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# **Guidebook for Caregivers of Children and Adolescents with Serious Emotional Disorders**



**NAMI New Hampshire**

National Alliance on Mental Illness New Hampshire

January 2007

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# Acknowledgments

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This Guidebook for Caregivers of Children and Adolescents with Serious Emotional Disorders was written and published by the National Alliance on Mental Illness New Hampshire (NAMI NH) with the help and guidance of many family members, professionals, and leaders in the state. We wish to acknowledge the families and providers who produced the original guidebook. Their efforts continue to support and empower caregivers of children and adolescents with serious emotional disorders.

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*Michael J. Cohen, MA, CAGS*, Executive Director, National Alliance on Mental Illness New Hampshire for his guidance on the project and final edit of the Guidebook.



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# Foreword

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We believe you are reading this book because you... or someone you love... provides care for a child with a serious emotional or behavioral disorder. Caring for a child or adolescent who has any of these disorders can be very overwhelming... and many caregivers feel alone and isolated. This Guidebook has been developed to make care giving more manageable by offering caregivers resources to help children with the disorders as well as to help themselves. It has been written by families and providers who embrace the values of child-centered and family-focused treatment in the context of a “whole person,” integrated approach to health care.

At the National Alliance on Mental Illness New Hampshire (NAMI NH), our goals are to educate and empower caregivers and families to: understand emotional and behavioral disorders experienced by their children, effectively negotiate the support and service systems, advocate for needed care, and promote their child's positive growth and development. Driven by these goals, this Guidebook provides a comprehensive resource of science-based information, skills, strategies, and supports.

We hope you will find it helpful as you face the many challenges of providing care for a child with a serious emotional or behavioral disorder.

*Claudia J. Ferber, MS*  
Child and Family Services Program Coordinator  
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# Chapter 1. Integrated Health Care

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## Chapter Overview

*A child or adolescent with serious emotional disorders may have both mental and physical health needs that require coordinated treatment from providers who communicate.*

*This chapter will help parents, families, or*

*other caregivers by providing: guidelines to ensure they are participating in treatment, REAL and MEANINGFUL options of care, and an understanding of the importance of their role in decision making.*

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## Total Well-Being

For people who live with mental illnesses, a healthy lifestyle is especially important.

It is easy to become so focused on treating the mental illness that physical health is ignored. But, having a healthy body contributes to emotional recovery. The importance of physical health in conjunction with mental health is more fully addressed in the Hearts and Minds booklet created by NAMI (website: [www.namih.org](http://www.namih.org) or call toll-free at (800) 242-6264.)

## What is Integrated Health Care?

*“Our 12-year-old son is 62 pounds and has absolutely no appetite. He has always been a terrible eater and extremely picky, but lately he eats just about nothing. He says he “can’t” eat, and often goes a whole day with just a piece of toast! I had him seen by an endocrinologist who said that he was in the 5th percentile for height and weight, and there was nothing she could do. He was told to eat better. His pediatrician says he is fine, healthy, so not to worry. He has been in therapy for years for OCD, anger management, and depression. We do feel that he is depressed now and is on medication and counseling. All this being said, he still won’t eat. What can we do? This is the time he should be growing and his body is getting NO nutrients. He can’t even take a multi-vitamin! We are terribly afraid for his health - and future health.”*

This real life question, addressed to an “Ask the Pediatrician” internet site, demonstrates the fragmented care often offered to families dealing with their child's complex mental illness. But, the more complicated the physical and/or mental problem, the greater the need for coordinated and integrated care. As an alternate scenario, the parent would likely not have these fears if the pediatrician, endocrinologist, and mental health counselor worked together as a team and communicated freely with each other and with the family.

Mental health services are frequently separated from physical health care, even though the symptoms cannot be so neatly divided. Policies and procedures present barriers to open communication between mental health counselors and medical professionals.

*Integrated health care* is a system of health care in which both mental and physical problems and disorders are treated at the same time. It is a system of care recognizing that mental disorders must be treated with equal importance as physical disorders. In an integrated health care system, effective mental health treatments will be available for most mental disorders. In an integrated health care system, primary care providers have the time, training, and resources to appropriately treat mental health problems and also have timely and appropriate access to mental health specialists for referrals.

Children with *serious emotional disorders* (SED) use services within one or more of these five distinct areas: schools, juvenile justice, child welfare, general health, and mental health. *Outcomes are improved, and often at lower cost, when providers within these fields work together.*

**Note:** This Guidebook includes a glossary intended to define the less familiar terminology used in the realm of mental disorders and related treatment plans. In

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addition, there are some familiar terms which take on particular connotations within the context of this Guidebook: *Family* can refer to the biological nuclear family, extended family caregivers, foster family, or adoptive family. The term *parent* refers to any guardian of a child, including the biological parent, foster parent, adoptive parent, grandparent, or relative who is filling the role of parent. The term *primary care provider (PCP)* refers to primary care physicians, nurse care practitioners, and others who provide medical or physical health care. The term *client* (or sometimes the term *consumer*) refers to any person receiving services from a publicly funded mental health program or provider.

### ***Why is Integrated Health Care Important?***

Mental health is fundamental to overall health! Therefore, it is important that mental health and physical health providers work together. Simply stated, the needs are significant, and yet a non-integrated approach often fails to meet these needs, as these findings indicate:

- Every year, about 20% of the United States adults and children experience a mental disorder.
- Despite having many known treatments, the majority of individuals with mental disorders do not receive proper treatment. Nationally, only one in five children with mental health disorders receives mental health services.
- One study shows that 40-60% leave therapy prematurely; another study finds that the great majority of children in outpatient therapy stop going after one or two visits. Of that number, 70% are youngsters with school behavioral problems and they are treated solely from limited resources of the public school system. A concerning statistic is that the dropout rate for children receiving mental health care is high.
- Many persons resist diagnosis and treatment of mental disorders because of the overwhelming societal stigma and discrimination applied to a person with mental illness.
- About 25% of individuals receiving primary care also have a diagnosable mental disorder.
- Primary care providers who are able to correctly diagnose a mental disorder may not adequately treat and monitor the person.
- Estimates state that approximately half of those with mental disorders go undiagnosed in primary care.

Despite its current deficiencies, primary care has great potential to engage individuals in need of mental health care.

The primary care provider is *often closer to home or work and more affordable* than specialty care and could provide cost-effective treatment, especially for less severe mental disorders.

Primary care has the potential for *early identification* of symptoms of mental disorders.

### ***The Collaborative Family Approach to Health Care***

The Collaborative Family Healthcare Association promotes the importance of collaboration between ALL providers (both mental and physical health) and believes the patient, family, community, and providers are *equal partners* in the treatment process. For more information about this approach, visit the Collaborative Family Healthcare Association website: [www.CFHA.net](http://www.CFHA.net).

### ***Necessary Components for Improving Care***

Barriers between patient, provider, and the medical system must be eliminated to create an effective system of care. “Mental Health Issues Today, Volume 7 (2)” is a publication that addresses this issue and outlines the necessary components for improving care for common mental disorders. From this publication, samples of these necessary components include:

- Educated clients or consumers, primary care providers, and mental health providers.
- Efficient and effective methods to screen for, diagnose, and monitor common mental disorders in primary care practices.
- Trained mental health staff who can support primary care providers with education, proactive follow-up, case management, psychotherapy, and consultation for patients who do not respond to first line treatments in primary care settings.

(This section was adapted from “An Integration of Mental Health Services and Primary Health Care” written by Michael J. Cohen, Executive Director of NAMI NH. To view the entire article, visit [www.naminh.org](http://www.naminh.org) and click on ‘Resources.’)

## **The Important Role of Your Primary Care Physician**

Most children with SED in New Hampshire have a primary care physician. Primary care physicians provide many of the prescriptions for psychotropic drugs. They also provide much of the initial mental health care to children with SED (even beyond common conditions like AD/HD and depression) until the child can be connected with mental health providers.

In New Hampshire, families are able to choose and change their pediatrician or family physician, but may be less able to select a specific therapist. The lack of choice may result from health insurance company regulations. Concern over this issue is frequently voiced by parents when they are receiving services within the public mental health system.

A family's lack of choice in selecting a mental health care provider implies that the family has no power to manage their child's mental health care. *This is not so.* That is the key message of this Guidebook.

### ***Reasons for the PCP to be Involved and Kept Informed***

Most children have a long-standing relationship with a *primary care physician* (PCP) who knows them, their health problems, and their families. It is also likely that parents have discussed some of the warning signs with the PCP (see the Chapter 3 section, “How to

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Know if Your Child Needs Help” on page 23). In contrast, insurance coverage can affect the length of time a child can be seen by a *therapist*, and turnover of therapists in the public mental health system remains high. *Continuity of care is more likely at the PCP level.*

Because the primary care physician may be the only professional freely chosen, the PCP can become an effective advocate for the family. As an advocate, the PCP can help parents work with the mental health system, provide a comfortable environment in which parents can raise questions and concerns about their child's treatment, and help parents become assertive members of their child's treatment *team*.

As a member of the child's treatment team, the PCP can support the mental health treatment plan and encourage parents to continue treatment even through times of despair and frustration... which otherwise might result in prematurely ending a recommended treatment plan.

Specific areas in which PCP involvement can be helpful to the child and family include the following:

- Making and monitoring referrals to mental health providers, collaborating with other systems (schools, juvenile justice, child welfare), and identifying and working with other community resources.
- Searching for medical conditions that may contribute to mental health problems while identifying those physical symptoms caused by mental conditions.
- Monitoring psychotropic drug effectiveness and side effects, as such medications may affect the *physical* health of the child. Families and the prescribing professional should maintain communication with the PCP about the child's medication regimen. It is essential the PCP know what medications are being prescribed, why they are being prescribed, what beneficial changes are expected, and what side effects should be watched for. Accordingly, the PCP should be informed if the dose is changed or the medication stopped.
- Managing psychiatric emergencies - the PCP needs to know about any crisis management plan (see Chapter 8, “Crisis Management Planning” beginning on page 101) as they are often called to assist when emergencies arise.
- Supporting the family's “choices” about the type, location, frequency, and duration of treatment.
- Reinforcing family strengths and the individual progress of the child with SED and helping the family understand the diagnosis and treatment plan. The likelihood of suddenly stopping therapy is less if the family feels like a valued member of the child's treatment team.

For young people with certain problems such as anorexia nervosa, bulimia, and substance abuse, a crisis management plan understood and agreed upon by the PCP may make a difference between life and death.

The PCP can see the children and adolescents with SED in the normal course of events. Once mental health treatment is stopped (for any reason, including completion), the PCP continues to provide care for the child. Therefore, it is important for the PCP to be part of the child's treatment team and an involved member of the “wraparound process.” (See Chapter 5, “Navigating the Treatment System” beginning on page 61.) *The PCP brings a*

*needed expertise to the team and ensures the child is receiving integrated care. (See Chapter 1, “Integrated Health Care” beginning on page 1.)*

### **Barriers to Communication - Real and Perceived**

*If communication between mental health professionals and the child's primary care physician is such a good idea, why is it not routine practice? Parents and professionals have identified several barriers to communication and coordination of care among professionals.*

*Confidentiality is often a barrier to communication between providers. Mental health professionals are able to share details of the mental health treatment plan with the PCP when a *consent to release medical information* is signed by the individual and/or guardian. (Certain information can be shared in times of medical emergency without a signed consent.)*

The child and family should review the issue of information sharing with the mental health provider and be encouraged to sign a consent to release medical information for their PCP.

Occasionally, families are reluctant to have information about their child's medical or mental health treatment shared. It is important for providers to work with families to develop trust so that information can be shared. *The child is best served if all the treating professionals are “on the same page” and this occurs when they are able to share pertinent information.*

Federal privacy laws (HIPAA) are often misinterpreted. Contrary to common belief, fax, phone/voice messages, and e-mail are allowable means of communication. However, parents should ask for clarification from the medical and mental health providers regarding their internal policies and procedures to ensure privacy and confidentiality.

Therapists and primary care physicians may have different office hours and work schedules, thus less opportunity to communicate. Accordingly, providers have suggested *scheduling* telephone contacts or using other means of communication (see above). *Nothing prevents communication between providers if a consent to release medical information is completed by the client and/or legal guardian.*

Mental health professionals and primary care physicians are rarely trained to interact with each other. They have different priorities, as they come from different professional cultures. Although some PCPs may even appear to lack interest in mental health issues, they indicate it is *not* a lack of interest, but rather a lack of mental health training. However, that is changing. The trend for integrated health care is a growing movement and will ensure continuity of care and better coordination.

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## **Solutions**

Individuals, medical specialty groups, and governmental agencies have recognized the lack of communication and collaboration as a problem and have offered a variety of ways to help. In the U.S., the National Mental Health Association and the American Academy of Child and Adolescent Psychiatry have programs and policies intended to integrate mental health care with other medical fields. In New Hampshire, a grant received from the federal Maternal and Child Health Bureau has encouraged psychiatrists and pediatricians in several areas to meet regularly to discuss problem cases, develop relationships, and learn from each other.

In some managed care plans, the PCP is, in effect, a manager of care and is required to be aware of everything about a patient's health care (medical and mental health).

Other possible solutions to ensure integrated health care might be:

- PCPs need to develop close contacts with their local mental health colleagues. Having lunch, dinner, or other social interaction with mental health providers on a regular basis will help develop a comfortable familiarity.
- The mental health provider and PCP must adopt the *common practice* of communicating, collaborating, and supporting the child and family in all aspects of their health treatment.
- On a state level, agencies involved with mental health, developmental disabilities, and substance abuse should: involve primary care physicians on mental health planning committees and advisory panels, incorporate the PCPs' ideas into planning for future health services, and reinforce the message that PCPs have a role to play in delivering mental health services.
- Workshops that focus on integrated health care should be co-sponsored and attended by primary care *and* mental health groups to further promote coordination and collaboration between the medical and mental health systems.
- Systems and procedures can be developed in every community for improving communication and collaboration. Types of collaboration that currently exist between physicians and school personnel may be copied in the mental health field. As an example, a community mental health center or mental health practice could identify a "contact person" who will regularly communicate and be available for consultation to local physicians.

## **What Parents Should Do**

Integrated health care means collaboration and the sharing of information including diagnosis, functional status, the treatment plan, symptoms, prognosis, and progress to date. Further helpful information for the PCP includes the family and child's strengths, whether the child is keeping appointments, when treatment is stopped, the crisis management plan, and if the child is suicidal or homicidal.

Parents should ask themselves, “Who should receive information to improve health care for my child?” *Parents have the right and responsibility to insist that information be shared on a regular basis.* Parents have a right to indicate *what* information will be shared, although in most cases, *full* sharing by all involved professionals improves the opportunity for the best results from the treatment plan.

Parents should insist that the mental health provider and primary care physician are communicating on a regular basis and that the necessary consents to release medical information are obtained.

At each PCP visit, parents (and child, depending on age) should discuss how the child is functioning at home, at school, and with friends. Discussions should address severity of behaviors, sources of current stress, and whether any other family member has been seen for mental health treatment.

Similarly, parents should expect the mental health provider to ask about medical problems. If there are significant new medical issues, these should be communicated by the PCP to the mental health provider. If the PCP prescribes psychotropic medication (such as for AD/HD), this information must be communicated to the therapist. *This is of course easiest to do when care is integrated and the PCP is an identified and active member of the child’s health care team.*

### **Resources**

The integrated health care approach and emphasis on working with your PCP is supported by current literature. Parents and youth are encouraged to review:

“The President’s New Freedom Commission on Mental Health, Executive Summary, Final Report, July 2003” (available by contacting NAMI NH at [www.naminh.org](http://www.naminh.org) or call toll-free at (800) 242-6264. Also available at [www.mentalhealthcommission.gov](http://www.mentalhealthcommission.gov) or call toll-free at (800) 789-2647).

“Report of a Surgeon General’s Working Meeting on the Integration of Mental Health Services and Primary Health Care” held on November 30-December 12, 2000 at the Carter Center: Atlanta, Georgia (available by contacting the Office of the Surgeon General, Rockville, MD 20857 or online at [www.surgeongeneral.gov/library](http://www.surgeongeneral.gov/library)).

## **Shared Decision Making**

### ***What is Shared Decision Making?***

Shared decision making is a process where treatment providers present information about the risks and benefits of treatment options to children and their family members. The child and family have an opportunity to ask questions and share their views and opinions. This sharing of information and conversations enables the “team” (child, family, and providers) to make quality health care decisions and promotes positive treatment outcomes for the child and family.

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## ***Framework for Shared Decision Making***

The relationship between the treatment providers, child, and family receiving services is important. Characteristics of the relationship that contribute to shared decision making are listed below:

To take full advantage of the shared decision making process and to work for positive treatment outcomes, each member of the team has a role and responsibility.

- **Partnership:** Everyone's contribution to a decision is valued and equally important including those of the child/adolescent, family/caregiver, and treatment provider.
- **Respect:** Parents are not blamed for their child's mental illness, and there is no blame assigned if an intervention does not work.
- **Open Communication:** Treatment begins with open discussion and active participation of all those involved. Treatment providers need to ask for and be open to feedback from the child and parent about what is working and what is not working so that changes can be made.
- **Knowledge:** Parents and children need to share their knowledge and experience of living with a mental illness with their treatment providers.
- **Sensitivity to Cultural Differences:** Parents and treatment providers need to remember that cultural, language, and socioeconomic differences between the family and treatment providers can affect access to and understanding of the treatment plan. (See the Chapter 4 section, "Cultural and Language Differences" on page 59.)
- **Flexibility:** People respond differently to medications and therapies. Treatment providers need to help the child and parent understand that the first outcome may not meet expectations. Often, the best outcomes require the treatment providers to adjust or change medications or frequency of therapy based upon continued information and feedback provided by the child and/or parent. The treatment providers should encourage HOPE even when expectations are not met.
- **Best Practices:** The treatment providers should carefully consider what is known about the safety and effectiveness of medications and therapies that are being considered. The treatment providers should also take into account the child's age and developmental stage in making the diagnosis and in offering treatment recommendations. When medication is prescribed, the treatment providers should include the child's age and development stage in determining the best safety, least side effects, and potential long-term implications of his or her prescribing decisions.
- **Responsibility:** Using the framework for shared decision making is everyone's responsibility (child, parent, and treatment providers) so that informed decisions about treatment can be made effectively. This process should include discussions about why a certain medication can be helpful as part of the treatment, or why a certain medication or treatment is not recommended based on the individual needs of the child and the latest evidence available.

## ***What are the Medications and Side Effects?***

Serious emotional disorders (SED) can be treated effectively with medication. Common disorders that are treated effectively are attention deficit hyperactivity disorder (AD/HD), mood disorders, anxiety disorders, thought disorders or psychosis, and autism. (See

Chapter 4, “About Serious Emotional Disorders and Behavioral Issues” beginning on page 35 for diagnosis descriptions.) The brief overview (below) of medications and side effects should provide a general understanding of medication treatment as part of a “broad” treatment plan. The information may also help suggest questions to be asked of the treatment providers. The overview is not intended to be comprehensive; additional information should be obtained from treatment providers and other resources. (See Appendix C, “Disorders” beginning on page 125.)

Not all stimulants and medications used for treating mental illness in children and adolescents have been fully studied. However, a great deal of evidence exists to show the usefulness of many medications in the treatment of SED. This overview focuses on:

- Medications that have had thorough research and U.S. Federal Drug Administration (FDA) approval for use with children and adolescents.
- Medications, approved for adults, that have been used with children and adolescents and have been evaluated but not yet approved for use with children and/or adolescents.
- Medications that are used with children in clinical settings, approved for adults, have limited evaluation, but suggested usefulness in children and adolescents.

### **Stimulant Medications**

FDA approved for use in the treatment of attention deficit hyperactivity disorder. These medications have been studied a great deal. Stimulant medications include: methylphenidate (Ritalin), D,L-amphetamine (Adderall XR). Stimulants are well established to be successful for AD/HD in school age children and adolescents. The most common side effects are difficulty falling asleep, loss of appetite, and jitteriness. Atomoxetine (Strattera) is not a stimulant and is more similar to antidepressant medications and is now approved for treating AD/HD.

### **Antidepressant Medications**

These include the older tricyclic antidepressants (e.g. imipramine), selective serotonin reuptake inhibitors or SSRIs including fluoxetine (Prozac), sertraline (Zoloft), paroxetine (Paxil), fluvoxamine (Luvox), citalopram (Celexa), and escitalopram (Lexapro), and other newer medications including venlafaxine (Effexor) and bupropion (Wellbutrin). With respect to the risk of overdoses, the SSRIs are among the safest choices for the treatment of depression and have more evidence supporting success in children than the older tricyclic antidepressant medications. Currently, Luvox, Prozac, and Zoloft have FDA approval for use with children and adolescents. Recently, however, concerns have been raised that the SSRI medications may bring on suicidal thoughts and behaviors in youth.

Indeed, side effects of the medications can include impulsivity, nausea, hyperactivity, jitteriness, sleeplessness, and interference with sexual activity. The side effects may be dose related and many doctors are now using lower starting doses than in the past.

At present, Paxil is no longer recommended for use with children and adolescents. If it is being used, a decision regarding its continuation should only be made on the recommendation and with the supervision of a physician. The National Institute of Mental Health (NIMH) is conducting research to help clarify the potential value and risks of antidepressants, and is exploring how medications compare with psychotherapy in adolescent depression. A research advisory issued August, 2004 noted that one SSRI

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(fluoxetine-Prozac) study confirmed that the most effective treatment for adolescents with depression is a combination of medication and psychotherapy. Presentations at the FDA advisory committee meetings September, 2004 made clear that there are gaping holes in the research related to suicidal behavior and the use of antidepressant medications for youth. Additional guidelines regarding the use of SSRIs in children have been issued in a “black box” warning set forth by the FDA. Check with your provider.

### **Mood Stabilizers**

Mostly classified as novel (new, “atypical”) or traditional (“typical”). Novel agents include olanzapine (Zyprexa), risperidone (Risperdal), quetiapine (Seroquel), ziprasidone (Geodon), and aripiprazole (Abilify). Traditional agents include haloperidol (Haldol) and thioridazine (Mellaril).

The older agents have been linked with neurological side effects and the novel agents are generally preferred today, although the newer agents may also be associated with neurological side effects. Additional side effects of the new agents include weight gain or interference with sexual function and menstruation. Most of the information available about safety and effectiveness are from studies of adults. There has been limited research evaluating several of these drugs in children and adolescents that show their usefulness.

### ***How Long is Medication Needed?***

The best possible length of medication treatment can vary widely depending on the individual’s response to the medication. Some individuals may need medication for a short period of time while others may require medication throughout their lifetime. Medications may need adjusting until the most effective dosage is reached, while experiencing minimal side effects. In addition, families should discuss (with the treatment provider) ‘workable’ medication schedules to ensure medication is taken as needed.

In most cases, treatment with medications works better when combined with non-medication treatments such as family education, individual therapy, family therapy, case management, and other services and supports.

(When children are taking medication, it is important to try to establish a medication schedule that does not require them to take the medication at school as this often results in the child being a victim of stigma.) In all cases, parents need to monitor medication administration... and providers need to continually evaluate the child on medication.

### ***Family Supports***

When and how to use medication treatment can pose tough questions that often do not have easy answers. We believe the shared decision making process will lead to the “best” answers. Help in finding the answers is available in other ways, as well. A family support and education organization such as the National Alliance on Mental Illness New Hampshire (NAMI NH) can be of service to families and treatment providers. NAMI NH understands that families coping with a child or adolescent who has SED can feel isolated and discriminated against. NAMI NH encourages parents to join education and support groups which can help them learn from the experiences of other parents and recognize they do not have to “go it alone.”

## Chapter 1. Integrated Health Care

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In addition, NAMI NH staff and volunteers can assist families with SED children in learning how to effectively navigate the multiple service systems including education, mental and physical health, and juvenile justice.

We believe that a decision to use medication for a child’s mental illness should be a fully informed one. We further believe that treatment effectiveness will be improved if parents, children (depending on age), and treatment providers use this *shared decision making process* and parents seek out support and education from organizations like NAMI NH.

(This section, “Shared Decision Making” has been adapted, with permission, from “Shared Decision Making: A Guide for Parents and Caregivers of Children & Adolescents with Mental Disorders Requiring Medications” written by Michael J. Cohen, MA, CAGS and Thomas A. Mellman, MD, October 2004.)

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# Chapter 2. Taking Care of the Caregiver

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## Chapter Overview

*We agree with airline flight attendants who tell you, if the need arises, to put an oxygen mask on yourself, **then** put an oxygen mask on your child. If **you're** not getting enough oxygen... if **you're** not getting what you need... you won't be able to help your child get what he or she needs.*

*Most of the information in this Guidebook is about caring for your child. This chapter is about caring for you, the caregiver... the person who has to connect **both** oxygen masks.*

*If you are adjusting to the idea that you have a child with a serious emotional*

*disorder (SED), you might feel overwhelmed with the changes, losses, and challenges brought to your life. Some parents describe this experience as a "triple whammy" – a family crisis, a marital crisis, and a personal crisis.*

*This chapter will help you to understand 1) the emotional reactions you and your family can expect to have as you adjust to your child's illness, 2) constructive ways to handle these emotional reactions, and 3) places where you can go to find the support you need.*

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### The Stresses of the Caregiver

Families *and* mental health professionals know the stresses of caring for a child with a serious emotional disorder (SED) are real. The stresses include changes to daily family life, anger, worry, feelings of loss (grief), social isolation, feeling blamed, and increased financial expenses.

Families with children who have SED commonly face some or all of these caregiver stresses. Surprisingly, these families also say the caregiver experience has enriched their lives and has provided them with feelings of empowerment they did not have before.

But to achieve this, a family needs enough information to understand the disorder, and enough support to become fuller, stronger, and enriched by the experience. The sections that follow are designed to give you the information you need to feel competent and complete.

“For a long time, I just hated Lonnie. I hated him for ruining my life, for causing the divorce, for being around at all. I could hardly look at him sometimes because he seemed to be the source of all my problems. Then I looked again, really looked, and saw the lost, frail child who had been there all along. Lonnie didn’t choose to be sick. At that moment, I loved him so much and felt so bad for all that I had been thinking.”

#### **Cultural Differences Bring Additional Challenges**

In addition to having a child with SED, some families have the added stress of belonging to a cultural group that is not understood and valued by the dominant American culture. Different cultural groups might have different attitudes toward mental illness, the practice of medicine, and sharing their private lives with strangers in order to receive care and support. If you are a member of any minority group, be aware that professionals should be providing you with “culturally sensitive care.” Professionals should also acknowledge how *your* cultural and language differences will impact your seeking support for yourself and your child.

Training for mental health professionals has begun to include awareness of the impact of a family’s religious, language, ethnic, economic, gender, and sexual differences. For example, the *Journal of Transcultural Nursing* has published research on how to care for the following different groups of people: Islamic, Jewish, Haitian, Eritrean, Jordanian, Cambodian, HIV-positive African Americans, Korean, Puerto Rican, lesbian, Hutterite, rural people of Appalachia, and residents of poor urban communities.

If professionals are not addressing the cultural, religious, or language differences in your family, mention the differences to them, and ask them to be sensitive to these differences, or to refer you to someone who can provide culturally sensitive care. This reminder should be enough. If it is not, call the New Hampshire Minority Health Coalition. (Contact information is provided in Appendix C, “New Hampshire Minority Health Coalition” on page 122.)

## Adapting to the Change in Your Life

“Why is this happening to us?”

“What have I done wrong?”

“When does it end?”

These are the questions parents often ask themselves after finding out their child has SED. The feelings and reactions to the news vary from family to family, and among members of the *same* family. However, there are some predictable emotional reactions that most will have sooner or later.

“Everywhere we turned, someone had something negative to say about the way we raised our son. They questioned us about everything we did. They blamed us for Ron’s crazy behavior. We were exhausted and began to think they were right. Maybe we were causing him to behave as he did!”

### ***Emotional Stages in the Adjustment Process***

Listed below are the predictable emotional stages of adjusting to the news that your child has SED. For each emotional stage, we describe the feelings, thoughts, and needs to expect in that stage. [Source: *Pathways*, pages 34-35. NAMI - Vermont, Brattleboro VT]

Stage	Our Feelings and Thoughts	Our Needs
<b>Crisis/Shock</b>	We feel overwhelmed, confused, and lost. Something shocking is happening, and we don’t know how to deal with it. We feel emotionally out of touch with ourselves and unable to grasp information or what is going on around us. We might rush around from one task to another without finishing any, or withdraw and sit for hours unable to move or function.	Support. Comfort. Help finding resources. Empathy for our confusion and pain.
<b>Denial</b>	We pretend not to notice our child’s strange behavior, or we think there is a logical explanation, or that it will go away. This protective reaction gives us time to process the painful news that has turned our lives upside down.	Support. Comfort. Help finding resources. Empathy for our confusion and pain.
<b>Unrealistic hopes</b>	We begin to think that if we make a huge effort, we can change everything, and our lives will go back to normal. This usually does not work, and another crisis or relapse startles us into seeing that our hopes are not realistic.	Support. Comfort. Help finding resources. Empathy for our confusion and pain.
<b>Anger, guilt, shame, resentment</b>	We are sick of the problem. We start “blaming the victim,” ourselves, or each other, expecting the ill child to “snap out of it.” We also, at the same time, are feeling guilty, suspecting that it might be our fault. Then we overcompensate and become overly involved with the problem. We reject our child and are overly caring at the same time. This mixture of feelings and reactions drains us emotionally and physically.	Vent feelings. Keep hope. Education. Self-care. Networking. Skill training. Letting go.

## Chapter 2. Taking Care of the Caregiver

Stage	Our Feelings and Thoughts	Our Needs
<b>Recognition</b>	The fact that our child has a serious illness starts to become real to us. Something tragic occurred that has changed our lives together as a family. We begin to divide our lives into two periods: before the illness, and after the illness.	Vent feelings. Keep hope. Education. Self-care. Networking. Skill training. Letting go.
<b>Grief (sorrow)</b>	We mourn the loss of our life together before the illness. We deeply feel the full tragedy of what our child is dealing with, and grieve for the future we had expected for our child, because it is uncertain.	Vent feelings. Keep hope. Self-care. Education. Networking. Skill training. Letting go. Cooperation from the system.
<b>Understanding</b>	We start to gain a solid, caring sense of what life is like for our child. With some of our fear behind us, we start to gain respect for our child's strength and courage.	Activism. Restoring balance in life. Responsiveness from the system.
<b>Acceptance</b>	"Yes," we finally say, "bad things do happen to good people." We do wish this had not happened to us, but it did, and we accept it. It is not our fault; it is not our child's fault; it is a sad and difficult business, and we will work together and learn to manage it.	Activism. Restoring balance in life. Responsiveness from the system.
<b>Advocacy and action</b>	We now start to focus our anger and grief, and work toward getting the care we and our child need. We "come out" and fight the shame toward mental illness. We join advocacy groups and get involved.	Activism. Restoring balance in life. Responsiveness from the system.

### ***Moving Back and Forth within the Stages***

The emotional stages in the preceding table seem to flow in a logical order from one to the other – but that's not the way they will be experienced.

After you have worked your way through a stage (no longer feeling extreme anger or guilt about your child's condition, for example), you might have those feelings again weeks or months later. Sometimes, you might experience more than one stage at the same time – with emotions that seem totally contradictory (acceptance *and* guilt, for example). None of these stages are wrong or right; they are normal reactions that anyone feels when faced with serious illness and a critical disruption in his or her life.

"I found myself hating my own kid, wishing he had never been born. I saw what he was doing to my wife, the way my daughter hid from him; I knew he was destroying us, and I hated him for it. Yet, deep inside, I loved him so strongly. He was ours and meant so much to us. How could I hate my own son?"

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## ***Variations within Your Family***

There is no “best way” to go through the stages in the adjustment process. You will go through the process *your way*. Other members of your family will go through it *their way*. Don’t expect other family members to be having the same feelings you are having while you are having them. For example, a mother might be having unrealistic hopes and working feverishly to find a “cure” for her son’s disorder; while the sister is feeling the anger-guilt-shame stage, aware mostly of the embarrassment her brother is causing her at school; and the grandfather is experiencing the deep grief of the loss of the grandson and family as they were before.

Knowing where you are in the process can help you to be more gentle with yourself and more understanding of others who might be at a different stage in the process.

## **Hints for Taking Care of Yourself**

Whether you are a parent, sister, brother, aunt, uncle, or grandparent, you will be better able to help the child with SED after you *take some time for yourself*, as well as spend time with others who understand your situation.

Find a book, a self-help group, or a class where you can learn how to practice one or more *relaxation techniques*, such as yoga, aerobic exercises, and meditation.

**Important!** An absolute *must* is getting enough rest.

In addition to getting enough rest, *good nutrition* is important, especially at the outset of researching and planning for your child’s care. Your body needs the right fuel to support a sustained energy level. Eat steady amounts of protein throughout the day, and limit “sweets,” which tend to give “bursts” of energy, followed by “crashes” of sleepiness or feeling depressed.

Another important consideration is establishing *your personal limits*. Acknowledge what your limits are, and avoid taking on responsibilities that are beyond what you can handle. Remember... you can only provide quality care if you take care of yourself. Set appropriate personal limits, and seek support from individuals, groups, and organizations who can help strengthen your ability to care for your child.

Some caregivers think that the best advice comes from the people who have lived through what they are going through now. We offer this kind of advice in the following section.

## ***Advice from Other Families***

The families of the National Alliance on Mental Illness (NAMI) indicate that the following actions made life easier as they cared for themselves and their child with SED.

- Learn all you can about the disorder that your child has.
- Remember, other family members (partners, brothers, sisters, aunts, grandparents, and friends) are also affected. They are probably feeling the same strong emotions that you are. Take the lead in keeping communication open by talking with them about this. Grandparents, aunts, and uncles might be your greatest source of strength and help.

- Feeling guilty is normal; don't let it get you down. Try not to place blame... on anyone.
- Find out about support systems while things are going *well*. Don't wait for a crisis.
- Anticipate troublesome situations. For example, if your child is feeling anxious, postpone that trip to the crowded supermarket.
- Do not stop medications because the symptoms seem better, or because the child says that the medication "makes me feel sick." Instead, give feedback to the doctor who prescribed the medication, and make sure the doctor understands your child's uncomfortable feelings. A change in medication or doctor might be required, but talk with the doctor first and agree on a shared decision. (See Chapter 1, "Integrated Health Care" beginning on page 1.)
- Set reasonable rules and limits, and stick to them. If this is difficult to do, ask the doctor or therapist to help you learn how to set firm limits with your child.
- Be realistic about what you can and cannot do and communicate these limitations. There are limits on how much time, physical energy, emotional energy, and money you have for your child. If a practitioner makes a recommendation for something that you know just is not going to happen (for whatever reason), *inform the practitioner* so that he or she can have a clearer understanding of your family situation, and possibly suggest an alternate activity.

### **Parents' Bill of Rights**

Parents are *very* aware of their responsibility to provide for their sons and daughters, but are seldom aware of the rights *they* have as caregivers:

#### **You have the right to...**

- Accept that you are doing the best you can, and that "it's good enough."
- Have needs that are as important as the needs of your child.
- Have your own hobbies and interests. (*"When I go back to doing the things I used to enjoy, like artwork and model building, I get out of my negative mood."*)
- Enjoy being alone at times, and let your child have his or her own privacy.
- Tell your child that his or her behavior is unacceptable.
- Get angry once in a while.
- Say you do not want to talk about your problems. (*"I'm tired of talking about my son or daughter."*)
- Not tell the whole truth to everyone. (*Say "fine" when someone asks how it is going.*)
- Devote as much time as you want to the cause of the illness, or get away from it for a while.
- Have a vacation away from your child every year, have dates, celebrations, weekends away, and time together with your partner to enhance your relationship.
- Be gentle with yourself!

**Important!** Parents who do not enjoy some of these rights are probably unhappy or tense most of the time. Parent martyrs are seldom appreciated by anybody, least of all by their son or daughter with SED.

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## Caregiver Support in New Hampshire

Contact information for the many organizations that can support you, your child, and your family is provided in Appendix C, “State and National Resources” beginning on page 119. In this section, we provide a more detailed description of the National Alliance on Mental Illness New Hampshire (NAMI NH) which provides support and advocacy for children with serious emotional disorders (SED) and their families.

### ***National Alliance on Mental Illness New Hampshire***

NAMI NH is the New Hampshire chapter of the National Alliance on Mental Illness. With a membership of over 500 families, NAMI NH promotes and supports a statewide network of family education and support groups.

NAMI NH works to empower family members to exercise their rights in order to improve the quality of their lives and the lives of their family members with SED. NAMI NH teaches families the skills they need to receive family-centered, culturally competent care for their children and support for themselves. NAMI NH offers the following programs and supports:

- An Information and Referral Service that can address:
  - Particular disorders and treatment options.
  - Finding and using services in New Hampshire.
  - The rights of the child and family.
  - Caregiver support.
  - Guidance and suggestions on how to be effective when working with service providers.
  - Any concern regarding a child’s mental illness.
- A lending library of materials about mental illness.
- Conferences and workshops where state and national experts discuss topics of interest to families and professionals.
- A local family educational series where family members can get a better understanding of their individual situations, their roles as advocates, and the legal rights of caregivers and children.
- Support for the families of adults with mental illness.
- “Parents Meeting the Challenge” support groups for parents/caregivers of children and adolescents with SED.
- “Family Members Support Groups” for family members and other individuals who have an adult loved one with mental illness.

“When I ask you to listen to me,  
and you start giving me advice, you have not  
done what I asked.”

“When I ask you to listen to me,  
and you begin telling me why I shouldn’t feel  
that way, you are trampling on my feelings.”

“When I ask you to listen to me,  
and you feel you have to do something to  
solve my problem, you have failed me,  
strange as that may seem.”

—From *On Listening*,  
by Ralph Broughton, M.D.

## Chapter 2. Taking Care of the Caregiver ---

- Training and consultation to professionals.
- Public educational programs on various mental health and mental illness related topics.
- “In Our Own Voice,” a recovery educational program presented by consumers of mental health services.
- Website: *www.naminh.org*

Contact information is provided in Appendix C, “National Alliance on Mental Illness New Hampshire (NAMI NH)” on page 128.

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# Chapter 3. Partnering in Your Child's Care

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## Chapter Overview

*This Guidebook is designed to empower your family in developing a treatment plan and educational goals for your child and to provide insight on working with community services and supports to achieve those goals.*

*This chapter will help you partner with*

*the professionals who work in the systems further explained in this Guidebook.*

*The first section of this chapter is designed to provide professionals with an understanding of the philosophy of partnership, which is the foundation of this Guidebook.*

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### Families and Professionals Working Together

#### ***Guidance for the Professional and the Family Working Together***

Current mental health literature describes *the family* as “their children’s most important resource. The role of professionals should be to assist families in meeting their own goals and to empower them to achieve mastery and control over their life circumstances.”

[Source: *Promoting Family Empowerment through Multiple Roles*. Susan L. McCammon, Ph.D., et al, 2001]

The best model that NAMI has found for empowering families to care for their children with serious emotional disorders (SED) is a *partnership* between the families and the professionals involved in their child’s care. This partnership relationship is based on sharing the skills, knowledge, and experiences of each partner. This empowers parents. They begin to take action to get what they need and they begin to contribute and offer valuable information to professionals to help develop the best treatment decisions. (See Chapter 1 section, “Shared Decision Making” on page 8.)

If a family has difficulty understanding a proposed treatment plan or are uncooperative with the treatment plan for their child, it may be a signal that mutual goal-setting did not occur. Families are likely to take an active role in the treatment plan when *their* definition of the problem and *their* choices about the type, location, frequency, and duration of services have been considered and incorporated into the plan.

“I can do for myself; I’m not helpless – maybe discouraged and faltering, but not helpless.”

“When you do something for me that I can and need to do for myself, you contribute to my fear and inadequacy.”

–From *On Listening*, by Ralph Broughton, M.D.

Here are some ideas that will help to foster a professional-parent partnership:

- Families with children who have special needs are more similar to other families than they are different. Although they handle more intense stresses, and handle them more often, they are trying to achieve the same quality of life and are using the same methods for relieving stress as are all families.
- Policies designed to serve children with SED can often become barriers to effective use of services. For example, social policies are often only responsive to families in crisis, encouraging intervention only after a problem or damage has occurred.
- Experience and research have shown that parents of children with SED generally welcome parent-to-parent support and often seek it in times of need, confusion, and discouragement. Parents who have “been there” can be effective resources for information and guidance, and can act as role models and advocates for other parents.
- Take a long-range perspective of children with SED while keeping an important focus on accomplishing short-term objectives through annual treatment and service planning.
- Family members can provide valid and well-informed assessment information, including identification and description of their child’s strengths and needs. When parents are *not* involved in decision making and service delivery, they can develop feelings of helplessness, dependency, and resentment.

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- Professionals are asked to listen carefully to what parents tell them and be open to new perspectives.
  - Studies (DeChillo, 1993) have found that increasing family involvement in discharge planning results in better post-discharge functioning and a lower likelihood of relapse.
  - Support systems, such as extended family, neighbors, churches, schools, and volunteer organizations, are critical for family success.

## How to Know if Your Child Needs Help

You are reading this Guidebook either because your child has a serious emotional disorder (SED), or because you *think* your child has SED. It is often difficult to know if a child's unusual behavior is beyond the child's control, or if the behavior is a temporary response as the child moves into a new developmental stage.

"I knew he was gradually breaking all the toys and furniture in his room, but I just kept cleaning up and hauling away the broken pieces as though nothing had happened. Disciplining him seemed to be such an effort, and did no good. Soon his room was bare and scarred. I was ashamed to go in."

### ***Where Do You Draw the Line?***

When a child's behavior is disruptive, even members of the child's family might not agree on whether the behavior is a problem. For example, a child who has frequent and severe temper outbursts or who destroys toys can seem to have a serious problem to one parent, while the other sees this behavior as showing independence or healthy willfulness.

Emotional extremes are part of growing up, and occur as children respond to changes in their growth and development, especially during the adolescent years. Every child faces emotional difficulties from time to time, as do adults. But, these problems usually disappear on their own or with a few sessions with a counselor. However, some children have challenging emotional and behavioral responses that persist over longer periods of time.

So, when is that "magic moment" when parents realize that their child's emotional or behavioral responses are beyond the boundary of what all children do? At what point are the responses alarming enough to justify a formal assessment? You probably will not have one "magic moment" but rather a gradual awareness that your child's emotional or behavioral development is not where it should be. But if you become familiar with some warning signs, you will be able to evaluate your child's behavior more clearly.

### ***Some Warning Signs***

Some behavior patterns are warning signs that a child might have SED. Because different behaviors are the normal responses to different developmental stages, we have listed the warning signs for elementary school children and adolescents separately.

#### **Children of elementary school age**

- Difficulty going to sleep.
- Difficulty participating in activities that a child of the same age may do without difficulty.

- Frequently refusing to go to school.
- Inability to make friends.
- Persistent nightmares.
- Frequent, unexplainable temper tantrums.
- Hyperactive behavior: fidgeting or constant movement outside regular playtime activities.
- A steady decline in school performance. Poor grades, despite trying very hard.
- A pattern of deliberate disobedience or aggression, and no remorse for breaking rules.
- Much difficulty with attention, concentration, or organization.

### **Children in junior and senior high school**

- Negative mood and attitude over a long period, often accompanied by poor appetite, difficulty sleeping, or thoughts of death.
- Opposition to authority, truancy, theft, vandalism, and consistent violation of the rights of others.
- Seeing and/or hearing things that are not there.
- Social withdrawal.
- Disregard for personal appearance and hygiene.
- Abuse of alcohol and/or drugs, or heavy tobacco use.
- Strong fear of becoming obese, in spite of normal or light body weight; repeated dieting; vomiting.
- Frequent outbursts of anger, or inability to cope with problems and daily activities.
- Sudden change in school performance.
- Sudden changes in sleeping and/or eating habits.
- Persistent nightmares.
- Many physical complaints.
- Threats to injure self or harm others. (See Chapter 4 section, “Child and Adolescent Suicide” on page 51.)

**Important!** If your child talks of suicide, or hurts himself or herself or others intentionally, *get immediate assistance and do not leave your child alone*. If necessary, take your child to an emergency room for a psychiatric assessment, or call the local police for assistance if you are afraid.

- Sexual acting out. (Having inappropriate sex and/or using sexuality in risky behaviors.)
- Threats to run away.
- Strange thoughts/feelings and/or unusual behaviors.

### **Validating Your Concerns**

It is helpful to learn how your child acts when he or she is not with you, and how teachers or child care providers compare his or her development with children of the same age.

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Carefully observe your child’s behavior, keeping in mind the warning signs. Compare these observations with those of others by talking to your child’s teacher, child-care or after-school provider, or a close relative or friend who sees your child often.

Based on this direct observation and feedback from others, you may determine that your child has behaviors that should probably be evaluated by a mental health professional.

### **Seeking an Assessment**

Your child’s primary care physician can help clarify the situation by: 1) ruling out physical health issues; and 2) referring you to a child or adolescent psychologist or psychiatrist who can administer the psychological assessment. (See Chapter 1, “Integrated Health Care” beginning on page 1.)

When you call to make the appointment for your child’s assessment, also ask for some time to talk to the doctor alone. Before going to the appointment, make a list of all your concerns about your child so you can discuss each one with the doctor.

“I’m so thankful we finally got to see a psychiatrist. When he told me Michael had obsessions because of an illness in his brain, everything fell into place. I suddenly thought of the whole animal kingdom and what it would mean for a bird to have a bum wing. I figure wing is to bird as brain is to boy – we have to treat Michael’s brain.”

–The mother of a 9-year old boy

If your concerns involve your child’s academic performance, you can request an evaluation for an *Individual Education Plan* (IEP). (See Chapter 6, “Safeguarding Your Child’s Education” beginning on page 85 for more details on what the educational system may be able to provide for your child and how you can become an active partner in that system.)

The costs of private assessments can be high, but funding does exist. Most insurance companies cover all or a portion of assessment costs. Private doctors or mental health professionals usually accept private insurance; some accept Medicaid and some may be willing to provide services on an adjusted fee basis. Healthy Kids (Medicaid) may cover the costs for eligible families. If your child is eligible for Healthy Kids, the “Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program” provides preventive health care, including assessment, diagnosis, and appropriate mental health services. (See Chapter 7, “Paying for Services” beginning on page 95 for more information on Healthy Kids eligibility and other ways to pay for services.)

*Community mental health centers* (CMHC) offer thorough assessment and some offer diagnostic testing for children and adolescents, and can provide these services on a “sliding scale”, income-adjusted basis. However, the demand for services at CMHC is great, and one may have to wait for an appointment. To find the regional community mental health center in your area, see Appendix C, “Community Mental Health Centers” on page 138.

### ***A Word on Cultural, Racial, and Lifestyle Differences***

If you feel the child's cultural or racial differences will affect assessment results, it is important to discuss this with the mental health professional. Everyone's test results are likely to be different (*if all people taking a test scored the same, the test would be of no use*). The essential aspect is that the test distinguishes one person from another *only* with regard to those areas the test was designed to measure, such as depression, anxiety, developmental disabilities, and so on. Tests should not distinguish one person from another based on culture, race, language, sexual orientation, or value systems.

Parents must clearly understand that homosexual orientation is not a mental disorder. The causes of homosexuality are not fully understood, but we do know that a person's sexual orientation is not a matter of choice – *People have no choice as to whether they are homosexual or heterosexual.*

Cultural differences can interfere with treatment (see Chapter 4 section, "Cultural and Language Differences" on page 59). If the professional who is performing the assessment (or later the treatment) is not of the same cultural background as your child, ask what his or her experiences have been in cross-cultural assessment or treatment. Professionals who are sensitive to issues of language, socio-economic status, or the cultural bias in assessment tools are happy to share this information with you.

**Important!** If you think that your child needs to be seen by a professional of a certain race, gender, or culture, start making this request during the assessment stage, and continue to request it during the treatment stages that follow. If you think that *you* need language translation services in order to understand your child's treatment, ask for these services as well.

## **How to Be a Partner in Your Child's Care**

Throughout the assessment, education, and treatment processes, expect to be *directly involved* with a team of professionals – asking questions, handling responsibilities, and contributing your insights.

If this is a new idea to you, you might be thinking, "*Are you joking? Me, working with a team of professionals? Right!*" If those are your thoughts, be assured that you have knowledge and skills that you do not yet appreciate. No one knows more about your child than you do. You are the expert on your child.

### ***Your Unique Position and Role***

Your unique position as the parent of a child with a serious emotional disorder prepares you to be a *partner* in planning, implementing, and evaluating your child's care. You are the only "constant," the one thing that stays the same throughout the years that you are involved with experts, programs, activities, and agencies. You are the link between the past and the present, and you are the bridge to the future. You personally know the longest history of information, you know what works, and you have a vested interest in the future. As the parent, you are the true expert on your child – you bring a perspective to planning and decision making that no one else can.

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- Who, better than you, will remember the *huge* amount of information about your child: special needs; abilities and strengths; the results of each doctor visit, test, and evaluation; each letter, treatment team meeting, and IEP team meeting?
  - Who else is going to know whether the different professionals and services are working together in an effective way? (*And if they are not, who else will work toward improvement?*)
  - Who else will read all those articles and brochures, write those letters, visit those programs, record all those conversations and meetings, organize and file all those documents, remember all the accomplishments, document significant events and dates, remember names and faces, meet with all those professionals, ask all those questions, and make all those difficult decisions?

*You will*, because only you know the answer to these questions. These tasks may appear daunting, but your role will not seem so overwhelming after you read this Guidebook and become familiar with the services, supports, and treatment systems available and understand how those systems work.

### ***Your Role in Your Child's Case Management***

Case management is the process of identifying the needs of your child and coordinating the community and family supports that can provide the care your child needs. If you understand the duties of the case manager, you will be able to:

- Ensure your child has service coordination.
- Ask for an appropriate service that is being overlooked in the absence of a case manager.
- Maintain documentation/files that a *new* case manager might need.

**Important!** Remember, you are working in a system that is often unable to deliver services to all those who request services. You must be persistent and continue to contact providers until you get the services and supports your family needs.

**Note:** Case management is one of the services offered through your community mental health centers for children who meet the eligibility criteria.

Service coordination provides the continuity of service that is so important in the long-term treatment plan. One key role you have in the case management process is to help provide this continuity with an organized filing system for contact notes, progress review notes, and a service log of the times and specific services provided to your child and family.

### ***How to Organize All That Documentation***

Since you are going to be an equal partner in planning, implementing, and evaluating your child's care, you will have to keep copies of all documents that relate to his or her life. This includes:

- Calendar of events. Keep an active calendar for current and future events (such as appointments, hospitalizations, or crisis

When you have an original document, make copies of it for other people. Keep the original in your files.

## Chapter 3. Partnering in Your Child's Care

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events) in your purse or wallet, on the kitchen wall, or near the phone, and save the outdated months in your filing system.

- Log of all contacts and correspondence.
- Communication log from school, and all other school documents. (See Chapter 6, “Safeguarding Your Child’s Education” beginning on page 85 for a more complete understanding of these documents.)
- Updated lists of local programs and services.
- Reports, test results, evaluations, assessments (mental and physical), and plans related to both.
- Envelopes from all correspondence, for proof of date.
- Scrapbooks of work samples, pictures, and portfolios.
- Directory of professionals and agencies, including names, addresses, phone numbers, and area of specialization/service.
- Recommendations made by professionals.
- List of questions you may have. (*Write* the answers; date and file any completed written question/answer list; start a new list when additional questions arise.)

Appendix D, “Forms You Might Find Useful” beginning on page 145 has blank forms that can help you organize some of the information listed above.

As time goes by, paperwork accumulates, and you will need a place to store it. The type of physical space you need depends on the method you use to organize the documents – and you can organize them any way that makes sense to you (*any way that allows you to find a particular paper when you or someone else needs it*).

Many parents like to file papers by *categories*. They keep papers in separate manila folders that are labeled for each category, and place newest items in the front of the folders.

Other parents keep all documents solely by *date*. When they obtain a new paper that relates to their child’s care, they date it and file it. These parents indicate that it takes a while to find something, but they do eventually find it. And that works for them!

As time goes by, you will become familiar with your child’s treatment plan, the different professionals working with your child, and meetings you need to attend. At that point, you can begin to keep the most recent versions of important papers in a separate, smaller container (folder, binder, basket, or box)... one portable enough to take to any of the meetings.

You decide how and where you want to store the papers; just make sure that you *save all paperwork*, and that each piece is dated before “dropping it in the box.”

Although electronic records should not be a substitute for original “hard copy” documentation, a personal computer might assist the data organization and retrieval process. Even a basic spreadsheet program could be used to note events. Columns could be set up for: date, category (such as “assessment”), mental health provider, medication, and so forth. And even if all paper documentation was filed solely by date, the electronic records could be re-sorted or searched by category, doctor, and so forth. Once the appropriate piece of information is “found” electronically, its paper version could be

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quickly located, since the “date” would now be known as well. Also, large volumes of “scanned,” electronic versions of documents can be conveniently stored, and e-mail could be a time and cost-effective means to communicate with multiple team members simultaneously, while leaving an automatic record of the correspondence.

### ***General Hints for Meetings and Conversations***

You will be meeting and talking with many professionals. The hints below will help you to achieve your goals and make more efficient use of everyone’s time.

#### **Keep meetings short**

The professionals you meet with will gain much respect for you if you help them to keep meetings short by bringing a list of questions to meetings. If you do this, the amount of meeting time you require will probably be no more than half an hour, and the people you are meeting with will appreciate how organized and efficient you are.

#### **Keep a record of everything**

Make a note of everything that happens during the meeting or bring someone who can take notes. Keep copies of anything that is distributed during the meeting. Be sure to note at least the name of everyone at the meeting and what their role is. If you have difficulty taking notes *and* participating in the meeting, ask meeting attendees (beforehand) if an electronic recording device may be used.

#### **Keep track of positive progress**

During meetings and other visits with professionals, *especially when your child is present*, be sure to mention any positive developments that have occurred since treatment began. If there has been no recent progress, mention past progress that has been maintained. For example, “*Well, I’m happy to say that Melissa is still starting her homework as soon as she comes in from school, and sticks with it until it’s all done!*”

Some professionals are so focused on solving problems that they only see the problems. After treatment has removed a problem from your child’s life, they start focusing on the next problem. They are not negative; they are just totally oriented to problem solving. If you remind everyone of the progress that has been made, you will help everyone keep focused on your child’s strengths.

#### **Get the answers that you need**

Make sure you ask questions and continue with follow-up questions until you understand the answers. Ask the professional or group to try to avoid any jargon (specialized language) or acronyms (See Appendix A, “Acronyms” beginning on page 115) which you might not understand.

Between meetings and visits with professionals, keep a list of questions that you and your child think of – they can be hard to remember later at the next meeting. If possible, have your child write his or her questions on the list as well. This is a good way to reinforce your child’s role in his or her own care.

### Things not to do

Just as certain techniques enhance meeting effectiveness, some situations tend to be counter-productive.

- Do not come late to appointments, and do not repeatedly cancel appointments that have already been made.
- Do not make an excessive number of special requests. Prioritize your special requests since there might not be enough time to address them all.
- Do not have long conversations that include unnecessary details.
- Do not make assumptions - be clear, direct, and deal with facts.

### What Questions to Ask and When to Ask Them

Being actively involved in your child's treatment plan, you will:

- Provide the support the treatment plan requires at home.
- Report to the treatment team on important changes and progress.
- Supply the important, "missing" information to the team.

In order to perform these key tasks, you must be fully informed about the purpose of any treatment routine, how it works, and what behavior or physical changes to expect in your child. And to become this informed, you'll need to ask many questions.

Asking the questions below will help you get the information needed for your role on the team. Questions are broadly organized by the stage of assessment and treatment process, but specific questions from more than one category may be most appropriate for your current situation.

Write down any answers obtained from telephone conversations. Bring questions to meetings, and write the answers while you are there (or electronically record them with permission from those present, and transcribe them later). Then date and file the questions/answers.

### When searching for the right practitioner/doctor

As previously discussed, your primary care physician can be helpful by referring you to a mental health provider. Whether you are looking for a primary care physician or a mental health provider, there are several questions you can ask while on the phone with the doctor's office:

- Do you see children who have serious emotional disorders?
- Do you have experience with children who have (*describe your child's disorder*)?
- Would you be comfortable working on a treatment team with other professionals?
- Can you schedule an extended appointment, if necessary?
- If the child needs services provided through a hospital or other facility:

Who sees your patients when you are not available?

Which hospital do you use for patients who require hospitalization or hospital-based tests?

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What are the facilities and accommodations of this hospital for children and families like mine?

- Are there additional charges for any of these arrangements?

#### **When scheduling an appointment for your child**

- My child has difficulty waiting patiently; is the first appointment of the morning, or one right after your lunch break available?
- If appointments are not necessary, and walk-in service is provided, what times of day, and which days of the week are least busy?
- Should I bring any records with me?

#### **After a mental health provider has completed the evaluation**

- Are you able to make a diagnosis at this time?
- Are you aware of any medical problem... or hearing, speech, language, or physical disability that needs follow-up evaluation or treatment?
- Would you recommend a specialist or a second opinion for this illness or disorder?
- Is there anything I should do immediately? Over the next few days?
- What are the long-term needs and concerns?
- How long does this disorder usually last?
- Should I monitor any symptoms at home to help you better understand my child? What are the indications he or she is getting better? How do I know if there are any complications or if the condition is getting worse?
- If I do notice complications, how can I contact you after your usual office hours? Who should I call in an emergency?
- When can my child go back to school? Is there anything I should tell my child's teacher?
- When can I expect a written report of the results of this evaluation?

#### **Before a medical or assessment test**

- What is the name of the test?
- What do you expect to learn from this test?
- Has this test been given to my child before? If so, can we compare the results?
- Does the school or health center also give this test? Is there any reason not to have it done there?
- How long will this test take?
- Is there anything I can explain to my child about this test to help prepare him or her?
- Can he or she eat before taking the test? Are there any other precautions I should take before or after the test?
- Should my child discontinue medications before the test?
- Should I bring any of my child's records with me?
- Who will receive the evaluation report, and who will explain it to me?

### When planning a treatment routine

Before your child begins any treatment routine, be sure to ask the following questions of the practitioner involved, whether a social worker, special education teacher, etc.

- What are all the recommended treatment options for my child's condition?
- How will I be involved with my child's treatment?
- How will we know if the treatment is working?
- How long should it take before I see improvement?
- If my child needs medication, what are the possible side effects to watch for?
- How should I provide you with feedback if the problems get worse, stay the same, or improve?
- How do I contact you after office hours in case of an emergency? Do you have an emergency contact number or answering service?
- Who covers for you when you are away from your office, out of town, or on vacation?

### When medications are prescribed

Many practitioners and parents are concerned about unnecessary medication prescriptions for children. Be sure you are satisfied with the answers to the following questions before agreeing to use medications in your child's treatment plan:

Medicating a child whose problems can be effectively remedied by therapy alone is as clinically misguided as denying medication to the child whose condition cannot improve without it.

- What are the consequences of *not* taking this medication?
- What other medications are available?
- How exactly will the medication help my child, and how long before I see any improvement?
- Is this medication indicated by the pharmaceutical company or Food and Drug Administration (FDA) specifically for use in children? Has this medication been helpful to other children with a similar condition?  
*If the clinician cannot answer "yes," then this medication is being prescribed "off label." That is, the pharmaceutical company that developed the medication has not yet shown that it is effective in treating children under the age of 18. If this is the case, insist on hearing the reasons for using the medication in question, and whether another form of treatment would be better.*
- Are there any laboratory tests (for example, heart or blood tests) that need to be done before my child begins taking the medication?
- How long will my child need to take this medication, and how often will progress be checked? How is the decision to "stop the medication" made?
- Is this medication addictive? Can it be abused? What precautions need to be taken with this medication?
- When should I give the medicine, and should it be taken with food, or at a particular time of day? If the prescription says "three times a day," does that mean every 8 hours, including during the night, or three times during the day?

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- What are the common side effects of this medication?
  - What is the expected cost of the medication? Is there a generic version, and has it been proven to be generally as helpful as the brand name medication?
  - Are there other medications or foods that my child should avoid while taking this medication? (*Be sure your practitioner knows all the medications your child is taking.*)
  - Does my child have to avoid any activities or sports while taking the medication? (e.g. exposure to sun)
  - Will any tests (x-rays, MRIs, lab work) be required while my child is taking the medication? How often should I expect these tests to be done?
  - Should I ask my child's teacher or school nurse to watch for changes as my child begins this medication?

**If hospitalization is required**

- Do you know how long my child will stay in the hospital?
- Who will be the attending doctor?
- How will the doctor communicate with me?
- Should I take any records with me, or will they be sent by you or another agency?
- Can I stay with my child overnight, or beyond normal visiting hours?
- Is there any information I can explain to my child to help prepare for this? Does the hospital have a children's program that explains about hospitals?
- When can I expect the first team meeting?
- How will discharge planning be handled?
- Who will receive the hospital records after discharge, and who will explain them to me?
- Will this stay be covered by my insurance?

## Chapter 3. Partnering in Your Child's Care ---

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# Chapter 4. About Serious Emotional Disorders and Behavioral Issues

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## Chapter Overview

*When a family begins to realize that something is very wrong with their child's emotional or mental health, consulting with a professional to resolve the confusion and determine what is wrong can be frightening. Despite these fears, it is important to realize that **an early intervention provides the best chance of minimizing the effects of the disorder.***

*If you are a caregiver of a child with a serious emotional disorder, a neurobiological brain disorder,*

*or mental illness, you should be included as a member of the team that assesses your child's illness, identifies your child's strengths and special needs, and finds the right services and supports to help you and your child. Your active participation in your child's treatment is essential.*

*This chapter provides the background information needed to start the dialog with the professionals who will be working with your child.*

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## Basic and Often Misunderstood Concepts

### ***What Causes Serious Emotional Disorders (SED)/Mental Illness?***

Some people still believe that most children with serious emotional disorders or mental illness suffer because of poor parenting. **There is much evidence to suggest that emotional disorders among children are biologically based.**

While statistics show a higher number of serious emotional disorders among children who experienced severe abuse and neglect, we *cannot* assume that a child with a serious emotional disorder has been in such a situation.

“As for me, you must know that I shouldn’t precisely have *chosen* madness if there had been any choice. What consoles me is that I am beginning to consider madness as an illness like any other, and that I accept it as such.”

–Vincent Van Gogh (1889)

### ***How Common are SED and Mental Illness?***

Serious emotional disorders (SED) and mental illnesses are more common than cancer, diabetes, or heart disease. One in every five families is affected in their lifetime by a serious mental illness, such as bipolar disorder, schizophrenia, or major depression. A conservative estimate is that 10% of this country’s youths under age 18 have mental, behavioral, or developmental disorders.

### ***In What Settings Can Children with SED Function?***

With appropriate treatment and supports, children can understand their illness, function well in their community and school, have meaningful relationships, and become adults living independently in their communities. It is important that each family faced with supporting a child with SED knows the child’s strengths, needs, and limitations. Some children with SED or mental illness need treatment in a *residential setting* for a certain period of time, with the ultimate goal of returning to their home and community. This refers to a professionally staffed therapeutic setting as distinguished from “home” (see Chapter 5 section, “Residential Treatment Centers and Private Schools” on page 67.)

### ***Is Treatment Successful?***

Through research, scientists have made great advances in unlocking the mysteries of mental illness. Research on new medications has led to numerous discoveries in the last two decades. Parents and practitioners are learning better ways to combine new medications with different types of therapies such as talk therapy, play therapy, recreational therapy, martial arts, therapeutic horseback riding, and cognitive-behavioral therapy.

## Chapter 4. About Serious Emotional Disorders and Behavioral Issues

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No single treatment benefits all children. Parents usually discover that the best treatment for *their* child is found through the process of trying and modifying different treatments and combinations of treatments.

There is compelling evidence that brain disorders do occur in children, that *untreated* mental illness places children at risk of developing the most debilitating forms of illness, and that the impact of *untreated* mental illness during their growing years is devastating.

Regardless of the disorder or the providers involved, the family is the foundation upon which effective treatment and other supports are built. It is therefore important for your family to be included in the design and implementation of the child's treatment plan. If your child is receiving counseling, your family should be consulted regarding whether the treatment is working or not.

### Disorders and Behavioral Issues

The terminology professionals use to describe your child's behavior can be confusing. This section provides descriptions to help remove that confusion and enable you to better understand your child's symptoms and how your child's illness affects his or her behavior. With this improved understanding, you can have more productive discussions with professionals, including educators.

"What did we do wrong? No one in our family has ever been mentally ill. Our other kids are normal. We treated them all the same. Why is this kid screwed up? What's the matter with us?"

**Important!** Be prepared that your child might be diagnosed with *several different disorders* over the course of his or her childhood. This is because as your child is growing up...

- his or her brain is physically developing.
- his or her endocrine system is introducing new and increasing amounts of hormones.
- he or she is moving into new developmental stages and developing better language skills, enabling better articulation of what is hurting and how it feels.

These changes, combined with overlapping symptoms of several disorders (described on the following pages), set the stage for your child to receive more than one diagnosis over the course of his or her childhood.

Different systems exist for naming psychological and emotional disorders; most of the terms explained in this section are from the system defined in the American Psychiatric Association *Diagnostic and Statistical Manual* (DSM-IV TR). In addition, there are three general terms used in this Guidebook and by mental health and educational professionals which are not defined in DSM-IV TR. These terms are: *serious emotional disorders*, *neurobiological brain disorders*, and *co-occurring disorders*.

Science has shown that mental disorders are best understood as a result of a combination of factors: disturbances in the brain's "wiring" process during early development, genetic influences, chemical imbalances, brain trauma, and severe life stress. Parents cannot be blamed (and should not blame themselves) for these disorders any more than they can be blamed for juvenile diabetes.

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**Serious emotional disorders (SED)** is not a medical diagnosis, but a broad term used to classify children who exhibit any of a wide variety of behavioral and emotional disorders or mental health problems that cause these children to act in unusual, irrational, or aggressive ways.

In order for a child to receive help from the mental health or school system, the child's emotional disorder must be significant enough to impair his or her ability to function adequately in school, at home, or in the community.

Mental health professionals generally use the term **neurobiological brain disorders (NBD)**, or mental illness, to describe a group of brain disorders that cause disturbances in thinking, feeling, or relating. These disorders can affect persons of any age, including children and adolescents. They can occur in any family.

Some disorders that you might hear being referred to as NBD are schizophrenia, schizoaffective disorder, bipolar disorder (manic-depression), major depression, obsessive compulsive disorder, panic disorder, autism, pervasive developmental disorder, Tourette Syndrome, and attention deficit disorder (with or without hyperactivity).

**Co-occurring disorders** (or dual disorders) refer to disorders that occur at the same time. There are two pairs of disorders that are referred to as co-occurring: mental illness and substance abuse, and mental illness and developmental disability.

- **Mental Illness and Substance Abuse.** Traditionally, substance abuse and mental illness have been treated separately by different agencies. Treating one illness first and then the other is called *sequential treatment*. Treating both illnesses at the same time through different systems is called *parallel treatment*. **Using one treatment provider and system to maximize continuity in treatment and understanding of the impact each disorder has on the other is called *integrated treatment*. Integrated treatment is the most effective method of treatment for these co-occurring disorders.** Finding providers who understand both mental illness and substance abuse maximizes success in addressing both issues. (See Appendix C, "State and National Resources" beginning on page 119.)
- **Mental Illness and Developmental Disability.** Just as mental illness may co-occur with other disorders, a small percentage of people with mental illness also have a developmental disability, such as mental retardation. Every region of New Hampshire has an area agency to meet the needs of people with developmental disabilities, just as there are community mental health centers in every region to serve people with mental illness. If your child is eligible for both agencies, and these organizations work collaboratively, a comprehensive treatment plan can be developed to help ensure that your child's needs are appropriately addressed. (See Appendix C, "Area Agencies for Developmental Disability Services" on page 124 and "Community Mental Health Centers" on page 138 for the locations and phone numbers of regional area agencies and community mental health centers.)

The following diagnoses, grouped by category, are defined in *DSM-IV TR*:

## Chapter 4. About Serious Emotional Disorders and Behavioral Issues

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### *Disorders of Infancy, Childhood, or Adolescence*

#### **Pervasive Developmental Disorder (PDD)**

The signs and symptoms of **pervasive developmental disorder (PDD)** usually appear by the time a child is three years old. Parents notice that their child does not smile, look at them, or “coo” in response to adults. The child acts as if no one is there, and does not react to the adult’s show of affection or playfulness.

Signs and symptoms of PDD can include the following:

- Total lack of social interaction or responsiveness.
- Dislike of physical contact and cuddling.
- Poor communication.
- Unusual repetitive movements.
- Bizarre reactions to people, even parents, making it difficult to relate or connect to people.
- Bizarre reactions to the environment.
- Does not imitate adult actions, such as waving “bye, bye.”
- Appears to live in his or her own world.
- Does not talk, or only mimics sounds.
- Possesses extraordinary or unexplained talents.

Some children have a mild form of PDD that produces only mild psycho-social problems. Some children with PDD have above average intellect, but severe adjustment problems. Other children have adjustment problems, as well as below normal intellect. It is common for children with this disorder to have compulsive and repetitive behaviors.

“He wakes up and laughs for the first half hour of the day. I think that’s the greatest thing in the world.”

–Father of a child with autism

The causes of PDD remain unclear. Experts believe, however, that maternal rubella, encephalitis, or meningitis might predispose a child to it. PDD is 50 times more common when brothers or sisters have PDD than it is in the general population.

#### **Asperger’s Disorder**

*Asperger’s Disorder* is on the autism spectrum and is characterized by lack of social skills. In general, a child with Asperger's Disorder functions at a higher level than the typical child with autism. For example, while most children with autism fail to develop language or have language delays, children with Asperger's Disorder are usually using words by the age of two, although their speech patterns may be somewhat odd. Most children with Asperger’s Disorder have difficulty interacting with their peers and tend to be loners. A child with Asperger's may spend hours each day preoccupied with counting cars passing on the street or watching only the weather channel on television. Coordination difficulties are also common with this disorder. These children often have special educational needs.

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## Attention Deficit (Hyperactivity) Disorder (AD/HD)

**AD/HD** is the most commonly diagnosed behavior disorder in children, affecting between 3% and 5% of the nation's school-age children. The main symptoms are inattention, impulsivity, and hyperactivity. There are three types of AD/HD, each with different symptoms: 1) predominantly inattentive; 2) predominantly hyperactive and impulsive; and 3) the combination of the first two. The third type is the most common.

Children with AD/HD have difficulty concentrating on tasks, and often do not have appropriate social skills for their age group. Some children with AD/HD also experience anxiety, depression, and some type of language or learning disability. Other children with AD/HD also have *conduct disorder* or *oppositional defiant disorder*.

Young people with AD/HD who get encouragement and proper help can become well-socialized and successfully educated young adults.

Children with the predominantly *inattentive* type of AD/HD often act in the following ways:

- Fail to pay attention to details or make careless mistakes.
- Have difficulty sustaining attention to tasks or leisure activities.
- Do not seem to listen when being directly spoken to.
- Do not follow through on instructions and fail to finish chores or schoolwork.
- Have difficulty organizing tasks and activities.
- Avoid tasks that require sustained mental effort.
- Lose things necessary for activities or tasks.
- Are easily distracted.
- Are unable to play games for the same amount of time as other children their age.
- Are forgetful in daily activities.

Children with the predominantly *hyperactive and impulsive* type of AD/HD often act in the following ways:

- Fidget with their hands or feet, or squirm in their seat at school or during mealtime.
- Leave their seat when remaining seated is expected.
- Move excessively or feel restless during situations in which such behavior is inappropriate.
- Have difficulty engaging in leisure activities quietly.
- Talk excessively.
- Are “on the go” or act as if “driven by a motor.”
- Blur out answers before questions have been completed, or interrupt conversations.
- Have difficulty waiting their turn.
- Intrude on others' personal space.

**It is not yet known what causes AD/HD, but it clearly has a biological basis, including a genetic factor since it tends to run in families, and is *not* caused by dysfunctional parenting. Also, children with AD/HD are usually very intelligent.**

## Chapter 4. About Serious Emotional Disorders and Behavioral Issues

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### Reactive Attachment Disorder (RAD)

**Reactive Attachment Disorder (RAD)** is a mental disorder with onset typically starting during infancy or early childhood. It is important to understand that children experience attachment issues across a continuum, with symptoms ranging from mild to severe. Children with less severe symptoms may not meet the criteria for a RAD diagnosis, but may still exhibit significant challenging behaviors. As with other serious emotional disorders, attachment disorder is biologically based; research has indicated neurological abnormalities in children who have been diagnosed with the disorder.

The disorder occurs when attachment between the infant child and the parent (or primary caregiver) is interrupted. The most common cause of disruption is emotional or physical neglect of the child. The infant who is repeatedly left for hours... crying from hunger or a dirty diaper... may be a likely candidate for developing attachment disorder. Severe mental illness or drug addiction of the caregiver may result in neglectful parenting, which in turn might contribute to RAD. Other causes of disrupted attachment include physical and sexual abuse, and abrupt transfer of the primary caregiver (many adopted children or foster children have attachment disorder).

As a result of this disrupted attachment and extremely poor relationship, the child learns that adults are at best... inconsistent or undependable, and at worst... dangerous. Children with attachment issues learn that adults cannot be trusted. Consequently, these children develop behaviors they perceive as essential to survival, but in reality the behaviors are destructive and negatively impact the ability to develop an intimate relationship with any adult. Children with attachment issues believe they must control everything for their basic survival. They unconsciously internalize the belief that they are not lovable and often have a deep-rooted sense of shame.

Symptoms of attachment disorder include:

- Oppositional behavior.
- Poor eye contact.
- Defiance.
- Pathological lying.
- Inability/refusal to be comforted.
- Sabotaging.
- Constant talking.
- Manipulative behavior.
- Fear of intimacy.

Children who have attachment disorder may also have concurrent depression, anxiety, trauma, Post-Traumatic Stress Disorder (PTSD), attention deficits (AD/HD), or other mental illnesses.

**Note:** Children with attachment disorder are sometimes misdiagnosed as having Oppositional Defiant Disorder (ODD).

In all but the most severe cases, the symptoms of attachment disorder occur mostly at home with the primary caregivers. Typically, the mother or primary caregiver figure is the recipient of the most hostile and aggressive behavior; the rest of the world (school,

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neighbors, family) often sees a charming, talkative, engaging child. *This can leave the parents/primary caregivers feeling isolated, or worse... criticized or "second-guessed" by other people in the child's support system.*

Considerations when dealing with a child with attachment disorder:

- Fear of intimacy may cause the child to drive a wedge between the parents.
- For two-parent families, it is essential that parents present a united front and consistent response to challenging behaviors.
- Standard parenting techniques typically do not work with children with attachment issues.
- Avoid giving the child a lot of freedom or choices.
- Hold the child accountable for his or her bad behavior.
- Time in (being with the parent) generally works better as a consequence than time out.
- Attachment issues do not diminish with time (nor with love); it is important to address them directly as soon as they are identified.

Getting Help:

- Find a therapist who has specific training dealing with attachment issues.
- Get information on attachment issues from books, websites, or other resources. A good book for parents or professionals is "Building the Bonds of Attachment" by Dan Hughes (available at the NAMI NH library).
- Casey Family Services in Concord, NH (website: [www.caseyfamilyservices.org](http://www.caseyfamilyservices.org) or call toll-free at (800) 417-7375) offers parent support groups, workshops, and services for families dealing with attachment issues.
- NAMI NH has an educational program for families/caregivers and service providers dealing with attachment issues.

### **Oppositional Defiant Disorder (ODD)**

The main feature of **ODD** is a recurrent pattern (lasting for at least six months) of negativistic, defiant, disobedient, and hostile behavior toward authority figures.

Children with ODD *frequently* act in the following ways:

- Deliberately annoy people.
- Blame others for their own mistakes.
- Are angry, resentful, and/or vindictive.

The disruptive behaviors of a child with ODD are not as severe as those of children with conduct disorder, and *typically do not include aggression* toward people or animals, destruction of property, or a pattern of theft or deceit.

A child with ODD symptoms should have a comprehensive evaluation, including looking for other disorders such as AD/HD, learning disabilities, mood disorders, and anxiety disorders. It may be difficult to improve the symptoms of ODD without treating a coexisting disorder. Some children can experience coexisting disorders, such as ODD with AD/HD or ODD with learning disorders.

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### Conduct Disorder

The essential feature of **conduct disorder** is a persistent pattern of violating the rights of others or major social rules. Children with conduct disorder often have these symptoms:

- Stay out late, in spite of parental objections.
- Run away from home.
- Are truant from school.
- Bully or threaten others.
- Initiate fights.
- Use weapons (for example, a broken bottle, knife, bat, or gun).
- Are physically cruel to people and animals, or force someone into sexual activity.

### Tourette Syndrome

**Tourette Syndrome**, also called Gilles de la Tourette Syndrome, is a neurobiological brain disorder characterized by involuntary muscular movements, uncontrollable vocal sounds, and inappropriate words. Approximately half of the children with Tourette Syndrome also have AD/HD (although only a small number of children with AD/HD have Tourette Syndrome). If your child only has motor tics, the disorder is called *chronic motor disorder*; if your child only has vocal tics, it is called *vocal tic disorder*.

At first, a person with Tourette Syndrome shows the following symptoms:

- Blinking his or her eyes excessively.
- Twitching his or her nose.
- Grimacing.

As the condition progresses, he or she may repeatedly show these symptoms:

- Stretching his or her neck.
- Stamping his or her feet.
- Twisting and bending his or her body.
- Eventually producing uncontrollable sounds.
- Continuously clearing his or her throat, coughing, sniffing, grunting, barking, or shouting.
- Involuntarily shouting obscenities (coprolalia), or constantly repeating the words of other people (echolalia).
- Touching other people excessively, or repeating actions obsessively and unnecessarily.
- Biting their lips and cheeks.
- Banging their heads against hard objects, and developing other self-destructive behaviors.

Individuals with Tourette Syndrome can sometimes control tics for a short time, but eventually tension mounts and the tics once again appear. Tics become worse during periods of stress. They improve when the individual is not anxious, or is absorbed in an activity. In most instances, tics disappear during sleep.

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The cause of Tourette Syndrome is unknown. Current research has focused on the possibility that a chemical abnormality affects neurotransmitter systems used by the brain to regulate movement and behavior. Neurotransmitters are chemicals that carry signals from one nerve cell to another in the brain, spinal cord, and along the nerves.

## ***Mood (Affective) Disorders***

### **Major Depression**

The highest incidence of **major** (or clinical) **depression** in children occurs in girls after puberty. Before puberty, depression is more likely to occur in boys. There is an increased risk of developing depression when there is a family history of the illness. Also, being in a low socio-economic group has proven to be a major risk factor for depression, except in some immigrant populations whose strong community ties protect them against the stresses of poverty.

The normal human emotion we sometimes call depression is a common response to a loss, failure, or disappointment. **Major depression is the correct diagnosis when the sad mood is severe, lasts more than two weeks, and has no outward cause.**

A child with major depression might show the following symptoms:

- A profoundly sad, angry, or irritable mood lasting at least two weeks.
- Major changes in sleep, appetite, energy, and ability to concentrate and remember.
- Loss of interest in his or her usual activities, and loss of the ability to experience pleasure.
- Feelings of hopelessness, worthlessness, sadness, emptiness, social isolation, or guilt.
- Inability to respond to the positive events or things in one's life.

The symptoms of major depression can lead to passive suicidal wishes, suicidal plans, and even attempted and completed suicide. Some symptoms of adolescent depression are similar to those in other age groups, but depressed adolescents may also “act out” by showing anger, becoming aggressive or delinquent, abusing drugs or alcohol, performing poorly in school, or running away.

Most likely, there is not a single cause of major depression. Functional studies of the brain, which are done by brain imaging or mapping, indicate a possible chemical dysfunction among depressed patients, and genetics may play a role. Life events, such as the death of a loved one, a major loss or change, or chronic stress, can trigger depression as well. Alcohol or drug abuse, certain medications, or even an individual's general outlook on life can also contribute to the development of the disorder. With all the major advances in scientific knowledge about major depression, there is still no single answer to the question of cause.

Depression involves a variety of disturbances in mood, concentration, sleep, activity, appetite, and social behavior. It is a serious medical illness that is much more than temporarily feeling sad or blue.

One major risk to young people with major depression is suicide. During the past three decades, suicide among adolescents has increased 300 percent. Major depression must be taken seriously and requires the support and help of the child's family. (See “Child and Adolescent Suicide” on page 51.)

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### Bipolar Disorder/Manic-Depressive Illness

**Bipolar disorder** (previously known as manic-depression) is less common than major depression, but still occurs among children and youth. The person with this disorder experiences severe mood swings, from mania (inflated self-esteem, decreased need for sleep, accelerated thinking and speaking, increased goal-directed activity, and psychomotor agitation) to depression (often as serious as major depression). These abnormally severe moods may last for days, weeks, or months. In children, the mania and depression may overlap (called “mixed mania”).

Bipolar disorder is rarely diagnosed by itself in children. A child with bipolar disorder often has clusters of symptoms that, at certain points in the child’s life, suggest other psychiatric disorders such as AD/HD, OCD, conduct disorder, or oppositional defiant disorder. It is also difficult to diagnose children and teens with bipolar disorder because they don’t always manifest either of the extreme symptoms but rather a combination of the two, or alternate quickly between the two, which is referred to as “**rapid cycling.**”

A person with bipolar disorder/manic-depressive illness may show the following symptoms during the two different phases:

During the manic phase:

- Hyperactivity and high energy, including non-stop talking.
- Explosive temper.
- Impaired judgment.
- Increased spending and sex drive.
- Aggressive behavior.
- Grandiose notions; sometimes delusions; feeling on top of the world.
- Little need for sleep.

During the depressive phase:

- Anger and irritability.
- Total lack of energy or enthusiasm.
- Extreme sadness; feeling that life is totally without pleasure; that his or her life is over.
- Loss of interest in usual activities.
- Loss of ability to experience pleasure; even eating is not enjoyable.
- Former interests seem boring or unrewarding.
- Loss of or diminished ability to feel and offer love.
- Changes in sleep patterns.
- Loss of ability to concentrate, remember, and make decisions.
- Low self-esteem.
- Feeling guilty and helpless.
- Poor personal hygiene.

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Depressive phases can lead to the wish to die, thoughts of suicide, or actual suicide. ***Any talk of suicide should always be taken seriously.*** (See Chapter 4 section, “Child and Adolescent Suicide” on page 51.)

**Note:** Not everyone with manic-depression experiences periods of mania and depression with the same intensity. A person with manic-depressive illness may also have periods of stability between mood swings.

## ***Thought Disorders***

### **Schizophrenia**

**Schizophrenia** is a serious psychiatric illness characterized by severe problems with a person’s thoughts, feelings, behavior, and use of words and language. Psychotic symptoms often include delusions and/or hallucinations. In schizophrenia, these delusions are often paranoid and persecutory in nature. Hallucinations are usually auditory and may include hearing voices speaking in the third person, as well as to each other, commenting on the affected person’s deeds and actions. **Schizophrenia does not mean “split personality.”** Most people who develop schizophrenia do so before 30 years of age with some having their first episode in the teenage years. However, it is an uncommon psychiatric illness in children and is hard to recognize in its early phases.

Most children with schizophrenia show delays in language and other functions long before psychotic symptoms appear, which is usually at age seven or later.

The behavior of children and adolescents with schizophrenia may differ from that of adults with this illness. Child and adolescent psychiatrists look for several of the following early warning signs in youngsters:

- Seeing things and hearing voices that are not real (hallucinations).
- Odd and eccentric behavior, and/or speech.
- Unusual or bizarre thoughts and ideas.
- Confusing television and dreams with reality.
- Confused thinking.
- Extreme moodiness.
- Thinking that people are “out to get them,” or talking about them.
- Severe anxiety and fearfulness.
- Difficulty relating to peers and keeping friends.
- Withdrawal and increased isolation.
- Decline in personal hygiene.

The behavior of children with schizophrenia may change slowly over time. For example, children who used to enjoy relationships with others may start to become more shy or withdrawn and seem to be in their own world. Sometimes, youngsters will begin talking about strange fears and ideas. They may start to cling to parents or say things that do not make much sense. The child’s teachers might be the first to notice these early problems.

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The cause of schizophrenia is not known; however, current research suggests that brain changes, and biochemical, genetic, and environmental factors may play a role. **Early diagnosis and medical treatment are important.** Schizophrenia is a lifelong disease that can be controlled but not cured. Children with the problems and symptoms listed above must have a complete evaluation.

For the first three quarters of the last century, psychoanalysts believed that the relationships between parents and children caused schizophrenia. Those theories have been proven to be false.

Usually, these children need comprehensive treatment plans involving other professionals. A combination of medication, individual therapy, family therapy, and specialized programs (such as school or activities) is often necessary. Psychiatric medication can be helpful for many of the symptoms. These medications require careful monitoring by a child and adolescent psychiatrist. Parents should ask their family physician or pediatrician to refer them to a child and adolescent psychiatrist who is specifically trained and skilled at evaluating, diagnosing, and treating children with schizophrenia.

### ***Anxiety Disorders***

**Anxiety disorders** are the most common mental illnesses in America, affecting up to one in ten young people. Unfortunately, these disorders are often difficult to recognize and can easily be considered just another phase of childhood. The most common forms of anxiety disorders in children are: obsessive-compulsive disorder, post-traumatic stress disorder, phobia, and generalized anxiety disorder.

### **Obsessive-Compulsive Disorder (OCD)**

**OCD** is characterized by repeated, intrusive, and unwanted thoughts (obsessions) and repetitive actions and rituals (compulsions). The obsessions or compulsions cause much anxiety, are time-consuming (taking more than one hour a day), or significantly interfere with the child's normal routine, social activities, or relationships.

Some of the most common obsessions are: fear of contamination or serious illness, fixating on lucky/unlucky numbers, fear of danger to self and others, need for symmetry or exactness, and excessive doubt. Some of the most common compulsions are: repetitive rituals such as cleaning or washing, touching, counting, repeating, arranging/organizing, checking/questioning, and hoarding. Sometimes the compulsions are driven by the obsessive thoughts. If your child is an adolescent, he or she might be aware and concerned that the symptoms do not make sense and are excessive. If your child is younger, he or she might be distressed only when prevented from carrying out the compulsive habit.

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## Post-Traumatic Stress Disorder (PTSD)

This anxiety disorder occurs after a person experiences, witnesses, or is confronted with an event that involved actual or threatened death, serious injury, or physical harm to self or others (including physical, mental, or sexual abuse, natural or man-made disasters, or exposure to violence). In the case of children, something as simple as attending a funeral and viewing the body of a dead relative can cause PTSD.

Frequently, the only thing the child is aware of are the feelings of anger, fear, and confusion. Especially if no physical violence was involved, children might not even be aware that they have been traumatized, although they have been.

Symptoms of PTSD include the following:

- Intense fears (of going to bed or being alone, for example).
- Nightmares.
- Flashbacks of the traumatic event.
- Triggers (such as smells or sounds associated with the event).
- Numb emotions.
- Depression.
- Violent play.
- Feeling inappropriately angry, irritable, and distracted.
- Hurting themselves (if abused, the abuser has taught them they deserve to be hurt).
- Being easily startled.
- Hoarding inappropriate objects (a child who has been held at knifepoint might hoard knives, not necessarily to hurt anyone or him/herself, but as a symbolic way to feel safer – *if the child has the knife, the child is in control*).
- Regression (baby talk, clinging to parents, and so forth).

Young children might engage in repetitive play that expresses themes or aspects of the trauma, or experience frightening dreams without recognizable content. Children also might express disorganized or agitated behavior, rather than more specific symptoms. Symptoms must last at least one full month before they are considered to be PTSD.

Symptoms of PTSD can cause significant impairment in social, occupational, or other important areas of functioning.

## Phobia

A **phobia** is a disabling and irrational fear of something that poses little or no actual danger. The fear leads to avoidance of objects or situations and causes extreme feelings of terror and dread. The avoidance, anxious anticipation, or distress in the feared situations interferes significantly with the person's normal routine, occupational or academic functioning, social activities, or relationships. Sometimes there is much distress about having the phobia. In children, the anxiety may be expressed by crying, tantrums, freezing in place, or clinging.

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Specific phobias center around particular objects (such as certain animals or imagined monsters) or situations (such as heights or enclosed spaces). Adults usually recognize that the fear is excessive, but children might not. For children under age 18, for a fear to be considered a phobia, it must last for at least six months.

### Generalized Anxiety Disorder

This anxiety disorder is characterized by exaggerated worry about everyday events and activities such as attending school, sports practice, or other performance-related activity. Children with this disorder usually anticipate the worst and often complain of fatigue, tension, headaches, and nausea.

Because this disorder is characterized by exaggerated worry, caregivers might think children will simply outgrow the symptoms, but it is important to have your child tested if you have noticed the symptoms for five months or more.

Anxiety and worry are accompanied by three or more of the following symptoms:

- Restlessness or feeling “keyed up” or “on edge.”
- Being easily fatigued.
- Difficulty concentrating or the mind going blank.
- Irritability.
- Muscle tension.
- Sleep disturbance (difficulty falling or staying asleep, or restless and unsatisfying sleep).

Only one symptom is required to indicate the *possibility* of generalized anxiety disorder. However, symptoms must last at least six months before a *diagnosis* of generalized anxiety disorder is possible.

### Eating Disorders

#### Anorexia Nervosa

The essential features of **anorexia nervosa** are refusing to maintain a minimally normal body weight, being extremely afraid of becoming fat, and having an irrational perception of the shape and size of his or her body. Although males can be affected, anorexia nervosa usually affects females. The median age of onset is 17 years, and women over 40 rarely have the disorder. A teenager with anorexia nervosa is typically a perfectionist and a high achiever in school. At the same time, she suffers from low self-esteem, irrationally believing she is fat regardless of how thin she becomes. Symptoms include extremely low

body weight, dry skin, hair loss, depressive symptoms, constipation, loss of menstruation, low blood pressure, and bizarre behaviors such as hiding food, binge eating and vomiting, excessive exercise, or a preoccupation with food.

#### Bulimia Nervosa

This disorder is characterized by episodes of binge-and-purge (vomiting) behavior where the child eats enormous amounts of food then either induces vomiting, abuses laxatives, uses diuretics, enemas, medications, or fasts to balance the effects of the binge eating. Most individuals who have bulimia nervosa are within the normal weight range; some are

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slightly under or over weight. Symptoms include fatigue or muscle weakness, gastrointestinal problems, intolerance of cold weather, and mouth sores and dental problems caused by excessive acid.

## **Behavioral Issues**

### **Child and Adolescent Suicide**

Youth from pre-adolescent through young adulthood can be at higher risk for problems such as substance abuse, difficulties in school, risk-taking behaviors, and problems with relationships. It is not unusual for young people to have thoughts of suicide. Not all risk factors lead to suicidal behavior, but a combination of risk factors, or severity of some problems, can increase the risk of suicide. For those at higher risk, suicidal thinking can become serious and may lead to suicide attempts. There are some cultural and gender patterns that emerge around suicidal behavior. Several state and national studies have found that gay, lesbian, and bisexual teens are more likely to seriously consider and attempt suicide than heterosexual teens [*National Youth Violence Prevention Resource Center; Suicide Facts* <http://www.safeyouth.org/scripts/faq/suicidefacts.asp>]. Hispanic females are the most likely to seriously report considering suicide of any ethnic group [*Sadness and Suicide Ideation and Attempts: (Source: CDC 2001 Youth Risk Behavior Survey* [http://www.ncbuy.com/education/yrbs01/nat\\_110.html](http://www.ncbuy.com/education/yrbs01/nat_110.html))]. Overall, females attempt suicide four times more often than males, but males actually die by suicide two to three times more than females. *In New Hampshire, suicide is the second leading cause of death for all young people between the ages of 15-24.* The **Centers for Disease Control** estimates that 90% of people who kill themselves have depression or another diagnosable mental or substance abuse disorder. However, depression and suicidal feelings are treatable disorders and suicide is generally preventable.

There are many things that parents can do to help prevent suicide. First, parents must **recognize** the risk factors and warning signs in their children. Then, parents must **connect** with their children by talking with them, making sure they have appropriate assessment and treatment if needed, and maintaining the supports their child needs by involving others who can help assure their child is safe.

If you think your child might be suicidal, seek immediate mental health treatment, or call 911 or the National Suicide Prevention Lifeline at 1-800-273-TALK (8255) if necessary, and do not leave your child alone.

### **Risk Factors for Suicide**

*Risk factors* are characteristics statistically associated with a health risk (suicide). Risk factors do not predict imminent danger for a particular person. Rather, they are an indication that an individual may be higher-than-normal risk. Although risk factors often include some observable behaviors, they can also include other factors that might not be readily observable to someone who only knows the individual casually. Many risk factors are uncovered during the process of having an assessment done by a qualified physician or mental health provider. *The following lists of risk factors were developed by the State of Maine Suicide Prevention Project and have been adopted by the National Center for Suicide Prevention Training.*

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### **Personal Risk Factors for Suicide:**

- Alcohol and other drug abuse.
- Isolation.
- Mental illness (depression, bipolar, schizophrenia, personality disorder).
- Poor impulse control.
- Confusion or conflict about sexual orientation.
- Compulsive, extreme perfectionism.
- Deficits in social skills (e.g. decision making, conflict and anger management, problem solving).
- Loss (perceived or real) of identity or status.
- Feelings of powerlessness, hopelessness, or helplessness.
- Pregnancy or fear of pregnancy.
- Exaggerated humiliation or fear of humiliation.
- Certain religious beliefs (e.g. that suicide is noble).

### **Behavioral Risk Factors:**

- Prior suicide attempt.
- Aggression, rage, defiance.
- Running away from home.
- School failure, truancy.
- Fascination with death and violence.

### **Family Risk Factors:**

- Family history of suicide.
- Changes in family structure (e.g. death, divorce, remarriage, etc.).
- Family involvement in alcoholism or other drug abuse.
- Lack of strong bonding/attachment within the family.
- Withdrawal of support.
- Unrealistic parental expectations.
- Violent, destructive parent-child interactions.
- Inconsistent, unpredictable parental behavior.
- Depressed, suicidal parents.
- Abuse (e.g. physical, emotional, or sexual).

### **Environmental Risk Factors:**

- Stigma associated with help-seeking.
- Lack of access to helping services.
- Access to lethal means (e.g. firearms).
- Frequent moves and changes in living situation.
- Social isolation or alienation from peers.

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- Exposure to suicide of a peer.
  - Anniversary of someone else's suicide.
  - Incarceration or loss of freedom, trouble with the law.
  - High levels of stress, including the pressure to succeed.
  - High levels of exposure to violence in mass media.

Most young people will experience some risk factors. When you are aware of such risk factors, keep open communication with your child and involve others who can help provide support or supervision as needed, and let your son/daughter know where they can go for help.

### **Protective Factors**

When considering risk factors and warning signs, it is also helpful to consider protective factors. These not only help reduce risk of suicide, but may also reduce the risk of other problems that young people face. Parents, as well as friends and other important people and resources in a young person's life can strengthen protective factors. These factors include:

- Strong bonds, especially with family and adults.
- A sense of connectedness with others, including pets.
- Availability of counseling from a trusted adult.
- Parents who are present at key times (such as when the youth is celebrating an achievement, or struggling with a difficult issue).
- A sense of responsibility (for example, an opportunity to contribute to school and/or community).

### **Suicide Warning Signs**

Many people give some "warning" signs when they are thinking of attempting suicide. Parents should pay close attention to their child if they see or hear any of these warning signs. Seek help as soon as possible by contacting a mental health professional or by calling the National Suicide Prevention Lifeline at 1-800-273-TALK (8255) if your child exhibits any of the following signs:

- Threatening to hurt or kill oneself or talking about wanting to hurt or kill oneself.
- Looking for ways to kill oneself by seeking access to firearms, available pills, or other means.
- Talking or writing about death, dying, or suicide when these actions are out of the ordinary for the person.
- Feeling hopeless.
- Feeling rage or uncontrolled anger or seeking revenge.
- Acting reckless or engaging in risky activities... seemingly without thinking.
- Feeling trapped... like there is no way out.
- Increasing alcohol or drug use.
- Withdrawing from friends, family, and society.
- Feeling anxious or agitated, being unable to sleep, or sleeping all the time.

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- Experiencing dramatic mood changes.
- Seeing no reason for living or having no sense of purpose in life.

### *Talking with your child*

If your child or adolescent says, “I want to kill myself,” or “I’m going to commit suicide,” or makes a similar, less direct statement, ***always take the statement seriously and seek evaluation from a child and adolescent psychiatrist, physician, or other qualified mental health professional.***

Parents often feel uncomfortable talking about death. However, asking your child whether he or she is depressed or thinking about suicide can be helpful. Rather than “putting thoughts in the child’s head,” such a question from you will provide assurance that somebody cares, and it will give your child a chance to talk about the problems.

If one or more of the symptoms/warning signs occur, talk to your child about your concerns. Do not leave your child alone. Make sure that your child does not have access to guns or other methods of suicide. Guns are the most lethal means and are used in most suicides in New Hampshire, and just the presence of a firearm in a household greatly increases the likelihood of a suicide. In many towns, police departments will store weapons at a family’s request. Parents should also consider locking alcohol, medications, and other dangerous substances, and providing supervision until there is reason to believe that the child is not at risk of attempting suicide. If you have concerns about your child’s safety or mental health, involve other key people such as school personnel or trusted family, friends, neighbors, or others in the community who can maintain contact with your child, watch for warning signs, and help him/her feel connected to supportive people who care. When many members of a community can ***recognize*** the risk factors for youth and are prepared to ***connect*** and respond, the greater the chances are that a suicide attempt will be reduced and help will be obtained. NAMI NH has developed the “Recognize, Connect! Frameworks Suicide Prevention Project” which includes protocols for professionals and gatekeepers in communities to learn about how to recognize youth at risk and connect with them to prevent suicide. For more information, contact NAMI NH, or visit the website: [www.naminh.org](http://www.naminh.org) and click on the “Suicide Prevention” followed by the “Community Protocols” links.

**Note:** A *gatekeeper* is anyone who has frequent contact with youth and can serve as a source to refer a youth for help. Gatekeepers may include friends, family, coaches, other youth, or professionals.

The majority of suicide attempts are expressions of extreme distress and/or symptoms of depression or another mental illness, not just harmless bids for attention. All warning signs and attempts should be taken seriously. ***If you think your child might be suicidal, seek immediate mental health treatment, or call 911 if necessary, and do not leave your child alone. In addition, you may call the National Suicide Prevention Lifeline at 1-800-273-TALK (8255).*** With treatment and support from family and friends, children and teenagers who are suicidal can heal and return to a healthier path of development. (See Appendix C, “Community Mental Health Centers” on page 138 for contact information, and “National Alliance on Mental Illness New Hampshire (NAMI NH)” on page 128 for resources and reference materials.)

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## **Violent Behavior in Children and Adolescents**

Violent behavior (often identified as anti-social behavior) in children and adolescents can include explosive temper tantrums, physical aggression, fighting, threats or attempts to hurt others, homicidal thoughts, use of weapons, cruelty toward animals, fire setting, intentional destruction of property, and vandalism.

Even preschoolers can exhibit violent behavior. Parents and other adults who see such behavior are often concerned, but do nothing, hoping that the child will “grow out of it.” Violent behavior at any age should always be taken seriously; it should not be dismissed as “just a phase they are going through.”

**Note:** To address concerns about weapons-related injuries in schools that developed because of highly televised scenes of violence in a few American schools, the Surgeon General’s report on youth violence states that “weapons-related injuries have not changed significantly in the past 20 years. Schools, when compared to other environments, including neighborhoods and homes, are relatively safe places for young people.”

### *Risk factors*

Risk factors that increase the likelihood of violent behavior in children and adolescents include the following:

- Previous aggressive or violent behavior.
- Being the victim of physical abuse, sexual abuse, or bullying by peers.
- Exposure to violence in the home or community.
- Genetic inheritance.
- Exposure to violence in the media (TV, movies, video games).
- Use of drugs or alcohol.
- A combination of stressful family situations (poverty, severe deprivation, marital breakup, single parenting, unemployment, loss of support from the extended family).
- Brain damage from head injury.

Many studies indicate that a single factor or single situation does not cause child or adolescent antisocial behavior. Instead, multiple risk factors shape violent behavior over the course of the child’s development.

Outside the home, one of the major factors contributing to youth violence is the influence of peers. In the early school years, much of the mild aggression and violence is related to peer rejection and competition for status and attention. More serious aggression and violence are associated with small groups of youths who band together after being rejected and/or bullied by their peers because they are perceived as being different. Successful adjustment at home increases the likelihood that children will overcome such challenges outside the home without becoming violent. However, exposure to violent or aggressive behavior within a family can influence a child further in the direction of violence.

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### *Warning signs*

Symptoms or warning signs for violent behavior include:

- Intense anger.
- Frequent loss of temper or blow-ups.
- Extreme irritability and overtly confrontational (“in your face”).
- Extreme impulsiveness.
- Withdrawal from normal activities.

### *The influence of TV/video games violence*

Violence on television and in video games is not only a significant contributor to aggressive and violent behavior; it can be the *cause* of such behavior. Television/video games can be a powerful influence in developing value systems and shaping behavior, and much of today’s television programming and video games are violent. Hundreds of studies of the effects of TV/video game violence have found that children and teenagers might respond as follows:

- Become immune to the horror of violence.
- Gradually accept violence as a way to solve problems.
- Imitate the violence they observe on TV/video games.
- Identify with certain victims and victimizers.

The impact of TV/video game violence may be immediate or may show up years later, and children can even be affected when there is no violence in the family environment.

Children who view shows in which violence is very realistic, frequently repeated, or unpunished are more likely to imitate what they see.

Here are some ways to protect your child from excessive TV/video game violence:

- Pay attention to the shows your child is watching and video games they are playing; watch some programs and play some of the video games with them.
- Point out that although the actor/figures have not been hurt or killed, in real life such violence results in pain or death.
- Set limits on the total TV viewing time and time spent playing video games.
- Do not allow your child to see shows known to be violent. Change the channel, or turn off the TV when something offensive comes on, and explain why.
- Do not allow your child to play video games that are violent, and explain why.
- Disapprove of the violent episodes in front of your child, stressing the belief that such behavior is not a good way to solve a problem.
- To offset peer pressure among friends, contact other parents and agree to enforce similar rules about the length of time and types of programs the children may watch and video games they play.

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You can also use these techniques to prevent the harmful effects of TV/video games in the areas of racial or sexual stereotyping. And, remember... the amount of time spent watching TV (regardless of the content) or playing video games keeps your child from other, more beneficial activities such as reading and playing with friends.

## **Adolescent Substance Abuse**

### *Prevalence of alcohol and other drugs*

Substance use (alcohol and other drugs) by America's youth has proven to be a rapidly changing phenomenon requiring frequent assessments and reassessments. Since the 1960's it has remained a major concern for our nation.

*Alcohol* use remains extremely widespread among today's teens and is the #1 drug used in New Hampshire. 50% of New Hampshire high school students report drinking alcohol in the last month and 31% of students report binge drinking, which is defined as consuming five or more drinks on one or more occasions in the last 30 days. The prevalence of alcohol use by youths increases from 2.6% at age 12 to a peak of 67.5% at 21 years old. **Youth who drink before they turn 15 are four times more likely to develop alcohol dependence than those who start drinking at 21.** [*Governor's Commission on Alcohol and Drug Abuse, Prevention, Intervention and Treatment - 2005*]

*Marijuana* is the second most used drug by New Hampshire's youth. In 2002, over 14 million Americans age 12 and older used marijuana at least once in the month prior to being surveyed, and 12.2% of past-year marijuana users used marijuana on 300 or more days during that 12 month period. The short-term effects of marijuana can include: problems with memory and learning, distorted perception, difficulty in thinking and problem solving, loss of coordination, and increased heart rate. Research indicates that long-term marijuana use produces some changes in the brain similar to those seen after long-term use of other major drugs of abuse. **Depression, anxiety, and personality disturbances have been associated with marijuana use.** Research clearly demonstrates that marijuana has the potential to cause problems in daily life or to make a person's existing problems worse. [[www.addiction-help-line.com/marijuana.html](http://www.addiction-help-line.com/marijuana.html)]

### *Availability of alcohol and other drugs*

In New Hampshire, 50% of middle school students and 77% of high school students surveyed think that it is "easy" or "very easy" to get beer, wine, or liquor. 25% of middle school students who drink state that they take alcohol from the supplies of their parents or friends' parents. More than 50% of high school students claim that they ask someone of legal age to provide them with alcohol. [*University of New Hampshire Teen Assessment Project Survey - 2004*]

More than 30% of high school students report having had 5 or more drinks in a row in the past month, but only 3% of parents think that their high school student has consumed alcohol at that level. A substantial portion of alcohol advertising reaches an underage audience. Youth see more advertising for beer than for juice, gum, sneakers, or jeans. [*Governor's Commission on Alcohol and Drug Abuse, Prevention, Intervention and Treatment*]

## Chapter 4. About Serious Emotional Disorders and Behavioral Issues

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Slightly more than 50% of youth age 12 to 17 indicated that it would be “fairly” or “very easy” to obtain marijuana. 26% of youth age 12 or 13 said it would be “easy,” but that rose to 79% for youth age 16 or 17. [[www.addiction-help-line.com/marijuana.html](http://www.addiction-help-line.com/marijuana.html)]

Other drugs of abuse are also available in New Hampshire. There has been a recent increase in *crack cocaine* availability. *Heroin* is available in street level quantities, supplied primarily by traffickers with bases of operation in the Lowell/Lawrence, Massachusetts areas. Availability of *methamphetamine* within the state has continued to grow in the past few years and it is anticipated that this trend will continue. [*US Drug Enforcement Administration, February and March 2004*]

### *Substance abuse*

For adolescents, any amount of alcohol or drug use is problematic. New technologies have shown that the brain does not stop forming until the late twenties. Introducing substances into a brain affects that development. **Alcohol and other drug abuse can compromise an adolescent’s psychological, emotional, and social development.** It also interferes with learning ability, thereby affecting educational achievement. For a youth who may already have difficulties in any of these areas, it is particularly dangerous. Parents and other concerned adults should talk with youth about their particular vulnerabilities and help them attain skills to make healthy decisions and act on them.

### *Addiction is a disease*

Some people who abuse drugs develop the disease of addiction. Addiction is a physiological disorder based in the brain that is influenced by behavioral and environmental factors. It is a primary, chronic, progressive, and potentially fatal disease. In all of these ways, it is similar to hypertension, diabetes, and asthma.

Dr. Steven Hyman from the National Institutes of Health describes it this way. “Addiction is a disease of the brain. In the vulnerable brain, if you use drugs at a high enough dose, frequently enough, and for long enough, you change the way nerve cells communicate in such a way that you develop this compulsive, out of control use, despite knowing that all kinds of terrible things can happen to you, and despite even experiencing many of those things.” Many factors can contribute to a “vulnerable brain.” There is clearly a genetic link. If someone has a parent or grandparent with addiction, it is much more likely that they will develop this disease. Starting alcohol or other drug use at a young age will also make a brain more vulnerable. **Finally, if someone has other problems with brain functioning, e.g. mental illness, AD/HD, trauma reactions, or developmental delays, they are at an increased risk of developing addiction.** Of course, the disease is only triggered if someone uses alcohol or other drugs. It is best to talk with youth about their particular situation and risk factors and advise them to protect themselves by avoiding use.

Physiological changes in the brain lead to preoccupation with the substance, distortions in thinking, and impaired control over using the substance despite adverse consequences. Behavioral changes such as mood swings, accidents, and lack of interest in friends and family are some of the changes seen at the onset of abuse. Once the youth has reached the point of addiction, environmental factors such as the people, places, and things that the youth associates with using the substance will trigger craving and urges in the brain to use the substance again. Internal factors like boredom, uncomfortable feelings, or memories

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of past trauma will also trigger craving. These urges are very difficult to resist and usually require help to overcome.

Fortunately, people with addiction respond well to treatment and many of them recover. In fact, research has shown that the disease of addiction has a higher rate of recovery than other chronic diseases such as hypertension and diabetes. Like these other chronic, relapsing diseases, addiction sometimes requires multiple courses of treatment. Recovery from addiction involves more than just stopping use of the drug. Recovery, like the disease, must encompass the physiological, behavioral, and environmental aspects of a person's life. This is hard work and it takes time. Family support is an essential factor in an adolescent's recovery.

#### *Local substance treatment centers and resources*

Contact information for alcohol and other drug service providers can be found in the "Resource Guide for Alcohol and Drug Prevention and Treatment Services" located at the New Hampshire Department of Health and Human Services website: [www.dhhs.state.nh.us](http://www.dhhs.state.nh.us). Click on the "Substance Abuse" link. Please note that not all facilities treat youth less than 18 years of age.

Some new adolescent treatment resources are being developed. Information about them is available at [www.new-futures.org](http://www.new-futures.org). Click on "Adolescent Treatment Initiative/Grantees Service Project." (See Appendix C, "State and National Resources" beginning on page 119.)

## **Cultural and Language Differences**

Mental health practitioners are very aware that mental health problems seldom occur in isolation from a child's and family's environment (employment, school, neighborhood, religious community, family traditions and lifestyle, extended family members, and so forth). Families who are immigrants, members of racial or cultural minority groups, or whose lifestyle is different from most families in their community know the importance of environmental and cultural differences all too well. For example, children whose gender identification or sexual orientation is not the same as most of their peers have particularly difficult stresses that complicate their emotional well-being.

Professionals have identified the environmental factors that usually affect the way a child responds to his or her treatment plan. We encourage you to search this list of environmental factors to find any that might be a part of your family's life at this point in time. If any of these factors apply, this needs to be communicated to the practitioner so that necessary supports can be incorporated into your child's treatment or educational plan.

Environmental factors that affect a child's response to treatment include the following:

- Lack of financial resources.
- Racial or cultural prejudice.

Environmental and cultural differences can complicate your child's everyday life – they can also interfere with your child's treatment plan if the practitioners who design the plan are not aware of them. When working with your child's providers, be sure to share non-medical factors such as racial, cultural, language, sexual/gender differences, a recent loss of a family member through death or divorce, financial pressures, and other significant family considerations.

## Chapter 4. About Serious Emotional Disorders and Behavioral Issues

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- Alternative sexual orientation or gender identification.
- Trying to fit into a new (American) culture.
- Language barrier for the child or parents.
- Divorce or other family loss or conflict.
- Unemployment in the family.
- Not living in your own home.
- Child abuse and domestic violence.
- Drug or alcohol abuse.
- Crime (in the family, or in the neighborhood/school).
- Physical illness, disability, or developmental disability.

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# Chapter 5. Navigating the Treatment System

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## Chapter Overview

*A serious emotional disorder touches every part of your family's life, so your family might need a variety of services. These services are provided by different types of professionals, who might have different treatment philosophies, and who work in different agencies. Navigating through the many state, community, and private agencies in the treatment system can be a frustrating experience if the services are not well coordinated.*

*The purpose of this chapter is to provide a working knowledge of the treatment system, enabling you to be a more effective advocate for your child. It describes most of the agencies you might work with, the services provided by each agency, and the*

*practitioners who provide the services.*

*The chapter offers guidelines for locating the appropriate services for your child and family. It outlines the treatment process along with suggestions on how to make it work better for your child and family. It ends with a description of your legal rights in the treatment system.*

*In addition to knowing how the treatment system works, **you need to be persistent and assertive about getting the services your child needs.** The demand for services is greater than the capacity of the system that provides them, so be prepared to advocate for what your child and your family needs.*

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## Organizations Providing Services

This section describes the variety of organizations that you and your child might be working with at different times. New Hampshire’s public mental health system is organized under the *Department of Health and Human Services* (DHHS) and continues to work toward providing extensive community-based mental health services.

### ***Community Mental Health Centers (CMHC)***

*Community Mental Health Centers* (CMHC) are private, not-for-profit agencies that have contracted with the New Hampshire Department of Health and Human Services, under its Division of Community Based Care Services - Bureau of Behavioral Health (BBH), to provide publicly funded mental health services to individuals and families who meet certain criteria. Your child must be assessed and found to be eligible for the services provided at the center.

**Note:** In this context, “publicly funded” means that the person qualifies for Medicaid insurance and can receive mental health services of varying intensities from the mental health center depending upon the severity of illness and ability to function in daily life. (See Chapter 7, “Paying for Services” beginning on page 95.)

Each of the ten regional CMHC (see Appendix C, “Community Mental Health Centers” on page 138) provides many outpatient mental health services to children and adults. (See “Types of Mental Health Services” in this chapter on page 69.) Each regional center has a geographic “catchment area,” and residents in that catchment area will utilize that particular CMHC; crossovers are rare.

CMHC are staffed by a variety of practitioners, including nurse practitioners, clinical social workers, clinical psychologists, psychiatric nurses, and mental health counselors. In addition, each center has a director of children’s services. However, individual centers differ from each other in staffing, the way services are provided, and the role that families play in the treatment process. If you find that you are not being included as a partner on your child’s treatment team, speak to your child’s case manager or therapist about becoming a part of the team. *Since your signature will be required on the treatment plan, you should be an active member of the team that develops the treatment plan.* Be certain you receive a copy of the treatment plan after you sign it.

Community mental health centers provide services to individuals covered by public insurance (such as Medicaid/Medicare) or private insurance. CMHC also provides services to individuals not covered by insurance on a “sliding scale” fee basis. *Check to see if your insurance carrier will cover the services of the CMHC.*

### ***Other New Hampshire Agencies***

#### **Division for Children, Youth, and Families (DCYF)**

The *Division for Children, Youth, and Families* (DCYF) is organized under the New Hampshire Department of Health and Human Services and manages protective programs on behalf of New Hampshire’s children, youth, and families. DCYF provides a wide range of family-centered services with the goal of meeting parent and child needs and

## Chapter 5. Navigating the Treatment System

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strengthening the family system. Services are designed to support families and children in their own homes and communities, whenever possible, and as long as safety is not an issue. DCYF has six major program areas and three key support service areas. The major programs and support services include:

### ***Bureau of Child Protection***

The *Bureau of Child Protection* works to protect children from abuse and neglect while attempting to preserve the family unit. *Child Protective Services* help prevent further harm to children from intentional physical or mental injury, sexual abuse, exploitation, or neglect by a person responsible for a child's health or welfare.

### ***Child Development Bureau***

The *Child Development Bureau* provides technical assistance and support to early care and educational programs. It provides client education as well as training to help communities develop and maintain their own child care programs. The bureau develops policy for the New Hampshire child care scholarship program, and maintains statistics on the supply and demand of child care throughout New Hampshire. Through the scholarship program, parents may apply for financial assistance to subsidize the cost of child care while they look for work, remain employed, or participate in training.

### ***Bureau of Community and Family Support***

- **Foster Care:** Specially trained Foster Care Workers in each DHHS District Office recruit, train, and license foster families and match children entering the system with a foster family best suited to meet the specific needs of each child.
- **Adoption:** Placement specialists provide assessment and case management services for children whose parents' parental rights have been terminated. Children are assessed for potential adoption and adoptive parents are recruited, trained, and provided with needed support.
- **Family Support:** Staff work with provider groups to ensure adequate delivery of statewide services.
- **Interstate Compact:** Staff monitors the placement of children in care who are either entering or leaving the State of New Hampshire.

### ***Teen Independent Living***

Child Protective Service Workers with specialized training work with children ages 16 and older, their foster care providers, and case managers to assist these youths in making the transition to adulthood.

### ***Domestic Violence Services***

*Domestic Violence Program Specialists* employed by local community crisis centers are located in each DHHS District Office to help identify domestic violence situations and provide support to victims of domestic violence. Within DHHS, a task force meets regularly to coordinate and collaborate on domestic violence and sexual assault issues that are critical to serving New Hampshire's client population. DHHS also administers several

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grants that support direct service delivery by community agencies and crisis centers for domestic violence and sexual abuse.

### **Division for Juvenile Justice Services (DJJS)**

If your child's behavior reaches into some of the areas judged by our society to be more serious, you and your child may become involved with the *Division for Juvenile Justice Services* (DJJS), which is organized under the New Hampshire Department of Health and Human Services. Different departments in DJJS provide the following continuum of services depending on the behavior "violation" of the child:

- Children who exhibit such behaviors as truancy from school, running away from home, uncontrollable disobedience at home, or placing themselves or others in danger are labeled *Children in Need of Services* (CHINS) and receive a particular level of services.
- Children who physically harm others, steal, destroy property, or commit other offenses that would be considered a felony or misdemeanor under the criminal code if committed by an adult are labeled *Delinquents*, and receive another level of services.

One of the services operated by DJJS is the *Youth Development Center* (YDC). Young people enter the YDC because they have been convicted of certain serious juvenile offenses. Many of these juveniles experience emotional disorders. A fair number of these juveniles have not been diagnosed and are, therefore, untreated. Although there are on-campus education services at YDC, all the residents are under various degrees of lockup and are provided with varying amounts of classroom instruction. Some YDC students go to local schools during the day, if eligible. Others go to part-time jobs off campus. In addition to receiving individual case counseling and participating in group meetings, residents may also receive mental health services from community providers.

If your child becomes involved in DJJS, or you think he or she is exhibiting behavior that might lead in that direction, call NAMI New Hampshire at (800) 242-6264 and ask for the pamphlet *Working with Juvenile Justice Services*, which explains: 1) the distinction between a Child in Need of Services (CHINS) and a Juvenile Delinquent; 2) how a CHINS petition is processed; 3) how a Juvenile Delinquent petition is processed; and 4) court diversion.

### **Bureau of Vocational Rehabilitation (BVR)**

The *Bureau of Vocational Rehabilitation* (BVR) is organized under the New Hampshire Department of Education. Qualified people with disabilities are entitled, through a federal program, to individualized services to help them: decide on a vocational goal; receive necessary training; obtain needed technology and equipment; find an appropriate job; and keep that job.

To receive BVR services, a person must have a vocational evaluation or interest assessment, especially if there is doubt about the individual's capability and vocational goal. The standard used for eligibility is that the person is experiencing a barrier to employment as a result of a disabling condition that is medically substantiated. Your child will likely qualify for BVR services if he or she has been diagnosed with a serious emotional disorder or mental illness. Eligibility for the program ends if your child demonstrates the ability to remain employed.

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For more information on acquiring services from BVR to transition out of school, see Chapter 6 section, “Transitioning Out of High School” on page 92. See Appendix C, “Bureau of Vocational Rehabilitation (New Hampshire Department of Education)” on page 142 for BVR contact information.

### **The Area Agencies for Developmental Services**

The *Bureau of Developmental Services* is organized under the New Hampshire Department of Health and Human Services - Division of Community Based Care Services and contracts with 12 statewide agencies that provide a broad range of services and supports to individuals with developmental disabilities or acquired brain disorders. If your child’s developmental disability is his or her primary disability, you can apply for services from your regional area agency for developmental disabilities. (See Appendix C, “Area Agencies for Developmental Disability Services” on page 124.) If your child is found eligible for services, the area agency can: provide case management; connect you to support groups, individual parents, appropriate agencies, and newsletters; and provide (or provide funding for) training and respite programs.

Children up to 3 years of age may be eligible for *Early Support and Services* (ESS) through the area agency. (You may also want to consider working with the local infant mental health team. See Appendix C, “Infant Mental Health Regional Team (IMH)” on page 130.) If your child is receiving services from ESS, about 6 months prior to your child’s 3rd birthday, you should work with the ESS service coordinator to refer your child to the school district and to help develop a plan to transition your child from ESS to the school district. This transition is covered under the federal *Individuals with Disabilities Education Improvement Act* (IDEA). (See Chapter 6, “Safeguarding Your Child’s Education” beginning on page 85.)

### **The Public School System**

Part of a child’s *Individual Education Program* (IEP) in the public schools can include the services of a psychologist or other mental health practitioner. (For more details on special education services and the IEP, see Chapter 6, “Safeguarding Your Child’s Education” beginning on page 85.)

Your child might receive counseling on a regular basis at school from the school psychologist or from a person that the school district hires to provide counseling during the school day. If you have a *crisis management plan* for your child, it may indicate the services to be provided by the school psychologist, guidance counselor, or special education teacher. If there is no crisis management plan for your child, ask to have one developed. (See Chapter 8, “Crisis Management Planning” beginning on page 101.)

As the number of professionals interacting with your child grows, there is more room for confusion and miscommunication. As with any other service, the goals and outcomes of these services should be clearly stated in your child’s IEP.

*Alternative educational programs* are available in many school districts. These programs provide educational and emotional and/or behavioral supports to assist your child in being schooled in his or her home community. This should be detailed in your child’s IEP.

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These programs provide segregated classrooms, sometimes called “resource rooms,” in the regular schools or in separate buildings where treatment services and the educational curriculum are sometimes combined.

### ***Residential Treatment Centers and Psychiatric Hospitals***

The organizations in this section are for children who are not benefiting from programs in a community setting and require a more intensive and restrictive treatment setting.

#### **Residential Treatment Centers and Private Schools**

*Residential treatment centers and private schools* provide greater structure and consistency in a child’s treatment. These agencies are most useful for a child who has mental health and academic needs that cannot be met in the community. The services at these agencies are often based on a strong philosophical model. For example, some centers believe in “tough love,” and others work through a more varied system of behavioral conditioning based on rewards and consequences. *Before agreeing to a placement, parents should ask questions to be sure they understand the philosophy of the agency.*

If your school district recommends a private treatment center or private school, you have the right to ask questions and refuse if you do not agree with the placement. *Before agreeing to a transfer to one of these agencies, make sure you understand the purpose of the placement, the intended goals and behavioral outcomes, the plan for re-entry into the community, and most of all, the philosophy of the center and the qualifications of staff members.* Alternative ways of taking classes within the public school system, credit for independent study and work-related activities, and other individualized programs can often, but not always, be more successful than moving a child to a residential facility away from home and community. (See Chapter 6 section, “Special Education Services in School” on page 87.)

#### **Private and Public Psychiatric Hospitals**

The hospitals described in this section are for children who are at risk to themselves or others and/or who require more intensive treatment or medication monitoring than can be offered on an outpatient basis. There are limited inpatient psychiatric facilities for children and adolescents. Although psychiatric hospital services are available, they are used for short-term crisis intervention and stabilization. Children with serious emotional disorders (SED) or mental illness do not stay in the psychiatric hospitals for extended periods of time. Instead, the goal is to have them stay at home, in school, at work, or in other more natural community settings and receive their mental health services and supports in their home community.

*Private, for-profit hospitals* are often linked to private physicians and practices. Some hospitals are designed as psychiatric hospitals, and others are general hospitals with separate psychiatric clinics or wards. A child or youth will be referred by the physician to a psychiatric hospital because of “acute” (serious) symptoms such as potential suicide, toxic drug use, delusions, or hallucinations. This is a very restrictive form of treatment, and should only be used when the child cannot be treated in any other setting. Such

hospitalizations can be very expensive; not all hospitals will accept Medicaid, so check your insurance coverage before admission.

*Private, nonprofit hospitals* provide the same services as private for-profit hospitals, but are organized differently. These hospitals are often associated with universities (*Dartmouth-Hitchcock Medical Center (DHMC)* in Lebanon, NH for example). DHMC is also linked to an outpatient clinic, allowing for better continuity of care once the patient is discharged; however, DHMC does not have an adolescent unit.

*Public hospitals* are owned and operated by local, state, or federal governments and may have psychiatric wards or clinics. New Hampshire has several public hospitals that can serve people with mental illness, though space in these facilities is limited. These facilities accept private insurance and Medicaid. The State of New Hampshire operates a psychiatric hospital (See “New Hampshire Hospital,” below) which includes a unit for adolescents, and a psychiatric hospital for children (the Anna Philbrook Center). Admission to New Hampshire Hospital is generally on an involuntary, emergency basis.

**Important!** Your child’s experience in a psychiatric hospital will have profound effects on his or her life. For this reason, be sure you fully understand why hospitalization is being recommended for your child, including specific goals, the scheduled time of release, and any necessary follow-up activities. (See “Involuntary Hospital Admission Rights” on page 82 within this chapter and the Chapter 3 section, “If hospitalization is required” on page 33 for more information.)

### **New Hampshire Hospital**

New Hampshire’s state, inpatient psychiatric hospital is *New Hampshire Hospital (NHH)*, organized under the New Hampshire Department of Health and Human Services. It is located in Concord and provides diagnostic and therapeutic psychiatric services to patients of all ages who have acute or chronic mental illness.

NHH offers services to children in two buildings on the hospital campus: the F Unit of the Acute Psychiatric Services (APS) building, and the Anna Philbrook Center (APC). Typically, children and adolescents up to age 15 years and 9 months are admitted to the Anna Philbrook Center, and children over that age are admitted to the F Unit of APS. Admission to either APC or APS can also be determined by hospital census.

A young person usually enters the APC for special evaluation (sometimes under court order) or because he or she is suicidal or otherwise acting in a way that is potentially harmful to himself, herself, or others. APC and the F Unit of APS are staffed by board certified child and adolescent psychiatrists and professionals in nursing, psychology, education, social work, and rehabilitation who have special training in working with children and adolescents.

*Admission to NHH* must be through your community mental health center, or through a private practitioner who has received privileges to admit to NHH. When your child is ready to return to your home and community, NHH coordinates the discharge planning through you and the appropriate agencies or practitioners unless another person has been identified as the guardian of your child. *Discharge planning should begin at the time of admission.*

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**Note:** For information on protections available regarding involuntary admission, see “Involuntary Hospital Admission Rights” on page 82 within this chapter.

### **Offices of Private Practitioners**

Private practitioners often work in groups with other practitioners, but can work as individual consultants. They frequently specialize in one or more disorders (for example, eating disorders or obsessive-compulsive disorder) or in certain types of therapies (for example, light therapy for people with Seasonal Affective Disorder, or reality therapy). Private practitioners can be medical doctors (including psychiatrists and neurologists), psychologists, therapists, social workers, pastoral counselors, and educational specialists.

Most private practitioners work according to a short-term medical model of treatment and are not expected to provide long-term services. Services are almost always provided in the practitioner’s office and are billed to your insurance or require personal payment. A private practitioner may refer a person to the community mental health system because the child and family need more services than the practitioner is able to provide.

Some private practitioners have made referrals to the community mental health system under the misconception that the public mental health system must provide services at no fee when private insurance benefits have reached the limit of coverage.

Have a good reference from a person or agency you trust before interviewing or visiting the office of a private practitioner. Be sure to have a clear sense of what you expect from the practitioner. And be aware that there might be a waiting list for the practitioner and that you may have to make the difficult decision of using another practitioner or waiting for the preferred one.

Before deciding to use the services of *any* practitioner, consider:

- What kind (specialty) of doctor or therapist do you want for your child?
- What type of person will your child be comfortable with?
- What kind of philosophy do you want the practitioner to have?
- What role do *you want to play* in your child’s treatment?
- How do you want the practitioner to treat your child?

## **Types of Mental Health Services**

This section describes the types of services provided in the public mental health system. You can refer to the state rules and regulations He-M 426 for more details. You can access these at the New Hampshire Department of Health and Human Services website: [www.dhhs.nh.gov](http://www.dhhs.nh.gov) or directly at [www.gencourt.state.nh.us/rules/he-m400.html](http://www.gencourt.state.nh.us/rules/he-m400.html). You can also contact NAMI NH for more information.

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Although certain services are available in the private sector or through other agencies, a comprehensive array of services is primarily provided by the community mental health centers. CMHC are contracted to provide a broad range of services, but individual centers differ in staffing and the way these services are provided:

- **Case Management**, including coordinating community-based support and treatment (wraparound services).
- **Psychiatric Assessment** (part of the intake procedure), evaluation and testing.
- **Medication Administration** and monitoring.
- **Psychotherapy** (individual, group, and family counseling).
- **IROS Functional Supports**  
(*Individual Resiliency and Recovery Oriented Services will be replacing MIMS - Mental Illness Management Services*).
- **Respite Services**.
- **Emergency Mental Health Services** (24 hours/day).

**Note:** Demand often exceeds CMHC capacity, so you might have to wait to receive certain services.

Some parents want to access only *selected* services (such as case management, IROS functional supports, respite, and emergency services) through the CMHC. However, some CMHC have policies that require a person to receive *all services* (the aforementioned plus therapy and psychiatry) through them, whereas other CMHC allow one to receive therapy or psychiatric services in the private sector. Discuss your questions and preferences with the director of the children's program.



### **Case Management**

Case management is a service that helps the child and family obtain and coordinate community services. If your child has serious emotional disorders, requires multiple, intensive services, and meets the eligibility criteria, your community mental health center

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may assign a case manager to your child. A case manager helps you and your child set up services for your child within the community mental health center, plan for services and support, connect you with resources within your community, and sometimes provides counseling to your child. Your child's case manager is also the person who can provide referral to your regional *wraparound team* if you ever find that CMHC services alone are unable to meet the needs of your child and family. (See "The Wraparound Concept of Care" in this chapter on page 79.) *Case management is a service not covered by private insurance carriers and is only covered by Medicaid.* (See Chapter 7, "Paying for Services" beginning on page 95.)

### ***Psychiatric Assessment and Testing***

Psychiatrists and certified nurse practitioners are able to provide assessment (evaluation) services for your child. An assessment is needed in order to diagnose (define) your child's condition and prescribe the correct clinical treatment, which might include medications. Some (but not all) CMHC have staff trained to do psychological testing. If your CMHC does not have a psychologist on staff, they can refer you to a provider in your community or you can contact your insurance carrier to get a list of providers. *Psychiatric services are covered by private insurance carriers and Medicaid, but there may be service limits to this coverage.* (See Chapter 7, "Paying for Services" beginning on page 95.) *Check with your insurance carrier to see if testing will be a covered service before the service is provided.*

### ***Medication Administration***

Based on your child's diagnosis, medications may be prescribed by a psychiatrist or nurse practitioner at the CMHC. The psychiatrist and therapist will help you and your child understand the purpose and potential side effects of any medications, and will work with you to monitor the effects of the medication and thus be able to change the frequency and dosage of prescriptions as necessary.

**Important!** After your child begins taking a prescribed medication, he or she might begin to feel much better, and symptoms might disappear. After a while, you and your child may begin to think the old problems have gone away, and that medication is no longer necessary. Your child should *never stop* taking the medication before you consult with your child's doctor and you *both agree* to start reducing the dosage. It can be dangerous for your child to suddenly stop taking the medication.

To help your child's practitioners monitor the medications, be sure to tell them about any changes (sleep, eating, or behavioral habits) that you notice in your child after he or she starts taking the medication. *In general, always keep your child's practitioners aware of important changes in your child's life, such as the death of a family member or pet, the loss of a friendship for whatever reason, or any changes at school.*

### **Psychotherapy**

Psychotherapy (counseling) for your child and your family should help you set personal and family goals, develop coping skills, and learn behavioral strategies. Depending on your child and your family's needs, the therapist will establish the frequency of sessions and determine if your child will be in brief or long-term therapy. Individual, group, and family counseling are a major part of the services at your community mental health center. Psychotherapy is sometimes provided along with other treatment supports such as medication, case management, and IROS.

*Psychotherapy is a covered service with private insurance carriers and Medicaid; however, there may be a limit on visits or funding available. It is important to be aware of the coverage and limits when you begin the service.*

“What I remember most is the suffering. Kids are supposed to be happy. Boy, that’s a joke. I was depressed for years and felt totally odd and isolated, almost despised. Growing up was a really miserable experience until I got help.”

–A young man in therapy, recalling his childhood

### **IROS Functional Supports**

IROS (*Individual Resiliency and Recovery Oriented Services* will be replacing *MIMS - Mental Illness Management Services*) functional supports are mental illness recovery and resiliency services which will be offered by the CMHC to provide strategies and techniques to help individuals manage symptoms and/or behaviors that interfere with daily functioning and self-care. Supports will also be provided to family members and significant others who want to learn how to assist an individual in managing behaviors in the home and community. These services are primarily provided in a community setting and are not an office-based support. To receive these services, an individual must meet certain eligibility criteria. *These services are covered by Medicaid.*

DHHS describes these services in He-M 426 which are the rules and regulations that govern the community mental health services. *Functional Support Services* include the following: medication education, symptom management, family support, and therapeutic behavioral services. According to the rules and regulations, these services are to be provided in the client's current living, employment, or educational setting or other community setting taking into account the preferences of the client. To get a copy of the He-M 426, you can visit the DHHS website: [www.dhhs.state.nh.us](http://www.dhhs.state.nh.us) or contact the DHHS Information and Referral Line (603) 271-5557 and ask for a copy of He-M 426.00.

### **Respite Services**

Respite is a short, temporary period of rest and relief for both the child with a serious emotional disorder (SED) and the child's family. Respite periods usually last a few hours, a day, or a weekend. There are different models of respite care... some in the home, some in the community, and some in other peoples' homes. Wherever respite is provided, parents should ensure the respite providers are receiving specialized, ongoing training and supervision. Parents should check on the respite facility's license through DHHS,

“Sometimes we’re not aware that we need relief until we find ourselves screaming at our child or bursting into tears over a small problem.”

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especially if the child will be at the respite home overnight. Respite is an important service that families need in order to be able to keep their child at home.

Respite periods are sometimes part of a child's treatment plan. For example, they can be used to help a child learn how to function within the community. When respite is a part of a child's treatment plan, the primary goal of respite services is the child's development, and a secondary goal is the relief it provides for the family. In other cases, the primary goal of respite services is to provide relief for the family.

Periods of relief (or simply knowing they are available when needed) can significantly reduce your family's level of stress and better enable you to effectively care for your child and cope with ongoing family issues. *Using respite services does not indicate that you are not able to care for your child.* Caring for a child with SED is a very intense, high-pressure activity. Regularly scheduled and anticipated breaks can only enhance your effectiveness.

If you have good friends or family members who are willing to care for your child when you need a break, be sure to ask for and gratefully accept their help. This may be difficult if you've always handled responsibilities yourself, but make yourself do it... you deserve it.

If your friends and relatives cannot provide the type of support you require, discuss your needs with the community mental health center. (Respite services may or may not be available through your CMHC, but your CMHC might be able to suggest other respite providers.) *Respite services are generally not covered by private nor public insurance.*

## **Emergency Services**

The community mental health center has an emergency service department that provides crisis intervention and evaluation for hospitalization. This involves working with a mental health practitioner and, in some cases, a psychiatrist. Emergency services are available 24 hours a day, 7 days a week. This service is usually provided at the CMHC or local hospital emergency room. This service is available to clients of the CMHC as well as individuals who are experiencing a mental health crisis but who are not connected with a mental health provider. However, not all CMHC emergency service staff have experience or training to work with children or adolescents, so it is important to have a current and comprehensive *crisis management plan*. (See Chapter 8, "Crisis Management Planning" beginning on page 101.) Individuals in treatment with private practitioners should contact their provider first, since these providers should have their own emergency support service. *Emergency Services are typically covered by private insurance and Medicaid.*

**Important!** If your child's life is at risk or someone else's life is in danger, **call 911** first. (See Chapter 4 section, "Child and Adolescent Suicide" on page 51.)

## **Family Mentors**

An additional service is the Family Mentor program. The family mentors are family members who have faced the challenges of raising children with serious emotional disorders. The services of a family mentor are only available to clients of the community mental health center. Their primary responsibility is to work with families, providing support and education. The family mentor's scope of work can vary from one community

mental health center to another based on the needs of the region. To access this service, contact the children’s department at the CMHC in your area. (See Appendix C, “Community Mental Health Centers” on page 138.)

### Types of Mental Health Practitioners

It is important to check credentials, since practitioners might not have the training you assume. For instance, any physician can practice psychiatry if he or she is interested in the field, but a fully trained psychiatrist has four years of specialized training in psychiatry in addition to a medical degree (M.D. or D.O.). Anyone can *call* himself or herself a counselor, but may or may not have a college degree.

#### ***Nurse Practitioner***

A nurse practitioner (nurse clinician) is a registered nurse who has received special training for diagnosing and treating routine or minor ailments. A nurse practitioner can also prescribe your child’s medication.

#### ***Pastoral Counselor***

A pastoral counselor is a member of the clergy who has received training in the use of psychotherapeutic techniques to assist parishioners who seek help for personal or emotional problems. If you receive counseling from the pastor of your church at no charge, your pastor does not need to be licensed. A New Hampshire licensed pastoral psychotherapist must have a masters degree from a theological school plus a Ph.D. in pastoral psychotherapy or psychology.

#### ***Physician or Pediatrician***

Your child’s primary care physician, whether he or she is a pediatrician or not, can play a key role in obtaining and managing services for your child. *If medications are prescribed by other medical professionals, be sure your child’s primary care physician is aware of these medications.* (See Chapter 1 section, “The Important Role of Your Primary Care Physician” on page 4.)

#### ***Psychiatrist***

A psychiatrist is a physician (medical doctor) who specializes in providing medical and psychiatric evaluation and treatment for emotional, behavioral, and psychiatric disorders. Because they are physicians, psychiatrists can prescribe and monitor medications. Since the proper treatment of many serious disorders requires an accurate diagnosis and the prescription of medications, you might need to consult a psychiatrist as part of the treatment process. *A child and adolescent psychiatrist* is a fully trained psychiatrist who has two additional years of training in the area of children, adolescents, and families.

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## **Psychologist**

A psychologist can provide psychological evaluation, testing, and treatment for emotional and behavioral problems and disorders. Currently, for a psychologist to be licensed by the State of New Hampshire, he or she must have earned a Ph.D. However, some psychologists possess a masters degree (M.S.) in psychology and are “grandfathered” under the law. Others have a doctoral degree (Ph.D., Psy.D., or Ed.D.) in clinical, educational, counseling, or research psychology.

Clinical psychologists have studied behavior and mental processes and are trained in the evaluation and treatment of emotional disorders.

School psychologists have studied mental processes and behavior and know how to manage behavior problems in the school setting. They are also trained to administer intelligence, aptitude, and achievement tests. Most school psychologists work primarily in the school environment, although some also practice privately.

## **Psychotherapist**

This is a general, descriptive term for anyone who treats emotional disorders. *It is important to find out about the therapist’s training and background to determine if he or she will be able to appropriately treat your child.*

## **Social Worker**

The term social worker can mean anyone who performs social work functions. Social workers are regularly expected to provide most forms of psychotherapy and counseling services. Those most likely to be helpful as therapists have been trained and licensed in the fields of clinical or psychiatric social work. To be licensed by the State of New Hampshire, social workers must have earned at least a M.S.W. degree and have completed two years of supervised clinical work. Some social workers have a bachelors degree (B.A., B.S.W., or B.S.) but cannot practice independently; many of these social workers are employed by the CMHC. However, most social workers have earned a masters degree (M.A., M.S., or M.S.W.), and some have Ph.D. or D.S.W. doctorate degrees.

## **How to Find the Appropriate Agency and Service**

This procedure may help you find the right agency and service for your child and family:

1. Before attempting to decide on the first agency to contact, **take some time to be clear about what you are looking for.** An effective way for you to gain this clarity is to write a short description of your child. Use it each time you speak to someone during the search. The description should include:
  - The type of service you are seeking.
  - Your child’s name, age, and gender.
  - Your child’s disabilities and special needs.
  - Your child’s abilities.

## Chapter 5. Navigating the Treatment System

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Here are some examples of how to include this information *in your own words*:

*“I am looking for support services for my two-year-old daughter, Sandy. She is in good health, but has temper tantrums. She is on medication for AD/HD. Please tell me the names of agencies that might be able to offer support services for her and our family.”*

*“I am looking for an alternative living arrangement and an educational program for my son, James. James has been diagnosed with ODD and bipolar disorder. He is 11 years old and weighs 75 pounds. He has violent outbursts. He is physically aggressive at home and school and is not compliant with medication. James is just too much for us to handle physically. We need to find a place for him to live and an educational program, but these services must be nearby so we can see him often and have him home on weekends.”*

*“I am trying to find employment training services for my daughter. JoAnne is 17 years old. She is in good health, but has been diagnosed with schizophrenia. She is on medication. She has been attending public schools for the past 12 years. She seems to make progress, but it is slow. She has ongoing auditory hallucinations that she usually manages. Please tell me if your agency can help me or if you know of some other agencies I should contact.”*

2. Now you are ready to **identify some agencies that seem to match your family’s and child’s needs**. Look through “Organizations Providing Services” on page 63, and Appendix C, “State and National Resources” beginning on page 119 for some agencies that appear to provide appropriate services. If your child has serious emotional disorders and will need extensive services, contact your community mental health center first, using the contact information in Appendix C, “Community Mental Health Centers” on page 138.
3. After selecting one or more possible agencies, **call or visit the agencies to get more details**. Memories fade fast, and you might be talking to several people in several different agencies before you finish, so keep a dated, written record of your conversations, including the names of the people you speak with and the information you receive. (See Chapter 3 section, “How to Organize All That Documentation” on page 27 for some suggestions on filing the notes and other paperwork you will be accumulating.)
4. When you have identified an agency that seems to provide the right services, **make an appointment to schedule an intake** (the first appointment that gathers information about your child and his/her current problem), and inquire if your child should attend this appointment. To more effectively address your concerns, formulate a *written* list of questions to bring to this appointment.
5. On **the first visit**, you will be able to talk and learn about the program, and address the written list of questions you’ve been developing. During part of the intake visit, the staff may want to meet with you without your child present. If your child is unable to sit alone in the waiting room (due to age or disability), consider bringing someone to sit with the child. It is best not to bring other children to this appointment.

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*If this first visit confirms that the services are ‘right’ for your child, make an appointment for a second visit. If not, repeat Steps 3 through 5 for each agency identified in Step 2.*

## The Treatment Process

In recent years, the most successful treatment models have combined clinical treatment (including medication) with supportive community services.

### **Stages in the Treatment Process**

Your efforts to seek help will be more productive if you move through the stages listed below with your child’s treatment team:

**Stage – 1 Assessment.** Regardless of the behavior that makes you think your child might have SED, first efforts are *clinical assessment and diagnosis*. The diagnosis is very important because it determines not only the treatments that will be prescribed for your child but insurance coverage as well.

**Stage – 2 Planning.** A *treatment plan* is then developed for your child. This plan includes extensive input from your family (and your child, whenever possible). The plan should combine a practical, community-based strategy along with traditional medical treatments.

Part of the treatment plan is to build a *treatment team*, including your family and all those who work with your child such as teachers, after school program staff, and your primary care physician. (See Chapter 1 section, “The Important Role of Your Primary Care Physician” on page 4.) All members of the team have a specific role to play and must understand their roles clearly. Parents are often asked to help with their child’s symptom management. Parents have an important role in the treatment team and are equal partners in decision making. (See Chapter 1 section “Shared Decision Making” on page 8.) Parents should request and participate in established educational programs and workshops to help them develop skills to be effective members of their child’s treatment team.

The goals of the treatment plan and the definition of “success” must be very clear and must be agreed to and understood by everyone, including the school district, IEP team, and especially your family.

**Stage – 3 Treatment.** Treatment usually involves a combination of services such as medication, behavior therapy, anger management therapy, case management, family support, counseling, and modification of daily structures at home and school.

While in treatment, your child should be closely monitored to be sure that he or she is benefiting from the treatment plan. If medications are prescribed, they should be monitored for the best possible frequency and dosage. Medications are often adjusted several times in the beginning and then less frequently as time goes by. Sometimes, finding the right *combination* of medications adds to the complexity of medication adjustment. Don’t be reluctant to ask questions... and be patient... the process takes time.

Regarding the monitoring of your child during treatment, *as the caregiver, you can provide the most accurate feedback to practitioners regarding your child's response to the treatment plan.* You are in a position to observe a behavior or mood change and also to be aware of other events in your child's life that might be the cause of the behavior change. For example, if part of your child's treatment plan is to meet with a social worker for psychotherapy once a week, and the social worker notices the child is despondent, the social worker might assume it is a reaction to a medication the child started a week ago whereas the child might be despondent because his only friend moved to Georgia last week. By calling the social worker before your child's appointment to mention the loss of his friend, not only will the false assumption about the medication be avoided, but the social worker can help your child work through the loss.

**Stage – 4 Re-evaluation.** Re-evaluation of the treatment plan can occur at preset times after treatment has begun or as needed in response to an emergency or change in your child's situation or behavior. Preset times should be defined in the treatment plan.

A common tension within treatment teams occurs when a family wants to change the treatment plan, and a practitioner (psychiatrist, therapist, or school practitioner) wants to stay with the planned strategy. *If you face this situation, you will be more successful in achieving a positive response from team members if you can clearly state the reason you feel a change is needed, and include evidence, such as the child's behavior, to support the request.*

After collaborative re-evaluation, the team returns to Stage 2 to update the treatment plan, and moves through the process again.

### **Medications as Part of the Treatment Plan**

Medications might be an important *part* of your child's treatment plan. *If only medication is offered, ask your treatment team why other forms of therapy or support are not being used.* (See Chapter 1 section "Shared Decision Making" on page 8.)

Ask questions until you are sure you understand the type of medication being prescribed and what it is expected to accomplish. If possible, include your child in the discussion about the medication, using words they understand.

If medication is a part of your child's treatment, start a *medication log* (See Appendix D, "Medication Log" on page 151) to indicate the date, name of the medication, and dosage. Keep this medication log up to date by making entries every time a new medication is prescribed or the dosage of an existing medication is changed. Also date and note any behavioral changes in your child after a medication starts or the dosage is changed.

Adolescents can feel humiliated about being singled out (in front of others) to report to the school nurse to take medications. Discuss this issue with your child and treatment team and see if there is another alternative to the medication schedule. If medication has to be taken during school hours, be

Some parents have observed that if their child did not go to the school nurse for the medication, the nurse did not follow up, and the child never took the medication.

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sure someone follows through on the necessary arrangements at school and be sure your child is actually taking his or her medications at school.

### ***The Wraparound Concept of Care***

*Wraparound* is a planning process used when a child and family find they have multiple needs in several different life areas, and traditional services and treatment planning are unable to meet these needs.

Wraparound is an ongoing and circular process in which the child, family, and their team identify the child's and family's strengths, supports, and most important needs. With guidance of a trained facilitator, they work together... taking action steps and finding creative solutions. Wraparound is not a one-time meeting or event and does not solve all issues immediately. There is no attachment of "blame or shame" if a plan does not work out the first time; the team keeps "working until it works." Once action steps are identified and implemented, the family evaluates whether its needs were met or if the team needs to identify new ideas and new possible strategies.

Many different kinds of planning meetings have been called "wraparound." This can be confusing for families, youth, and service providers alike. The New Hampshire Bureau of Behavioral Health endorses a model that is *evidence-based* - in other words, supported by scientific studies indicating that it is very effective when done correctly.

Wraparound is based on values and principles called the "CASSP Values" after the Child and Adolescent Service System Project. *The CASSP values state that all planning should be done by a local community team whose members know the child and family. The process must be child-centered, family-driven, and strengths-based.* This is founded on the theory that people's strengths get them through hard times and that a family's strengths and supports can help them most in this planning and decision making process. (See Chapter 1 section "Shared Decision Making" on page 8.) A wraparound team involves school personnel, agencies' staff, medical providers, and informal supports (coaches, grandparents, friends, neighbors) who know the child and family and bring expertise to the table. It may or may not include all the people formally working with the child and family. Wraparound teams should change over time, with people coming in and out as they are needed.

To determine if your process is really "wraparound," the team should ensure that:

- the person who is facilitating the process should have some training in the process and should understand the values and principles behind the process.
- the process should always start with the family and youth identifying their own strengths and needs. The needs identified by the family should form the core of the plan. Needs not identified by the family are not part of the plan.
- the goals and action steps can change at any time based on what has become more important or critical to the family.
- the team is always identifiable by the family.

- there is a mechanism for the team to ask for help or review from a “case review” team - a group of people in each region who can help with financial or regulatory barriers that otherwise would stop a team from fully reaching its goal.
- it truly feels like it is *your family’s team* and that the first and foremost goal is to support you in this family-driven process.

### Your Rights and Protections Within the Treatment System

You may feel that you have no control over decisions about your child’s treatment, but in fact, special laws ensure that your child’s rights are protected and that you as parent or legal advocate have the right to full knowledge of what is happening and why it is happening.

**Important!** Your family is your child’s primary and natural advocate. Become familiar with the rights you can exercise on behalf of your child to obtain necessary care. In addition, understand how the preferences and desires of your child should be incorporated into the treatment plan.

Families who participate in services offered by community mental health centers and New Hampshire Hospital have additional protections outlined in NH Rules He-M 309 and He-M 311. The State Library in Concord has copies of all state rules and laws mentioned in this Guidebook; they are also available online at the New Hampshire state website: [www.nh.gov](http://www.nh.gov) under the *Laws and Rules* online link, or by calling the Bureau of Behavioral Health (603) 271-5000.

#### **Fundamental Rights**

Providers of mental health services must do the following:

- Accommodate a person’s disabilities (per the Americans with Disabilities Act).
- Accommodate people whose primary language is not English by providing interpreters, translators, or other assistance.
- Be available to anyone, regardless of race, religion, national origin, or gender.
- Be free from religious or other bias.

Treatment at community mental health centers, as well as at private outpatient and inpatient clinics, is generally *voluntary*. If you are dissatisfied with the proposed treatment, you have the right to seek another opinion.

Ultimately, if you are *still* concerned and cannot come to a mutual agreement with the provider, you may terminate treatment and seek services elsewhere.

You should only terminate treatment after discussing your concerns with the treatment provider and carefully considering the options.

Treatment that is *involuntary*, however, such as an *involuntary emergency admission* (IEA) is bound by a legal process, and *parents cannot withdraw a child from a facility to which the child has been involuntarily committed*. However, commitment periods do have time limitations and parents continue to have the right to be involved in their child’s

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treatment plan during the commitment. (For more information on your rights during the IEA procedure, see “Involuntary Hospital Admission Rights” within this chapter on page 82.)

### ***Personal Rights***

Every child and family is entitled to respectful and responsive services and to be treated with dignity and confidentiality. Specifically, information about your child and family cannot be shared with anyone unless you (the parent or legal guardian) have given your consent in writing, except as specifically stated in law. You can withdraw your consent to share information at any time.

Also remember that as well as *rights*, the patient has *responsibilities* to follow the rules and regulations within the system of care. Some centers provide a list of such responsibilities that must be followed. This balance of rights and responsibilities also recognizes that treatment is a two-way process, and that the client must be “active” in that process.

### ***Treatment Rights***

The principal treatment right is the right to *make informed decisions* about the care of your child. You cannot make informed decisions if you are not informed – stay informed, as outlined below.

Practitioners must provide enough information for you to know *what* is happening, *why* it is happening, and *for how long* it will happen.

- Feel free to ask and re-ask questions until you get answers that you understand. Do not be intimidated because you think you are the only person in the room who does not know what is going on. *You are the parent; you are not supposed to know about the treatment system. You are the person who knows about your child.*
- If a hospital admission is required, you may be asked to authorize treatments ahead of time. You can give this authorization if you like. However, if you do not want to pre-authorize treatments or changes to treatment, you can ask the staff to contact you if they want to change your child’s treatment or medications. Ask for and keep copies of all hospital records in your child’s files.
- If an outpatient treatment plan is developed, make sure you understand it. You will be asked to sign the plan to acknowledge that you agree with what it says. Take your time and ask questions before signing it; then ask for a copy of the plan and keep it in your child’s files.
- You may ask to see your child’s medical records. Usually, records can be shared, but at times there might be information the staff needs to discuss with you before merely furnishing the records.

**Note:** A child over the age of 12 may seek treatment for drug abuse without the knowledge and permission of his or her parents. In this case, the parents are not responsible for the costs of the treatment and do not have access to information regarding the treatment without the consent of the child.

- You may ask any questions or express any concerns or complaints that you have, and the mental health center should give you a quick and appropriate response. *Ask*

*questions with the assurance that as the parent or guardian it is your right and your responsibility to understand and agree to your child's treatment plan.*

### **Grievance Processes**

The community mental health center (CMHC) has a grievance process and you should have received a written copy of this when your child began receiving services. If your child is receiving services from your CMHC and you think your child is not receiving the care/treatment that he or she is entitled to, discuss your concerns with your child's case manager or therapist. If talking directly to your child's practitioner fails to resolve the problem, follow the CMHC grievance procedure (which is to contact the department supervisor, then the CMHC complaint investigator, and then the CMHC Executive Director). If you cannot resolve your problem at the local level, you can request a hearing at the state level by calling the **Bureau of Behavioral Health**. (See Appendix C, "Bureau of Behavioral Health (BBH)" on page 138.)

If you think your child's primary care practitioner (doctor or pediatrician) is not providing appropriate treatment or is terminating treatment too early, complain directly to the practitioner first. If you are not satisfied with the results, call your insurance company and then the state licensing board for that practitioner's field.

If you need assistance with legal services and advocacy regarding disabilities, including serious emotional disorders, contact the **Disability Rights Center**. (See Appendix C, "Disabilities Rights Center, Inc. (New Hampshire)" on page 136.)

### **Involuntary Hospital Admission Rights**

An *Involuntary Emergency Admission* (IEA) is a legal process and admission can only be made to a state hospital or a designated receiving facility.

#### **Involuntary Admission Requirements**

Involuntary hospitalization may happen only in an emergency in which:

- the child or others are in danger due to the child's recent suicide attempt, threat of suicide, or threat of assault to others

*or*

- there is a serious threat to the child's health because the child cannot care for himself or herself

*and*

- the child cannot be managed in a less restrictive setting.

#### **Involuntary Emergency Admission Process**

The Involuntary Emergency Admission (IEA) process is as follows:

1. Your child will receive a clinical evaluation, often in a local hospital emergency room or community mental health center. This evaluation must be performed by a physician who has been approved by a mental health center or a hospital or other facility to which your child might be admitted.

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**Important!** If a child refuses to attend the evaluation, a petition can be completed to compel the examination. It will authorize a police officer to forcibly bring the child to the designated site for evaluation. This is called a *Prayer and Complaint for a Compulsory Mental Examination*. Your child’s CMHC treatment team or the emergency services department staff can guide you through this process.

The person seeking the admission will “sign as the *petitioner*” and must attend the district court hearing that will be held within 72 hours of admission. The petitioner should be able to speak to the concerns identified in the petition. Other persons who observed the dangerous behavior are listed as witnesses. The witnesses should also attend the hearing.

A child does not require a specific diagnosis to qualify for involuntary admission. The law only requires evidence of severe disturbances of thinking or emotions. *A person under the influence of alcohol or drugs cannot be hospitalized under these procedures for substance abuse alone*, but after intoxication passes, a person may be admitted if he or she has both a mental illness and a substance abuse problem.

At the end of the evaluation, a decision is made as to whether the child will be admitted to the hospital. Admission is not guaranteed at this point. The evaluator will have to speak with the doctor on call at the receiving facility to discuss the admission. The receiving facility can refuse the admission if they do not feel it meets the acute level of care criteria.

2. Your child will be transported to New Hampshire Hospital (NHH). (See “New Hampshire Hospital” within this chapter on page 68 for more information on NHH.)

**Note:** If you have time to consult with your physician before the IEA process begins, and the physician determines that your child does not require the degree of security provided by a law enforcement officer, the physician can request that an ambulance transport your child from the point of evaluation to the hospital. Many communities have difficulty accessing ambulance transportation for the IEA as many private ambulance companies will not accept a transport for an IEA unless the individual has been cleared by a medical facility.

*The decision to admit your child (per item 1 above) only authorizes the admission itself; you still have the right to agree or disagree on medication or other treatment unless an emergency situation arises.*

3. Within 72 hours of admission, your child will have a district court hearing (at a designated room in the hospital) to determine if there was reasonable cause for the admission. *The legal department of the hospital will notify the petitioner regarding the day and time of the hearing. The petitioner must attend this hearing; if the petitioner does not attend the hearing, the petition will be abandoned and the child will be discharged unless a voluntary admission is offered to the child and parent.* The child is appointed an attorney to represent him/her in this process. If the judge finds reasonable cause for the admission, your child may be held for additional evaluation and treatment for up to 10 days from the date of admission. During this phase, the hospital actively consults with you, the school, and community care providers about the needs of your child and begins to prepare for returning the child to his or her home.

4. If your child needs an additional period of involuntary admission, the hospital may petition the probate court for an extension, and another hearing will be held. Family members may be asked to testify a second time.

At any time during this process, you and your child have a right to retain independent counsel (hire a lawyer) to ensure that your child's rights are upheld. Also, at any point during the admission process, the hospital may determine that your child is no longer a danger to himself/herself or others. If this occurs, the hospital will make arrangements for the discharge of your child. *Clinical staff at the hospital have the responsibility to transition your child to a less restrictive setting as soon as his or her condition is stabilized.*

**Note:** At times, an Involuntary Emergency Admission may occur before an individual is able to obtain "prior approval" from his or her private insurance carrier. In these circumstances, the individual may be held responsible for all related expenses. Be aware that these circumstances and/or other insurance company restrictions might unfortunately be a factor in releasing your child before you or the staff think that he or she is ready.

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# Chapter 6. Safeguarding Your Child's Education

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## Chapter Overview

*Your child will be spending a large part of his or her waking hours in some type of educational setting. Federal laws clearly control the way special education programs provide for children with serious emotional disorders.*

*This chapter provides the legal and*

*practical information you need to make sure your child receives all the special education services he or she is entitled to by law. Please be aware that as we publish this Guidebook, education laws are under review, and they might change from the way they are defined here.*

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### Getting Off to a Good Start

To help your child to learn at school and to establish a cooperative working relationship with your child's teacher, try the following suggestions immediately after your child starts each school year:

- Let your child's teachers know that you want to work as a partner to help educate your child.
- Offer to explain any special equipment, medication, or behavioral or medical problem that your child has.
- If your child's teacher is not familiar with your child's illness and its symptoms, offer to provide information. Many teachers do not have a clear understanding of serious emotional disorders, but most are willing to learn.
- Inform teachers of any activities or significant events at home that might influence your child's performance in school. For example, children with serious emotional disorders are extremely sensitive to deaths in the family, losing a friend, illness or discord at home; they may get over-excited about happy events, as well.
- Offer to start up a "communication booklet" that you and the teacher write in each day and your child carries back and forth between school and home.
- Ask for suggestions of how you can continue, expand, and reinforce school activities at home.

"There's a child in my class whom I think has symptoms of psychiatric illness. It's not just his behavior; it seems to be something deeper. I don't know how to help him, or how to approach his parents, or where to refer them for help. This is something that everyone is reluctant to discuss. I care very much about this child and fear if we don't get him some help soon, we may lose him."

—A teacher in Rhode Island

**Chapter note:** If you want more detailed information on any of the topics discussed in this chapter, a good place to start is at the *Parent Information Center*. (Contact information is provided in Appendix C, "Parent Information Center (PIC)" on page 127.)

### Early Intervention

The **Early Intervention Program for Infants and Toddlers with Disabilities** is spelled out in Part C of the federal *Individuals with Disabilities Education Improvement Act of 2004* (IDEA). In New Hampshire, early intervention is known as *Family Centered Early Support and Services* (ESS) and is provided through the local area agencies. (See Appendix C, "Developmental Disabilities" on page 123.) It provides services to infants and toddlers (birth to age 3) and ensures the following:

- Access to services through a single, integrated *Individualized Family Service Plan* (IFSP).
- Services are delivered in the child's natural environment.

After your child and family needs have been assessed and the child is found to be eligible for services, a *service coordinator* will be assigned to your family. The service coordinator should have a background in early childhood development, understand methods for helping young children who might have development delays, and know the policies for early intervention programs and services in New Hampshire. When your child

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reaches 3 years of age, the service coordinator helps your family transition to preschool education or another community-based program. You, the service coordinator, and other professionals develop an IFSP that describes the following:

- Your child's developmental levels.
- Major goals expected to be achieved for your child and family.
- Services your child and family will be receiving to help achieve those goals.

## Special Education Services in School

### **About Special Education Services**

#### **Laws defining special education services**

#### **New Hampshire Rules for the Education of Children with**

**Disabilities** and the federal **Individuals with Disabilities Education Improvement Act of 2004 (IDEA)** (see Appendix C, “Transitioning from Youth to Adult Services” on page 139) state that every child with disabilities, no matter how severe, is entitled to a *free and appropriate public education* (FAPE) in the least restrictive environment, and that the child’s local school district must work with the family to develop appropriate instructional and related services. These services are available to children with disabilities from age 3 through 21 (or upon graduation with a regular high school diploma, whichever comes first). For additional information about IDEA services, contact NAMI NH (800) 242-6264 or Parent Information Center (603) 224-7005 for updates on the adoption of new education laws.

“I had a big discussion with my daughter’s teacher. She thought it was wrong to saddle Becky with a psychiatric label. I told her, ‘What difference does it make? She’s already been labeled a rotten kid.’ What could be worse for Becky than that?”

–The father of a 14-year-old girl

Once a child is identified as eligible for special education, services should be designed to meet the individual needs of the child. According to IDEA’s *least restrictive environment* (LRE), the school districts are required to educate children with disabilities in regular classrooms with their nondisabled peers, in the same school they would attend if not disabled, and with appropriate services and supports. This mandate has been interpreted in the courts to mean that a disabled child should be placed in the LRE that will provide him or her with a meaningful educational benefit.

Problems first surfacing at home are often amplified in the school setting. By law, schools provide the critical link between a child in crisis and the referral for evaluation.

**Important!** If your child does not qualify for special education services under IDEA guidelines, he or she might qualify under **Section 504 of the Rehabilitation Act of 1973**, which states that no “otherwise qualified handicapped individual” shall be excluded from participation in a program or activity that receives federal funding. The interpretation of “handicapped” under Section 504 is quite generous in that it includes any person who: 1) has a mental or physical impairment that substantially limits one or more of the person’s major life activities; 2) has a record of such an impairment; or 3) is regarded as having such an impairment.

### **Obtaining Special Education Services**

It is extremely important that you acquire special education services as soon as possible to avoid the negative behavior cycle that often leads to placement in a more restrictive setting such as a segregated classroom, alternative school, or residential program.

#### **When to request special education services**

The following list is not complete, but illustrates appropriate concerns that might prompt a parent to request special education services for a child between the ages of 3 and 21 who has not received a regular high school diploma:

- A medical diagnosis of an educational disability.
- Short attention span; inability to concentrate.
- Failure to pass a vision or hearing test.
- Unsatisfactory performance on group achievement tests or other assessments.
- Extreme, ongoing anxiety or reluctance to attend school.
- Performance well below expectations with no obvious reason.
- Multiple academic and/or behavioral warnings.
- Repeated failure in one or more academic subjects.
- Speech and/or language or physical issues.
- Inability to get along with others.

"My son is a constant horror-show at home. He does things that are way beyond our control despite everything we do to help him. His school performance is a disaster. I know something is really wrong with him, but I can't get his teachers at school to see that he's got a mental illness; they say it's a 'behavioral disorder,' and that we should go to parenting class."

—A mother in Virginia

#### **An Overview of the New Hampshire Special Education Process**

(Used with permission of the Parent Information Center. See Appendix C, "Parent Information Center (PIC)" on page 127.)

##### **1 Referral to Consider Special Education**

Anyone, including a parent, may refer a child to be evaluated for special education.

If the parent makes a referral, the parent should write a letter, include the date, and keep a copy.

If the referral is made by anyone other than the parent, the parent must be notified in writing immediately.

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## 2 Decision Making Meeting (Disposition of Referral)

**After the school receives a referral, they must schedule a meeting, to include the parent(s), within 15 calendar days.** The Individual Education Program (IEP) team meets to determine if the child's needs can be met through regular education services or if the child should be evaluated for special education. Written parental permission is needed before the school can evaluate.

The IEP team must include:

- A parent/guardian
- The child, if age appropriate
- A special educator or service provider
- A general education teacher
- A representative of the Local Education Agency (person who can commit the resources of the district)
- Others as determined by the team

## ★ Early Intervention Services

Schools may choose to provide services to children in grades K-12 who have not been identified as needing special education but who need additional academic and behavioral support to succeed in the general education environment.

These services may include:

- Supplemental or remedial reading program
- Behavioral plan
- Additional assistance
- Tutoring

## 3 Evaluation and Eligibility

Once the team determines a child needs to be evaluated for special education, the team meets to determine what additional testing is needed.

After receiving written permission from the parent, the school district will evaluate the child to determine eligibility and educational needs. **The evaluations must be completed within 45 days.**

If parents disagree with the school's evaluations, they may request an independent evaluation at public expense or they may pay for their own independent evaluation.

Based on the evaluation results, the IEP team decides if the child is eligible for special education and determines a disability classification. To be eligible, the child's disability must negatively impact his or her educational performance.

### 4 Development of the Individual Education Program (IEP)

**Within 30 days after a child is found eligible for special education, the IEP team meets to develop the IEP.**

The IEP is reviewed/revised annually and must be in place at the start of each school year.

**The parent has 14 days to sign the IEP. The parent may choose to agree, agree with exceptions, or disagree.**

### 5 Determination of Educational Placement

After the IEP has been signed by the parent and the school district, the IEP team determines the child's educational placement and implements the IEP.

Placement options may include a variety of settings, but must be in the Least Restrictive Environment (LRE). LRE means the child will be educated in the regular classroom unless their needs cannot be met in that setting.

### 6 Monitoring

The IEP includes a statement of how the child's progress toward the annual goals will be measured and when it will be reported. The parent should ask for an IEP meeting if they have concerns about their child's progress.

**Each year, the IEP team must meet to review and revise the IEP, if needed.**

A child is formally reevaluated at least once every 3 years unless the parent and school district agree it is not needed or a parent requests an evaluation sooner.

### ★ Some Additional Parental Rights

- Participate in all meetings
- Give or withhold written consent
- Access their child's educational records
- Be notified about important decisions regarding their child's education (Written Prior Notice)
- **10 days written notice of IEP meetings**
- Receive information in a way that is understandable
- Be provided with an interpreter or translator, if needed
- File a complaint, request mediation, request due process hearing, or a neutral conference

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## ***Helping Develop Your Child's IEP***

Parents *must* be invited to the IEP meeting **in writing at least 10 days prior to the meeting date**. Parents have the right to request the meeting be scheduled at a time when they can attend, and they can invite anyone to attend with them. *We strongly recommend that you attend this meeting.*

Once the IEP is complete, you have the right to take **14 calendar days to read, understand, and sign the IEP**. *We recommend that you take advantage of this time and not sign the IEP immediately. If you disagree with the IEP, you can ask for another meeting, request mediation, or request a due process hearing.*

### **Your role at the IEP meeting**

**Your role as parent is clear; you are the expert on your child.** You are emotionally attuned to your child and notice small but important changes in your child's behavior and emotions that might be overlooked by others. (This helps to explain why your opinion about your child may be quite different from that of the educators who only observe your child in the school setting.) Sometimes, the child and parent attend the IEP meeting but feel uncomfortable being part of a discussion with a group of professionals, so they do not say much. Never hesitate to express your opinion on what is being discussed at the IEP meeting. *You are the only person who can represent your unique perspective on the child; that is why the law requires that you be invited to the meeting.*

If there are areas that you think the IEP team is overlooking, feel free to remind the team of these areas. *For example, from past experience you might know that your child regresses in reading or classroom skills over the summer. If the issue of providing services over the summer vacation has not been mentioned at the meeting, and if you think summer school is needed, explain why... and ask to have it written into the IEP. Or, if your child has reached the age of 14 and the team is not discussing transition planning yet, ask to discuss this topic.*

### **IEP meeting strategies**

The parent and child should keep the following strategies in mind when attending the meeting to develop the IEP. You and your child may need help in establishing educational goals and this is why you have a educational support services team.

- **Set specific, measurable goals.** It is up to the team to identify and agree upon goals and how they will be measured for success. Goals must be written clearly and concisely. Anyone who has a question on how goals will be measured should raise the question before the IEP is signed.
- **Think creatively.** Strategies will be successfully implemented if they are individualized and built upon the child's strengths. Some children need independent study or the ability to work at home to complete their assignments, while others need to spend part of their day working independently and part of the day in classes.
- **Collaborate and integrate.** When mental health and family support services are provided outside the school system, it is important for them to be brought into the team process. When everyone on the "child's team" is part of the meeting conversation, they are better able to support the child and family by sharing resources and strategies and not duplicating efforts.

- **Listen to and voice your “gut” feelings.** Ask questions. *As the parent, you are the consistent member of your child's educational team and have the responsibility to share information about your child to help the team set appropriate educational goals and develop strategies to attain those goals.* If you are not clear or feel uncomfortable with any part of the process, it is important to share this with the team.
- **Focus on positive behavioral interventions and strategies.** The team should address how to assist your child in learning appropriate ways to behave and interact in school and community settings. These strategies should be incorporated into the IEP. **When your child has behavioral difficulty, teaching new approaches should be used instead of punishment.**

### ***Special Considerations for Children with SED***

Children with SED may have many challenges to face in school community settings. To ensure success in academics, the child must also have success in social and emotional experiences. In developing an IEP, attention must be given to ensure the development and/or enhancement of the child's social, communication, self-advocacy, and self-care skills. The child must have opportunities to learn new ways to interact with peers and adults. The goals in this area must be measurable and reasonable for the child based on his or her strengths and challenges.

**The team should be proactive in planning for times when the child may experience symptoms or behaviors that may require increased supports and services.** The IEP should outline how the team will address the child's needs at such times by developing a *crisis intervention plan*. (Example: if the child is hospitalized, the IEP states how the child will transition back to school.)

It is important for the child to maintain as much of a daily routine as possible to minimize the loss of academic progress.

Many children with SED or mental illness enjoy summers with their families. For some, however, progress made during the school year may be lost if the child does not receive services during the summer. In these instances, the IEP team will agree to *extended school year services* (ESY) for the child. Typical summer services include summer school classes, summer camp tuition and related supports, a summer vocational program, respite services with mental health or educational goals, and reading classes.

## **Transitioning Out of High School**

Children and youth with disabilities are entitled to special education services until they graduate from high school with a regular high school diploma, or until they reach the age of 21. Unfortunately, some studies indicate that as many as 60% of all young people with emotional disabilities or mental illness leave high school before graduation. If your child has an IEP and quits school, he or she can return to school up to the age of 21.

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## **Transition Planning**

Transition planning is designed to help the child prepare for life after high school. Transition services must be designed to help the student achieve real-life outcomes such as employment, post-secondary education, independent living, adult services, and community participation.

Federal law states that transition planning cannot occur any later than age 16; however, parents can request this planning process begin earlier (age 14) depending on their child's needs.

The services must be based on the needs of your child and reflect his or her preferences and interests. (For example, your child may be considering college. The transition plan should identify what it will take to make sure your child has every opportunity to achieve that goal.) The transition plan should include your child's course of study during high school years. The plan can be adapted along the way as the child's goals or interests change, but having a plan supports the child in knowing what they need to accomplish to meet their goals. *They can measure their own successes.*

Transition services might require contact with vocational rehabilitation, and the vocational assessment process can start as early as age 14. If your child will require help in independent living, adult services, community participation, or if he or she plans to get further education, the IEP should reflect these needs.

**Note:** If you believe your child will need to continue receiving services after high school, have your child reevaluated during your child's senior year of high school. (If you postpone this until after your child leaves high school, you will have to pay for an independent evaluation at that time.)

### **A Successful Transition Plan**

Transition planning starts with the child's future goals; there are several tools available to help the child establish these goals. It is important to focus on whether the goal is employment planning or post-secondary education planning.

In transition planning, the team needs to be sure services and supports are available to develop and/or enhance the following skills to ensure a successful transition to adulthood: e.g. independent living skills, self-help skills, self-advocacy skills, ability to connect with community resources, manage health care, and rights and responsibilities of adulthood. The adolescent now becomes an active participant in the IEP process. The Special Educational Law requires the adolescent be invited to all meetings when transition is being discussed and planned. Ideally, the adolescent will be provided opportunities to learn about the process, his or her rights and responsibilities, and how to conduct himself/herself in this process. (For more information about youth leadership training, see Appendix C, "Transitioning from Youth to Adult Services" on page 139.)

## Chapter 6. Safeguarding Your Child's Education ---

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# Chapter 7. Paying for Services

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## Chapter Overview

*Fewer and fewer children in need of mental health care are covered under private health insurance. In spite of strong advocacy for a system of care for children with mental health problems, such a system does not exist. So, finding and paying for care varies from region to region. Nevertheless, there are some ways to get affordable care.*

*The availability of most mental health services is based on one's eligibility for either privately funded or publicly funded treatment. (In this context, "publicly*

*funded" indicates that a service provider can bill a client's Medicaid Insurance. In a few cases, the client may have additional co-insurance or co-payment responsibility.)*

*This chapter provides a brief overview of the funding sources for children who are cared for by their families.*

*In addition to the insurance provisions and financial assistance programs discussed in this chapter, remember that out-of-pocket expenses to alleviate your child's mental or physical condition may qualify as income tax deductions.*

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### Private Health Insurance

Private health insurance plans cover both physical and mental health services. It is important for you to know the types of mental health services that are covered by your insurance plan and any limitations on those coverages. Private insurance plans usually cover therapy, psychiatric evaluations, medication monitoring, emergency services, and inpatient hospitalizations. Some insurance plans are written with coverage limits (such as 12 therapy sessions per year or \$1,800 for therapy each year). Please note that in addition, you may be responsible for charges above what the insurance plan considers “reasonable and customary fees.” Depending on your plan, you may also be responsible to meet a deductible or have a co-pay.

Some insurance plans require prior authorization for services. Other insurance plans require a referral from your primary care physician or pediatrician. You may also have to personally call your insurance carrier to access mental health services.

If you are denied an authorization for services or payment, contact the insurance carrier. If the person you are speaking with is not able to assist you, ask for the procedure to file an appeal. The insurance carrier must provide you with written information about an appeal process.

Keep a written record of your conversations with the insurer, including dates, who you spoke with, and content of the discussions. In addition, the form in Appendix D, “Tracking Expenses and Insurance Claims” on page 155 might be useful for monitoring claim forms submitted to your insurance carrier.

If you have trouble accessing mental health services for your child, call the NAMI NH office toll-free at (800) 242-6264 and ask for the Information and Referral Service. You can also visit the NAMI NH website: [www.naminh.org](http://www.naminh.org).

Regarding insurance coverage for your child, the State of New Hampshire has “parity,” which requires insurance plans to provide the same benefits for treatment and diagnosis of the following mental illnesses as they do for physical illnesses:

- Schizophrenia and other Psychotic Disorders.
- Schizo-affective Disorder.
- Major Depressive Disorder.
- Bipolar Disorder.
- Anorexia Nervosa and Bulimia Nervosa.
- Obsessive-Compulsive Disorder.
- Panic Disorder.
- Pervasive Developmental Disorder or Autism.
- Chronic Post-Traumatic Stress Disorder.

If you have questions about “parity,” you can contact the New Hampshire Insurance Department consumer line (800) 852-3416 or the NAMI NH office (800) 242-6264.

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## Public Health Benefit Programs

### ***Child Health Program (CHP)***

The *Child Health Program (CHP)* is part of the *Maternal and Child Health Program* organized under the Bureau of Community Health Services within the New Hampshire Department of Health and Human Services - Division of Public Health Services. Services are provided primarily to children from birth through age 10.

Community health agencies and community health centers administer the Child Health Program. The CHP allows health care providers to offer comprehensive, preventive health care to children of low-income families through clinics and home visits. Services include physical exams, health screenings, immunizations, social services, and case management.

In addition, some community health agencies offer child and family health support services to families who need medical care for their child and also need additional services. Additional services include assistance with health care enrollment, referrals, case management, care coordination, education, and counseling. These services are provided in person or by telephone.

(Contact information for CHP health centers is provided in Appendix C, “Child Health Program” on page 133.)

### ***Medicaid***

New Hampshire *Medicaid* is administered through the New Hampshire Department of Health and Human Services - Division of Family Assistance (DFA). Medicaid is a program designed to pay medical bills for low-income persons.

Medicaid provides comprehensive coverage for outpatient and inpatient services. There are some limits to coverage and some services may require prior authorizations. This information is available by calling the New Hampshire Department of Health and Human Services - Medicaid Client Services Office (800) 852-3345. Medicaid does provide prescription coverage with a co-pay. Transportation for medical appointments is also a covered service. However, Medicaid is not accepted by all medical and mental health providers, so inquire before services are provided.

You can apply for Medicaid at any of the New Hampshire Department of Health and Human Services district offices. (See Appendix C, “New Hampshire Department of Health and Human Services” on page 120.) You will be required to file an application, attend a face-to-face interview, and provide standard verifications such as birth certificate, proof of residence, social security number, income, and resources. When providing verification of income and resources, documentation must be current (within the last 30 days).

Children and adolescents with serious emotional disorders are often eligible for Medicaid despite the income and financial resources of the family. This is because Medicaid has programs that count the income and financial resources of only the child/adolescent.

Depending on the program, you may be asked to provide medical information and complete a Family Information Form. Current reports from medical and mental health providers will help you complete this portion of the application. Also, include a copy of any other evaluations that reflect your child's needs along with a copy of your child's Individualized Education Plan/504 plan. (For more details on special education services and the IEP, see Chapter 6, “Safeguarding Your Child’s Education” beginning on page 85.)

Medicaid is available to New Hampshire children under the age of 19 through these programs:

- Healthy Kids Gold
- Healthy Kids Silver
- Home Care for Children with Severe Disabilities (HC-CSD)
- Children with Severe Disabilities (CSD)
- Transitional Aid for Needy Families (TANF)

The Family Information Form can be taken home and completed. The information requested should reflect your *child's* needs.

To find out about the eligibility criteria for these programs, you can: contact the Medicaid Client Office (800) 852-3345, speak with the Benefit Specialists at the community mental health center or area agency, or contact the Information and Referral Service at NAMI NH (800) 242-6264.

### **Social Security Benefits**

When an adult receives *Social Security Disability or Retiree Benefits*, or if a parent who is entitled to a Social Security benefit dies, any minor children of that adult will also get Social Security benefits until age 18 (or age 19, if still in high school). The Social Security benefit for the child is usually a *portion* of the parent’s benefit and is distributed monthly to the child’s parent or guardian. If the parent’s Social Security benefit ends, the child’s benefit ends as well.

To determine if your child is eligible for Social Security benefits, or to apply for these benefits, contact your regional Social Security Administration office. Phone numbers of the district offices are provided in Appendix C, “Social Security Administration (New Hampshire offices)” on page 132.

### **Supplemental Security Income (SSI) Benefits**

*Supplemental Security Income* (SSI) is a federal program that provides a minimum income for low-income adults and children with disabilities as well as for low-income elderly adults.

#### **To qualify for SSI, your child must...**

- Be under age 18.
- Be in a low-income family (qualifying as “low-income” depends on the size of household/number of dependents, your type and level of monthly income, and your family’s assets).
- Have a disability that “severely limits his or her ability to function” when compared to other children of the same age.

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The amount of the SSI benefit is adjusted for your family's income. After your child reaches 18, he or she may apply for SSI as a disabled adult at which time *your* income is no longer a qualifying consideration. *Begin this application process at least six months prior to your child's 18th birthday.*

If you think your child might be eligible for the SSI program, apply at your local Social Security Administration office. The phone numbers of district offices are provided in Appendix C, "Social Security Administration (New Hampshire offices)" on page 132.

### ***Individuals with Disabilities Education Act (IDEA)***

This federal law, the *Individuals with Disabilities Education Act (IDEA)*, states that all children with disabilities have a federally protected civil right to a "free, appropriate public education" that meets their educational and related needs in the least restrictive environment. Some of the "related needs" can be services provided and paid for through the school district. This would be written into your child's *Individual Education Plan (IEP)*. *If the IEP process identifies a required service, the school district is responsible for its payment.* (See Chapter 6, "Safeguarding Your Child's Education" beginning on page 85.)



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# Chapter 8. Crisis Management Planning

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## Chapter Overview

*It is possible that one day your child may experience a mental health crisis. Now is the time to develop an action plan, so that if there is a crisis, you will be able to get the assistance you need... faster, and with less stress!*

*This intent of this chapter is to help you develop a crisis management plan that matches your child's and family's needs with the available resources in your community.*

*You will learn:*

- *how to recognize if your child is experiencing a mental health crisis;*
- *what must be done on the day of the crisis;*
- *the steps you should take to prepare for a crisis;*
- *what information to gather beforehand so it is available during a crisis; and*
- *how to describe the crisis to the emergency team.*

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### What is a Crisis Management Plan?

Your child will, of course, have good days and bad days, and some of the bad days may be pretty scary for both of you. Your therapist can work with you and your child to develop a *crisis management plan* which will identify what you as a parent can do to help the child on a “bad day” and what the child can do to manage his or her

symptoms. The plan must also identify when the situation becomes a *mental health crisis*... and what you as a parent must do.

“Bad days” are more common occurrences and can be very disruptive to the family. After these events, you and your child can use the experience to learn how to communicate feelings and find ways to manage them. This takes much practice and time.

### What is a Mental Health Crisis?

When your child or adolescent is experiencing a *mental health crisis*, **you are not able to control his or her behavior... and at least one of the following is true:**

- He or she is **at serious risk of hurting himself or herself**. (See Chapter 4 section, “Child and Adolescent Suicide” on page 51 for more information on the special emergency of suicide.) *Seek help as soon as possible by contacting a mental health professional or by calling the National Suicide Prevention Lifeline at 1-800-273-TALK (8255) if your child exhibits any of the following warning signs:*

If you think your child might be suicidal, seek immediate mental health treatment, or call 911 or the National Suicide Prevention Lifeline at 1-800-273-TALK (8255) if necessary, and do not leave your child alone.

- Threatening to hurt or kill oneself or talking about wanting to hurt or kill oneself.
  - Looking for ways to kill oneself by seeking access to firearms, available pills, or other means.
  - Talking or writing about death, dying, or suicide when these actions are out of the ordinary for the person.
  - Feeling hopeless.
  - Feeling rage or uncontrolled anger or seeking revenge.
  - Acting reckless or engaging in risky activities... seemingly without thinking.
  - Feeling trapped... like there is no way out.
  - Increasing alcohol or drug use.
  - Withdrawing from friends, family, and society.
  - Feeling anxious or agitated, being unable to sleep, or sleeping all the time.
  - Experiencing dramatic mood changes.
  - Seeing no reason for living or having no sense of purpose in life.
- He or she is **at serious risk of hurting others**.  
Call for help if *you* feel threatened; it is not appropriate to fear for your safety.
  - He or she is **experiencing disorganized and dangerous thinking**.

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For example: shifting from one thought to another with no logical connection, making up words or using sounds or rhymes in place of words, seeing things and hearing voices that are not real, confusing television and dreams with reality, and thinking that people are “out to get them.”

## Steps to Take During a Mental Health Crisis

If your child experiences a mental health crisis, you need to take the following two steps:

1. **Arrange for a mental health evaluation** to determine if your child needs hospitalization or some other service.

Although services in various regions differ, emergency mental health evaluations are usually conducted by the regional community mental health center emergency team clinician. Evaluations are conducted at the mental health center or in the emergency room of the local hospital. (See Chapter 5 section, “Emergency Services” on page 73.)

If your child is in treatment with a private mental health provider rather than the community mental health center, your provider should conduct the evaluation. *Inquire beforehand* about your provider’s procedure for handling a mental health crisis.

2. If the evaluation determines hospitalization is necessary, **discuss all options with the emergency services clinician and make a decision... together.**

In most cases, the emergency services clinician will contact your insurance provider for authorization. If an insurance reviewer questions the need for hospitalization, the emergency services clinician or attending physician can address those questions; a choice of treatment facility may be limited due to restrictions of the insurance policy.

## Preparing for a Mental Health Crisis

*Now* is the time to gather information about the organizations and facilities you will be working with if a crisis arises. Having needed information at your fingertips, and being familiar with the places you and your child might have to go, will prepare you to better manage the crisis at that stressful time.

### ***Become Familiar with Procedures and Terminology***

If your child experiences a mental health crisis, there are three organizations you will be working with, directly or indirectly: your insurance carrier (if you have one), the emergency services clinician who performs the psychiatric evaluation, and the hospital or other facility to which your child might be admitted.

Follow these steps *before a crisis arises* to become familiar with the procedures and terminology used by these organizations and to have the pertinent information written into your child’s crisis management plan.

1. **Talk with your private insurance carrier** (if you have one) to determine if there are any restrictions regarding who you can use to provide emergency services identified in

## Chapter 8. Crisis Management Planning

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Step 1 above, or which hospital or facility you can use to provide psychiatric services identified in Step 2 above.

2. **Talk with one or more of your child’s mental health providers** to inform them about any restrictions that your insurance carrier might have and to determine the names, locations, and phone numbers of the following:
  - The emergency services community mental health center or private provider that will conduct a psychiatric evaluation. (This could be your child’s therapist/case manager, depending on time of day and their availability.)
  - The facility to which your child might be admitted.
3. **Call your child’s therapist or case manager.** Work with them to develop a crisis management plan for your child. Suggestions for the discussion and development of a crisis management plan are:
  - Find out how to assess whether you can safely transport your child to the emergency services location or the local hospital.
  - Determine if there is any situation for which you should call the local police for transportation assistance.
  - Ask for driving directions to the emergency services location; you will use these directions later. (See “Develop a Transportation Plan” below.)
  - Determine which facilities your child might be admitted to if he or she had to be hospitalized.
  - Ask if there is any other information they think you should know.
4. **Call the hospital** or facility that your child could possibly be admitted to and tell them you are developing a plan for handling a mental health crisis for your child. Ask them to tell you about their crisis procedure.

Language and terminology can vary between the facilities and providers, so be alert for different words being used for the same thing by the emergency services clinician and the hospital staff. Do not hesitate to ask questions.

Ask for driving directions to the hospital; you will use these directions later. (See “Develop a Transportation Plan” below.) Ask if there is any other information they think you should know.

### ***Develop a Transportation Plan***

If you need to transport your child to receive an evaluation or to be hospitalized, there are some decisions to make, some information to gather, some people to contact, and some trips to rehearse *before the crisis*:

- Ideally, you should **have at least one other person able to drive... or available to manage your child while you drive.** Who will be that other person? Depending on your family and neighborhood situation, options might include a neighbor, taxi, ambulance, or the local police.

Be aware that if your child is being transported by police officers, they might decide to handcuff or otherwise restrain your child during transport. When your child is transported by police or ambulance, you may follow in your own car.

- In the event that you will be driving yourself and your child, use the directions you obtained in the previous procedure to **make a “dry run” trip** to the emergency services location and from there to the psychiatric hospital. Here is a “dry run” trip checklist:
  - Become familiar with the routes and the length of both trips.
  - Locate parking and find the correct entrances.
  - Go inside and find the admitting desk and waiting area.
  - Speak with someone at the admitting desk and inquire about what to expect when you and your child arrive for a mental health evaluation. Find out if your child would utilize this same entrance during an emergency.
- You might need help **getting your child safely from the car to the emergency room**. Who will assist you if no one is able to come with you and your child? Speak to your child’s therapist and ask for advice on handling this part of the trip.
- Will you need to **arrange for the care of other children** while you are transporting your child in crisis? If “yes,” what are your options... parents, in-laws, siblings, neighbors, regular baby sitters? Call two or three (in case you call one and get no answer at the time of the crisis) and ask if you can rely on them for this help.

### ***Gather Phone Numbers and Medical Information***

After you work through the steps in “Become Familiar with Procedures and Terminology” on page 103 and “Develop a Transportation Plan” on page 104, *compile the names, locations, and phone numbers of the following organizations and people:*

- Mental health emergency services provider.
- Local police department.
- Your child’s mental health team members: psychiatrist, psychotherapist, case manager, social worker.
- Nearest NAMI NH local affiliate contact person.
- Nearby family, friends, and neighbors who have volunteered to help during a crisis.

Keep your compiled “crisis contacts list” where you can find it quickly when you need to phone for help.

Keep the medical and insurance “information sheet” in a place where you will be sure to have it (wallet, glove compartment, etc.) when you arrive at the emergency services location or hospital. *This written information can be passed from one professional to another, if necessary, without loss of accuracy.*

Some parents recommend keeping *multiple copies* of this information in case someone misplaces one during the crisis. *Review and update the information at least twice each year.*

*To aid the professionals who will be working with your child, have the following medical and insurance information already written down:*

- Your child’s diagnosis or diagnoses.
- Medications, including dosages, schedule of how often the medication is taken, and whether it is taken with or without food.
- Name and phone number of your child’s prescribing doctor (if your child is taking medications), or the professional who is most familiar with your child’s emotional disorder (therapist, case manager, primary care physician).
- Name and phone number of your child’s insurance carrier; your child’s policy number.

### Rehearsing the Call to Emergency Services

#### ***What to Tell the Emergency Services Clinician***

Here is a checklist of the types of information you need to give to the emergency services clinician when you call. Use any/all items appropriate to your child's situation:

When a crisis arises and you talk to the emergency services clinician, try to focus on why your child is **not safe**. The clinician is there to help you and your child, and is *better able to help if you provide the kind of information the clinician needs*.

- Describe your child's **current actions and their impact**. The actions should clearly indicate how your child is: 1) a danger to self; 2) a danger to others; and/or 3) experiencing disorganized and dangerous thinking. *Give clear examples as to why your child is not safe and/or why family members or community members are not safe.*
- Identify your child's **diagnosis**, if he or she has one.
- Explain how these actions have **escalated over the past three days** (which indicates that this is not typical behavior for your child).
- Share **recent concerns of other individuals** in your child's life such as school teachers, guidance counselors, neighbors, friends, and so forth.
- Indicate if your child has a **past history of self-harm, harming others, or threats of such behaviors**.

#### ***Examples of Ineffective and Effective Descriptions***

This section includes examples of calls from caregivers to emergency services clinicians. Each example illustrates one ineffective and one effective description of the same situation. Note that...

- *Ineffective descriptions* are more focused on frustrations with your child's behavioral problems, and are not necessarily reporting a mental health crisis.
- *Effective descriptions* give specific information regarding a child's diagnosis, actions, and the dangers of those actions.

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### ***Describing a Danger to Self***

<b>Ineffective Description</b>	<b>Effective Description</b>
Danny is locked in the bathroom and won't come out. He's skipping school and refuses to talk to anyone at home or school.	Danny locked himself in the bathroom and is threatening to kill himself. He becomes more agitated when I try to calm him down.
He has no respect for his stuff. He gave all his birthday presents away to his friends.	Danny's threats to kill himself have gotten worse over the past few days. He has hidden pills all over the house as part of his plan to kill himself. He has withdrawn from the family, skipped school, and stated that he would be better off dead. Danny gave away his birthday presents to kids at school stating that he won't be needing them.
He has threatened to kill himself by taking all the pills in the house. He is doing everything possible to scare me.	Danny's guidance counselor at school has called and is very concerned about his behavior.

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### ***Describing a Danger to Others***

<b>Ineffective Description</b>	<b>Effective Description</b>
Karen is very angry and is breaking furniture and windows in the house. I cannot take her acting like this anymore.	Karen is in the living room stabbing the walls with a knife. Her anger is out of control and she cannot explain why she is so angry. When I try to intervene, she threatens me and my other children verbally and physically.
Karen will not answer my questions. I keep asking her why she is doing this, but she swears at me and calls me terrible names.	She has threatened to hurt anyone who comes into the room. I am afraid that she may hurt her brother and sister. Karen ignores me and will not stop these actions. I am afraid of her, and for her.
She is mean to her brother and sister. Karen likes to fight with everyone. She hates her brother and sister, as well as me.	Karen is diagnosed with major depression and oppositional defiant disorder. We have been trying to stabilize her with medication and have not found the right combination yet.
Karen does not like any authority figures. She will not do what any adult tells her to do. I cannot live like this anymore.	In the past week, Karen's anger has escalated. She has broken mirrors and windows with no regard for her own safety or the safety of her sisters and brothers.
	I have called her psychiatrist and he feels she needs to be seen by the crisis team.
	Karen was hospitalized three months ago and has been struggling ever since.

### *Describing Dangerous Thinking*

<b>Ineffective Description</b>	<b>Effective Description</b>
<p>I cannot get Jimmy to come into the house. He just wants to be left alone. He's sitting on the roof. I have tried to tell him to come in the house, but he just yells at me and tells me to leave him alone.</p> <p>The school does not know what to do with him. He has been fighting with the kids at school. No matter what I say to him, he just yells at me and tells me not to bother him. He stays up all night watching TV, and then I cannot get him up for school. When he does go to school, the principal calls and tells me to pick him up because they do not know what to do with him. Jimmy is either fighting with the teachers and students or sleeping in class.</p> <p>Someone has to do something with this kid. I cannot control him.</p>	<p>Jimmy is sitting on the roof and threatening to jump.</p> <p>Jimmy believes he can jump off the roof and not be hurt. His thoughts are racing with the fantasy that he is superhuman. I do not feel Jimmy is safe. I want him to be evaluated for emergency services. He does not respond to his name and becomes more agitated and defiant when I speak to him. When I speak to him, he screams nonsense statements back at me. He believes I am trying to hurt him.</p> <p>Jimmy is diagnosed with bipolar disorder. He is being treated by a psychiatrist and psychologist. I have called and left messages for each of them and have not heard back.</p> <p>Jimmy has been acting more detached over the past several days. He sleeps most of the day, stays awake most of the night, and has fallen asleep in school. He has been in several fights at school with teachers and friends.</p> <p>His principal called to tell me that Jimmy is oppositional beyond his usual behavior, and he's concerned about disciplining Jimmy because he appears so emotionally fragile and unstable.</p>

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# Chapter 9. Transitioning to Adult Health Care Services

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## Chapter Overview

*As young people with serious emotional disorders and/or other special needs experience personal growth and approach adulthood, their efforts are toward independence in the areas of housing, employment, health care, personal finance, recreation, relationships, and personal advocacy.*

*Some areas of transition are addressed by school systems through the Individuals with Disabilities Education Act (IDEA).*

*However, there is no legislation that governs the overall transition to adult services for young people with serious emotional disorders, special health needs, or disabilities.*

*This chapter will provide you with information to ensure your adolescent has access to mental health and medical services as he or she transitions from the child and adolescent systems of care to the adult systems of care.*

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### Transitioning to Adult Health Care Services

The issues surrounding the transition of an adolescent to adulthood for both medical and mental health care can be overwhelming for the parent/caregiver as well as the adolescent. *Within the life of the adolescent, the role of the parent/caregiver is changing; it is important to take time to talk about this change.* Discuss the support your adolescent would like you to provide as he or she moves toward independence and self-reliance. The adolescent with serious emotional disorders (SED) will require ongoing supports and services for both mental health and medical care; planning and advocacy will be required to ensure continuity. Here are some recommendations about what parents/caregivers can do to ensure that supports and services continue without interruption:

The process of transitioning to the adult health care system should begin before the adolescent's 18th birthday and it is recommended that conversations on this topic begin when the child is age 14.

#### ***Medical Care - What Parents/Caregivers Can Do***

Parents/caregivers want to be assured their adolescent will have quality medical care in adulthood. Addressing the considerations below will help you support your adolescent's transition from pediatrician to primary care physician. Parents/caregivers are encouraged to start researching and discussing these issues with their child when he or she is 14 or 15 years old:

1. Encourage your adolescent to develop an independent relationship with the pediatrician. This will help prepare for future relationships with adult providers. Before appointments, suggest the adolescent prepare a list of his or her questions or concerns to be addressed by the physician.
2. Find out if your pediatrician has a policy regarding age limitations for service.
3. Ask your health insurance carrier about the age limit of pediatric care.
4. Determine your insurance carrier's policy on requiring referrals for consultations and transitioning to an adult provider.
5. Ask your pediatrician to recommend an adult medical provider who would be sensitive and knowledgeable in the area of your adolescent's disabilities and health care needs.
6. Ask your adolescent about the qualities and characteristics he or she would like in a provider.
7. Determine when coverage through your current health insurance plan will terminate and explore other health insurance coverage options.
8. Describe to your adolescent how the current insurance plan works; discuss what will be needed in the future.
9. If you believe your adolescent will be covered by Medicaid after age 18, make sure the prospective adult provider will accept New Hampshire Medicaid.

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10. Contact the New Hampshire Department of Health and Human Services district office and research the Medicaid programs for adults with disabilities. One program, *Aid for the Permanently and Totally Disabled* (APTD), provides financial and medical assistance for low-income adults with disabilities. The application process can be started 6 months before the adolescent's 18th birthday; however, no determinations are made before the adolescent is 18 years old. If the adolescent will be applying for the APTD program, then he or she will also have to apply for *Supplemental Security Income* (SSI).
  11. If you believe your adolescent may have problems making informed decisions when he or she reaches age 18, obtain recommendations from your adolescent's current mental health providers and seek legal counsel about the legal options available to you. (See Appendix C, "Legal Support" on page 135 and "Guardianship Rights" on page 132.)

### ***Mental Health Care - What Parents/Caregivers Can Do***

Parents/caregivers play an important role in helping adolescents enter the adult mental health care system. Through years of navigating the children's mental health system, parents/caregivers have developed many skills. *This is the time to help your adolescent develop and practice those skills.*

When the adolescent is 15 or 16 years old, parents/caregivers should discuss long-term mental health needs with the adolescent's current providers. In addition, parents/caregivers should explore and discuss the following issues to prepare for the transition:

1. Find out if your current provider has a policy regarding age limitations for service.
2. If your adolescent must change providers, discuss what qualities or characteristics he or she would like in a new provider.
3. Have your adolescent talk with his or her primary care physician/current mental health provider about a mental health professional they might recommend if a change of provider is necessary.
4. Determine if the adolescent will have services through the private or public sector.
5. Discuss with the current mental health provider if the adolescent will require extensive supports and services. If "yes," then begin the application for community support services through the community mental health system 6 months before the adolescent's 18th birthday. The adolescent must participate in this process.
6. Determine your insurance carrier's policy on requiring referrals for consultations and transitioning to an adult provider.

It is important to remember that an adolescent who is currently receiving extensive services may not require or be eligible for the same level of support when he or she is an adult. Adolescents can begin preparing for the transition to the adult mental health systems of care by being involved in their current treatment planning, and by learning and practicing self-advocacy and self-care skills. The adolescent who gradually assumes responsibility for his or her own care will make a smoother transition into adulthood.

## Chapter 9. Transitioning to Adult Health Care Services —

7. Determine when coverage through your current health insurance plan will terminate and explore other health insurance coverage options.
8. Describe to your adolescent how the current insurance plan works; discuss what will be needed in the future.
9. Contact the New Hampshire Department of Health and Human Services district office and research the Medicaid programs for adults with disabilities. One program, *Aid for the Permanently and Totally Disabled* (APTD), provides financial and medical assistance for low-income adults with disabilities. The application process can be started 6 months before the adolescent’s 18th birthday; however, no determinations are made before the adolescent is 18 years old.
10. If the adolescent will be applying for the Aid for the Permanently and Totally Disabled (APTD) program, then he or she will also have to apply for *Supplemental Security Income* (SSI). This application process can be started 6 months before the adolescent’s 18th birthday.
11. If you believe your adolescent may have problems making informed decisions when he or she reaches age 18, obtain recommendations from your adolescent’s current mental health providers and seek legal counsel about the legal options available to you. (See Appendix C, “Legal Support” on page 135 and “Guardianship Rights” on page 132.)

The topic of transitioning out of the school system is covered in Chapter 6 section, “Transitioning Out of High School” on page 92. Parents/caregivers may also want to review Chapter 1, “Integrated Health Care” beginning on page 1. For more details and information on overall transitioning, see Appendix C, “Transitioning from Youth to Adult Services” on page 139 and/or visit the NAMI NH website: [www.naminh.org](http://www.naminh.org).

### Legal Considerations

As a parent/caregiver of an adolescent with SED, you may be concerned about his or her ability to make “informed decisions” (*not the same issue as making good or bad choices*). If it is believed that the young adult has or will have difficulty making informed decisions, there are several alternatives to be considered... ranging from “least restrictive” to “most restrictive” means of transferring medical decision making and/or financial management rights to others. Parents/caregivers are encouraged to speak with their adolescent’s mental health providers when considering any of these alternatives. In some cases, the mental health provider will have to provide information to the courts. (For resources, see Appendix C, “Legal Support” on page 135.)

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## ***Least Restrictive***

### **Consent to Release Information**

A **consent to release information**, signed by your adult child, allows the mental health provider to share information with you. This consent to release information can be very broad or limited. This is the least restrictive form of maintaining involvement in your child's care. *It allows you to continue to be a part of your young adult's team but does not allow you any decision making authority.*

### **Durable Power of Attorney**

A **durable power of attorney** allows a person (an "agent") to make decisions for someone who is unable to do so. *The agent is not subject to supervision of the court, so it is very important for the individual to name an agent that he or she trusts.* If an agent abuses the power of attorney, the court can, upon review of the case, remove him or her from that role.

### **Conservatorship**

A **conservatorship** can be considered a midpoint between "power of attorney" and "guardianship." With conservatorship, if an individual needs help in making decisions, he or she can ask for a "conservator" to be appointed by the probate court. *The conservator does the same things that an "agent" does under a durable power of attorney, but the conservator is appointed by the court and operates under supervision of the court.*

### **Representative Payee**

A **representative payee** is assigned for individuals who are not able to manage their own *Social Security Administration* (SSA) benefits. (See Chapter 7 section, "Supplemental Security Income (SSI) Benefits" on page 98.) This can be at the request of the applicant or be assigned by Social Security Administration. The attending physician provides a recommendation to SSA regarding the applicant's ability to manage his or her funds, and the representative payee files an annual report with SSA accounting for the funds he or she has been entrusted with. (Rights and responsibilities of the representative payee are more fully explained in free booklets available through Social Security Administration.)

### **Authorized Representative**

An **authorized representative** has the same responsibilities as a "representative payee" but for individuals who are not able to manage their own benefits received through the New Hampshire Department of Health and Human Services, such as *Aid for the Permanently and Totally Disabled* (APTD). The authorized representative is chosen by the applicant. Financial assistance benefits are sent to the authorized representative to manage on behalf of the applicant.

### **Most Restrictive**

#### **Guardianship**

A **guardianship** is the most restrictive alternative available to someone who needs help with financial and/or medical decisions. *The probate court will appoint a guardian when the person is declared legally incapacitated (if the person's abilities are so limited that he or she is not capable of making decisions nor able to participate in decision-making).* In a guardianship proceeding, the court will hold a hearing and will appoint an attorney to represent the person over whom guardianship is being sought. The person seeking guardianship will have to testify and might be subject to cross-examination. The guardian will be required to post a bond (purchased through an insurance company) and must report to the court annually about the incapacitated person's finances and health condition.

### **Advance Directives and Estate Planning**

#### **Advance Directives**

**Advance directives** is another term for “health care powers of attorney” and “living will declarations.” *A “living will” can state that you do not want to be kept alive if you are terminally ill and are being sustained by artificial means only. With a “health care power of attorney” you appoint a third party (an “agent”) who can make medical decisions for you, including terminating life support.* Even if you sign a health care power of attorney when you are well, it does not become effective until your doctor certifies that you have become unable to make medical decisions.

#### **Estate Planning**

*Although most people do not like to think about such things... no one lives forever.*

Therefore, it is essential to plan now for your child's future and to establish alternative supports for when you are no longer here to provide care. Such planning can range from making a simple will to entering into complex insurance and trust arrangements. Basic considerations should include who you would like to become your minor child's legal guardian, and who you would like to manage his or her inheritance.

**Note:** If your child is receiving government benefits such as Medicaid or SSI, it would be important to create a will or trust with “special needs provisions.” These provisions may allow your child to have the benefit of an inheritance, but contain restrictions preventing the government from otherwise counting the inheritance as an asset (which might disqualify your child from the government benefits). Since these trusts are often subject to changes in state law, it is important to periodically check with your attorney to assure that the trust meets your intentions to restrict the government from accessing inheritance.

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## Appendix A. Acronyms

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Some of the acronyms in this Appendix are not used in this Guidebook, but they might be used by the organizations and providers you interface with.

<b>504</b> Section 504 of the Rehabilitation Act of 1973	<b>DHHS</b> Department of Health & Human Services
<b>ADA</b> Americans with Disabilities Act	<b>DJJS</b> Division of Juvenile Justice Services
<b>ADD</b> Attention Deficit Disorder	<b>DOE</b> Department of Education
<b>AD/HD</b> Attention Deficit/(Hyperactivity) Disorder	<b>DRC</b> Disability Resource Center
<b>APC</b> Anna Philbrook Center (at NHH)	<b>EBD</b> Emotional/Behavioral Disorder
<b>APS</b> Acute Psychiatric Services (at NHH)	<b>EH</b> Emotional Handicap
<b>BBH</b> Bureau of Behavioral Health	<b>EI</b> Early Intervention
<b>CASSP</b> Child and Adolescent Service System Project	<b>EPSDT</b> Early and Periodic Screening, Diagnosis, and Treatment
<b>CHINS</b> Child in Need of Services	<b>ESS</b> Early Supports and Services
<b>CMHC</b> Community Mental Health Center	<b>ESY</b> Extended School Year
<b>CPSW</b> Child Protection Service Worker	<b>FAPE</b> Free and Appropriate Public Education
<b>DCYF</b> Division for Children, Youth, and Families	<b>FBA</b> Functional Behavioral Assessment
<b>DD</b> Developmental Disability	<b>FDA</b> Federal Drug Administration
<b>DFA</b> Division of Family Assistance	<b>FERPA</b> Family Educational Rights and Privacy Act
	<b>IDEA</b> Individuals with Disabilities Education Act

## Appendix A. Acronyms

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<b>IEA</b> Involuntary Emergency Admission	<b>OSEP</b> Office of Special Education Programs
<b>IEP</b> Individual Education Program	<b>OT</b> Occupational Therapy
<b>IFSP</b> Individualized Family Service Plan	<b>PBIS</b> Positive Behavioral Intervention Service
<b>IROS</b> Individual Resiliency and Recovery Oriented Services	<b>PCP</b> Primary Care Physician
<b>JPPPO</b> Juvenile Probation and Parole Officer	<b>PDD</b> Pervasive Developmental Disorder
<b>LD</b> Learning Disorder/Disability	<b>PIC</b> Parent Information Center
<b>LEA</b> Local Education Agency	<b>PT</b> Physical Therapy
<b>LRE</b> Least Restrictive Environment	<b>PTSD</b> Post-Traumatic Stress Disorder
<b>NAMI NH</b> National Alliance on Mental Illness New Hampshire	<b>RSA</b> Revised Statute Annotated
<b>NHH</b> New Hampshire Hospital	<b>S&amp;L</b> Speech and Language
<b>NIMH</b> National Institute of Mental Health	<b>SA</b> Substance Abuse
<b>OCR</b> Office of Civil Rights	<b>SED</b> Serious Emotional Disorder
<b>ODD</b> Oppositional Defiant Disorder	<b>SLD</b> Specific Learning Disability
<b>OHI</b> Other Health Impairment	<b>TBI</b> Traumatic Brain Injury
	<b>YDC</b> Youth Detention Center

Note: Acronyms can have different meanings between various organizations and disciplines. Unless the meaning is clear to you... request that acronyms be defined... or avoided.

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## Appendix B. Glossary

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### **adjudicatory hearing**

The court hearing where both the prosecution and defense present their evidence, and a judge decides whether the charges made against the defendant are true or not true. This hearing occurs after a plea has been entered by the juvenile at arraignment.

### **arraignment**

The initial court hearing at which the court advises a juvenile of his or her rights, reads the offense the juvenile is being charged with, appoints legal counsel to represent the juvenile, establishes conditions for his or her release, and sets an adjudicatory hearing date.

### **behavioral disorder**

A disorder characterized by displaying behaviors, over a long period of time, that significantly deviate from socially acceptable norms for the individual's age and situation.

### **Child in Need of Services (CHINS)**

A child under the age of 18 who exhibits one of the behavioral difficulties listed in RSA 169-D:2, and who is in need of care, guidance, counseling, discipline, supervision, treatment, and/or rehabilitation.

### **cognitive-behavioral therapy**

A form of psychotherapy that emphasizes the important role of how the way we think impacts on what we feel and what we do.

### **community-based**

This term applies to services that are provided by professionals to the child and family in their home, school, recreational, and/or natural setting. Generally, it may also relate to services not provided in restrictive environments such as a hospital or residential facility.

### **consumer**

Any person receiving services from a publicly funded mental health program or provider.

### **co-occurring disorders**

A diagnosis of an emotional disorder and another simultaneous disorder such as a medical illness, learning disability, developmental delay, or drug and alcohol disorder.

### **cultural competence**

A way of designing and delivering services that incorporates the religious, regional, racial, ethnic, and life-style values and beliefs of the child or family being served.

### **delinquency**

Violation of the law by a child or youth (usually under age 18).

### **delusion**

A false belief that does not change, in spite of being shown facts that contradict the belief.

### **developmental disorders**

Disorders begin at an early age and are characterized by major disturbances in the normal development of language, cognitive, and/or motor skills.

**dispositional hearing**

The court hearing at which the judge issues a final decision, or settlement, of a court case.

**evaluation**

A process conducted by mental health professionals, which results in an opinion about a child's mental or emotional status, and may include recommendations about treatment support services and/or placement.

**family**

In this Guidebook, this term can mean the biological nuclear family, extended family caregivers, foster family, adoptive family, or any other legal guardian.

**hallucination**

Seeing, feeling, smelling, or touching something that does not exist outside the mind.

**least restrictive environment (LRE)**

The program or services which least inhibits a client's freedom of movement, informed decisions, and participation in the community while achieving the purposes of habilitation and treatment.

**parent**

In this Guidebook, this term can mean any guardian of a child, including the biological parent, foster parent, adoptive parent, grandparent, or relative who is filling the role of parent.

**residential treatment**

Live-in facilities that provide treatment and care for children with emotional disorders who require continuous medication and/or supervision or relief from environmental stressors.

**serious emotional disorder (SED)**

This is not a medical diagnosis, but a broad term used to classify children who exhibit any of a wide variety of behavioral disorders or mental health problems that cause the child or youth to act in an unusual, irrational, or aggressive way and which negatively impact on day-to-day functioning.

**strength-based**

A model of treatment planning whereby the positive aspects of the child, family, and community are considered and are integrated and reinforced in the plan.

**substance abuse**

The misuse of alcohol or drugs.

**system of care**

A range of effective supports and services coordinated to meet the needs of the child and family. These research-based supports and services embrace a common set of values and beliefs.

**treatment plan**

A written plan developed by the child (where appropriate), parents, and providers that identifies the strengths of the child and family, measurable goals and objectives, and the services and supports that will be provided by the community mental health center and coordinated with other needed services and supports.

**truant**

Absent from school without permission.

## Appendix C. State and National Resources

*This Appendix of organizations and resources is primarily arranged alphabetically by major topic, with the exception of the New Hampshire Department of Health and Human Services (DHHS), which provides services across many topic areas.*

*In addition to the specific organizations in this Appendix, remember to use the following resources:*

**NAMI NH** – (800) 242-6264

**NH Help Line** – (800) 852-3388

**Schools** – Call an administrator in your public school for information on local community services.

**Elected Officials** – Call your representatives, senators, and town officials.

**Churches** – Most members of the clergy know about community services and are glad to help.

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### New Hampshire Department of Health and Human Services

The *New Hampshire Department of Health and Human Services* (DHHS) provides assistance for Medicaid, Medicare, employment, finances, food stamps, youth, families, and the Healthy Kids insurance programs at the regional offices listed below.

General New Hampshire DHHS information and referrals: (603) 271-5557

All TDD access: (800) 735-2964

Website: [www.dhhs.state.nh.us](http://www.dhhs.state.nh.us)

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**Berlin**

231 Main Street  
Berlin, NH 03570  
(800) 972-6111

**Littleton**

80 North Littleton Road  
Littleton, NH 03561  
(800) 552-8959

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**Claremont**

17 Water Street, Suite 301  
Claremont, NH 03743  
(800) 982-1001

**Manchester**

195 McGregor Street  
South Tower, Suite 110  
Manchester, NH 03102  
(800) 852-7493

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**Concord**

40 Terrill Park Drive  
Concord, NH 03301  
(800) 322-9191

**Nashua**

19 Chestnut Street  
Nashua, NH 03060  
(800) 852-0632

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**Conway**

73 Hobbs Street  
Conway, NH 03818  
(800) 552-4628

**Portsmouth**

30 Maplewood Avenue, Suite 200  
Portsmouth, NH 03801  
(800) 821-0326

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**Keene**

809 Court Street  
Keene, NH 03431  
(800) 624-9700

**Rochester**

150 Wakefield Street, Suite 22  
Rochester, NH 03867  
(800) 862-5300

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**Laconia**

65 Beacon Street West  
Laconia, NH 03246  
(800) 322-2121

**Salem**

154 Main Street, Suite 1  
Salem, NH 03079  
(800) 852-7492

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## Resources - Alphabetic by Topic

### Alcohol/Substance Abuse and Smoking Prevention and Treatment

#### **New Hampshire Department of Health and Human Services (DHHS)**

Office of Alcohol and Drug Abuse Policy  
105 Pleasant Street  
Concord, NH 03301  
Phone: (800) 804-0909 or (603) 271-6110  
Website: [www.dhhs.state.nh.us/DHHS/COMMDRUGABUSE](http://www.dhhs.state.nh.us/DHHS/COMMDRUGABUSE)  
(Go to website for “Resource Guide for Alcohol and Drug Prevention and Treatment Services.”)

#### **New Hampshire Division of Public Health Services**

Alcohol and Other Drug Abuse Treatment  
29 Hazen Drive  
Concord, NH 03301  
Phone: (603) 271-4936  
Website: [www.dhhs.state.nh.us/DHHS/ATODTREATMENT/CONTACT+INFO/default](http://www.dhhs.state.nh.us/DHHS/ATODTREATMENT/CONTACT+INFO/default)

#### **New Futures**

8 Continental Drive, Suite G  
Exeter, NH 03801  
Phone: (603) 658-2770  
Website: [www.new-futures.org](http://www.new-futures.org)

#### **Substance Abuse Treatment Facility Locator (website resource)**

The Substance Abuse Treatment Facility Locator is a website resource that provides listings for substance abuse treatment and related care for every state in the USA.

Phone: (800) 662-HELP (800) 662-4357  
TDD: (800) 487-4889  
Website: [findtreatment.samhsa.gov/about.htm](http://findtreatment.samhsa.gov/about.htm)

#### **The Cool Spot (website resource)**

A place where children and adolescents can learn the truth about alcohol and underage drinking.

Website: [www.thecoolspot.gov](http://www.thecoolspot.gov)

## Appendix C. State and National Resources

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### Try-to-Stop Tobacco Resource Center of New Hampshire

“We’re here to help you quit.”

Phone: (800) TRY TO STOP (800) 879-8676

(800) 833-1477 (TTY)

Website: [www.trytostop.org](http://www.trytostop.org)

## Child Protection

### New Hampshire Division for Children, Youth, and Families (DCYF)

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#### State Office

129 Pleasant Street

Concord, NH 03301-3857

(603) 271-4451 (Voice)

(800) 735-2964 (TDD)

[www.dhhs.state.nh.us/DHHS/DCYF](http://www.dhhs.state.nh.us/DHHS/DCYF)

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#### To report child abuse, call...

(603) 271-6562 (Voice)

(800) 894-5533 (Toll-Free)

(800) 735-2964 (TDD)

New Hampshire DCYF provides the following protective and support services.

**Bureau of Child Protection.** Works to protect children from abuse and neglect while attempting to preserve the family unit. Phone: (603) 271-8821 or (800) 852-3345

**Foster Care Program.**

Phone: (603) 271-4711 or (800) 852-3345

**Teen Independent Living Program.**

Phone: (603) 271-4706 or (800) 852-3345

**Domestic Violence Services.**

Phone: (603) 271-4702 or (800) 852-3345

**Adoption.**

Phone: (603) 271-4707 or (800) 852-3345

**Child Development Bureau.**

Phone: (603) 271-4451 or (800) 852-3345

## Cultural Diversity

### New Hampshire Minority Health Coalition

Helps individuals from various cultures obtain health and mental health services in Manchester.

25 Lowell Street

Manchester, NH 03101

Phone: (603) 627-7703

Website: [www.nhhealthequity.org](http://www.nhhealthequity.org)

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### **NH DHHS Minority Health Office**

Provides services to individuals to resolve issues of access to DHHS services.

129 Pleasant Street  
Concord, NH 03301  
Phone: (603) 271-3986 or (800) 852-3345  
TDD: (800) 735-2964

### **Office for Civil Rights (OCR), US Department of Health and Human Services**

OCR enforces federal statutes that prohibit discrimination based on race, color, national origin, sex, age, or disability in education programs receiving federal financial assistance.

Government Center  
JF Kennedy Federal Building, Room 1875  
Boston, MA 02203  
Phone: (617) 565-1340  
(617) 565-1343 (Voice/TTY)

## **Developmental Disabilities**

### **National Information Center for Children and Youth with Disabilities (NICHCY)**

Provides information on disabilities and disability-related issues (especially regarding children and youth to age 22) to families, educators, administrators, journalists, and students.

P.O. Box 1492  
Washington, DC 20013  
(800) 695-0285 (Voice/TTY)  
Website: [www.nichcy.org](http://www.nichcy.org)

### **NH DHHS Developmental Services**

Funding of supports and services for people with developmental disabilities and acquired brain disorders. Main office in Concord and contracts with (12) area agencies.

*Main Office:*

105 Pleasant Street  
Concord, NH 03301  
Phone: (603) 271-5034 or (800) 852-3345  
Website: [www.dhhs.state.nh.us/DHHS/DDS/default.htm](http://www.dhhs.state.nh.us/DHHS/DDS/default.htm)

## Appendix C. State and National Resources

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### *Area Agencies for Developmental Disability Services*

<b>REGION 1</b> <b>Northern Human Services</b> 87 Washington Street Conway, NH 03818 (603) 447-3347	<b>REGION 7</b> <b>Moore Center Services</b> 132 Titus Avenue Manchester, NH 03103 (603) 668-5423
<b>REGION 2</b> <b>Developmental Services of Sullivan County</b> 654 Main Street Claremont, NH 03743 (603) 542-8706	<b>REGION 8</b> <b>Community Development Svcs Agency</b> Parade Office Mall, Suite 40 195 Hanover Street Portsmouth, NH 03801 (603) 436-6111
<b>REGION 3</b> <b>Lakes Region Community Services Council</b> 67 Communication Drive, P. O. Box 509 Laconia, NH 03247 (603) 524-8811	<b>REGION 9</b> <b>Community Partners</b> Forum Court, Suite 1 113 Crosby Road Dover, NH 03820 (603) 749-4015
<b>REGION 4</b> <b>Community Bridges</b> 525 Clinton Street Bow, NH 03304 (603) 225-4153 or (800) 499-4153	<b>REGION 10</b> <b>Community Support Services</b> 8 Commerce Drive Atkinson, NH 03811 (603) 893-1299
<b>REGION 5</b> <b>Monadnock Developmental Services</b> 121 Railroad Street Keene, NH 03431 (603) 352-1304	<b>REGION 11</b> <b>Center of Hope, Inc.</b> 626 Eastman Road Center Conway, NH 03813 (603) 356-6921
<b>REGION 6</b> <b>Area Agency of Greater Nashua</b> 144 Canal Street Nashua, NH 03060 (603) 882-6333	<b>REGION 12</b> <b>United Developmental Services</b> 85 Mechanic Street, Suite 300 Lebanon, NH 03766 (603) 448-2077

### **Family Centered Early Supports and Services**

State Office Park South  
105 Pleasant Street  
Concord, NH 03301  
Phone: (603) 271-5122  
Website: [www.nhdds.org/programs/famchild/earlysupports](http://www.nhdds.org/programs/famchild/earlysupports)

### **Recommended Reading**

*The New Hampshire Challenge*. An informative quarterly newsletter that addresses disability issues from a family perspective. (Available online at: [www.nhchallenge.org](http://www.nhchallenge.org).)

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## Disorders

### ***Disorders of Infancy, Childhood, and Adolescence***

#### **Autism Society of New Hampshire**

Parent driven organization dedicated to those living and dealing with autism in New Hampshire. Its main goals are education, awareness, and advocacy.

P.O. Box 68  
Concord, NH 03302-0068  
Phone: (603) 679-2424  
Website: [www.autism-society-NH.org](http://www.autism-society-NH.org)

#### **Children and Adults with Attention Deficit (Hyperactivity) Disorder (National)**

CHADD works to improve the lives of people affected with AD/HD through collaboration, leadership, advocacy, research, education, and support.

8181 Professional Place, Suite 201  
Landover, MD 20785  
Phone: (800) 233-4050  
Website: [www.chadd.org](http://www.chadd.org)

#### **National Attention Deficit (Hyperactivity) Disorder Association**

Serves persons with AD/HD as well as those who love, teach, counsel, and treat them.

1788 Second Street, Suite 200  
Highland Park, IL 60035  
Phone: (847) 432-2332  
Website: [www.add.org](http://www.add.org)

### ***Mood Disorders***

#### **Depression and Bipolar Support Alliance (DBSA)**

Provides support groups, patient support, patient assistance programs, advocacy, publications, referrals, and book catalog. Use the *Find A DBSA Support Group in Your Area* link on their website to find a local support group in the New Hampshire area.

730 N. Franklin Street, Suite 501  
Chicago, IL 60610-7224  
Phone: (800) 826-3632  
Website: [www.DBSAAlliance.org](http://www.DBSAAlliance.org)

## Appendix C. State and National Resources

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### **Child and Adolescent Bipolar Foundation**

A web-based membership organization of families raising children diagnosed with, or at risk for early onset bipolar disorder. This website includes information and resources.

1000 Skokie Boulevard, Suite 570  
Wilmette, IL 60091  
Phone: (847) 256-8525  
Website: [www.bpkids.org](http://www.bpkids.org)

### ***Thought Disorders***

#### **Recommended Reading**

*Living with Schizophrenia: A Guide for Parents and Their Families.* Contemporary Books, Chicago, IL, 1987.

*Coping with Schizophrenia: A Guide for Families.* Mueser, Kim and Gingerich, Susan. New Harbinger Publications, Oakland, CA, 1994.

*Social Skills Training for Schizophrenia, Second Edition: A Step-By-Step Guide.* Bellack, Alan, and Mueser, Kim and Gingerich, Susan. Guilford Press, New York, NY, 2004.

*The Complete Family Guide to Schizophrenia: Helping Your Loved One Get the Most Out of Life.* Mueser, Kim and Gingerich, Susan. Guilford Press, New York, NY, 2006.

### ***Anxiety Disorders***

#### **Anxiety Disorders Association of America**

Promotes the early diagnosis, treatment, and cure of anxiety disorders, and is committed to improving the lives of the people who suffer from them.

8730 Georgia Avenue, Suite 600  
Silver Spring, MD 20910  
Phone: (240) 485-1001  
Website: [www.adaa.org](http://www.adaa.org)

#### **OCD Resource Center**

Information and resources available on obsessive compulsive disorder.

Website: [www.ocdresource.com](http://www.ocdresource.com)

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## Education

### ***General Issues***

#### **New Hampshire Department of Education**

101 Pleasant Street  
Concord, NH 03301  
Phone: (603) 271-3494  
Website: [www.ed.state.nh.us/education/](http://www.ed.state.nh.us/education/)

#### **Bureau of Special Education of the New Hampshire Department of Education**

Oversees and implements educational programs for New Hampshire students with disabilities. The Bureau provides technical assistance and support to lawmakers, public and non-public school officials, parents, and community members. You may contact them for a copy of the NH Rules for the Education of Children with Disabilities and IDEA.

101 Pleasant Street (State Office Park South)  
Concord, NH 03301  
Phone: (603) 271-6693  
Critical Call Line: (603) 271-3741  
Website: [www.ed.state.nh.us/SpecialEd/special1.htm](http://www.ed.state.nh.us/SpecialEd/special1.htm)

#### **Head Start Program**

Child-focused program that has the overall goal of increasing the school readiness of young children (birth - age 5).

Division of Child, Youth, and Families  
129 Pleasant Street  
Concord, NH 03301  
Phone: (800) 852-3345 ext. 7190 or (603) 271-7190  
E-mail: [ewheatley@dhhs.state.nh.us](mailto:ewheatley@dhhs.state.nh.us)

#### **Parent Information Center (PIC)**

“Putting Children with Disabilities on the Path to Success” - PIC believes that all children can succeed with the right support. PIC provides a wealth of services designed to help parents understand their child’s special needs and the laws that govern the special education process. PIC assists families and schools to increase parental involvement in children’s education with the goal of increasing student academic achievement. PIC supports the building of family/school/community partnerships that help parents of all students get involved in their children’s education.

P.O. Box 2045  
151A Manchester Street  
Concord, NH 03302-2405  
(603) 224-7005 (Voice and TDD)  
(800) 947-7005  
Website: [www.parentinformationcenter.org](http://www.parentinformationcenter.org)

## Appendix C. State and National Resources

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### **The Southeastern Regional Education Service Center (SERESC)**

Provides consultation and training services that are designed to support the school team in meeting the challenges faced by students who have serious multiple disabilities.

29 Commerce Drive  
Bedford, NH 03110  
Phone: (603) 206-6800  
Website: [www.seresc.k12.nh.us](http://www.seresc.k12.nh.us)

### **State Mediation System**

New Hampshire Department of Education  
101 Pleasant Street  
Concord, NH 03301  
Phone: (603) 271-2299  
Website: [www.ed.state.nh.us/hearings/mediate.htm](http://www.ed.state.nh.us/hearings/mediate.htm)

### **Wrightslaw (website resource)**

This website provides parents, advocates, educators, and attorneys with accurate, up-to-date information about special education law and advocacy for children with disabilities.

Website: [www.wrightslaw.com](http://www.wrightslaw.com)

### **Recommended Reading**

*Steps in the New Hampshire Special Education Process*, Parent Information Center, January, 2005.

## **Family Support, Advocacy, and Referral Services**

### **National Alliance on Mental Illness New Hampshire (NAMI NH)**

NAMI NH provides education, support, and advocacy for persons with mental illness and/or serious emotional disorders and their families. (The national organization website: [www.nami.org](http://www.nami.org) also provides a Child and Adolescent Action Center, which includes the newsletter, *Because Kids Grow Up*.)

Members of NAMI are children and adults with mental illness, along with parents, spouses, siblings, and friends of people with mental illness. ***Become a member of NAMI NH today!***

15 Green Street  
Concord, NH 03301  
Phone: (800) 242-6264 or (603) 225-5359  
E-mail: [naminh@naminh.org](mailto:naminh@naminh.org)  
Website: [www.naminh.org](http://www.naminh.org)

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### *Information and Referral*

The NAMI NH Information/Referral service (800) 242-6264 connects callers with trained individuals who: answer questions; help access information about mental illness, serious emotional disorders, treatments and services; provide connection to local NAMI NH support groups; and provide referrals to appropriate organizations.

The NAMI NH website: [www.naminh.org](http://www.naminh.org) offers treatment information, mental illness fact sheets, links to New Hampshire and national organizations, information on support group meetings, and much more. There are several fact sheets/brochures addressing issues surrounding suicide, including: *Do You Care for Someone Who's at Risk of Suicide?*, *Suicide: Taking Care of Yourself After an Attempt*, and *Suicide: Taking Care of Yourself & Your Family After an Attempt*.

A mental health lending library is located on site, and a computer is available for research.

### *NAMI NH Affiliate Support Groups*

“Parents Meeting the Challenge” are support groups that meet regularly throughout the state to serve individuals with a child under age 18 who is affected by a serious emotional disorder. The support groups follow the NAMI support group model and are led by parents trained as support group facilitators. Members help each other to cope and share information about local services and professionals. Many groups offer educational sessions. For information on a meeting in your area, call the NAMI NH office at (800) 242-6264, ext. 40 or visit the website: [www.naminh.org](http://www.naminh.org).

### *Educational Programs*

NAMI NH offers volunteer trained educational programs to parents of children with SED. They are usually offered at no fee to parents. Educational programs are also available for professionals at nominal fees. Please contact the NAMI Coordinator of Child and Family Services for more information.

### **Community Mental Health Centers (CMHC)**

Professional family support services are sometimes available through community mental health centers. If your child receives treatment from a local mental health center, talk to them about the supports available for family members. See “Community Mental Health Centers” on page 138 for contact information for your local mental health center.

### **ServiceLink (New Hampshire)**

If you are a grandparent age 60 or older caring for a grandchild with a serious emotional disorder, this organization will provide referrals for support services for your family.

Phone: (866) 634-9412

Website: [www.state.nh.us/servicelink](http://www.state.nh.us/servicelink)

### **Family Resource Connection**

This service of the New Hampshire state library provides a wide range of information and a statewide calendar of events.

Phone: (800) 298-4321

(800) 735-2964 (TDD)

Website: [www.state.nh.us/nhsl/frc](http://www.state.nh.us/nhsl/frc)

### **Infant Mental Health Regional Team (IMH)**

The IMH teams are supported through funding from the New Hampshire Children's Care Management Collaborative and technical assistance through the Preschool Technical Assistance Network. The teams are comprised of families and professionals from various disciplines committed to increase awareness and access to comprehensive community services for children (birth through age 6) and their families. To contact the IMH team in your region, contact:

PTAN

29 Commerce Drive

Bedford, NH 03110

Phone: (603) 206-6800

E-mail: [jizen@seresc.net](mailto:jizen@seresc.net)

Website: [www.ptan.seresc.net](http://www.ptan.seresc.net)

### **Parent to Parent of New Hampshire**

This organization provides references and support to parents of children with special needs. Among its other services, Parent to Parent will connect you with other parents who are handling the same issues and disorders that you are.

12 Flynn Street

Lebanon, NH 03766

Phone: (800) 698-LINK (5465)

Website: [www.parenttoparentnh.org](http://www.parenttoparentnh.org)

### **New Hampshire Connections**

A network of partners guided by research based systems of care committed to improving outcomes for children and youth through the educational system.

Linking Family, School, and Community

Parent Information Center

P.O. Box 2045

Concord, NH 03302-2405

Phone: (800) 232-0986

TTY: (603) 224-7005

### **New Hampshire Child Care Resource & Referral Network (NHCCR&R)**

The NHCCR&R Network is composed of community based Child Care Resource and Referral programs. These strategically situated programs educate and support families, providers and the community regarding child care issues. Each of the 10 CCR&R

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agencies in New Hampshire is *Quality Assured through Child Care Aware*®. This program seeks to ensure that families are receiving consistent, high quality consumer education and referral services. New Hampshire is the only volunteer network and one of only six states in the nation in which all of its CCR&Rs are Quality Assured.

Website: [www.nhccrr.org](http://www.nhccrr.org)

### **Federation of Families for Children's Mental Health (FFCMH)**

A New Hampshire, parent-run organization that focuses on the needs of children and adolescents with mental disorders and on the families of these children and adolescents. The organization provides training and information about children's mental health.

Granite State FFCMH  
250 Commercial Street, Suite 4017  
Manchester, NH 03101  
Phone: (603) 296-0692  
Website: [www.ffcmh.org](http://www.ffcmh.org)

### **Casey Family Services**

105 Loudon Road, Building 2  
Concord, NH 03301  
Phone: (603) 224-8909 or (800) 417-7375  
Fax: (603) 224-2584  
Website: [www.caseyfamilyservices.org](http://www.caseyfamilyservices.org)

### **Recommended Reading**

*Promoting Family Empowerment through Multiple Roles.* McCammon, Susan L. Ph.D., Spencer, Sandra A. B.A., Friesen, Barbara J. Ph.D. A manuscript published by The Hayworth Press, Inc., 2001. (Available through the NAMI NH office.)

## Financial Supports

Referrals for basic needs (rent, auto repair, child care, food, shelter, etc.)

<b>Carroll County</b> HealthLine (800) 499-4171	<b>Monadnock</b> United Way (603) 352-4209
<b>Lebanon and Upper Grafton County</b> HeadRest (800) 804-0909 or (603) 448-4400	<b>Greater Nashua</b> Information and Referral Services (603) 883-9330
<b>Greater Manchester</b> InfoBank (603) 668-8600	<b>Seacoast</b> InfoLink (888) 499-2525

Also see “New Hampshire Department of Health and Human Services” on page 120.

### Social Security Administration (New Hampshire offices)

70 Commercial Street, Suite 100 Concord, NH 03301-5005 (603) 224-1939 (603) 225-8475 (TTY)	2 Wall Street, Suite 301 Manchester, NH 03101 (603) 641-2180 (603) 645-5230 (TTY)
34 Mechanic Street Keene, NH 03431 (603) 352-3487 (603) 357-2034 (TTY)	175 Amherst Street Nashua, NH 03064 (603) 880-0295 (603) 889-5270 (TTY)
177 Main Street Littleton, NH 03561 (603) 444-2945 (603) 444-4028 (TTY)	80 Daniel Street, Federal Building, Rm 200 Portsmouth, NH 03802 (603) 433-0716 (603) 436-3086 (TTY)

### Claimant’s Disability

P.O. Box 5232  
Manchester, NH 03232  
Phone: (888) 472-2291

## Guardianship Rights

A listing of the revised New Hampshire statutes having to do with Guardians and Conservators (Title XLIV) is available at the state library in Concord and online at: [www.gencourt.state.nh.us/rsa/html/indexes/XLIV.html](http://www.gencourt.state.nh.us/rsa/html/indexes/XLIV.html)

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Office of Public Guardian  
10 Whale Street  
Concord, NH 03301  
Phone: (603) 224-8041

Granite State Guardianship Services  
Main Office - 34 Jefferson Road  
Whitefield, NH 03598  
Phone: (603) 837-9561 Concord: (603) 224-0805  
Website: [www.gsgs.org](http://www.gsgs.org)

## Health Care for Children

### Special Medical Services

Provides medical and financial services to children with physical disabilities, chronic illnesses, and special health care needs.

29 Hazen Drive  
Concord, NH 03301  
Phone: (800) 852-3345 ext. 4488 or (603) 271-4488  
Website: [www.dhhs.state.nh.us/DHHS/SPECIALMEDSRVCS/default.htm](http://www.dhhs.state.nh.us/DHHS/SPECIALMEDSRVCS/default.htm)

### Child Health Program

The *Child Health Program* (CHP) is a part of the New Hampshire Bureau of Maternal and Child Health Program within the NH DHHS division of Public Health Services - Bureau of Community Health Services. It allocates federal Medicaid funds to local agencies such as community health centers. Services include physical exams, health screenings, immunizations, social services, and case management. The following agencies provide health care to children:

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**Families First of the Greater Seacoast**  
100 Campus Drive, Suite 12  
Portsmouth, NH 03801  
(603) 422-8208

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**Coos County Family Health Center**  
133 Pleasant Street  
Berlin, NH 03570  
(603) 752-2040

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**White Mt. Community Health Center**  
Conway site: (603) 447-8900  
Wolfeboro site: (603) 569-3145

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**Capital Region Family Health Center**  
Concord site: (603) 228-4677 ext. 2341  
Hillsboro site: (603) 478-3141

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**Ammonoosuc Community Health Services**  
Warren site: (603) 764-5704  
Littleton site: (603) 444-2464  
Woodsville site: (603) 837-2333  
Whitefield site: (603) 837-2333

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**Lamprey Health Care**  
Newmarket site: (603) 659-2494  
Raymond site: (603) 895-3351  
Nashua site: (603) 883-1626

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## Appendix C. State and National Resources

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**Avis Goodwin Community Health Center**

Rochester site: (603) 749-2346  
Dover site: (603) 749-2346

**Health First Family Care Center**

841 Central Street  
Franklin, NH 03235  
(603) 934-1464

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**Manchester Community Health Care**

1415 Elm Street  
Manchester, NH 03101  
(603) 626-9500

**Valley Regional Health Care**

167 Summer Street  
Newport, NH 03773  
(603) 543-6960

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**Maternal and Child Health Library**

Online “Knowledge Path” website designed to help find available resources that can address child and family needs.

Website: [www.mchlibrary.info/knowledgePath/kp\\_community.html](http://www.mchlibrary.info/knowledgePath/kp_community.html)

**Insure Kids Now**

A national campaign to link the nation’s 10 million children to free and low cost health insurance.

Website: [www.insurekidsnow.gov](http://www.insurekidsnow.gov)

**New Hampshire Family Voices**

Family-to-family health information and resources. “Maneuvering through the Maze” is a guidebook available on their website for downloading.

Family to Family Health Information and Education Center

29 Hazen Drive

Concord, NH 03301

Phone: (800) 852-3345 ext. 4525 or (603) 271-4525

E-mail: [nhfv@yahoo.com](mailto:nhfv@yahoo.com)

Website: [www.nhfv.org](http://www.nhfv.org)

**Donated Dental Services**

In conjunction with the NH Dental Society.

P.O. Box 3487

Concord, NH 03302

Phone: (603) 223-1531 or (800) 292-1241

Website: [www.nfdh.org/state/NH.html](http://www.nfdh.org/state/NH.html)

Applications can be downloaded from website. A wait list exists.

**Dental Programs**

Contact the local school district or school nurse in these areas:

- Cheshire Medical Center, Keene
- Claremont School Dental Program, Claremont
- Coos County Family Health Services, Berlin
- Health First Family Care Center, Franklin

- 
- Lamprey Health Care, Newmarket
  - Lamprey Health Care, Raymond
  - Milford School District, Milford
  - Spere Memorial Hospital School Dental Program, Plymouth
  - Upper Connecticut Valley Hospital, “Miles of Smiles in the Great North Woods School Dental Program,” Colebrook
  - Alexander Eastman School-Based Dental Program, Derry
  - The Rock Dental Clinic, New London
  - Frisbee Memorial Hospital School Dental Program, Rochester

**Health Resources and Services Administration (Federal)**

This branch of the US Department of Health and Human Services (DHHS) provides publications, resources, and referrals on health care services for low-income, uninsured individuals and those with special health care needs.

Phone: (888) 275-4772  
 Website: [www.ask.hrsa.gov](http://www.ask.hrsa.gov)

**Medicaid**

Contact the central New Hampshire Health Planning and Medicaid program office listed below, or contact your local DHHS district office. (See “New Hampshire Department of Health and Human Services” on page 120.)

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129 Pleasant Street Concord, NH 03301 (603) 271-5254 or (800) 852-3345 ext. 5254 (800) 735-2964 (TDD access) <a href="http://www.dhhs.state.nh.us/DHHS/MedicaidProgram">www.dhhs.state.nh.us/DHHS/MedicaidProgram</a>	Medicaid Client Services (603) 271-4344 (800) 852-3345 ext. 4344
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## Legal Support

**Client Assistance Program (CAP) (New Hampshire)**

This disabilities rights agency provides information about vocational rehabilitation services, advises you of your rights and responsibilities, investigates your complaint, helps resolve problems with your vocational plan, and represents you at administrative reviews and fair hearings. (Also see “Developmental Disabilities” on page 123 and “Vocational Rehabilitation” on page 142 in this Appendix.)

## Appendix C. State and National Resources

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Client Assistance Program  
Governor's Commission on Disability  
57 Regional Drive  
Concord, NH 03301-9686  
Phone: (603) 271-4175  
TTY: (603) 271-2774  
Website: [www.state.nh.us/disability/caphomepage.html](http://www.state.nh.us/disability/caphomepage.html)

### **Disabilities Rights Center, Inc. (New Hampshire)**

A private, nonprofit agency that provides legal information, referrals, representation, and advocacy for people with disabilities, including serious emotional disorders.

18 Low Avenue  
P.O. Box 3660  
Concord, NH 03302-3660  
Phone: (603) 228-0432  
(800) 834-1721 (Voice and TTY)  
E-mail: [advocacy@drcnh.org](mailto:advocacy@drcnh.org)  
Website: [www.drcnh.org](http://www.drcnh.org)

### **Judge David L. Bazelon Center for Mental Health Law**

A legal advocacy organization that works on a broad array of children's mental health issues. See the *Children's Issues* link on their website.

Phone: (202) 467-5730  
(202) 467-4232 (TDD)  
Website: [www.bazelon.org](http://www.bazelon.org)

### **Youth Law Center**

Investigates reports of abuse of youth in adult jails, juvenile detention facilities, state institutions, and child welfare systems and uses training, technical assistance, and negotiation to bring about needed change. If abusive conditions or practices continue, the Center uses litigation as a last resort.

Website: [www.ylc.com](http://www.ylc.com)

### **NH DHHS Ombudsman Office**

The Ombudsman Office utilizes investigation, mediation, and other alternative dispute resolution methods to address matters under the jurisdiction of DHHS. Also provides information and referral.

129 Pleasant Street  
Concord, NH 03301  
Phone: (800) 852-3345 ext. 6941 or (603) 271-6941

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### Legal Assistance Area Offices

Provides legal assistance to low-income people of all ages.

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<b>Manchester Office</b> (and administrative offices) 1361 Elm Street, Suite 307 Manchester, NH 03101 (603) 668-2900 or (800) 562-3174	<b>Littleton Office</b> 58 Main Street Littleton, NH 03561 (603) 444-8800 or (800) 548-1886
<b>Claremont Office</b> 24 Tremont Square, 206 Moody Building Claremont, NH 03743 (603) 542-8795 or (800) 562-3994	<b>Portsmouth Office</b> 154 High Street, P.O. Box 778 Portsmouth, NH 03802-0778 (603) 431-7411 or (800) 334-3135

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## Mental Health

### New Hampshire Hospital (State psychiatric hospital)

Provides acute treatment services for New Hampshire children, adolescents, and adults who have severe mental illness or who are experiencing a severe mental health crisis.

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New Hampshire Hospital Acute Psychiatric Services 36 Clinton Street Concord, NH 03301 (603) 271-5300 (800) 735-2964 (TDD) <a href="http://www.dhhs.state.nh.us/DHHS/NHH">www.dhhs.state.nh.us/DHHS/NHH</a>	Anna Philbrook Center South Fruit Street Concord, NH 03301 (603) 271-5900 (800) 735-2964 (TDD)
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### National Institute of Mental Health (NIMH) (Federal)

The mission of NIMH is to diminish the burden of mental illness through research. This requires powerful scientific tools to achieve better understanding, treatment, and prevention of mental illness.

NIMH Public Inquiries  
6001 Executive Boulevard, Room 8184, MSC 9663  
Bethesda, MD 20892-9663  
Phone: (301) 443-4513  
(301) 443-8431 (TTY)  
Website: [www.nimh.nih.gov](http://www.nimh.nih.gov)

### Substance Abuse and Mental Health Services Administration (SAMHSA) Center for Mental Health Services

This DHHS website provides an extensive array of information and references. Of particular interest is the *Consumer Survivor* link.

## Appendix C. State and National Resources

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Phone: (800) 789-2647

TDD: (866) 889-2647

Website: [www.mentalhealth.org](http://www.mentalhealth.org)

Also explore “Caring for Every Child’s Mental Health Campaign” at [www.mentalhealth.org/child](http://www.mentalhealth.org/child).

### Community Mental Health Centers

*Community Mental Health Centers* (CMHC) are private, not-for-profit agencies that have contracted with the New Hampshire Department of Health and Human Services, under its Division of Community Based Care Services - *Bureau of Behavioral Health* (BBH), to provide publicly funded mental health services to individuals and families who meet certain criteria. Each of the ten regional CMHC provides many outpatient mental health services to children and adults.

#### *Bureau of Behavioral Health (BBH)*

105 Pleasant Street

Concord, NH 03301

Main BBH office - phone: (603) 271-5000 or (800) 852-3345

BBH Children’s Administrator - phone: (603) 271-5095

Website: [www.dhhs.state.nh.us/DHHS/BBH](http://www.dhhs.state.nh.us/DHHS/BBH)

#### *Regional Community Health Centers*

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#### **Riverbend Community Mental Health Center**

105 Loudon Road

Concord, NH 03301

(603) 228-0547

#### **West Central Behavioral Health Services**

9 Hanover Street, Suite 2

Lebanon, NH 03766

(603) 448-0126

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#### **Northern New Hampshire Mental Health and Development Services**

87 Washington Street

Conway, NH 03818

(603) 447-3347

#### **Mental Health Center of Greater Manchester**

401 Cypress Street

Manchester, NH 03103

(603) 668-4111

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#### **Behavioral Health & Development Services of Strafford County**

**Community Partners**

113 Crosby Road, Suite 1

Dover, NH 03820

(603) 749-4015

#### **Community Council of Nashua**

7 Prospect Street

Nashua, NH 03060-3990

(603) 889-6147

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**Monadnock Family Services**

64 Main Street, Suite 301  
Keene, NH 03431  
(603) 357-6878

**Seacoast Mental Health Center**

1145 Sagamore Avenue  
Portsmouth, NH 03801  
(603) 431-6703

**Genesis Behavioral Health**

111 Church Street  
Laconia, NH 03246  
(603) 524-1100

**Center for Life Management Behavioral Health Systems**

44 Stiles Road, Salem Professional Park  
Salem, NH 03079  
(603) 893-3548

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**The Youth Council**

Provides counseling services to youth, including the areas of substance abuse, sexual abuse, and anger management.

112 West Pearl Street  
Nashua, NH 03060  
Phone: (603) 889-1090  
Website: [www.theyouthcouncil.org](http://www.theyouthcouncil.org)

## Transitioning from Youth to Adult Services

**Alliance for Community Supports**

“Renew,” a career and education program designed to assist youth and young adults who have serious emotional or behavioral challenges to finish high school, obtain jobs, and enter adulthood in a positive manner. Mentors work one-on-one with “Renew” participants to help achieve their career and education goals.

250 Commercial Street, Suite 4017  
Manchester, NH 03101  
Phone: (603) 628-7681

**Granite State Independent Living Foundation (New Hampshire)**

Provides skills training for independent living, housing, funding resources, and youth peer support to people with disabilities, including mental illness.

21 Chenell Drive  
P.O. Box 7268  
Concord, NH 03302-7268  
(800) 826-3700 (Voice and TTY)  
Website: [www.gsil.org](http://www.gsil.org)

**Institute on Disability (New Hampshire)**

Supports local and national projects in family support, community building, early childhood, assistive technology, inclusive education, employment support, housing support, classroom support, literacy, transportation, home ownership, post-secondary

## Appendix C. State and National Resources

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education, and maternal and child health to improve the lives of individuals with disabilities and their families.

Institute on Disability  
University of New Hampshire  
7 Leavitt Lane, Suite 101  
Durham, NH 03824  
Phone: (603) 862-4320  
Website: [www.iod.unh.edu](http://www.iod.unh.edu)

### **Institute on Disability / University Affiliated Programs**

Addresses the needs of high school students and young adults with disabilities relative to achieving success in post-secondary educational settings.

University of New Hampshire  
7 Leavitt Lane, Suite 101  
Durham, NH 03824  
(603) 862-4230 (Voice and TTY)  
Website: [www.iod.unh.edu](http://www.iod.unh.edu)

### **Institute for Child Health Policy (National)**

The *Healthy and Ready to Work* initiative promotes a comprehensive system of family-centered, culturally competent care for children with special health needs who are approaching adulthood and might need assistance in making the transition from pediatric to adult health care and to post-secondary education and/or employment.

Website: [www.mchbhrtw.org](http://www.mchbhrtw.org)  
*Healthy and Ready to Work* website: [www.hrtw.org](http://www.hrtw.org)

### **National Information Center for Children and Youth with Disabilities**

Provides a thorough, comprehensive explanation of how to develop a transition plan.

Website: [www.nichcy.org/pubs/transum/ts10txt.htm](http://www.nichcy.org/pubs/transum/ts10txt.htm)

### **HEATH Resource Center**

The national clearinghouse on post-secondary education for individuals with disabilities.

George Washington University Graduate School of Education and Human Development  
2121 K Street N.W., Suite 220  
Washington, DC 20037  
(800) 544-3284 (Voice and TTY)  
Website: [www.heath.gwu.edu](http://www.heath.gwu.edu)

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### **New Hampshire Housing Finance Authority**

Rental assistance programs, home ownership programs, multi-family housing programs.

P.O. Box 5087  
Manchester, NH 03108  
Phone: (800) 640-7239 or (603) 472-8623  
TDD: (603) 472-2089  
Website: [www.nhhfa.org](http://www.nhhfa.org)

### **National Council on Independent Living (NCIL)**

NCIL is a membership organization that advances the independent living philosophy and advocates for the human rights of, and services for, people with disabilities to further their full integration and participation in society.

1916 Wilson Boulevard, Suite 209  
Arlington, VA 22201  
Phone: (703) 525-3406  
(703) 525-4153 (TTY)  
Website: [www.ncil.org](http://www.ncil.org)

### **National Center on Workforce and Disability (NCWD)**

NCWD provides training, technical assistance, policy analysis, and information to improve access for all in the workforce development system.

Institute for Community Inclusion  
University of Massachusetts Boston  
100 Morrissey Blvd.  
Boston, MA 02125  
(888) 886-9898 (Voice and TTY)  
Website: [www.onestops.info](http://www.onestops.info)

### **Substance Abuse and Mental Health Services Administration (SAMHSA)**

Website: [www.mentalhealth.org](http://www.mentalhealth.org) or [www.mentalhealth.samhsa.gov](http://www.mentalhealth.samhsa.gov)

### **Recommended Reading**

*Transition: A Manual for Young People with Disabilities and Their Families (Revised 2004)*. Malloy, JoAnne M., University of New Hampshire's Institute on Disability/UCED.

*Transition Education and Services for Adolescents with Disabilities (3rd ed.)*. Sitlington, P.L., Clark, G.M., & Kolstoe, O.P. (2000). Needham Heights, MA: Allyn & Bacon. (Available by telephone at: (800) 666-9433 or online at: [www.ablongman.com](http://www.ablongman.com).)

*Transition to Adult Life for Individuals with Disabilities (1992)*. A summary of resources, including books, journal and magazine articles, video tapes, and training curriculum. (Available from: Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Dr. SE, Minneapolis, MN 55455; or by telephone at: (612) 624-4512.)

*Transition to Adulthood: A Resource for Assisting Young People with Emotional or Behavioral Difficulties.* Hewitt Clark and Maryann Davis, co-editors, Brookes Publishing Company. Provides practical and proven methods for helping young people move into the world of career-oriented education, work, and independent living. (Available at major booksellers; by telephone at: (800) 638-3775; or online at: [www.brookespublishing.com](http://www.brookespublishing.com).)

### Vocational Rehabilitation

#### **New Hampshire Job Training Council (JTC)**

Provides a variety of assessment, training, and placement services to economically disadvantaged people, including youth, public assistance recipients, and laid-off workers.

Entrance requirements might screen out some people with disabilities, so ask a New Hampshire Vocational Rehabilitation or other counselor to help your child apply for services. Youth with disabilities will often qualify for the Council's Summer Youth Programs, which offer summer jobs in the public sector combined with a classroom program. Tuition assistance and support is also part of JTC services. Students with disabilities should ask their special education teachers about Job Training Council programs in their school or region.

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#### **Concord Office**

64 B Old Suncook Road  
Concord, NH 03301  
(800) 772-7001

#### **East Swanzey Office**

217 B Old Homestead Highway  
East Swanzey, NH 03446  
(603) 358-1082

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#### **Bureau of Vocational Rehabilitation (New Hampshire Department of Education)**

The *Bureau of Vocational Rehabilitation* (BVR) helps people with disabilities develop an employment plan and assists with job training, education, and supports.

Statewide contact information is provided below:

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#### **General Services**

21 South Fruit Street, Suite 20  
Concord, NH 03301  
(800) 339-9900  
(603) 271-3471 (Voice or TTY)  
[www.ed.state.nh.us/VR](http://www.ed.state.nh.us/VR)

#### **Services for Blind and Visually Impaired**

21 South Fruit Street, Suite 20  
Concord, NH 03301  
(603) 271-3537 (Voice or TTY)  
[www.nhbvi.com/SBVI/index.html](http://www.nhbvi.com/SBVI/index.html)

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Contact information for regional offices is provided below:

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**Berlin Regional Office**  
3 Twelfth Street, Unit A  
Berlin, NH 03570  
(888) 300-9550 or (603) 752-2271  
(Voice or TTY)

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**Manchester Regional Office**  
195 McGregor Street, Suite 120  
Manchester, NH 03103  
(800) 627-9304 or (603) 669-8733  
(Voice or TTY)

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**Concord Regional Office**  
2 Industrial Park Drive, Bldg. 2  
Concord, NH 03301  
(800) 299-1647 or (603) 271-2327  
(Voice or TTY)

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**Nashua Regional Office**  
25 Riverside Drive, Suite 102  
Nashua, NH 03063  
(800) 635-9614 or (603) 889-6844  
(Voice or TTY)

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**Keene Regional Office**  
103 Roxbury Street  
Keene, NH 03431  
(800) 620-7688 or (603) 357-0226  
(Voice or TTY)

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**Portsmouth Regional Office**  
30 Maplewood Avenue  
Portsmouth, NH 03801  
(800) 882-2744 or (603) 436-8884  
(Voice or TTY)

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**Lebanon Regional Office**  
85 Mechanic Street, Suite 260A  
Lebanon, NH 03766  
(800) 621-7876 or (603) 448-5793  
(Voice or TTY)

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## Appendix C. State and National Resources ---

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## Appendix D. Forms You Might Find Useful

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*We suggest that you not write on the forms in this Appendix, but instead photocopy them and write on the copies.*

*Refer to Chapter 3 section, “How to Organize All That Documentation”*

*on page 27 for suggestions on filing all the paperwork you will be accumulating, including any forms you create yourself from the samples in this Appendix.*

### Chapter Content

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## Child's Educational History

### *Schools Attended and Performance*

Name of School	Location	Grades	Dates Attended
			From: / /
			To: / /
			From: / /
			To: / /
			From: / /
			To: / /
			From: / /
			To: / /
			From: / /
			To: / /
			From: / /
			To: / /
			From: / /
			To: / /

Any nursery school or small-group experiences before Kindergarten:  Yes  No

If Yes, at what ages? \_\_\_\_\_. Where? \_\_\_\_\_

Age child started Kindergarten \_\_\_\_ years and \_\_\_\_ months.

Age child started First Grade \_\_\_\_ years and \_\_\_\_ months.

Has child ever repeated a grade or class?  Yes  No

If Yes, which grade or class? \_\_\_\_\_

---

### ***Educational Testing***

Speak with the educational specialist working with your child to obtain the following information every time your child is tested. Be sure you understand what the results or recommendations mean.

<b>Name of Test, Person Administering</b>	<b>Areas Tested*</b>	<b>Dates Given</b>	<b>Results/Recommendations (How do results address the referral question?)</b>

- \*Areas tested:**
- A. Mental Abilities
  - B. Motor Skills
  - C. Self-Help Skills
  - D. Social/Play Skills
  - E. Emotional Skills
  - F. Language Skills
  - G. Pre-Academic Skills
  - H. Other \_\_\_\_\_



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## Child's Medical History

### *Agencies and Practitioners Contacted*

**Dates:**

<b>First Visit</b>	<b>Practitioner/Agency,</b>	<b>Phone,</b>	<b>Purpose of Visit</b>
<b>Last Visit</b>	<b>Address</b>	<b>Fax, E-mail</b>	

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**Medication Log**

Name of Medication / What it Treats	Prescribed by	Dosage and Frequency	Reactions	Date Started Date Ended
				From: / /
				To: / /
				From: / /
				To: / /
				From: / /
				To: / /
				From: / /
				To: / /
				From: / /
				To: / /
				From: / /
				To: / /
				From: / /
				To: / /
Any allergies to medications? _____				
Which ones? _____				
_____				
_____				
_____				



***Immunizations and Contagious Diseases***

<b>Date</b>	<b>Immunization</b>	<b>Reaction</b>
/ /	Hepatitis B (HBV)	
/ /	Diphtheria, Tetanus (DTaP)	
/ /	Acellular Pertussis	
/ /	Haemophilus Influenza type B (HHib)	
/ /	Inactivated polio vaccine (IPV) or Oral polio vaccine (OPV)	
/ /		
/ /	Measles, Mumps, Rubella (MMR)	
/ /	Varicella (chickenpox) (VAR)	
/ /	Tetanus, Diphtheria (Td) for people over age 7 years	
/ /		
/ /		

<b>Date</b>	<b>Contagious Disease</b>	<b>Severity (include temperature)</b>
/ /		
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## Appendix D. Forms You Might Find Useful ---

# **NAMI New Hampshire**

*Improving the lives of all persons affected by mental illness  
and/or serious emotional disorders*

## **About NAMI NH**

NAMI NH is the New Hampshire chapter of the *National Alliance on Mental Illness (NAMI)*. NAMI NH is a statewide grassroots network of affiliate chapters, staff, and volunteers that provides information, education, and support to persons of all ages who are affected by mental illness.

NAMI NH programs are financially supported in part by our membership dues. To become a member, contact NAMI NH at the phone number or e-mail address listed below.

## **Our Mission**

The National Alliance on Mental Illness New Hampshire (NAMI NH), a grassroots organization of families, consumers and other volunteers, is dedicated to improving the quality of life of persons of all ages affected by mental illness and/or serious emotional disorders through education, support, and advocacy.

## **Our Vision**

People of all ages with mental illness and/or serious emotional disorders and their families will have access to comprehensive, integrated health care and community-based supports without discrimination or stigma.

## **Our Goals**

- The general public will have an accurate understanding of mental illness and serious emotional disorders and what is helpful and hurtful to those affected by it.
- Mental illness and serious emotional disorders will have parity with other medical conditions in the access to and quality of treatment, support services, and financing available to promote recovery and build resilience.
- People with mental illness and/or serious emotional disorders will be treated with dignity and respect and have the opportunity to build resiliency, recover, achieve their aspirations, and live, learn, work, and play in supportive communities without discrimination or stigma.
- Individuals and families affected by mental illness and/or serious emotional disorders will have the education, information, and support needed to make informed health decisions.

## **NAMI New Hampshire**

15 Green Street, Concord, NH 03301

Phone: (603) 225-5359 or (800) 242-6264

Fax: (603) 228-8848

E-mail: [info@naminh.org](mailto:info@naminh.org)

To view this Guidebook online, go to:

[www.naminh.org](http://www.naminh.org)

**NAMI New Hampshire**

15 Green Street, Concord, NH 03301

Phone: (603) 225-5359 or (800) 242-6264

Fax: (603) 228-8848

E-mail: [info@naminh.org](mailto:info@naminh.org)