Crisis Team. The team will determine whether your child requires hospitalization. These services are covered by MassHealth if your child is Medicaid-eligible.

For other DMH services, you will need to fill out an application, and the DMH will then determine whether your child is eligible for services. Applications are available at DMH offices and can also be downloaded from the DMH

Whenever

## **Advocacy Tip**

Whenever you apply for services at a state agency, be sure to describe your child on a very bad day. If you minimize your child's symptoms, the agency may fail to address all of his or her needs.

website. Note that the application is complicated and much of it must be filled out by a mental health professional.

#### 3. Types of services

For children who are eligible for DMH programs, DMH services may include:

- Extended-stay inpatient treatment
- Intensive residential treatment
- Additional residential care treatment options
- Day treatment and/or in-home treatment
- Case management and medication management services
- Family support services
- After-school programs
- Skills training and support services for children and families
- Clubs and other community-based continuing care services

The DMH also offers specialized services, funded jointly by the Department of Social Services, for children with severe mental health concerns who are at serious risk for out-of-home placements. This is called the Collaborative Assessment Program (CAP).

## **Advocacy Tip**

If you have kept your child's paperwork evaluations, reports, hospital and medical records—send copies in with the DMH application. This will help expedite the application process.

DMH services vary widely from

office to office in terms of the types of services available. Your experience with DMH may be very different than someone else's experience.

Some DMH services, such as inpatient and intensive residential programs, are limited due to the number of available beds or spaces in the programs. For any DMH

service, your child will be closely evaluated to determine his or her eligibility for that service.

#### 4. Paying for services

DMH services are funded with public dollars, but the availability of most DMH services is severely limited by the size of DMH's budget as determined each year by the state legislature. Any child who meets DMH eligibility requirements should be able to receive DMH services at no cost to the parents. However, even if your child is eligible for services, he or she may be placed on a very long waiting list if the demand for services exceeds the available funding. Note that if you have private health insurance and your child receives DMH services, the DMH will try to collect some payment from your insurer.

#### 5. Appealing DMH eligibility decisions

The DMH has an internal grievance procedure for handling eligibility appeals. Because this procedure is designed to resolve questions of eligibility, it does not apply if your child has been placed on a waiting list. It only applies when the DMH has determined that your child is not eligible for services at all.

## **Advocacy Tip**

You may be able to find a good case manager at the DMH. Keep in mind that some state employees who manage cases do not have "case manager" in their job title.

If you are not able to resolve the eligibility issues with the DMH directly, you can appeal this decision through the Fair Hearing Appeals process. The best way to request a hearing is to fax your request to the Commissioner of the DMH. Your denial notice from the DMH will contain

Department of Public Health

#### 1. Early Intervention

#### Overview and eligibility

The Department of Public Health's Early Intervention program provides services for children from birth up to age 3 who have disabilities or developmental problems. Generally, children who are referred to Early

instructions about how to request a hearing.

Intervention are those who were born prematurely,

have sight or hearing problems, have a health condition, or are slow to sit up, stand, walk, or talk. In some cases, a child who is identified as "at risk" due to family circumstances (such as very young parents, a lack of food, a lack of clothing or shelter, or the presence of violence in the family) may also be eligible for Early Intervention services.

## **Advocacy Tip**

Pay close attention to DMH's strict timeline for appealing an eligibility decision! If you miss the deadline, you will have to start over at the beginning by applying for services again.

The Department of Public Health (DPH) is the "lead agency" for Early Intervention, which means it receives funding and certifies the private providers who will provide Early Intervention services. The DPH itself does not provide Early Intervention services onsite.

## Getting Early Intervention mental health services

Families usually learn about Early Intervention services from a pediatrician, teacher, social worker, or other health care professional. Sometimes, a parent will contact the program directly. Although referrals are usually made because a child seems to have a developmental problem, an

## **Advocacy Tip**

At age 3, your child will stop receiving Early Intervention services. You should then find out whether he or she is eligible for special education services (see Chapter 5).

evaluation by the Early Intervention staff may reveal that the child has a mental health problem. In these cases, Early Intervention will provide mental health services.

If you are referred to Early Intervention or if you contact them directly, the program must respond to you within 10 working days. Within 45 working days of the referral, the program must determine whether your child is eligible and must perform a complete assessment of his or her condition.

#### Types of services

After the Early Intervention staff evaluate your child, they will create an Individualized Family Service Plan (IFSP). This plan must be completed within 45 days of the referral to Early Intervention.

Your child's IFSP will be based on his or her individual needs and your family's needs and preferences. The services spelled out by the plan will be delivered by a team of providers, including the parent(s) (you), other members of your family, and your child's pediatrician. Depending on your child's needs, the team may also include therapists, social workers, early childhood specialists, and other mental health care professionals.

Ideally, the Early Intervention services will take place in "natural environments" such as your home, a childcare center, a community playgroup, or a library. These services may include:

- home visits
- toddler groups
- parent-child groups
- parent training, education, and support groups
- individual and/or group speech and occupational therapy sessions
- assistance locating additional services

The IFSP must be updated at least every 6 months by your child's team working in partnership with you and your family.

## **Advocacy Tip**

The only state services generally available to pre-schoolers besides Early Intervention and special education are offered by the Department of Mental Health. The DMH services are limited—but worth a try.

#### Paying for services

Some of the basic Early Intervention services are provided at no cost to families. However, most families pay an annual "participation fee" for services. The fee is based on your family's income and size and is collected once a year. For some families, the current fee is \$25 per year plus an additional \$20 fee if more than one child in the family is receiving El services. For families with more income, the current annual fee is \$50 plus an additional \$50 if more than one child is receiving El services.

Note that if you have private health insurance, your insurer is required by law to cover Early Intervention services. These private health insurance funds will be your first resource when paying for El services.

#### 2. Care Coordination Program

## Overview and eligibility

Care Coordination services are provided directly by DPH staff located in the six DPH regional offices or in the offices of pediatric primary care providers. The families eligible for these services are those with children up to age 22 who have special health needs, such as an ongoing illness or a disability. Note that if your child needs mental health services but has no other special medical needs, DPH is likely to refer you to another agency, such as DMH.

#### **Getting Care Coordination services**

First, discuss Care Coordination with your child's pediatrician. Some pediatricians provide Care Coordination services as part of their medical practice. If your child's pediatrician doesn't provide these services, the next step is to call the DPH's toll-free Community Support Line. This will put you in contact with a DPH Resource Specialist who can provide you with a referral to the Care Coordination program. (For information about the Community Support Line, please see the Resource list at the back of this Guide.)

#### Types of services

A DPH Care Coordinator will try to help you and your family avoid some of the frustration and difficulties that go along with searching for health care for your child. Care Coordinators maintain contacts with various local agencies and can provide families with services such as:

- Emotional support and advice
- Information about available community resources and agencies
- Help contacting agencies and getting agency services
- Help finding other families in similar situations
- Help with transitions, such as when a teenager leaves school

Care Coordinators also work with pediatricians to help them understand more about the benefits and community-based services available to children with special health needs.

#### Paying for services

Care Coordination services are provided at no cost to you and your family.

#### 3. The Bureau of Substance Abuse Services

#### Overview and eligibility

The DPH's Bureau of Substance Abuse Services (BSAS) provides a range of services for children and teenagers with alcohol and other drug problems and addictions. The BSAS also offers Youth Services programs aimed at preventing teenagers from developing addictions to drugs or alcohol. BSAS services may include certain mental health care services, but the BSAS does not coordinate care for mental or physical health conditions unrelated to substance abuse. The BSAS also does not offer case management services.

Most outpatient BSAS services are available to all children and teenagers regardless of their insurance coverage. Residential services are limited to high-risk teenagers ages 14-18 who are experiencing severe problems as a result of their drug or alcohol use. Certain community-based BSAS programs may be limited to the children and teenagers in that community.

## **Getting BSAS services**

If you are interested in BSAS services for your child, you can contact the BSAS directly and/or call the BSAS helpline. The BSAS website is also a good source of useful information. When you contact the BSAS, you will receive information about its services and referrals to its programs. Generally, BSAS services are

provided in schools, community agencies and health centers, neighborhood centers, and other community-based locations.

#### Types of services

The BSAS provides a range of services, including:

- A referral helpline
- Assessment and treatment planning
- Outpatient counseling (individual, group, and family)
- Day treatment programs
- Residential treatment programs (limited enrollment)
- Prevention programs
- Education and skill-building for teenagers
- HIV and AIDS education

#### Paying for services

Many BSAS services are covered by private insurance, MassHealth insurance programs, and/or the Children's Medical Security Plan. Certain outpatient services and a limited number of residential placements are funded by the BSAS.

## **Department** of Mental Retardation

#### 1. Overview and eligibility

The Department of Mental Retardation (DMR) provides resources, services, and financial assistance to families with disabilities. Its goals include making the family environment safe and stable, and helping families stay together. DMR services are provided by Family Support Services Providers.

# **Advocacy Tip**

You may encounter a waiting list for BSAS services for your child.

A child and his or her family are eligible for DMR services if the child is aged 5 to 18, lives in Massachusetts, and has a developmental disability. The DMR defines a developmental disability as a long-lasting severe mental and/or physical impairment that may be permanent and places serious limitations on the child's major life activities. At least three of the following major life activities must be affected: self-care, learning, mobility, ability to receive and express language, self-direction, ability to live independently, and/or ability to support oneself financially.

Note that autism does not fit neatly within the domain of any state agency, and a child with autism is not necessarily eligible for DMR services.

Technically, a family with a child under the age of 5

DMR are communi
based services.

qualifying disability. However, in most cases, children
from birth to age 3 receive Early Intervention services from
the DPH, and children aged 3 or older receive Special Education services.

If your child is eligible for DMR services and has also been diagnosed with a mental health disorder, he or she will be able to receive mental health services from the DMR. However, DMR's mental health services are very limited—and if your child's primary diagnosis is a mental health disorder instead of mental retardation, he or she will have to seek mental health treatment from an agency other than DMR.

# **Advocacy Tip**

All of the services available through the DMR are community-based services.

## **Advocacy Tip**

Children who receive DMR mental health services have a primary diagnosis of developmental disability and an accompanying mental health disorder.

### 2. Getting DMR mental health services

If your child has been diagnosed with a developmental disability, you can fill out an application for DMR services. Applications are available at local DMR Area Offices, Family Support Provider Agencies, and in other community locations including schools, health centers, hospitals, and other state agencies. Once you have applied to DMR services, a Regional Eligibility Team will determine whether you and your child are eligible. The eligibility assessment and decision must be completed within 45 days of your application for services.

The availability of DMR family support services will also depend on the local resources and demand for services in your area. The DMA Area Director determines which families and children take priority based on the severity of each child's need.

#### 3. Types of services

Family Support Provider Agencies provide a wide variety of flexible, individualized services to families and children. If your child has a mental health disorder, you may find many of these services helpful, including:

- Information about community resources
- Referral services
- Education, training, and support groups
- Support and treatment planning, including emergency treatment

## **Advocacy Tip**

The DMR application is easier to fill out than the DMH application because it doesn't require input from a health care professional.

- Case management services
- In-home and out-of-home services including respite, skill building, and recreational activities
- Encouragement for families prepared to take a leadership role in treatment planning and advocating for services
- Related support services such as childcare and transportation

#### 4. Paying for services

If you and your child are eligible for DMR services, you will receive a family support allocation from your Family Support Provider Agency. This support allocation may either be in the form of a stipend (a payment that is made directly to you, so that you can pay directly or be reimbursed for services) or a "direct provider agency payment" (payments for services will go through your Family Support Provider Agency). These two options will be discussed with your family during the family support planning process, and you may select the option that best suits the family's needs.

The amount of your family support allocation will be based on a needs assessment performed by the DMR, the availability of services and resources in your area, and the priority assigned to your child and family.

## **Advocacy Tip**

Try to get a primary diagnosis for your child's condition. If your child has dual or multiple diagnoses, it is more likely that he or she will get bounced back and forth between agencies.

### **Department** of Social Services

#### 1. Overview and eligibility

Most parents do not welcome involvement with the Department of Social Services (DSS). The DSS is primarily responsible for protecting children who are at risk of harm. Under some circumstances, the DSS may ask a judge to place the child in question into DSS custody. If you are a foster parent caring for a child who is receiving DSS services or if a judge has ordered the DSS to get involved with your family, it will be useful for you to know about the mental health services that are available.

Children under the age of 18 are generally eligible for services from the DSS. In limited cases, DSS services may be available to a child who is between the ages of 18 and 21, particularly if the child received DSS services prior to his or her eighteenth birthday. Note that DSS services are more limited in a situation where there are no concerns about a child's safety.

In many cases, children who are under the protection of the DSS and/or who are receiving DSS services also suffer from serious emotional issues or mental health disorders. Situations that require the attention of the DSS—such as when a child is the victim of physical or sexual abuse—can damage a child's mental health and well-being. In some cases, a child's existing mental health disorder can play a key role in creating a situation that calls for DSS involvement, such as when a child's emotional issues lead him or her to get in trouble with the police.

# **Advocacy Tip**

The DSS is the largest funder of residential services for children. In fact, certain residential programs are only available through the DSS.

#### 2. Getting DSS services

It is important to know that—in most situations—long term help from the DSS means you will have to share custody of your child with the DSS or even give up custody. Recent changes in the law have made it easier for parents to request a termination of DSS custody. However, because of these custody issues, many parents decide not to seek DSS services voluntarily. Be sure to consider the question of custody when deciding whether to seek help for your child from the DSS.

If DSS services have been requested in an emergency situation, the DSS will conduct a preliminary eligibility assessment and will provide the services (if the family is eligible) within 7 days. If the request for services is made on a nonemergency basis, the DSS will conduct a longer assessment that must be completed within 45 days of the request. If the request is limited to a single DSS service, the DSS may conduct a more limited assessment and will provide the service within 10 days of the request.

# **Advocacy Tip**

Once the DSS is involved with your family, it may keep a very close watch on you and your child. If the agency observes signs of abuse or neglect, it may seek custody of your child.

In general, the family assessment is used to determine whether a family needs DSS services and what the best options are for providing these services to the family. A social worker will be assigned to the family during the assessment. He or she will ask a number of questions about family members, including children, and/or other members of the household. The social worker may also want to talk with doctors, teachers, and/or therapists who are familiar with the family's children.

If you have questions or concerns about becoming involved with the DSS, you may want to seek legal advice.

# **Advocacy Tip**

Keep in mind that you can appeal a DSS family assessment and the plan it has created for your family.

#### 3. Types of services

If your child or foster child is found eligible for DSS services, the family assessment will result in a service plan that outlines the DSS services that will be provided, the desired outcome from these services, and the costs that you will be responsible for paying.

In situations where a child has emotional issues and/or a mental health disorder, the following DSS services may prove helpful:

- Evaluation services
- Family support services
- Counseling and case management services
- Collaborative Assessment Program (CAP) (a joint program with the Department of Mental Health, mentioned earlier in this chapter)

In general, DSS services are provided by service providers who have contracts with the DSS and not by the DSS itself. Some DSS services are limited in terms of the hours of service a family can receive. The availability of some DSS services may also be limited by demand, and your family may be placed on a waiting list for those services.

#### 4. Paying for services

The DSS evaluates the family's financial situation and may charge a fee for services based on a sliding scale. If a child receives Social Security income or Supplemental Security Income (SSI), the DSS may require the family to use a significant portion of this income to pay for DSS services. If the DSS determines that the family has the ability to pay for services through some other agency or provider, the DSS may offer only information and referral services (at no cost) to the family.

## Juvenile Justice System

#### 1. Overview

As discussed in Chapter 2, a child who has been taken into police custody and is in need of mental health services will receive some limited assistance from the Department of Youth Services. This is not a situation you and your child want to be in. If your child is in police custody and has a mental health disorder, be sure to seek mental health treatment for him or her instead of detention. It is important for parents to realize that it is not a waste of time to make such a request. Treatment is generally a better option than detention—and a judge may grant your request.

If the judge agrees that your child needs mental health care, he or she will order an evaluation. The judge may also take an active role in trying to find a state agency that will take responsibility for your child's treatment. However, as explained in Chapter 2, the juvenile justice system is not a good answer for children who need mental health care.

Parents are often encouraged to file a Child in Need of Services (CHINS) petition in the Juvenile Court as a way to access DSS and other state services for their children. A CHINS petition may be filed when a child runs away from home, skips school, breaks school rules, or "refuses to obey the lawful and reasonable command" of his or her parent(s). However, most advocates for children believe that a CHINS petition is not a good way to get services for a child with mental health needs.

When you first try to file a CHINS petition, you may find that the probation officer at the court will recommend that you seek services in your community instead. If you proceed with the CHINS petition, you and your family will become entangled in a legal proceeding that requires many court appearances. In addition, you will not a party to the court proceedings and you will not

# **Advocacy Tip**

A CHINS petition should only be used as a very last resort.

entangled in a legal proceeding that requires many court appearances. In addition, you will not be a party to the court proceedings and you will not be entitled to representation, even though you filed the CHINS petition. In some cases, the court awards custody to the DSS, and the DSS can make decisions about a child's care regardless of whether the parents agree with these decisions. For these reasons, you should consider other options—such as appealing a school district's or agency's eligibility decision—very carefully before filing a CHINS petition.

## Summary and things to remember

The mental health services for children offered by state agencies can be a key component in a child's treatment—but are often unavailable or difficult to obtain due to eligibility requirements, budget issues, and a high demand. It can also be challenging to coordinate care if a child is receiving services from more than one agency.

The Executive Office of Health and Human Services is working to make improvements to the state mental health care system. In the meantime, if you believe your child is eligible for services from one or more state agencies, it is important to seek those services. You may want to get help from a mental health advocate or a case manager. If your child is eligible for (or is receiving) services from several different agencies, consider trying to get one of those

## **Advocacy Tip**

If an agency tells you that it is not the right agency for your child, be sure to ask where you should go next. The people working at the agency should be able to help steer you in the right direction.

agencies to take primary responsibility for your child. Case conferences with everyone involved in your child's situation can also be very useful. Although the state mental health care system is complicated, you will find that the people working in the agencies want to help.

In some cases, parents find that their child has entered the mental health system but treatment has stalled, either because the child is "boarded" (kept in a medical ward or emergency department waiting for a bed to open up in a mental health setting) or "stuck" (ready to leave a particular mental health

setting but unable to be discharged because the next level of care is unavailable for one reason or another). If your child is "boarded" or "stuck," he or she is not receiving appropriate care. You will want to seek immediate help from an agency, advocate, or attorney to remedy the situation.

Remember that your active involvement in your child's situation can make all the difference as you seek mental health care for him or her. You may find yourself feeling frustrated, angry, desperate, or all of the above. It's important to know that you are not alone—many other parents feel exactly the same way. In the long run, the knowledge that you are working hard to find the best possible care for your child may help you stay focused and keep trying.

# Glossary

**Acute in-hospital treatment** is the medical treatment provided in a hospital to a patient who has been admitted to the hospital due to an intense illness and/or an emergency situation.

**Anorexia Nervosa (Anorexia)** is an eating disorder characterized by voluntary starvation and overexercise. Anorexia is a complex disease involving psychological, sociological, and physiological elements. A person suffering from Anorexia is known as an **anorectic** (although the terms **anorexic** and **anoretic** are also used).

**Anxiety disorder** is a generalized term used to describe mental health disorders relating to fear, phobias, and nervousness. A person suffering from an anxiety disorder may have panic attacks and may be unable to pursue normal daily routines.

**Appeal** in this Guide refers to the process parents will follow when they seek to challenge a denial of mental health services. In most situations, there is a higher authority who can review a denial, and it is important for parents to learn about the appeal process and undertake an appeal if necessary.

**Assessment** is the process of measuring a child's knowledge, skills, or needs. Most assessments are performed by professionals. In schools, for example, an assessment can help determine whether a child needs special services.

**Attention Deficit Hyperactivity Disorder (ADHD)** is one of the most commonly diagnosed mental disorders among children. Its symptoms include

inattention, overactivity, and a tendency to be too impulsive. Medication can help—but parents should avoid jumping to the conclusion that any child who is inattentive or overactive has ADHD.

**Behavioral problem or disorder** is a generalized term used when a child or teenager behaves—over a long period of time—in ways that are not socially acceptable for his or her age and situation or in ways that are destructive or self-destructive.

**Benefits** in this Guide refers to the services or payments provided for you, your family, or your child by private or public insurers or agencies.

**Bipolar disorder** is a mood disorder characterized by severe mood swings. A person with this disorder may go from being manic, extremely elated, and energetic to being depressed, sad, and sluggish. People with this disorder are sometimes known as **manic depressives**.

**Bulimia Nervosa** (commonly known as **Bulimia**) is an eating disorder characterized by extreme overeating or "binge" eating followed by intentional vomiting, excessive exercising, inappropriate use of laxatives or enemas, or fasting.

**Carve-out** in this Guide refers to a situation where a private insurer or government agency has made a private contractor responsible for the mental health services available through that insurer or agency. The private contractor is often known as the **carve-out company**, and the services under its control are **carved-out services**.

Case manager is someone who is trained to perform assessments and provide assistance to parents, families, and individuals who need to plan and manage patient services and care.

CHINS (Child in Need of Services) petition is a petition that a parent may file with the court when a child runs away from home, skips school, breaks school rules, or "refuses to obey the lawful and reasonable command" of his or her parent(s). However, filing a CHINS petition will trigger a complicated legal proceeding that may result in a transfer of custody to the Department of Social Services. Parents should only file a CHINS petition as a very last resort.

**Clinician** is an individual who is trained to practice medicine or psychology and who works directly with people instead of in a laboratory.

**Community agency** in this Guide refers to a private nonprofit organization located in a particular city, town, or neighborhood, and dedicated to providing services to individuals and families in the surrounding community.

**Consultation** in this Guide means a meeting with a mental health professional to obtain advice and/or treatment for your child.

Co-payment in this Guide means a payment you must make as part of the total payment for a service which is mostly paid for by an insurance company.

**Coverage** in this Guide means the mental health services you and/or your child are entitled to receive under a private insurance contract or a government program.

**Crisis counseling** refers to intensive meetings between a professional and an individual who is experiencing overwhelming or traumatic mental health problems. Crisis counseling is usually short term, lasting for 1-3 months, and is not a substitute for long term psychological or psychiatric care.

**Crisis intervention and screening** in this Guide refers to a situation where a child is experiencing overwhelming or traumatic mental health problems and a professional (or team of professionals) steps in to provide some immediate help to this child. The professional will assess the child to try and identify the most appropriate treatment.

**Crisis stabilization** in this Guide refers to a brief (usually between 2-10 days) period of hospitalization during which a child who is experiencing a mental health crisis receives intensive treatment and is stabilized.

**Day Treatment** refers to an intensive program that involves the patient during the daytime hours but permits the patient to return home at night.

**Deductible** in this Guide refers to two situations: (1) the expenses that can be deducted from your income in calculating whether you qualify for government benefits; or (2) the amount in an insurance contract that you must pay out-of-pocket before your insurance policy provides for payment by the insurer.

**Depression (clinical)** is a mental health disorder characterized by a sad mood that is both prolonged and severe. Clinical depression can be treated with medication, therapy, and hospitalization if necessary.

Developmental problem, condition, or disability refers to a severe condition that stems from mental and/or physical impairments and is generally permanent. People with developmental disabilities have trouble with major life activities such as language, mobility, learning, self-help, and independent living.

Diagnostic evaluation in this Guide refers to when a clinician assesses the symptoms presented by your child in order to come to an informed opinion about what condition is causing those symptoms.

**Disability** is a general term referring to any condition that impedes a person's ability to complete daily tasks using traditional methods.

**Dual diagnosis** is a term used to describe a situation where one person is diagnosed with two different conditions and needs treatment for both. For example, a person who is clinically depressed and also addicted to drugs has two different mental health conditions.

**Eligibility** in this Guide means meeting all of the conditions set forth in state or federal law that must be met before you, your family, or your child can qualify for a particular program's benefits under that law.

**Emergency services team (EST)** refers to a team of mental health professionals that responds to emergencies. All children in Massachusetts are entitled to receive EST services. However, a child who is uninsured or covered by MassHealth, and who is experiencing a mental health emergency, must be evaluated by an EST. The Team can provide crisis intervention, stabilization, and referral services.

**Family stabilization services** in this Guide means intense, specific services provided to a family after an initial crisis has been addressed. It includes counseling and supervision to help at-risk families gain strength and stability.

**Grievance** in this Guide refers to a situation where a parent wants to formally complain about the quality of services being provided by an agency, the delay in providing these services, or a denial of services. Grievance processes are often internal, within an agency, and are typically less formal than appeal processes.

**Group insurance** refers to insurance that is purchased by a group (such as the employees of a company). As part of the group, individual members usually enjoy a reduced rate (compared to the rate charged to non-group individuals).

**Hearing** refers to a proceeding held in front of a decision-maker where you have the opportunity to present facts and arguments about why your child should receive the services you are seeking.

**Hyperthyroidism** is a disorder that results when the thyroid gland is more active than normal (or is overactive). Typical symptoms include weight loss, chest pains, cramps, diarrhea, and nervousness.

**Hypoglycemia** is a disorder that results when a person's blood sugar (or glucose) levels are too low. It can be caused by too much insulin in the body, too much exercise, or not enough food. Symptoms include fatigue, trembling, nervousness, hunger, or (in extreme cases) coma.

**Inpatient treatment** in this Guide refers to mental health services delivered in either a general hospital or a psychiatric hospital while your child is staying overnight at that facility.

**Insurance (private)** is a contract between an insurance company and an individual, an employer, or a group of individuals. The insurance company provides coverage for certain health care services (for example) and charges a monthly premium to the individual, employer, or group.

**Insurance (public)** is similar to private insurance but is provided under state and/or federal law and is typically intended for individuals and families who cannot afford to pay private insurance premiums.

Licensed Social Worker refers to someone who is licensed under state law to provide social work services. The license demonstrates that the person has completed sufficient education and training to satisfy the state's requirements for licensing and is therefore qualified to practice.

**Locked ward** refers to a section of a hospital or mental health treatment center where patients are confined to a specific area, hallway, or floor. Locked wards are generally for psychiatric patients who are so ill that (in the judgment of mental health professionals and/or a court) they present a threat of harm to themselves or others.

**Medication management** in this Guide refers to the process of monitoring a child's use of medication(s). Usually, the monitoring is done by a qualified professional such as a psychopharmacologist.

**Mental health network** in this Guide refers to a group of mental health professionals who are licensed to provide services and who have contracted with an insurance company (or carve-out company) to provide mental health services at a discount to people insured under that company's insurance policies.

**Mental health professional** refers to a person who is trained to provide mental health services and has been certified to do so by a licensing authority. This category includes psychiatrists, psychologists, psychiatric social workers, and others with similar training.

**Mood disorder** is a generalized term referring to mental health disorders where a person's general mood is distorted or inappropriate given the circumstances. Clinical depression and bipolar disorder are both mood disorders.

**Nurse Practitioner** refers to a person with an Advanced Practice Nurse (APN) degree who manages patient care and provides primary care services as well as specialty services. Unlike most nurses, nurse practitioners can diagnose patients and prescribe medications.

**Open ward** in this Guide means a ward where patients are not confined involuntarily, but are free to leave without professional or court permission.

**Oppositional Defiant Disorder** is a mental health condition characterized by recurring disobedient and hostile behavior that persists for at least 6 months. A child with this disorder may often argue with adults, throw severe temper tantrums, deliberately break rules, and actively refuse to comply with requests.

**Out-of-network** refers to a mental health care provider, for example, who is not a member of your insurance company or HMO's network of providers. If you bring your child to an out-of-network provider, the insurance company or HMO will provide less coverage or no coverage of the mental health services you receive from that provider. Generally, exceptions are made for extreme emergencies or urgent care that is needed when you are traveling away from home.

**Outpatient** is a term used to describe patients who are receiving treatment at a hospital or health care center but who do not reside at that hospital or center.

**Partial hospitalization** refers to intensive day treatment programs (see definition above) where the patient spends nights at home.

**Phobia** is a mental health disorder characterized by extreme fear. A person who suffers from a phobia is often seriously disabled by the condition and unable to function under certain circumstances. Different phobias have different names. Arachnophobia, for example, is an extreme fear of spiders.

**Post-Traumatic Stress Disorder (PTSD)** is an anxiety disorder directly associated with a traumatic event. Symptoms include extreme guilt, reliving the trauma in dreams, numbness and lack of involvement with reality, or recurrent thoughts and images.

**Premium** refers to the monthly payment that you are required to pay your insurance company in order to receive benefits.

**Prior approval** in this Guide refers to the process under either private or public insurance where you seek approval from your insurer for mental health treatment that has been recommended for your child. In many cases, you must get prior approval for services or the services will not be covered by your insurer.

**Provider network** refers to a group of health care professionals who are licensed to provide services and who have contracted with an insurance company to provide health care services at a discount to people insured under that company's insurance policies.

**Psychiatric day treatment** refers to an intensive program that involves the patient during the daytime hours but permits the patient to return home at night.

**Psychiatrist** refers to a mental health professional who also has a medical degree and is able to prescribe medication.

**Psychological testing** is a kind of assessment based on small samples of behavior. The specialist performing the assessment observes a child's behaviors over a limited amount of time and then forms conclusions based on research and statistics.

**Psychologist** refers to a mental health professional who is not a medical doctor and who does not prescribe medication. Clinical psychologists have extensive training in therapy and psychological testing.

**Referral** in this Guide refers to a recommendation you receive from one health care professional suggesting that your child seek help from a different health care professional. For example, your child's pediatrician might give you a referral to a mental health specialist if he or she feels your child needs specialized care. Some insurance companies require referrals before they will cover services.

**Residential treatment** in this Guide refers to treatment received in a setting where your child lives away from his or her home, usually for an extended period of time.

**School counselor** in this Guide refers to a trained professional at your child's school whose duties include mental health counseling.

**Section 504 services** are services your child's school is required to provide under Section 504 of the Rehabilitation Act if 1) your child has a disability and is having trouble learning and 2) additional services or reasonable changes in the rules or policies at the school will help your child learn.

**Self-insured** in this Guide refers to employers who provide coverage (see above) to employees and their families by taking direct responsibility for payment of the covered services (or a portion of the services) rather than buying an insurance policy.

**Social services agency** refers to a private organization, often funded with government dollars, which is dedicated to providing services (including mental health services) to individuals and/or families.

**Special education** is a kind of service provided to children aged 3 to 22 who are in need of specialized services as defined by the Individuals with Disabilities Education Act (a federal law that entitles children who are documented to have special needs to receive sufficient services to ensure that these children receive an adequate education).

**Summary plan description** refers to the detailed description of the health (and mental health) services that will be provided to you and your family by your employer or insurance company. The employer or insurance company is required by federal law to give you this summary plan description.

**Therapist** in this Guide refers to a mental health professional (typically a psychiatrist, psychologist, or social worker) who provides mental health services through one-on-one meetings, group meetings, or family treatment.

**Therapy (individual, family, group)** refers to mental health treatment that relies on talking, medication, role-play, and other methods.

**Transitional care** in this Guide refers to care for patients who require a short-term phase intensive therapy or treatment following an acute hospital stay. It is meant for patients who are not ready to be at home, but who do not need to remain in a hospital.

**Traumatic event** refers to an emotionally overwhelming experience such as a serious injury, the loss of a loved one, or abuse (mental, physical, or sexual).

# Resource list

#### Introduction

There are many different places parents can go to for help with the problems identified in this Guide. The following list of agencies and organizations corresponds to the Guide's chapters and is a good place to start. As we mention elsewhere, there is also an increasing amount of mental health information available on the Internet. If you do not have an Internet connection at home, you may be able to get online at your local public library, adult education program, or community center.

#### Parent support and advice groups

Many people find that other parents are their best source of information and advice. Other parents can also help you decide which of the resources in this list may be most helpful for you and your family. There are several terrific parents' organizations in Massachusetts. The two listed below can be contacted by phone or email and can help you find other resources and groups.

#### Parent/Professional Advocacy League (PAL): 617-542-7860

www.ppal.net — Offers advice and support for parents and runs a hotline. PAL is the statewide chapter of The Federation of Families for Children's Mental Health. The FFCMH website also has useful information: www.ffcmh.org.

## Federation for Children with Special Needs: 617-236-7210

www.fcsn.org — Statewide organization that helps parents of children with special needs; services include information and support groups.

#### Information about mental health diagnoses

There is a wide variety of information available on the Internet about mental health in general and also about specific conditions. Many of these websites have parent information sections, and a few have areas where parents can ask questions and get responses online.

#### **General sites**

TalkListen.org (run by the Boston Public Health Commission) www.talklisten.org

American Academy of Child and Adolescent Psychiatry www.aacap.org

National Mental Health Information Center www.mentalhealth.org

#### **Specific diagnoses**

Families for Depression Awareness www.familyaware.org

The Children's Hospital Boston "Depression Experience Journal" www.experiencejournal.com

National Center for Post Traumatic Stress Disorder (PTSD) www.ncptsd.org/facts/specific/fs\_children.html

#### ADD/ADHD Information Library

www.chadd.org

#### **Eating Disorder Referral and Information Center**

www.edreferral.com

#### Keep Kids Healthy: Childhood and Adolescent Anxiety Disorders

www.keepkidshealthy.com/welcome/conditions/anxiety disorders.html

#### **Finding a Provider**

If you have insurance, you should start by calling the member services number that is usually printed on your insurance card. Note that there may be a separate number to call for mental health services.

### Massachusetts Behavioral Health Partnership: 800-495-0086

www.masspartnership.com — Can help many MassHealth members locate a provider and has useful contact information for emergency situations.

# Massachusetts Society for the Prevention of Cruelty to Children: 617-587-1500

www.mspcc.org — MSPCC runs a number of parent support and counseling programs across the state.

#### Massachusetts Psychological Association: 781-263-0080 (10)

MPA provides access to psychologists in Massachusetts through their members. Contact the office at the number above, tell them 1) the type of service you need, 2) your location, and 3) your insurance information, and they will email your request to their membership list.

#### Massachusetts Association of Social Workers: 617-720-2828

MASW has a therapy referral service that you can access at the number above. You will be contacted by a social worker who can help you locate a provider with the specialty, location, and service you need.

#### **Getting Access to Health Care**

Massachusetts has many organizations and state offices dedicated to helping parents find health care coverage. Several key starting points are listed below.

#### Health Care for All: 617-350-7279

www.hcfama.org — Health Care For All is the leading consumer advocacy organization in the state. It runs a helpline that can answer many of your questions about how to pay for health insurance.

#### Boston Public Health Commission: 617-534-5050

www.bphc.org — For people living in the city of Boston, the Public Health Commission maintains a wide range of resources to help you find care. The Mayor's Healthline provides information and referral services.

#### Massachusetts Division of Health Care Finance and Policy: 617-988-3125

This Division publishes a comprehensive guide to health programs available in Massachusetts. It can be downloaded from the internet at www.mass.gov/dhcfp/pages/pdf/access.pdf.

# Employee Benefits Security Administration in the U.S. Department of Labor, Boston Regional Office: 617-565-9600

Information about self-funded ERISA plans as well as mental health parity law.

#### Massachusetts Division of Insurance

www.mass.gov/doi

#### MassHealth Information

There are many resources that provide information about the MassHealth program. In addition to those listed above under "Getting Access to Health Care," you may want to look at:

#### MassHealth Main Information

www.mass.gov/dma — This is the main website for the state office that runs MassHealth, and it includes application information, forms you can download, and contact information.

#### Community Health, Inc.

www.compartners.org — This is a website with good information about the different MassHealth programs, and it includes some links to local organizations that can help with applications.

#### Office of Medicaid Board of Hearings: 800-655-0338

To appeal a decision through the Fair Hearings Board process, fax your request for a hearing to 617-210-5820.

## **Legal Assistance**

If you need legal advocacy or information, the following organizations may be able to help:

#### Health Law Advocates: 617-338-5241

www.hla-inc.org — Helps with health care problems including mental health issues.

#### Massachusetts Advocates for Children: 617-357-8431

www.massadvocates.org — Has a special expertise in school issues.

#### Mental Health Legal Advisors Committee: 617-338-2345

www.mass.gov/mhlac — State-funded program that helps with mental health issues and has a number of publications on the legal rights of people with mental health problems.

#### Massachusetts Legal Help

www.masslegalhelp.org — This website is run by legal services offices in Massachusetts, and it has a great deal of information on health care and other issues. The website has a complete listing of legal services agencies in the state, and you can use this list to find an advocate in your area.

#### **School Services and Information**

Because special education is run by each city or town's school system, the best starting place is often your own school's special education coordinator. If you are having difficulties or want more general information about special education in Massachusetts, the Massachusetts Department of Education is a good starting point.

#### Massachusetts Department of Education — Special Education

www.doe.mass.edu/sped — The parent information section of this website includes a number of useful guides as well as links to services in your community.

## Section 504: Free Appropriate Public Education

www.ed.gov/about/offices/list/ocr/docs/edlite-FAPE504.html

## Special Needs Advocacy Network

www.spanmass.org — Provides information and resources on special needs to parents and professionals.

#### Wrightslaw

www.wrightslaw.com — Special education advocacy information and services

#### **Other State Departments and Agencies**

Department of Public Health: 617-624-6000

www.mass.gov/dph/dphhome.htm

DPH Community Support Line: 1-800-882-1435

Office of Patient Protection: 1-800-436-7757

www.mass.gov/dph/opp —

For filing complaints about your managed care company.

Bureau of Substance Abuse Services: 617-624-5111

www.mass.gov/dph/bsas/bsas.htm —

For help locating substance abuse services.

Department of Mental Health: 617-626-8000

 $www.mass.gov/dmh-Applications\ can\ be\ downloaded.$ 

Massachusetts Department of Social Services: 617-748-2000

www.mass.gov/dss

#### **Juvenile Justice System**

#### Citizens for Juvenile Justice: 617-338-1050

www.cfjj.org — Publishes a useful guide called "From a Parent's Perspective: A Handbook for Parents of Children Committed to the Massachusetts Department of Youth Services." This guide is available on their site at: www.cfjj.org/myweb4/Handbook2.pdf

Parent/Professional Advocacy League (See contact info on page 135) has also developed a "pocket guide" that helps parents talk to police officers about their child's mental health issues. The "Pocket Police Guide: Responding to Youth with Mental Health Needs" is available at www.ppal.net/downloads/PPG 6-10-2002.doc.

# **Afterword**

As this Guide explains, it can be hard to find your way in the mental health system. We have tried to give you a map of how the system works to help you. However, we understand that this is only part of the answer. Learning to find your way through the current system is useful, but changing and improving the way the system works is equally important. Parents and their advocates can be a crucial force in making the child mental health care system better. At the Boston Bar Association, we are committed to working with parents and advocates to make a positive difference in the lives of children.

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