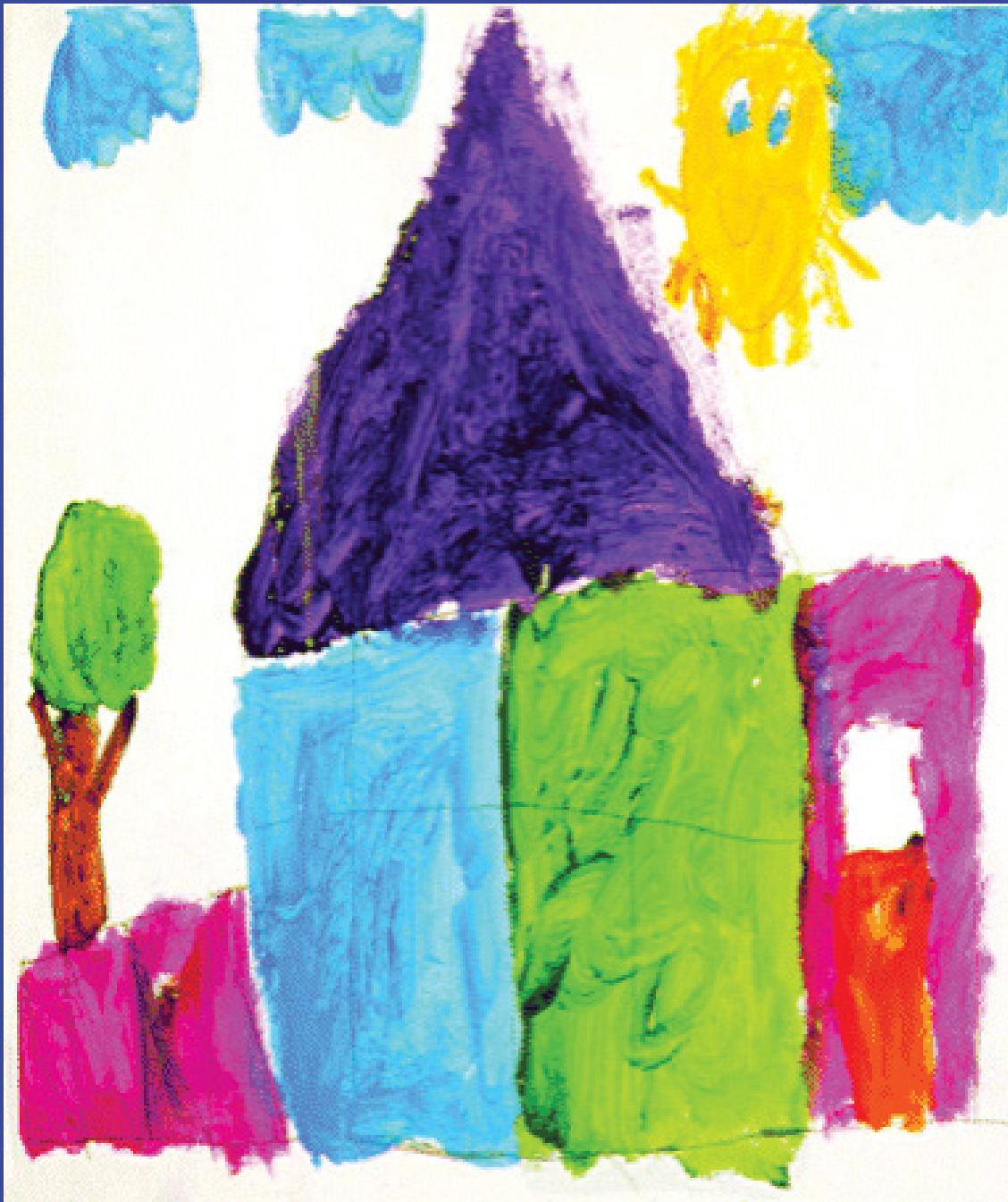

Guidebook for Caregivers of Children and Adolescents with Serious Emotional Disorders



**NAMI New Hampshire
National Alliance on Mental Illness New Hampshire
2015**

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Acknowledgements

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2015 Edition (update of 2007 Edition)

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Foreword

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 was developed to make caregiving more manageable by providing the resources and information to help children living with the disorders and their caregivers. It has been written by families and providers who embrace the values of family-driven and youth-guided treatment in an integrated approach to health care.

At NAMI New Hampshire, 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 care for a child with a serious emotional or behavioral disorder. Remember — you are not alone.

Chapter 1. Taking Care of the Caregiver

Chapter Overview

Airline flight attendants tell you, if the need arises, to put an oxygen mask on yourself first and then help your child. If you're not getting enough oxygen and can't meet your own needs, 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. You have to connect both oxygen masks, and self-care is essential.

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) how 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, blame, and increased financial burden.

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.

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

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 and linguistically sensitive care.” Professionals should also acknowledge how your cultural and language differences will impact your willingness and ability to seek support for yourself and your child.

Training for mental health professionals includes awareness of the impact of a family’s religious, language, ethnic, economic, gender, and sexual differences on accessing and engaging in treatment. It is a recognized challenge that New Hampshire does not have a culturally diverse workforce. 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. You may ask to be referred to someone who can provide culturally and linguistically sensitive care. If you do not feel you can approach them or the professionals do not respond to your needs, then contact the Office of Minority Health & Refugee Affairs at (603) 271-3986 for assistance. The Information and Resource Line at NAMI NH is an additional resource, and can be reached at (800) 242-6264, ext. 4 or (603) 225-5359.

"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."

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 family members. However, there are some predictable emotional reactions that most caregivers and family members 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
Crisis/Shock	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.
Denial	We pretend not to notice our child's strange behavior. 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.
Unrealistic Hopes	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 our hopes are not realistic.	Support. Comfort. Help finding resources. Empathy for our confusion and pain.
Anger, Guilt, Shame, Resentment	We are sick of the problem. We start "blaming the victim," ourselves, or blaming each other, expecting the child with SED to "snap out of it". Simultaneously we feel guilty, suspecting that it might be our fault. 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 1. Taking Care of the Caregiver

Stage	Our Feelings and Thoughts	Our Needs
Recognition	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.
Grief (sorrow)	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.
Understanding	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.
Acceptance	"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 and 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.
Advocacy and Action	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?"

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 have the same feelings as you at the same time.

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.

For example, a mother might be having unrealistic hopes and is working feverishly to find a “cure” for her son’s disorder; while the sister is feeling the anger-guilt-shame stage, due to 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. Accessing family peer to peer support programs through NAMI NH has proven helpful for many families. To learn about the NAMI NH support programs for parents and primary caregivers of children and adolescents with serious emotional disorders, visit www.naminh.org and click on Support or call (603) 225-5359.

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 by taking time for yourself and spending time with others who understand your situation.

Find a book, a self-help group, or a class where you can learn how to practice 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 essential 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 sugary foods which tend to give “bursts” of energy, followed by “crashes” of sleepiness or depression.

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 for your child if you take care of yourself. Set appropriate personal limits and seek respite.

Some caregivers think the best advice and support comes from others who have lived through the same experience. Seek support from individuals, groups, and organizations such as NAMI NH that can help strengthen your ability to care for yourself, your child, and your family.

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 (www.nami.org).

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

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- Feeling guilty is normal - don't let it get you down. Try not to place blame on anyone.
- Connect and maintain involvement with support programs while things are going well. Don't wait for a crisis.
- Anticipate and try to avoid troublesome situations when possible. 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. 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 2, "Integrated Health Care" beginning on page 9.)
- 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 you know is not feasible (for whatever reason), inform the practitioner so he or she can have a clearer understanding of your family situation and suggest an alternate treatment or 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 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 recognize and 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.)

Parent and 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 NAMI NH which provides support, education, leadership training and advocacy for children with serious emotional disorders (SED) and their families.

National Alliance on Mental Illness New Hampshire (NAMI NH)

NAMI NH is the New Hampshire chapter of the National Alliance on Mental Illness. NAMI NH is a grassroots membership organization that promotes and supports a statewide network of family support, education, leadership training programs and advocacy.

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 Serious Mental Illness or Serious Emotional Disorders. NAMI NH teaches families the skills they need to receive family-driven, person-centered, and culturally competent and community-based services and supports. NAMI NH’s programs serve families across the lifespan.

"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.

Current NAMI NH programs include:

- A Mental Health Resource Center that lends materials about mental health.
- Family Educational Programs:
 - Parents Meeting the Challenge - an 8-session program for parents and primary caregivers of children and adolescents with serious emotional disorders;
 - Family-to-Family - a 12-session program for family and friends who have an adult in their life with mental illness;
 - Side by Side - a series of six two-hour workshops for family members and caregivers of older adults with mental illness.
- Support Programs:
 - Community-based support groups for parents of children with serious emotional disorders; family and friends of adults with mental illness; adults with mental illness; and adults who have lost a loved one to suicide.
 - One-on-One “family peer to peer support.”
 - Social Media Family Support Groups
 - Message Boards
- Leadership Training for those interested in “paying forward” what they have learned and received through NAMI NH’s programs.

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- Public Policy Advocacy
- Conferences, workshops, and webinars where state and national experts discuss topics of interest to families, consumers, and professionals.
- Speakers Bureau
 - “In Our Own Voice,” a recovery educational program presented by consumers who want to share their success and experience.
 - “Life Interrupted,” an educational program presented by family members who have a loved one with a serious emotional disorder/mental illness.
- Public educational and awareness programs on various mental health and mental illness related topics.
- Suicide Prevention and Postvention Training Programs
- Professional Development programs and consultation

At the time of this publication, these programs are provided free of charge to family members, friends, and adults with mental illness. The fees for these programs are generously funded through donations, fundraising events, and grants. To learn more about those listed above and other programs visit www.naminh.org or contact the Information and Resource line at (800) 242-6264, ext. 4 or (603) 225-5359.

Chapter 2. Integrated Health Care

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 with each other.

This chapter will help parents, families, and other caregivers by providing guidelines to

ensure their participation in the treatment process is real and meaningful, and help them understand the importance of their role in decision-making.

This chapter will help you partner with the professionals who work in the systems further explained in this guidebook.

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Total Well-Being

For a child living with a serious emotional disorder, 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 essential for children to meet their developmental milestones and prevent serious physical health conditions in adulthood.

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. 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.

Integrated health care is a system of health care in which both mental and physical problems and disorders are treated at the same time. This system recognizes that mental disorders must be treated with equal importance as physical disorders, and ensures effective mental health treatments are 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 have adequate access to mental health specialists for referrals.

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.

Children with SED use services within one or more of these six distinct areas: schools, juvenile justice, child welfare, general health, and mental health. Outcomes are improved and costs are reduced when providers within these fields work together.

Note: The term *primary care provider* (PCP) refers to primary care physicians, pediatricians, nurse care practitioners, and others who provide physical health care.

The American Academy of Pediatrics (www.aap.org) and the National Center for Medical Homes Implementation (www.medicalhomeinfo.org) promote the creation of medical homes for all children, including children with special health care needs. If the term medical home is new to you, you are not alone. A medical home is an approach to providing comprehensive, integrated health care guided by a specific set of values and principles. New Hampshire has

several pilot programs to develop the medical home model in pediatric care practices which will, hopefully, become standard practice. To learn more about the medical home approach, visit NH Family Voices' website at www.nhfv.org.

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. The needs of people with mental illness are significant. Yet, a non-integrated approach often fails to meet these needs, as these findings indicate:

- Every year, about 20% of adults and children in the United States 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% of children leave therapy prematurely, and 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 who are treated solely with the limited resources of the public school system. 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.
- 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

(This section was adapted from “An Integration of Mental Health Services and Primary Health Care” written by Michael J. Cohen, MA, CAGS.)

In March 2013, New Hampshire released the NH Children’s Behavioral Health Plan. The plan established nine core goals that will move New Hampshire’s multiple child and family-serving systems to a comprehensive, integrated behavioral health system of care. The role of primary care is the focus of Goal 7 which states, “To maximize opportunities for integration of mental health and substance use disorders prevention, intervention and treatment with primary care.” More about the plan can be found in Chapter 3, Partnering in Your Child’s Care, beginning on page 19.

The full plan and strategies for implementation can be found on the NH Children’s Behavioral Health Collaborative website at www.NH4Youth.org/about/cbhc_plan.

The Important Role of Your Primary Care Physician (PCP)

Most children with SED in New Hampshire have a primary care physician. Primary care physicians are most often the first provider a family will approach when they have concerns about their child. Many PCPs provide prescriptions for psychotropic drugs. In some situations, they also provide the initial mental health care to children with SED (even beyond common conditions like ADD and depression) until the child can be connected with mental health providers.

The PCP brings a needed expertise to the team and ensures the child is receiving integrated care.

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 and caregivers have discussed some of the warning signs with the PCP (See Chapter 3, “How to Know if Your Child Needs Help,” beginning on page 19).

The PCP can become an effective advocate for the family. As an advocate, the PCP can help caregivers 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 knows what medications are being prescribed, why they are being prescribed, what beneficial changes are expected, and what side effects may occur. The PCP should be informed if the dose is changed or the medication stopped.
- Managing psychiatric emergencies - and assisting in the development of your child’s crisis management plan (see Chapter 8, “Managing a Mental Health Crisis” beginning on page 101).
- Supporting the family’s “choices” about the type, location, frequency, and duration of treatment.

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.

- 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.

The PCP can see 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 physical health 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 Concept of Care" on page 78.

Barriers to Communication - Real and Perceived

Parents and professionals have identified several barriers to communication and coordination of care.

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 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.

If communication between mental health professionals and the child's primary care physician is such a good idea, why is it not routine practice?

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" regarding his or her care, 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 and caregivers should ask for clarification from the physical 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, and thus less opportunity to communicate. Accordingly, providers have suggested scheduling telephone contact or using other means of communication. Nothing prevents communication between providers if consent to release medical information is completed by the client and/or legal guardian.

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.

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. A perceived lack of interest in mental health issues can be attributed to a lack of mental health training. However, this culture is changing. The trend for integrated health care is a growing movement that ensures continuity of care and better coordination.

Solutions

Individuals, medical specialty groups, and governmental agencies have recognized the lack of communication and collaboration among providers as a problem and have offered a variety of ways to help. In the United States, 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 such as the medical home model previously mentioned.

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).

Some possible solutions to ensure integrated health care include:

- Improving relationship development between PCPs and mental health providers through regular social interaction to 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 treatment.
- On a state level, agencies involved with mental health, developmental disabilities, and substance abuse should involve PCPs on mental health planning committees and advisory panels, incorporate their ideas into planning for future health services, and reinforce the message that PCPs have a role to play in delivering mental health services.
- Ensuring workshops that focus on integrated health care are co-sponsored and attended by primary care and mental health groups to further promote coordination and collaboration between the medical and mental health systems.
- Developing systems and procedures to improve communication and collaboration, and bringing existing models of collaboration between physicians and school personnel to 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, treatment plan, symptoms, prognosis, and progress to date. Additional helpful information for the PCP includes the family and child's strengths, ability to keep appointments, when and why treatment is stopped, and if the child is suicidal or homicidal, (see Appendix D. “Useful Forms” starting on page 137). 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. At each PCP visit, parents (and the 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 new and significant medical issues, these should be communicated by the PCP to the mental health provider. If the PCP prescribes psychotropic medication (such as for ADHD), 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 SAMHSA’s National Mental Health Information Center at (800) 789-2647 or online at www.govinfo.library.unt.edu/mentalhealthcommission/reports/reports.htm.]

“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, GA (available online at www.ncbi.nlm.nih.gov/books/NBK44340/).

Shared Decision-Making

What is Shared Decision-Making?

Shared decision-making is a process in which 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. These conversations enable the “team” (child, family, and providers) to make quality health care decisions. Information sharing promotes positive treatment outcomes for the child and family.

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.

Framework for Shared Decision-Making

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

- **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 evaluate 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.

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. Many families struggle with the risk versus benefits of medications. Not all medications used for treating emotional disorders in children and adolescents have been fully studied. However, a great deal of evidence exists to show the usefulness of many medications along with other treatment options. The use of medication should be a fully informed one. 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.

Medications

Serious emotional disorders (SED) can be treated effectively with medication, including attention deficit disorders, mood disorders, anxiety disorders, thought disorders or psychosis, and autism. (See Chapter 4, “About Serious Emotional Disorders and Behavioral Issues” beginning on page 35.) The following brief overview 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. This overview is not intended to be medical advice and is not comprehensive. Parents and caregivers should obtain additional information from treatment providers and other resources.

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

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.

What are the Medications and Side Effects?

Stimulant Medications

Stimulant Medications are FDA approved for use in the treatment of attention deficit hyperactivity disorder (ADHD). These medications have been studied extensively and include: methylphenidate (Ritalin), D, L-amphetamine (Adderall XR). Stimulants are well established to be successful for ADHD 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. It is now approved for treating ADHD.

Antidepressant Medications

These include the older tricyclic antidepressants (e.g. imipramine), selective serotonin reuptake inhibitors (SSRI) including fluoxetine (Prozac), sertraline (Zoloft), paroxetine (Paxil), fluvoxamine (Luvox), citalopram (Celexa), 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 SSRI medications may cause suicidal thoughts and behaviors in youth.

Side effects of these 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 in August 2004 noted that one SSRI (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 in 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. Parents and caregivers should discuss the use of these medications with the child’s provider.

Mood Stabilizers

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

The traditional 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 the usefulness of several of these drugs in children and adolescents.

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 “workable” medication schedules with their provider to ensure medication is taken as needed. In all cases, parents need to monitor medication administration and providers need to continually evaluate the child’s response and reaction to the medication.

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.

Family Supports -“Don’t Go It Alone”

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.” In addition, NAMI NH staff and volunteers can assist families with SED children in learning how to effectively navigate multiple service systems, including education, mental and physical health, child protection, and juvenile justice. Families can connect with NAMI NH by calling the Information and Resource Line at (800) 242-6264 ext. 4, email info@naminh.org or visit the website at www.naminh.org.

(The section, “Shared Decision-Making” in this chapter 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.)

Chapter 3. Partnering in Your Child's Care

Chapter Overview

This chapter is designed to empower you to work effectively with the professionals in the systems further explained in this Guidebook. You will be provided information that will help you decide when your child needs help and learn how to navigate the system to access the needed services and supports.

Family and professional partnerships are key to the success of our children.

The first part of this chapter is designed to provide professionals with an understanding of the philosophy of partnership, which is the foundation of this Guidebook. It provides you and the professionals involved with your child's care an introduction to the System of Care Concept that is beginning to influence policy and practice across New Hampshire's child and family serving systems.

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Families and Professionals Working Together

Guidance for an Effective Partnership

Current mental health literature describes the family as “their child’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]

"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.

The best approach that NAMI NH has found for empowering families to care for their children with serious emotional disorders (SED) is a *partnership* between the family and the professionals involved in the child’s care. This partnership relationship is based on sharing a set of core values and guiding principles known as the System of Care Concept.

The most current definition of a System of Care is “a spectrum of effective, **community-based services and supports** for children and youth with or at risk for mental health challenges and their families, that is organized into a coordinated network, **builds meaningful partnerships with families and youth**, and addresses their **cultural and linguistic needs**, in order to help them to function better at home, in school, in the community, and throughout life.” [Strouhl, B. & Friedman, R. (2011) Georgetown University Child Development Center, Washington, DC].

On a national level, the System of Care Concept has been used for over 30 years to better serve children and adolescents with emotional disorders (including those at-risk) and their families. The System of Care Concept is the foundation for the NH Children’s Behavioral Health Plan, the road map for transforming New Hampshire’s behavioral health system. Over the next decade, the System of Care Core Values of family-driven, youth-guided, community-based and culturally and linguistically effective services and supports and the System of Care Guiding Principles will influence policy and practice. To learn more about the System of Care Concept, Core Values and Guiding Principles visit www.NH4Youth.org or contact NAMI NH at (800) 242-6264 or (603) 225-5359.

When professionals ensure their policies and practices are aligned with the System of Care Core Values and Guiding Principles, they will experience more effective partnerships with families and see better outcomes for children and adolescents.

The following suggestions can help foster effective family-professional partnerships:

- Research has proven the child and family begin to take action when they are part of the treatment planning process (identify their goals, strengths, needs and have choice about the type, location, frequency, and duration of services and supports written into the child’s plan).
- Families with children who have emotional disorders are more similar to other families than they are different. Although they experience more intense stresses, 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.

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- Families that appear to be uncooperative or having difficulty understanding a proposed treatment plan or educational plan for their child may be a signal that mutual goal-setting did not occur.
 - 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 has occurred.
 - Experience and research have shown that parents of children with SED generally welcome peer-to-peer support and often seek it in times of need, confusion, and discouragement. Parents who have “been there” can be effective resources, role models and advocates for other parents.
 - Ensure 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.
 - Professionals are asked to listen carefully to what parents tell them and be open to new perspectives.
 - 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.

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. They 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. 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.

"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."

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. 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. Different behaviors are the normal responses to different developmental stages; therefore the warning signs for elementary school children and adolescents are listed 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, such as fidgeting or constant movement outside regular playtime activities.
- A steady decline in school performance. May get 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.
- Frequent outbursts of anger, or inability to cope with problems and daily activities.
- 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.
- Social withdrawal.
- Sudden change in school performance.
- Sudden changes in sleeping and/or eating habits.
- Persistent nightmares.
- Many physical complaints.
- Sexual acting out, such as having inappropriate sex and/or using sexuality in risky behaviors.
- Threatens to run away.
- Strange thoughts/feelings and/or unusual behaviors.

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.

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.

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 2, "Integrated Health Care" beginning on page 9.)

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.

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 providers accept Medicaid and some may be willing to provide services on an adjusted fee basis. If your child is eligible for Medicaid, 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 (CMHCs) offer thorough assessment and some offer diagnostic testing for children and adolescents. They accept Medicaid and many private insurances, and may provide services on a "sliding scale" income-adjusted basis. However, the demand for services at CMHCs 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, "State and National Resources" beginning on page 119.

"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 figured wing is to bird as brain it to boy – we have to treat Michael's brain."

– The mother of a 9-year old boy

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. 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, “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. If you feel the need for support, contact NAMI NH at (800) 242-6264 or (603) 225-5359.

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 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 outcome. 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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- You will remember the vast amount of information about your child - his or her special needs, abilities and strengths; the results of each doctor visit, test, and evaluation; and every letter, treatment team meeting, and IEP team meeting.
 - You will know whether the different professionals and services are working together in an effective way. And if they are not, you will work with them toward improvement.
 - You will read articles and brochures, write letters, visit programs, record conversations and meetings, organize and file documents, remember all the accomplishments, document significant events and dates, remember names and faces, meet with professionals, ask questions, and make difficult decisions.

You will, because only you know the answers 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.
- Maintain documentation and files that can inform treatment providers.

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: Targeted Case Management is one of the services offered through your community mental health centers for children who meet the eligibility criteria and can provide service coordination.

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.

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

How to Organize All That Documentation

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

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- 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.)
- Update lists of your child’s involvement in 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 presented to professionals. Write the answers; date and file any completed written question/answer list; start a new list when additional questions arise.

Appendix D, “Useful Forms” beginning on page 137 has blank forms that can help you organize some of the information listed above.

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 (such as folder, binder, basket, or box) – one portable enough to take to any of the meetings.

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.

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.

You decide how and where you want to store the documents. Make sure that you save all paperwork, and that each piece is dated before you file it.

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. Even if all paper documentation was filed solely by date, the electronic records could be re-sorted or searched as needed. Once the appropriate piece of information is found electronically, its paper version could be quickly located, since the date would now be known as well. 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 with whom you meet will gain much respect for you if you come to meetings prepared with a list of questions. If you do this, the amount of meeting time you require will be greatly reduced, and the team will appreciate your organization and efficiency. If possible, provide your questions to the team before the meeting so they can be prepared.

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. Request a copy of the attendance sheet before you leave the meeting, or make note of the names of all participants and their role. If you have difficulty taking notes *and* participating in the meeting, ask meeting attendees (beforehand) if an electronic recording device may be used. Request a copy of the meeting minutes before leaving the meeting. Often these are handwritten during the meeting.

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.

Keep track of positive progress

At each meeting or 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!"*

Get the answers 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, as 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.

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Things not to do

Just as certain techniques enhance meeting effectiveness, some situations tend to be counterproductive.

- Do not come late to appointments, and do not repeatedly cancel appointments that have already been made.
- Time is of the essence. 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 factual.

What Questions to Ask and When to Ask Them

As an active member of 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. To become informed, you'll need to ask many questions.

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 provider

Your primary care physician can help by referring you to a mental health provider. There are several questions you can ask when speaking to prospective providers.

- 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 there is an emergency in the evening or on weekends, do you provide emergency coverage?
- 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 your patients who require hospitalization or hospital-based tests?
 - What are the facilities and accommodations of this hospital for children with serious emotional disorders and their families?
 - 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?
- Did the evaluation include a trauma screening? Substance use screening? If yes, is there a need for follow-up?
- 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?
- Is the test covered by my insurance plan? How do I find out if it is?

When planning a treatment routine

Before your child begins any treatment routine, be sure to ask the following questions of the practitioner and/or team.

- 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?
- Is the treatment covered by my insurance 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.

When medications are prescribed

As previously discussed in Chapter 2, page 16, "Medications" 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.

- 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." 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?

- 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

- Is this a voluntary or involuntary hospitalization?
- 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 or child life specialist to explain 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?

If residential (out of home) placement is recommended

Sometimes a residential program is the best place if your child requires brief respite, an assessment that cannot be done outpatient, medication stabilization, or to learn specific skills to maintain him/herself safely in the community. Be sure you have spoken with providers and advocates to see if there are intensive services available in your community that would meet his/her needs and avoid the need for residential placement. The best programs begin discharge upon admission, with measurable goals and identified outcomes that will indicate when your child is ready to return to the community. The best programs involve the family members as much as possible throughout the residential placement and welcome their questions and feedback. If placement in a residential program is in the best interest of the child, the following information can be helpful in making a decision.

Resource if considering residential placement

Caring for a child with a mental illness can be overwhelming and often strains marriages and family relationships. Children with serious mental illnesses may struggle in school, threaten violence to themselves or others, or get caught in the juvenile justice or criminal justice systems. Meanwhile caregivers often experience frustration, guilt, or anxiety as they struggle to find help for their child.

Although most children with mental illness respond to standard treatments, some children with more serious mental illness continue to struggle. If you are a caregiver who has utterly exhausted community mental health care resources, you may be considering residential treatment.

Residential treatment is an extreme measure that should only be taken if local resources have proven inadequate. Conscientious residential programs that use evidence-based psychotherapy, drug and alcohol counseling, parent support and education, and social skills training can strengthen families and help facilitate lifesaving changes.

The time spent in a residential program should be as short as possible, with the goal of returning your child to his family and community with the least amount of stress and disruption possible.

The following lists of suggestions, questions and information have been compiled from various sources to help you make an informed decision about sending your child to residential treatment.

Action Steps

- Take time. Resist pressure to make an immediate decision. Residential treatment should not be used in place of local emergency resources in the event your child is in immediate danger. Beware of programs that push you to “act now” to prevent serious harm.
- Seek an objective, professional opinion before committing to a program. Ask about pre-admission assessments and admission criteria to determine whether your child qualifies.
- Request an individualized plan for your child that details the therapies, interventions and supports that will address your child’s specific needs as well as the transition from treatment back to community-based care.
- If possible, visit the residential program and take a tour of the facilities before making a decision.
- Interview staff members.
- Talk to young people currently in the program.
- Talk to past students and their families.
- Verify the program’s licensing and accreditation claims.
- Verify the credentials of the clinical director and staff.
- Check with the Board of Education in the state where the program operates to be sure that the educational program is licensed in that state.
- Contact the Department of Education in your state to verify that academic credits will transfer.
- Obtain copies of publicly available information about the residential program, including complaints or actions filed against the residential program, site visit evaluations, violations and corrective actions.
- Ask about the program’s philosophy on medications. Programs should neither over-medicate to sedate or have an anti-medication philosophy, especially if your child is currently relying on medications to cope with their diagnosed disorder.

Licensing and Accreditation Checklist

Program is accredited through an independent organization, such as the following:

- Joint Commission on the Accreditation of the Healthcare Organizations (JCAHO)
- Council on Accreditation (COA)
- Commission on Accreditation of Rehabilitation Facilities (CARF)
- Accreditation covers all components of the program: the base program, the drug and alcohol component, the wilderness program, etc.
- Program is licensed through the State Department of Health and Human Services or its equivalent.
- License covers the educational, mental/behavioral health, and residential components of the program.
- Program has full-time licensed therapists and medical professionals on staff to serve youth with specific psychiatric diagnoses.
- All claims can be verified with the appropriate licensing or accreditation office.
- Program performs background checks on all of its staff members.
- Staff is certified in CPR and other emergency medical procedures.
- Academic teachers are licensed and certified with degrees from accredited colleges.

What to Consider

- Which staff members will be working with your child and what is the experience that qualifies them?
- What are the program's disciplinary policies and procedures?
- How will the program respond to specific behaviors exhibited by your child?
- How much written and verbal contact do they allow between the parents/caregivers and the child?
- Do parents/caregivers have open access to the facility?
- How does the program define and measure outcomes and success?
- What academic curriculum does the program use?
- What is the ratio of students to teachers?
- Does the program offer classroom learning or independent study?
- Are academics ongoing or only offered when the young person reaches a certain point in the recovery process?
- Have there been any reports of unsanitary or unsafe living conditions, nutritionally compromised diets, exposure to extreme environmental conditions or extreme physical exertion, inadequate staff supervision, medical neglect, physical or sexual abuse of youth, or any violations of youth or family rights?
- What relationship exists between the residential program and agencies or individuals that have referred family to the program?
- What is the average length of stay for youth in the program?
- How does the program prepare youth to return to their home and community?

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- Does the program provide necessary referrals or connections for after release from the program including assisted housing, supported employment, vocational rehabilitation, life skills training, and others?

Rights of youth and families to prevent abuse and neglect

- Youth should have reasonable access to a telephone to make uncensored calls.
- Youth and parent/caregiver should always be provided with hotlines to call at any time if they feel that their rights are being violated or they are being mistreated.
- Parent/caregiver should always be notified if their child is sick or injured.
- Parent/caregiver should always be notified within 24 hours about medication changes and missed dosages.
- Parent/caregiver should always be notified within 48 hours of any on-site investigations or reports of child abuse and neglect, violation of health and safety standards, or violations of state licensing standards.
- Youth should never be subject to abusive disciplinary methods, such as seclusion, restraint, corporal punishment, fear tactics, humiliation, forced labor, medicinal sedation or the withholding of food, water, clothing, shelter or medical care.
- Parent/caregiver should never be approached with funding incentives to relinquish custody of their child.

(Note: This was adapted from “A Resource for Families Considering Residential Treatment Programs for their Children” prepared by NAMI, www.nami.org.)

Chapter 4. About Serious Emotional Disorders and Behavioral Issues

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 **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, neurobiological brain disorder, or mental illness, your active

participation in your child's treatment team is essential. The team must work with you to identify your child's and family's strengths and needs, and help you access the right services and supports to help you, your child and family.

This chapter provides you with basic information to prepare you for your role on your child's team. This information is not provided as medical advice and you should consult the professionals with whom you work to ensure you have the most current information.

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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. **However, 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. When a child is evaluated for a mental health concern, a trauma screening should be administered. Often, untreated trauma can present as an emotional disorder.

“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. It is estimated that one in ten school age children has a diagnosable serious emotional disorder. A conservative estimate is that 10% of this country's youth 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 3 section, How to be a Partner in Your Child's Care on page 24 and Chapter 5 section, “Residential Treatment Centers and Alternative 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. Research has shown that when a child is receiving medication and therapy and is involved with natural supports, the treatment success rate is higher.

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.

Chapter 4. About Serious Emotional Disorders and Behavioral Issues

Natural supports are activities such as extracurricular activities in school, sports, community recreation programs, Boys and Girls Clubs, scouting and community service projects. 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/or combinations of treatments.

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.

Is Trauma a Mental Illness?

Trauma is not a mental illness. It is an emotional response to a traumatic event. Every child will respond differently. Immediately after the event, shock and denial are typical. Some will have no ill effects; others may suffer an immediate and acute effect. Still others may not show signs of stress until sometime after the event. Longer term reactions include unpredictable emotions, flashbacks, strained relationships, and even physical symptoms like headaches or nausea. While these feelings are normal, some children have difficulty moving on with their lives. Understanding the emotions and normal responses that follow a disaster or other traumatic event can help your child cope with his/her feelings, thoughts and behaviors - and can help him/her on their path to recovery. Mental health professionals can help your child find constructive ways of managing his/her or their emotions.

Adapted from the American Psychological Association (www.apa.org) A Help Center article, "*Recovering emotionally from disaster.*"

Disorders and Behavioral Issues

The terminology professionals use to describe your child's behavior can be confusing. This section provides descriptions to help alleviate 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 those disorders any more than they can be blamed for juvenile diabetes.

Serious emotional disorders (SED) are 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 use disorders, and mental illness and developmental disability.

- **Mental Illness and Substance Use Disorders.** Traditionally, substance use disorders 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 use disorders 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.

Chapter 4. About Serious Emotional Disorders and Behavioral Issues

If your child is eligible for both agencies, and these organizations work corroboratively, a comprehensive treatment plan can be developed to help ensure your child's needs are appropriately addressed. (See Appendix C, beginning on page 119 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.

Note: At the time of this publication the DSM V is being released which may result in some changes in criteria and category of some diagnosis. New information can be found on the National Institute on Mental Health's website www.nimh.org. The following information in this section is provided for educational purposes and is not intended as a medical diagnostic tool.

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 Disorder

Asperger Disorder is on the autism spectrum and is characterized by a lack of social skills. In general, a child with Asperger 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 Disorder are usually using words by the age of two, although their speech patterns may be somewhat odd. Most children with Asperger Disorder have difficulty interacting with their peers and tend to be loners. A child with Asperger 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.

Attention Deficit (Hyperactivity) Disorder (ADD)

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

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

Children with the predominantly *inattentive* type of ADD 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 ADHD 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.

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- 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 ADD. It clearly has a biological basis, including a genetic factor since it tends to run in families, and is not caused by dysfunctional parenting. Children with ADD are usually very intelligent.

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 addition 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 their 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.

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- 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 (ADHD), 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, neighbors, family) often sees a charming, talkative, and engaging child. This can leave the parents/primary caregivers feeling isolated, 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 Resource Center).

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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 that looks for other disorders such as ADHD, learning disabilities, mood disorders, and anxiety disorders. It may be difficult to improve the symptoms of ODD without treating a co-existing disorder. Some children can experience co-existing disorders, such as ODD with ADHD or ODD with learning disorders.

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 ADHD (although only a small number of children with ADHD 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.

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. In addition, 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.

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.

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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.

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.)

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 ADHD, 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; and 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, and 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.

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 “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.

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- Confusing television and dreams with reality.
- Confused thinking.
- Extreme moodiness.
- Thinking 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.

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

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.

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.

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.

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.

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.

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 knife-point 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.

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.

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

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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.

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, a fear must last for at least six months to be considered a phobia.

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.

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 followed by 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 induces vomiting, abuses laxatives, uses diuretics, uses enemas, takes 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 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 age 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 [*The Trevor Project, Facts About Suicide*; <http://www.thetrevorproject.org/pages/facts-about-suicide>].

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

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 15-34.* **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 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.

Risk Factors for Suicide

Risk factors are characteristics statistically associated with a health risk, such as suicide. Risk factors do not predict imminent danger for a particular person. Rather, they are an indication that an individual may be a 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 and/or defiance.
- Running away from home.
- School failure and/or 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).

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- Frequent moves and changes in living situation.
 - Social isolation or alienation from peers.
 - 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. Let your child 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 911 or the National Suicide Prevention Lifeline at (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.

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- 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.

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. 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 up 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 “***CONNECT suicide prevention program***” which includes protocols for professionals and gatekeepers in communities to learn how to recognize youth at-risk and connect with them to prevent suicide. For more information, contact NAMI NH, or visit www.theconnectprogram.org.

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 126 for contact information, and “National Alliance on Mental Illness New Hampshire (NAMI NH)” on page 121.

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.

Chapter 4. About Serious Emotional Disorders and Behavioral Issues

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.

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

The influence of violence from TV and video games

Violence on television and in video games can be a contributor to aggressive and violent 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.

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

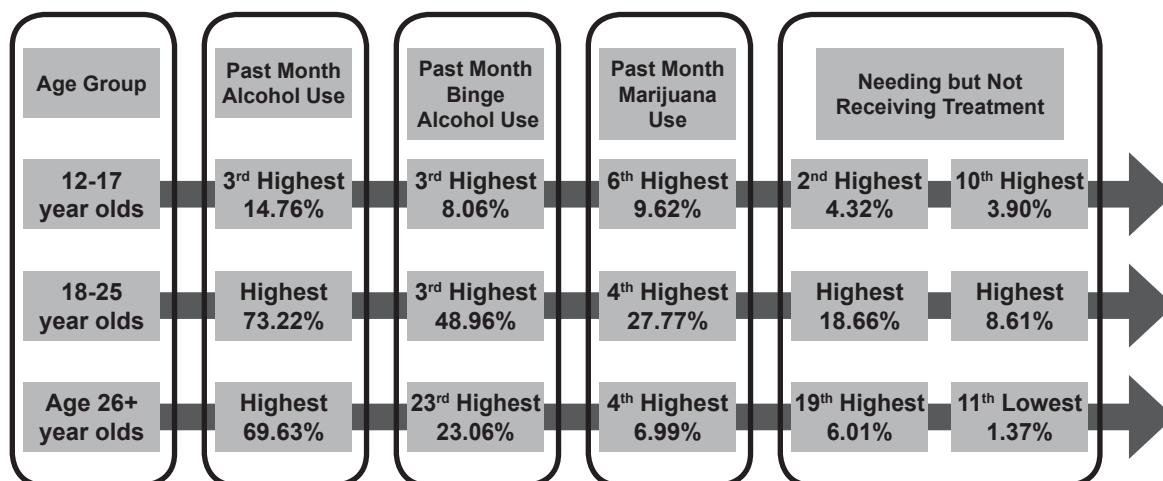
- Pay attention to the shows your child is watching and the video games they are playing. Watch some programs and play some of the video games with them.
- Point out that although the actor/figures have not been hurt or killed, in real life such violence results in pain or death.
- Set limits on the 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.

You can also use these techniques to prevent the harmful effects of TV/video games in the areas of racial or sexual stereotyping. 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 Misuse

The Problem

New Hampshire's rates of youth alcohol and drug misuse, though declining, continue to be some of the highest in the country.



Source: 2012-2013 National Survey on Drug Use and Health

The Substances

Alcohol use remains widespread among youth and is the number one drug used in New Hampshire. The use of alcohol in adolescence is linked to poorer grades, depressed thoughts, and a number of risky behaviors, including unprotected sexual contact. Further, **young people who drink before the age of 15 are four times more likely to develop alcohol problems in adulthood than those who start drinking at 21.**

Marijuana is the second most used drug by New Hampshire's youth. 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, as has the onset or exacerbation of schizophrenia in young people. Contrary to popular myth, **marijuana is an addictive substance** that causes significant health and life problems over time.

Prescription Drugs have become a problem and need to be monitored closely. The rising rates of prescription drug misuse are a grave concern in New Hampshire and have led to a number of **fatal incidents**. Many prescriptions that may be in your medicine cabinet are abuse-able. Pay careful attention to who can access them, and lock them if necessary.

Chapter 4. About Serious Emotional Disorders and Behavioral Issues

Substance Use Disorders

For adolescents, any amount of alcohol or drug use is problematic. Alcohol and other drug misuse 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.

Substance use disorders range from mild to severe. An adolescent with a severe substance use disorder may have developed what is commonly referred to as an addiction. Addiction is a physiological disorder of the brain that is chronic, progressive and potentially fatal. Fortunately, adolescents with substance use disorders respond well to treatment and can recover. In fact, research has shown that substance use disorders have a higher rate of recovery than other chronic diseases, such as hypertension and diabetes.

What can parents/adults do?

Parents and other key adults in young people's lives have more influence over their alcohol and drug choices than they think they do. There are three crucial steps to take:

1. Have a clear "no use rule" for any amount of alcohol or drugs for people under the age of 21 in your home, neighborhood, and community. Make sure your children and their friends know it is unacceptable.
2. Talk with your child at every developmental stage about the health risks and consequences of using alcohol and other drugs.
 - No quantity of alcohol is safe for the young brain and body.
 - Alcohol, marijuana and other drugs are addictive substances and the younger you are when you start using the more likely you are to develop a problem – if they are interested tell them to WAIT.
 - Addiction is hereditary – if there are alcohol or drug problems in your family tree (as there are for many families), make sure your children understand they are more vulnerable to developing problems.
 - The negative consequences of alcohol and drug use are completely prevented by not using!
3. Talk with your child about the negative impact that alcohol and/or drug use will have on their mental/emotional health. **If someone has other problems with brain functioning, such as mental illness, ADHD, trauma reactions, or developmental delays, they are at an increased risk of developing an addictive disorder.**

Finally, **90% of all adults with addictive disorders began using substances before the age of 17.** If you are concerned about a young person's alcohol or drug use, reach out for help to their pediatrician, their school or their counselor. You can also contact 211 and ask for Licensed Alcohol and Drug Counselors in your area, or call your insurance company and ask for a list of qualified providers.

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.

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.

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.
- 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.

Chapter 4. About Serious Emotional Disorders and Behavioral Issues

Chapter 5. Navigating the Treatment System

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. They might have different treatment philosophies and may 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 providers 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. The chapter 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 during treatment. New Hampshire's public mental health system is organized under the *Department of Health and Human Services* (DHHS) and continues to work toward providing access to integrated, comprehensive community-based mental health services and supports.

Community Mental Health Centers (CMHCs)

Community Mental Health Centers (CMHCs) 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 CMHC.

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 CMHCs (see Appendix C, “Community Mental Health Centers” on page 126) provides many outpatient mental health services to children and adults. (See “Types of Mental Health Services” in this chapter on page 70.) Each regional center has a geographic “catchment area,” and residents in that catchment area will utilize that particular CMHC. However, there are circumstances when a resident of one catchment area can receive services from a CMHC of another catchment area. If you find yourself in this situation, the process begins with contacting the CMHC, and speaking with the director of the department that serves children and adolescents and their families.

The CMHCs are staffed by a variety of practitioners, including psychiatrists, nurse practitioners, clinical social workers, clinical psychologists, psychiatric nurses, and mental health counselors. In addition, each center has a director of child and adolescent 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.

As the parent and/or guardian, you must be included as a partner on your child's treatment team. This is a core value and guiding principle of a system of care approach that all providers are asked to embed in their practice. If you find you are not being included, speak to your child's case manager or therapist about your concern. *Your signature is required on the treatment plan, and 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. Recently, Medicaid has moved into a managed care model which requires, in some cases, prior authorization for services. This is something you should clarify before accepting any services. CMHCs also provide services to individuals not covered by insurance on a “sliding scale” or “reduced fee” basis.

Check to see if your insurance carrier, including Medicaid, will cover the services of the CMHC.

Other New Hampshire State Agencies

Division for Children, Youth and Families (DCYF) and Major Program Areas of DCYF

The Division for Children, Youth and Families manages protective and juvenile justice programs on behalf of New Hampshire's children and youth and their families. DCYF staff provides a wide range of family-centered services with the goal of meeting the needs of parents and their children and strengthening the family system. Services are designed to support families and children in their own homes and communities whenever possible.

DCYF has designed and implemented a statewide Practice Model that reflects the core beliefs and guiding principles that serve as the “touchstones” for our work with children and their families. These speak to prevention, safety, permanency, well-being, courtesy, and respect, and acknowledge that children belong with their families and that all families have strengths. Staff work out of District Offices that serve specific geographic areas. The following information was adapted from the Department of Health and Human Services website.

The major program areas of DCYF are:

Child Protection

The Bureau of Child Protection works to protect children from abuse and neglect while attempting to maintain the family unit. Child Protective Service Workers work with families to 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. If community-based treatment and rehabilitative services are unable to provide a safe environment for the children, temporary out-of-home placement with a relative or in foster care may be used to provide children with the safety they require. DCYF's primary goal when a child is removed is to reunify them with their family as soon as possible. If it is determined that children cannot safely return home, other options are considered in order to achieve permanency and stability for them. To further ensure the safety of NH children, a Special Investigations Unit (SIU) investigates all allegations of abuse and neglect in foster homes, institutional settings, and residential, educational, and treatment facilities. You can learn more by visiting their website at www.dhhs.state.nh.us/dcyf/cps/index.htm.

PLEASE REMEMBER

Anyone who **suspects** that a child is being abused or neglected is **required** by NH Law to make a report.

Call: DCYF Central Intake Unit

Hours of operation are 8:00 AM to 4:30 PM Monday-Friday

Telephone: 800-894-5533 (In-state only) or 603-271-6562

During non-business hours, the public is asked to call local law enforcement for emergency responses.

Juvenile Justice Services (JJS)

Juvenile Justice Services (JJS) is responsible for providing supervision and rehabilitative services to youth adjudicated under state law as delinquent or as Children in Need of Services (CHINS). Involvement with CHINS can also be voluntary. JJS provides supervision, case management, and an array of rehabilitative services through its staff of Juvenile Probation and Parole Officers (JPPOs) and a network of community-based providers who are licensed and/or certified by DHHS. The Sununu Youth Services Center and the Youth Detention Services Unit are residential service programs overseen by JJS. You can learn more about these programs by contacting JJS at (603) 625-5471 or visiting <http://www.dhhs.nh.gov/djjs/>.

Permanency

Permanency means that a child has a long term, safe, and stable environment that fosters a lifelong relationship with a nurturing caregiver to establish the foundation for a child's healthy development. Permanency workers located in each District Office are trained to assist children and their families to identify permanent, lifelong connections. Reunification is the preferred permanency option. When reunification is not possible, adoption, guardianship or another permanent living arrangement is sought.

Adolescents

The Adolescent program is designed to ensure that current and former youth involved with DCYF obtain the preparation, resources and positive youth development they need to establish permanent connections and become healthy, self-sufficient, and successful adults. Adolescent workers with specialized training lead, educate, and collaborate with youth, colleagues, and the community to ensure the implementation of best practices for adolescents.

Foster Care

The Foster Care Program provides foster family homes and a family experience for children who cannot be safely cared for in their own homes. Specially trained Resource Workers in each DCYF District Office recruit, train and license foster families. They match children in need of out-of-home care with a foster family best suited to meet the specific needs of each child.

Foster Care Health Program (FCHP)

The FCHP is committed to meeting the health care needs of children in out-of-home placement. Through healthcare coordination and consultation, children in DCYF out-of-home placements will receive the ongoing care they need to achieve and maintain optimal physical, emotional, and developmental health.

Adoption

The Adoption program provides a vast array of services to families who adopt children through DCYF. These services include case management, education, information and referral, financial assistance, support groups, assistance to adoptees searching for their birth families, and Community and Family Support Services.

Community and Family Support Services are provided both to families in their communities and to families that are involved with DCYF. They include funding for community-based programs that work to prevent child abuse and neglect, juvenile delinquency, out-of-home placement of children and youth, clinical services and mental health support for children involved with DCYF, and educational advocacy and support for children involved with DCYF.

Child Development Bureau

The Child Development Bureau provides a wide range of services and supports including providing technical assistance and support to early care and education programs, consumer education and child care training programs. The Bureau maintains statistics on the supply and demand of child care throughout NH, and develops policy for the NH Child Care Scholarship Program. Through the scholarship program, parents may apply for payments to subsidize the cost of child care when needed to look for work, remain employed or participate in training.

Head Start State Collaborative Office

The NH Head Start State Collaboration Office fosters collaboration and teamwork among the Head Start community, and state and local public and private partners concerned with pregnant women and families of young children aged birth to five years. To improve long-term outcomes for income-eligible families, this office works closely with the NH Head Start Directors Association to support coordination efforts in 10 priority areas: Health care (mental health, oral health, physical health), child care, family financial assistance, early childhood education opportunities, community services, family literacy, children with disabilities and their families, education (transition and alignment with K-12), and services for children without homes.

The Bureau of Developmental Services (BDS)

The Bureau of Developmental Services is committed to joining communities and families in providing opportunities for citizens to achieve health and independence. In partnership with consumers, families, and community-based service networks, BDS affirms the vision that all citizens should participate in the life of their community while receiving the supports they need to be productive and valued community members. BDS takes a leadership role for the NH developmental services system. BDS is comprised of a main office in Concord and ten designated non-profit “area agencies” that represent specific geographic NH regions. (See Appendix C, “State and National Resources beginning on page 119.) All services and supports to individuals and families are provided through contractual agreements between BDS and the Area Agencies. Supports include service coordination, Early Supports and Services and Early Intervention, assistive technology services and specialty services, and flexible family supports including respite services and environmental modifications.

Children up to 3 years of age may be eligible for *Early Supports and Services* (ESS) through the Area Agency. If your child is receiving services from ESS, about 6 months prior to your child’s third 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.)

NH Department of Education - Bureau of Special Education

The Bureau of Special Education’s mission is to provide and promote leadership, technical assistance, and collaboration statewide to ensure that all children and youth with disabilities receive a free, appropriate and public education. They are charged with providing oversight and implementation of federal and state laws that ensure a free appropriate public education for all children and youth with disabilities in New Hampshire. They guide and direct a comprehensive array of statewide educational initiatives in the following five areas: Early Childhood Transitions, Free Appropriate Public Education in the Least Restrictive Environment (FAPE), General Supervision, Parent Involvement, and Secondary Transition.

You can learn more details about these educational initiatives by visiting www.education.nh.gov. The Bureau monitors and oversees ***Alternative Educational Programs*** that are available in many school districts. These programs provide educational, 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 Individual Education Plan (IEP). 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. For more details on special education services and the IEP, see Chapter 6, "Safeguarding Your Child's Education" beginning on page 85.

NH Department of Education - Bureau of Vocational Rehabilitation

Vocational Rehabilitation (VR) has a long history of providing direct and indirect services to youth with disabilities as they transition from school to work. The services provided can enable your student to obtain successful employment. This agency is committed to increasing access and improving overall quality of services offered to school age youth. In 1990 the requirement for Transition Services was added to the Individuals with Disabilities Act (IDEA). If your child has an IEP, the school should be discussing with you the inclusion of a VR counselor on your child's IEP team. A referral to VR can be made as early as age 16 to begin to cover postsecondary/vocational training, employment, community participation, or independent living, if appropriate. VR has several informative pamphlets and booklets available on their website: www.education.nh.gov/career/vocational.

Residential Treatment Centers and Psychiatric Hospitals

The organizations in this section are often options for children who have not benefited from programs in a community-based setting and require more intensive services and supports in a more restrictive treatment setting.

Residential Treatment Centers and Alternative Schools

Residential treatment centers and alternative 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 by community-based programs. The services through 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. (For more information refer to Chapter 3, "Partnering in Your Child's Care," beginning on page 19.)

If your school district recommends a private treatment center or alternative school, you have the right to ask questions and refuse if you do not agree with the placement. 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 your child to a residential facility away from home and community or an alternative day program. (See Chapter 6 section, "Special Education Services in School" on page 87.)

Before agreeing to a transfer to one of these alternative education placements, make sure you understand the purpose of the placement, the intended goals and behavioral outcomes, the plan for transition back into the community, and, most of all, the philosophy of the center and the qualifications of staff members.

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 in New Hampshire. In-patient psychiatric hospital services 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 return to their home, school, and other more natural community settings to 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. Your child or youth may 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 your child cannot be treated in any other setting. Such hospitalizations can be very expensive, and not all hospitals will accept Medicaid. 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. The State of New Hampshire operates New Hampshire Hospital, a psychiatric hospital described below. Admission to New Hampshire Hospital is generally on an involuntary, emergency basis. The hospitalization is covered by insurance; however, this should be verified before admission. Sometimes due to limited capacity there can be a wait for an inpatient bed.

Important! Your child’s admission and in-patient 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 81 and Chapter 3 section, “If Hospitalization is Required” on page 31 for more information.)

New Hampshire Hospital (NHH)

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. Admission to NHH is usually through an Involuntary Emergency Admission (IEA) and must be through your community mental health center, or through a private practitioner who has received privileges to admit to NHH. Admission to NHH can be delayed based on capacity (hospital census).

A young person can be admitted to NHH's Anna Philbrook Unit 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. The Unit is staffed by board certified child and adolescent psychiatrists and professionals in nursing, psychology, education, social work, and rehabilitation who have special training and expertise in working with children and adolescents. NHH has a school liaison position which allows for communication between the hospital and school district (with a signed release from parent/guardian). This is especially important for students with Individual Education Plans (IEP).

When your child is ready to return to your home and community, NHH coordinates the discharge planning through the parent or guardian and the appropriate agencies and providers.

Discharge planning should begin at the time of admission.

Note: For information on protections available regarding involuntary emergency admission, see "Involuntary Hospital Admission Rights" on page 81.

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, anxiety, ADHD, 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 your child and family to the community mental health system when there is a need for more services than the practitioner is able to provide.

Obtain references from a person or agency you trust before interviewing or visiting the office of any private practitioner. Be sure to have a clear sense of what you expect from all practitioners. 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, you and your child (depending on age and maturity) should consider:

- What kind (specialty) of doctor or therapist do you want for your child?
- What type of person will your child be most 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 on New Hampshire Department of Health and Human Services website at www.dhhs.nh.gov or www.gencourt.state.nh.us/rules/he-m400.html. You can also contact NAMI NH's Information and Resource Line at (800) 242-6264 Ext 4 for more information.

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. CMHCs contract with the NH Department of Health and Human Services, Bureau of Behavioral Health to provide a broad range of services; however, individual centers differ in staffing and the way these services are provided. At intake a Child and Adolescent Needs and Strengths Assessment will be completed which will determine if your child is eligible to receive any/all of the following 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 CMHCs have policies that require a person to receive *all services* (the aforementioned plus therapy and psychiatry) through them, whereas other CMHCs allow a person to receive therapy or psychiatric services in the private sector. Discuss your questions and preferences with the director of the children's program.

- **Targeted Case Management**
- **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 Service*)
- **Respite Services**
- **Emergency Mental Health Services** (24 hours/day)

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



Targeted Case Management

Targeted Case Management is defined in He-M 426.15, which is one of the rules and regulations that governs community mental health services. The focus of targeted case management is on your child's broader medical, education and social needs. The case manager has expertise regarding the service delivery system. They have knowledge of what services exist and know how to assist you in accessing those services. They will conduct a case management assessment, develop a plan for referral and linkage, and monitor any components of the plan related to community mental health services. An example of a referral would be to Wraparound. (See "The Wraparound Concept of Care" in this chapter on page 78.) **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 to diagnose (define) your child's condition and prescribe the correct clinical treatment, which might include medications. Some (but not all) CMHCs 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.

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. They 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 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 frequency of sessions and if your child will be in brief or long-term therapy is a discussion you and the therapist must have. 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.

"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

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.

IROS Functional Supports

IROS (*Individual Resiliency and Recovery Oriented Services*) functional supports are mental illness recovery and resiliency services offered by the CMHC to provide strategies and techniques to help your child manage symptoms and/or behaviors that interfere with his daily functioning and self-care. Supports will also be provided to your family members and significant others who want to learn how to assist your child 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 at the present time only through Medicaid.* DHHS describes these services in He-M 426, which are the rules and regulations that govern 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 your child's current living, employment, or educational setting, or other community setting taking into account the preferences of your child and family. To get a copy of the He-M 426, you can visit the DHHS website at 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.

RENEW

RENEW is a structured planning and individualized wraparound process for youth with emotional and behavioral challenges. Currently, this model is available at the community mental health centers through a collaboration between UNH/Institute on Disability, NH's 10 community mental health centers, and the NH Department of Health and Human Services and is a covered service through Medicaid. RENEW services are available to youth with emotional and behavioral disorders in every region of the state.

The model focuses on supporting each youth to design and pursue a person-centered plan for the transition from school to adult life. If your child is of transition age (14 through 21) and is a client of the CMHC, then speak to your child's case manager or therapist about this program. RENEW has substantially increased high school completion, employment and post-secondary education rates among youth with SED.

Respite Services

Respite is a short, temporary period of rest and relief for both your child with a serious emotional disorder (SED) and your family. Respite periods usually last a few hours, a day, or a weekend. There are different models of respite care. Respite can be offered in the home, a community setting, and in some cases, 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 NH DHHS. Respite is an important service that families need in order to be able to keep their child at home. Respite is not a Medicaid covered service at this time or covered by private insurance; however, some CMHCs have found ways to financially cover this service. When it is a CMHC provided service, respite is written into the child's treatment plan. When

"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."

respite is a part of a child's treatment plan, the primary goal of respite services is the child's development and ability to learn to manage his symptoms/behaviors. In other cases, when it is not a part of the child's treatment plan, the primary goal of respite services is to provide relief for the family.

Using respite services does not indicate that you are not able to care for your child. Parenting a child with SED is a very high-pressure activity. Regularly scheduled and anticipated breaks can significantly enhance your health and well-being, reduce your family's level of stress, and better enable you to care for your child and cope with other family issues.

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.*

Emergency Services

The community mental health center has an emergency services department that provides crisis intervention and evaluation for hospitalization (acute care). 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 and are 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 and are not connected with a mental health provider. Not all CMHC emergency services staff has training to work with children or adolescents, so it is important to have a current and comprehensive *crisis management plan*. (See Chapter 8, "Managing a Mental Health Crisis" beginning on page 101.) If your child is in treatment with a private practitioner, you should contact the provider first, since they will know your child's clinical needs. 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.)

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 2, "Integrated Health Care" beginning on page 9.)

Psychiatrist

A psychiatrist is a physician (medical doctor) who specializes in providing medical and psychiatric evaluation and treatment for emotional, behavioral, and psychiatric disorders. Psychiatrists are physicians and 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.

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 master 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 bachelor 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 in your child's treatment.** 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.

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 ADHD. 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 126.
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, with whom you speak and the information you receive. (See Chapter 3 section, "How to Organize All That Documentation" on page 25 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.

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.

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.

Part of the *treatment plan* is to build a *treatment team*, including your family and those who work with your child, such as teachers, after school program staff, and your primary care physician. (See Chapter 2 section, "The Important Role of Your Primary Care Physician" on page 12.) 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 2 section "Shared Decision-Making" on page 15.) 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.

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. Be patient - the process takes time.

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 you are likely 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 2 section "Shared Decision Making" on page 15.)

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

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.

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 the family's strengths, supports, and needs. With the 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." These 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, strengths-based, culturally and linguistically appropriate, and community-based.* The theory of Wraparound is 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. A wraparound team involves the child (age appropriate), family members, 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 their expertise and resources are needed.

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

- The person who is facilitating the process is trained in the process and understands the values and principles behind the process.
- The process always starts with your family and youth identifying their own strengths and needs. The needs identified by your family should form the core of the plan. Needs not identified by your family are not part of the plan unless there is a safety issue.
- The goals and action steps can change at any time based on what has become more important or critical to your family.
- The team is always identified by your family.
- It truly feels like it is *your family's team* and that the first and foremost goal is to support you and your child in this family-driven process.

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 or on the state level who can help with financial or regulatory barriers that otherwise would stop a team from fully reaching its goal.

Family Support Programs

There are different models of family support programs. The CMHCs offer an intervention program that is written into a child's treatment plan and is provided by staff of an agency. Their primary responsibility is to work with families, providing support and education to assist the child in meeting the goals identified in their treatment plan. To access this service, speak with a member of your child's treatment team. The service is covered through Medicaid but not by private insurance at this time.

Another model of "peer-to-peer" support is offered statewide by NAMI NH. In this model, the family support is provided by a family member who has faced the challenges of raising children with serious emotional disorders. They have completed a training program and receive ongoing supervision. The focus of the support is identified by the family member, no treatment plans or notes are kept, and the support can be accessed as needed. This support focuses on the importance of self-care and can include education, referral to other resources, connecting with other families with similar experiences, coaching, mentoring and sometimes just a "listening" ear. To access this support program, contact NAMI NH by calling the Information and Resource Line at (800) 242-6264 ext. 4 or (603) 225-5359.

Your Rights and Protections within the Treatment System

You may feel you have no control over decisions about your child's treatment, but, in fact, special laws ensure your child's rights are protected and that you as parent or legal guardian 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 at www.nh.gov under the *Laws and Rules*, or by calling the Bureau of Behavioral Health at (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

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

cannot come to a mutual agreement with the provider, you may terminate treatment and seek services elsewhere.

Treatment that is *involuntary* 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 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 81.)

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.

It is important to 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 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 appropriate decisions if you are not informed. Use the guidelines below to help you make informed decisions for your child.

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 come with the knowledge 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 treatment that is not clearly identified at the time of admission. If you do not want to pre-authorize treatment or changes to treatment without being consulted, you can sign the authorization asking to be consulted about any changes in your child's treatment or medications. Ask for and keep copies of all forms you sign and hospital documentation 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.

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

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 misuse or addiction 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 medical 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 or private provider 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

Every community mental health center (CMHC) has a grievance process and you should receive a written copy of this when your child begins 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** (BBH). (See Appendix C, "Bureau of Behavioral Health" on page 126.)

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 *Disabilities Rights Center*. (See Appendix C, "Disabilities Rights Center, Inc." on page 135.)

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 (DRF). As a family member this process can be very distressing and confusing to understand. If you find you need support, contact NAMI NH through the Information and Resource Line (800) 242-6264 Ext. 4 or call (603) 225-5359 and someone will assist you.

Involuntary Admission Requirements

A child shall be eligible for an Involuntary Emergency Admission if he/she meets the criteria of RSA 135-C:27, which states that within 40 days of the petition being completed he/she:

- is in such mental condition as a result of mental illness to pose a likelihood of danger to himself/herself or others; OR
- has inflicted serious bodily injury on himself/herself or has attempted suicide or serious self-injury and there is a likelihood the act or attempted act will recur if admission is not ordered; OR
- so lacks the capacity to care for his/her own welfare that there is a likelihood of death, serious bodily injury, or serious debilitation if admission is not ordered;

AND meets all of the following criteria:

- has been determined to have a mental illness for a period of at least one year; AND
- has not been appointed a guardian through the courts; AND
- is not subject to a conditional discharge; AND
- has refused the treatment determined necessary by a mental health program approved by the department; AND

- has had one involuntary admission in the last two years (there are some specific rules around this); AND
- has been determined by a psychiatrist at a mental health program approved by the department that there is a substantial probability that the person's refusal to accept necessary treatment will lead to death, serious bodily injury, or serious debilitation if admission is not ordered.

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.

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 which involves the services of local law enforcement.

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, if possible, attend the hearing.

A child does not require a specific diagnosis to qualify for involuntary emergency 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 meets the criteria and has a psychiatric diagnosis or evidence of a psychiatric condition.

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 NHH or the Designated 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) or the Designated Receiving Facility. (For more information on NHH, refer to Chapter 5, page 68.)

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 #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.
 5. 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. At any point during the admission process, the hospital may determine that your child no longer meets the criteria for this level of care. If this occurs, the hospital will make arrangements for the discharge of your child. *The 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.

Chapter 6. Safeguarding Your Child's Education

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 services and supports for children with serious emotional disorders. In the school system, children with serious emotional disorders are identified as having an emotional disturbance.

This chapter provides the regulatory and practical information you need to make sure your child receives all the special education services he or she is entitled to by law. In this Chapter, we discuss the importance of Transition Planning. 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 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.
- Schedule a meeting to explain your child's needs: special equipment, medication, or behavioral or medical challenges.
- Provide the teacher with information about your child's illness and its symptoms, including strategies that help him/her manage symptoms/behaviors. 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, and illness or discord at home. They may get over-excited about happy events, as well.
- Offer to start up a "communication book" 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* (PIC). PIC is a statewide resource available to parents of children with disabilities to help parents support their child's success in school and in life. Visit their website at www.picnh.org or call (603) 224-7005.

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 Supports and Services (ESS) and is provided through the local area agencies. (See Appendix C, "State and National Resources" beginning on page 119.)

The eligibility criteria for the program are:

- New Hampshire resident,
- No income guidelines,
- Experiencing a developmental delay or atypical behavior,
- Has a diagnosed or established condition that has a high probability of resulting in a delay, or
- Is at risk for substantial developmental delays if services are not provided.

ESS 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 and a child and family team will be created. 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 reaches 3 years of age, the service coordinator helps your family transition to preschool education or another community-based program.

The IFSP is a legal document and is a roadmap for ESS services. It will help guide the services and supports needed to achieve the goals set by you and the team. To learn more about ESS and the IFSP, you can contact your Area Agency (See Appendix C, "State and National Resources" beginning on page 119.)

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)** 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 at (800) 242-6264 or the Parent Information Center at (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, 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 is referred to as the least restrictive environment (LRE). 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. It is important to keep in mind that a Section 504 plan provides accommodations but no legal relationship between the child, family and school district.

Obtaining Special Education Services

It is extremely important that you access 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 or 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 a 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 123.]

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.

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 (the person who can commit the resources of the school district) and 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 and 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.

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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. Similarly, 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 are equal partners on the educational support services team. You may need help in establishing educational goals, and this is why you have an 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 and 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.

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 Parent Information Center offers workshops and training that provide parents with the knowledge and tools to understand and effectively participate in the special education process.

Visit their website at www.picnh.org for information on these resources and more detailed information about the special education process.

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.

Transition Planning

Transition planning is designed to help the child prepare for life after high school. Transition Planning is required by the Individuals with Disabilities Education Improvement Act of 2004 (IDEA 2004) and the NH Rules for Education of Children with Disabilities (NH

Rules). Transition planning begins no later than the first Individualized Education Plan (IEP) that is in place by age 16, or younger if the student's transition team decides it's appropriate. The team includes the student, parent/family members, school personnel, vocational rehabilitation counselor, and others the student and parents would like to be on their team.

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.

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: 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.

The Parent Information Center provides "Life After High School," a Transition Tool Kit. This guide provides strategies, tools and resources for families of youth with disabilities to assist in creating successful plans for life after high school. The tool kit can be downloaded from their website at www.picnh.org or call (603) 224-7005 to request a copy.

Chapter 6. Safeguarding Your Child's Education _____

Chapter 7. Paying for Services

Chapter Overview

Finding and paying for mental health care varies in New Hampshire 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.

Remember that out-of-pocket expenses to alleviate your child's mental or physical condition may qualify as income tax deductions.

This Chapter provides a brief overview of the health coverage resources for children with disabilities. We have included information about the NH Medicaid Program's transition to a Medicaid Care Management (MCM) Program in December 2013.

Questions about private insurance can be directed to the NH Insurance Department by calling (603) 271-2261 or by e-mailing consumerservices@ins.nh.gov.

Questions about Medicaid can be directed to Medicaid Client Services at (800) 852-3345 ext. 4344.

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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 coverage. 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 to insurance premiums, 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 with whom you are speaking 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, monitoring claim forms submitted to your insurance carrier might be useful. In Appendix D, “Tracking Expenses and Insurance Claims” is provided on page 147. If you have trouble accessing mental health services for your child, call the NAMI NH Information and Resource Line at (800) 242-6264 or email info@naminh.org.

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, Schizoaffective Disorder, Major Depressive Disorder, Bipolar Disorder, Anorexia Nervosa and Bulimia Nervosa, Obsessive-Compulsive Disorder, Panic Disorder, Pervasive Developmental Disorder or Autism, and/or Chronic Post-Traumatic Stress Disorder. If you have questions about “parity,” you can contact the New Hampshire Insurance Department consumer line at (603) 271-2261 or the NAMI NH Information and Resource Line at (800) 242-6264.

Public Health Benefit Programs

Child Health Program (CHP)

The *Child Health Program* (CHP) is part of the Maternal and Child Health Section under the New Hampshire Department of Health and Human Services. Services are provided primarily to children from birth through age 10 but are available for children up to age 19.

The Maternal and Child Health Section funds and oversees ten community health centers and one health agency to provide health care services to children in their community. Services are targeted to low income, uninsured, or underinsured children and provided through the clinics and home visits. Based on the financial situation of the family, services are free or available by a sliding fee scale.

Services include assistance with health care enrollment, physical exams, health screenings, immunizations, referrals, health education, case management, and care coordination.

For a list of current community health centers and the one health agency visit www.dhhs.nh.gov/dphs/bchs/mch/child.htm. There is a link on that page for the location and contact information for the community health centers and the health agency.

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 ensure the health of all New Hampshire children under the age of 19. It provides comprehensive medical and dental at no cost to your family. This includes well child check-ups and immunizations. Children and adolescents with serious emotional disorders are often eligible for Medicaid despite the income and financial resources of the family. This is because there are Medicaid programs that count only the child's income and financial resources.

Questions?

Call Medicaid Client Services
(800) 852-3345 Ext. 4344

3 Ways to Enroll

Call the Enrollment Center
1-888-901-4999

On Line Filing of Applications
NH EASY at www.nheasy.nh.gov

Visit the local NH Department of Health and Human Services District Office. For the office closest to you call Medicaid Client Services.

Medicaid is an income-based eligibility program and you must file an application to be determined eligible for coverage. This can be done online or by visiting one of the NH Department of Health and Human Services District offices. You will be asked to provide proof of identity for all household members, the household's income and resources (within the last 30 days), social security cards, and birth certificates. There are different categories of eligibility. If you are not sure which category best fits your situation, you can call Medicaid Client Services. They can also assist if you are not sure you are within the income guidelines. Visit the NH Department of Health and Human Services website at www.dhhs.org/ombp/medicaid/index.htm to find information on income and resource guidelines.

In December 2013, New Hampshire began transitioning to Medicaid Care Management. This means you must choose from one of the health plans offered that will provide the insurance coverage and, when needed, help coordinating care. The health plans cover the same services as NH Medicaid and offer additional services and other resources to promote health and wellness. To learn about the plans offered and the coverage, go to the NH Department of Health and Human Services website at www.dhhs.nh.gov/ombp/caremgmt/index/htm.

Previous to December 2013, the NH Healthy Kids Program offered *Healthy Kids-Silver*. This program provided Medicaid coverage through a private insurance carrier for families that were above the poverty level. In that program, based on the household's income, they would pay a premium for insurance coverage. When Medicaid Care Management was introduced, the children covered under Healthy Kids Silver were then given the opportunity to enroll in one of the health plans and premiums were suspended for the 2014 year.

You will still have Medicaid so be sure to always show both health cards when accessing health care services. It is important when choosing a plan you are aware of what your child's needs are, and if his providers are in the plan's network. *A Tool for Families Having Children with Special Healthcare Needs* developed by NH Family Voices, can be found in Appendix D. Useful Forms, page 148. This form was adapted with permission from NH Family Voices.

Know Your Rights and Responsibilities

As a recipient of Medicaid, you do have Rights and Responsibilities. You are responsible to provide verification and documentation when it is requested within 10 days of the request. You are responsible to report any changes in your household (for example, if you move, income changes, resources change) within 10 days of the change.

If your application for Medicaid is denied, you have the Right to Appeal. Before you file the appeal, be sure you review the Eligibility Determination Notice to be sure that the information you reported is accurately reflected in the notice. The notice clearly states why your application was denied. You must file this appeal within the timeframe identified in the Eligibility Determination Notice. The appeal will be handled by the Administrative Appeals Unit (AAU) located in Concord, NH. They will conduct a Fair Hearing where you will be asked to provide proof of why the denial was incorrect. The AAU contact information is (800) 852-3345 Ext. 4292. The AAU is independent of NH DHHS Program Offices and Divisions. Its mission is to conduct impartial hearings and render decisions in accordance with the requirements of NH Statutes and Administrative Rules.

If you are a recipient of a Medicaid Health Plan, you have a right to file an appeal or grievance if you are dissatisfied with the plan.

In New Hampshire you must appeal to the Medicaid Health Plan before requesting a Fair Hearing through the Administrative Appeals Unit (AAU) at (800) 852-3345 Ext. 4292.

If you need advice or assistance about the Right to Appeal or Fair Hearing process, contact the Disabilities Rights Center at (800) 834-1721.

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. The phone numbers of NH district offices are provided in Appendix C, “Social Security Administration (SSA)” on page 133.

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.

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. You should begin this application process at least six months prior to your child’s eighteenth 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 NH district offices are provided in Appendix C, “Social Security Administration (SSA)” on page 133.

Individuals with Disabilities Education Act (IDEA)

The Individuals with Disabilities Education Act (IDEA) is a federal law that 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 program is called “Medicaid to Schools.” This allows the school district to receive part of the costs for services and supports that are medically necessary and written into a student’s IEP from the federal government. See Chapter 6, “Safeguarding Your Child’s Education” beginning on page 85.

Chapter 8. Managing a Mental Health Crisis

Chapter Overview

It is possible that one day your child may experience a mental health crisis. Managing a mental health crisis is more than being told to call 911.

This chapter will help prepare you to manage 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!

The intent of this chapter is to help you develop a plan that matches your child's and family's needs with the available resources in your community. We have provided a tool that many families have found helpful.

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Managing a Mental Health Crisis

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 and he/she are not able to control his/her behavior, and at least one of the following is true:**

- He/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 (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 (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 “911” for help if you feel threatened; it is not appropriate to fear for your safety.
- He or she is **experiencing disorganized and dangerous thinking**.

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 differ in various regions, emergency mental health evaluations are usually conducted by the regional community mental health center emergency services 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. The 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. You will be better prepared to manage the crisis if you have the needed information readily accessible, and are familiar with the process and places involved in a mental health crisis.

Becoming 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 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 plan for your child. Suggestions for the discussion and development of a 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.
- 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.

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.

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**. 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 may 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 "Becoming 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, and 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 contact 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 and your child's policy number.

To assist you with compiling this information, a Mental Health Emergency Information Form can be found in Appendix D on page 151.

Rehearsing the Call to Emergency Services

What to Tell the Emergency Services Clinician

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

- 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.

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*.

Examples of Ineffective and Effective Descriptions

Note:

- *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.

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

Describing a Danger to Self

Ineffective Description

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.

He has no respect for his stuff. He gave all his birthday presents away to his friends.

He has threatened to kill himself by taking all the pills in the house. He is doing everything possible to scare me.

Effective Description

Danny locked himself in the bathroom and is threatening to kill himself. He becomes more agitated when I try to calm him down.

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.

Danny's guidance counselor at school has called and is very concerned about his behavior.

Describing a Danger to Others

Ineffective Description

Karen is very angry and is breaking furniture and windows in the house. I cannot take her acting like this anymore.

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 is mean to her brother and sister. Karen likes to fight with everyone. She hates her brother and sister, as well as me.

Karen does not like any authority figures. She will not do what any adult tells her to do. I cannot live like this anymore.

Effective Description

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.

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.

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.

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.

Note: NAMI NH does not provide “crisis response” services; however, after the event you may find a need to process the event and would find talking with another parent who “has been there”. Call the NAMI NH office at (603) 225-5359 and ask for the Information and Resource Line or to speak with a Family Support Specialist.

Describing a Dangerous Thinking

Ineffective Description

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.

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 or students or sleeping in class.

Someone has to do something with this kid. I cannot control him.

Effective Description

Jimmy is sitting on the roof and threatening to jump.

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.

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.

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.

His principal called to tell me that Jimmy is oppositional beyond his usual behavior, and he’s concerned about disciplining Jimmy because he appears to be emotionally fragile and unstable.

Chapter 9. Transitioning to Adult Health Care Services

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 finances, 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 of care. The following recommendations will help ensure services and supports continue without interruption.

Around age 14, begin to have conversations with your teen about how he can begin to take responsibility for his health care. This is a time of learning about his illness and medications, health insurance coverage, making appointments and learning to self advocate.

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 a 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 and 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.
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 and Advocacy Services" on page 135 and "Guardianship Rights" on page 133.)

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.

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.
7. Determine when coverage through your current health insurance plan will terminate and explore other health insurance coverage options. Currently there is coverage through age 26.
8. Describe to your adolescent how the current insurance plan works and discuss what will be needed in the future.

9. Contact the New Hampshire Department of Health and Human Services (NH DHHS) Medicaid Client Services at (800) 852-3345 ext. 4344 for information about programs available for individuals over the age of 18.
10. NH DHHS does administer a program, *Aid for the Permanently and Totally Disabled* (APTD), that 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.
11. 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.
12. 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 and Advocacy Services" on page 135 and "Guardianship Rights" on page 133.)

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 2 "Integrated Health Care" beginning on page 9.

Legal Considerations

As a parent/caregiver of an adolescent with SED, you may be concerned about his or her ability to make "informed decisions" (this is 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 and Advocacy Services" on page 135.)

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 99.) This can be at the request of the applicant or be assigned by the 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 with which he or she has been entrusted. (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.

Appendix A. Acronyms

Some of the acronyms in this Appendix are not used in this Guidebook, but they might be used by the organizations and providers with whom you work. Acronyms can have different meanings between various organizations and disciplines. Unless the meaning is clear to you, request that acronyms be defined or avoided.

504

Section 504 of the Rehabilitation Act
of 1973

ADA

Americans with Disabilities Act

ADD

Attention Deficit Disorder

ADHD

Attention Deficit/(Hyperactivity) Disorder

APC

Anna Philbrook Center (at NHH)

APS

Acute Psychiatric Services (at NHH)

BBH

Bureau of Behavioral Health

CASSP

Child and Adolescent Service System
Project

CHINS

Child in Need of Services

CMHC

Community Mental Health Center

CPSW

Child Protection Service Worker

DCYF

Division of Children, Youth, and Families

DD

Developmentally Disabled

DFA

Division of Family Assistance

DHHS

Department of Health & Human Services

DJJS

Division of Juvenile Justice Services

DOE

Department of Education

DRC

Disabilities Rights Center

EBD

Emotional and Behavioral Disorder

EH

Emotionally Handicapped

EI

Early Intervention (Special Education)

EPSDT

Early and Periodic Screening, Diagnosis,
and Treatment

ESS

Early Supports and Services

ESY

Extended School Year

FAPE

Free Appropriate Public Education

FBA

Functional Behavioral Assessment

FDA

Federal Drug Administration

FERPA

Family Educational Rights and Privacy
Act

IDEA

Individuals with Disabilities Education Act

IEA

Involuntary Emergency Admission

Appendix A. Acronyms

IEP

Individual Education Program

IFSP

Individualized Family Service Plan

IROS

Individual Resiliency and Recovery
Oriented Services

JPPO

Juvenile Probation and Parole Officer

LD

Learning Disabled

LEA

Local Education Agency

LRE

Least Restrictive Environment

MCM

Medicaid Care Management

NAMI NH

National Alliance on Mental Illness
New Hampshire

NHH

New Hampshire Hospital

NIMH

National Institute of Mental Health

OCR

Office of Civil Rights

ODD

Oppositional Defiant Disorder

OHI

Other Health Impairment

OSEP

Office of Special Education Programs

OT

Occupational Therapy

PBIS

Positive Behavioral Intervention Service

PCP

Primary Care Physician

PDD

Pervasive Developmental Disorder

PIC

Parent Information Center

PT

Physical Therapy

PTSD

Post-Traumatic Stress Disorder

RSA

Revised Statute Annotated

S/L

Speech and Language

SA

Substance Abuse

SED

Serious Emotional Disorder

SLD

Specific Learning Disability

TBI

Traumatic Brain Injury

YDC

Youth Detention Center

Appendix B. Glossary

acute care

Acute mental illness is characterized by significant and distressing symptoms of a mental illness requiring immediate treatment. The onset is sudden or rapid and the symptoms usually respond to treatment.

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. Involvement with CHINS can be voluntary or involuntary.

catchment area

A geographic area served by an agency or organization.

cognitive-behavioral therapy

A form of psychotherapy that emphasizes the important role of how the way we think impacts 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 that 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 Resource

Seeking resources can often be frustrating and overwhelming. Be sure to keep a log of who you call and speak with, date of the call and what was the result of the call. This will help if you must follow up with the agency/organization.

This Appendix will provide you with contact information for agencies and organizations on the state and national level. Be sure to call before visiting any offices because locations often change. You can also find eligibility information for programs on the agency and organization's website.

In the opening of this section you will find the statewide information and resource/referral organizations that can provide you quickly with resources.

The New Hampshire Department of Health and Human Services which offers a wide range of programs, services and supports and can provide information on DHHS, federal and local programs, services and supports.

We have also included other resources that may be of assistance to you.

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Information and Resource/Referral Organizations (I&R)

The following are organizations that provide information and resource/referral services at no cost to callers. Some of the organizations provide I&R to specific populations, service areas and others have general I&R programs. All of those listed are statewide organizations and are resources for families, caregivers, educators, mental health and medical providers and other professionals working with children, youth and their families. Several of these organizations are family led and provide “family-to-family” or “parent-to-parent” supports and education.

National Alliance on Mental Illness New Hampshire (NAMI NH)

NAMI New Hampshire provides support, education, and public policy advocacy for persons with mental illness and/or serious emotional disorders (SED) and their families. These programs and advocacy are developed to meet the needs of individuals across the lifespan. There is an Information and Resource (I&R) Program with one-to-one phone assistance, information available through the website, and a mental health resource center at their office. NAMI New Hampshire also provides professional development training and through the Connect program offers suicide prevention and postvention trainings and supports to families who have lost a loved one to suicide.

85 No. State Street
Concord, NH 03301
Information and Resource Line: (800) 242-6264
Phone: (603) 225-5359
E-mail: info@naminh.org
Website: www.NAMINH.org

Child Care Aware® of New Hampshire

Southern New Hampshire Services Child Care Resource and Referral (CCR&R) provides FREE Child Care Information for families seeking child care in the state of New Hampshire. Additionally CCR&R provides ongoing training and technical assistance consultations to support the professional development of child care programs and providers. To learn about the CCR & R program in your region visit www.nhccrr.org.

Community Action Agencies

There is an agency that provides information and referrals for each county in New Hampshire. The agencies work with low income families and the elderly to assist them in their efforts to become or remain financially and socially independent. They provide a wide range of programs that can assist with basic needs (i.e., rent, child care, auto repair, heat assistance, weatherization programs).

Strafford County
Phone: (603) 516-8130
Website: www.traffcap.org

Belknap-Merrimack Counties
Phone: (603) 225-3295
Website: www.bm-cap.org

Southern New Hampshire, Inc.

Phone: (603) 668-8010

Website: www.snhs.org

Southwestern Community Services, Inc.

Phone: (603) 352-7512

Website: <http://www.scshehelps.org/default.htm>

Tri-County Community Action Program, Inc.

Phone: (603) 752-7001

Website: www.tccap.org

Family Resource Connection (FRC)

FRC is a statewide library and clearinghouse of information, resources, and support concerning aspects of caring for, educating and raising children with an emphasis on children with special needs.

New Hampshire State Library

20 Park Street

Concord, NH 03301

Phone: (800) 298-4321 – (800) 735-2964 (TDD)

Email: [FRC@ dcr.nh.org](mailto:FRC@dcn.nh.org)

Website: www.nh.gov/nhsl/frc

NH 2-1-1

NH 2-1-1 connects callers to information about critical health and human services available in the caller's community. They offer a call line and an online database of community services. This database contains information for over 1,800 health and human service providers and 4,500 service locations.

PO Box 211

Manchester, NH 03105

Information and Resource Line: 211

Phone: (866) 444-4211; TTY Number: (603) 634-3388

Email: 211nh@211nh.org

Website: www.211nh.org

NH Children's Behavioral Health Collaborative

The Collaborative is a multi-disciplinary initiative fixing barriers and improving behavioral health outcomes for children, youth and their families in New Hampshire. The Collaborative represents the largest ever collaboration of New Hampshire child and family organizations and agencies – more than 50 – focused on mental health and substance use disorders for children, youth and families. The goal of the Collaborative was to develop and implement a plan that would transform the current delivery system.

10 Ferry Street, Suite 308

Concord, NH 03301

Phone: (603) 225-9540, ext. 119

Email: emalley@new-futures.org

Website: www.nh4youth.org

New Hampshire Family Voices (NHFV)

NHFV operates a “Family to Family Health and Education Center” with one-to-one phone assistance, educational materials, a lending library and quarterly newsletter.

129 Pleasant Street
Concord, NH 03301
Toll Free Number: (800) 852-3345, ext. 4525
Phone: (603) 271-4525
E-mail: nhfamilyvoices@nhfv.org
Website: www.nhfv.org

Parent Information Center (PIC)

PIC provides information, support and programs on the special education process for parents, families, educators and other professionals who work with children and families.

54 Old Suncook Road
Concord, NH 03302-2405
Phone: (603) 224-7005
Voice and TDD (800) 947-7005 (NH only)
Website: www.picnh.org

NH Department of Health and Human Services (NH DHHS)

NH DHHS is the largest agency in NH state government, responsible for the health, safety and well-being of all NH citizens. The agency partners with many private organizations to meet the needs of individuals, children, families and older adults. NH DHHS administers programs and services such as mental health, developmental disability, substance use and public health.

129 Pleasant Street
Concord, NH 03301
General Phone: (603) 852-3345
General Website: www.dhhs.state.nh.us

The following are district offices/bureaus/divisions and/or programs that apply to children and families and provide you with information about state and local resources/programs.

District Offices

The NH DHHS has district offices in 11 locations across the state. NH citizens can visit these offices to apply for financial and medical programs administered by the state and house staff who work in child protection, juvenile justice and the elderly and older adults programs serving the specific catchment area.

Phone: (603) 852-3345
Website: www.dhhs.state.nh.us/contactus/districtoffices.htm

NH DHHS DISTRICT OFFICES

Berlin District Office & NH Employment Program

650 Main Street, Suite 200
Berlin, NH 03570
(603) 752-7800; (800) 972-6111
TDD Access Relay: (800) 735-2964
Fax: (603) 752-2230

Claremont District Office & NH Employment Program

17 Water Street, Suite 301
Claremont, NH 03743
(603) 542-9544; (800) 982-1001
TDD Access Relay: (800) 735-2964
Fax: (603) 542-2367

Concord District Office & NH Employment Program

40 Terrill Park Drive
Concord, NH 03301
(603) 271-6200; (800) 322-9191
TDD Access Relay: (800) 735-2964
Fax: (603) 271-6451

Conway District Office & NH Employment Program

73 Hobbs Street
Conway, NH 03818
(603) 447-3841; (800) 552-4628
TDD Access Relay: (800) 735-2964
Fax: (603) 447-1988

Keene District Office & NH Employment Program

111 Key Road
Keene, NH 03431
(603) 357-3510; (800) 624-9700
TDD Access Relay: (800) 735-2964
Fax: (603) 352-2598

Laconia District Office & NH Employment Program

65 Beacon Street West
Laconia, NH 03246
(603) 524-4485; (800) 322-2121
TDD Access Relay: (800) 735-2964
Fax: (603) 528-4105

Littleton District Office & NH Employment Program

80 North Littleton Road
Littleton, NH 03561
(603) 444-6786; (800) 552-8959
TDD Access Relay: (800) 735-2964
Fax: (603) 444-0348

Manchester District Office & NH Employment Program

195 McGregor Street, South Tower, Suite 110
Manchester, NH 03102
(603) 668-2330; (800) 852-7493
TDD Access Relay: (800) 735-2964
Fax: (603) 668-5442

Rochester District Office & NH Employment Program

150 Wakefield Street, Suite 22
Rochester, NH 03867
(603) 332-9120; (800) 862-5300
TDD Access Relay: (800) 735-2964
Fax: (603) 335-5993

Seacoast District Office & NH Employment Program

(formerly Portsmouth District Office)
50 International Drive
Portsmouth, NH 03801
(603) 433-8300; (800) 821-0326
TDD Access Relay: (800) 735-2964
Fax: (603) 431-0731

Southern District Office & NH Employment Program

(formerly Nashua District Office)
3 Pine Street Extension, Suite Q
Nashua, NH 03060
(603) 883-7726; (800) 852-0632
TDD Access Relay: (800) 735-2964
Fax: (603) 883-2064

Medicaid

Medicaid federal and state funded health care programs for individuals, children, and the disabled populations.

Phone: (603) 271-4344

Website: www.dhhs.nh.gov/ombp/medicaid/children

Medicaid Care Management will provide coverage through private health care insurance carriers to NH Medicaid recipients, as well as, assist when needed in the coordination of their health care.

Phone: (888) 901-4999

Website: www.dhhs.nh.gov/ombp/caremgmt

Email: nhmedicaidcaremanagment@dhhs.state.nh.us

Office of the Ombudsman

This office responds to complaints and requests for assistance from clients, employees, and members of the general public to resolve disagreements in matters that involve DHHS. It is not a replacement for normal complaint resolution.

Phone: (603) 271-6941

Website: www.dhhs.nh.gov/OOS/ombudsman/index.htm

Bureau of Behavioral Health (BBH)

BBH works to ensure the provision of efficient and effective services to those citizens who meet the criteria for Serious Mental Illness (SMI) for adults and older adults, and Serious Emotional Disturbance (SED) for children set by NH laws and rules. BBH has a main office in Concord and contracts with the ten designated non-profit community mental health centers. The community mental health center that serves your region can be located at: www.dhhs.state.nh.us/dcbcs/bbh/centers.htm.)

Phone: (603) 271-5000

Website: www.dhhs.state.nh.us/dcbcs/bbh.htm

Community Mental Health Centers

REGION I *(North Country)*

Northern Human Services

87 Washington Street

Conway, NH 03818

Telephone: (603) 447-3347

Areas Served: Albany, Bartlett, Bath, Benton, Berlin, Bethlehem, Brookfield, Carroll, Chatham, Clarksville, Colebrook, Columbia, Conway, Dalton, Dixville, Dummer, Easton, Eaton, Effingham, Errol, Franconia, Freedom, Gorham, Hart's Location, Haverhill, Jackson, Jefferson, Lancaster, Landaff, Lincoln, Lisbon, Littleton Lyman, Madison, Milan, Monroe, Moultonborough, Northumberland, Ossipee, Piermont, Pittsburg, Randolph, Sandwich, Shelburne, Stark, Stewartstown, Stratford, Sugar Hill, Tamworth, Tuftonboro, Wakefield, Warren, Waterville, Wentworth Location, Whitefield, Wolfeboro, Woodstock

REGION II *(Upper Valley)*

West Central Behavioral Health

9 Hanover Street, Suite 2

Lebanon, NH 03766

Telephone: (603) 448-0126

Areas Served: Acworth, Canaan, Charlestown, Claremont, Cornish, Croydon, Dorchester, Enfield, Goshen, Grafton, Grantham, Hanover, Langdon, Lebanon, Lempster, Lyme, Newport, Orange, Orford, Plainfield, Springfield, Sunapee, Unity, Washington

REGION III (Lakes)

Genesis Behavioral Health
111 Church Street
Laconia, NH 03246
Telephone: (603) 524-1100

Areas Served: Alexandria, Alton, Ashland, Barnstead, Belmont, Bridgewater, Bristol, Campton, Center Harbor, Ellsworth, Gilford, Gilmanton, Groton, Hebron, Holderness, Laconia, Meredith, New Hampson, Plymouth, Rumney, Sanbornton, Thornton, Tilton, Wentworth

REGION IV (Central)

Riverbend Community Mental Health Center
3 No. State Street, PO Box 2032
Concord, NH 03301
Telephone: (603) 228-1551

Areas Served: Allenstown, Andover, Boscawen, Bow, Bradford, Canterbury, Chichester, Concord, Danbury, Deering, Dunbarton, Epsom, Franklin, Henniker, Hill, Hillsboro, Hopkinton, Loudon, New London, Newbury, Northfield, Pembroke, Pittsfield, Salisbury, Sutton, Warner, Weare, Webster, Wilmot, Windsor

REGION V (Monadnock)

Monadnock Family Services
64 Main Street, Suite 301
Keene, NH 03431
Telephone: (603) 357-4400

Areas Served: Alstead, Antrim, Bennington, Chesterfield, Dublin, Fitzwilliam, Francestown, Gilsum, Greenville, Hancock, Harrisville, Hinsdale, Jaffrey, Keene, Lyndeborough, Marlborough, Marlow, Nelson, New Ipswich, Peterborough, Richmond, Rindge, Roxbury, Sharon, Stoddard, Sullivan, Surry, Swanzey, Temple, Troy, Walpole, Westmoreland, Wilton, Winchester

REGION VI (Nashua and surrounding towns)

Greater Nashua Mental Health Center at Community Council
100 West Pearl Street
Nashua, NH 03060
Telephone: (603) 889-6147

Areas Served: Amherst, Brookline, Hollis, Hudson, Litchfield, Mason, Merrimack, Milford, Mont Vernon, Nashua

REGION VII (Manchester and surrounding towns)

Mental Health Center of Greater Manchester
401 Cypress Street
Manchester, NH 03103
Telephone: (603) 668-4111

Areas Served: Auburn, Bedford, Candia, Goffstown, Hooksett, Londonderry, Manchester, New Boston

REGION VIII (Seacoast)

Seacoast Mental Health Center, Inc.
1145 Sagamore Avenue
Portsmouth, NH 03801
Telephone: (603) 431-6703

Areas Served: Brentwood, Deerfield, East Kingston, Epping, Exeter, Fremont, Greenland, Hampton, Hampton Falls, Kensington, Kingston, New Castle, Newfields, Newington, Newmarket, North Hampton, Northwood, Nottingham, Portsmouth, Raymond, Rye, Seabrook, South Hampton, Stratham

REGION IX (Strafford County)

Community Partners
113 Crosby Street, Suite 1
Dover, NH 03820
Telephone: (603) 516-9300

Areas Served: Barrington, Dover, Durham, Farmington, Lee, Madbury, Middleton, Milton, New Durham, Rochester, Somersworth, Strafford

REGION XI (Southern)

Center for Life Management
10 Tsienneto Road
Derry, NH 03038
Telephone: (603) 434-1577

Areas Served: Atkinson, Chester, Danville, Derry, Hampstead, Newton, Pelham, Plaistow, Salem, Sandown, Windham

Bureau of Developmental Services (BDS)

BDS offers individuals with developmental disabilities and acquired brain disorders a wide range of supports and services within their own communities. BDS has a main office in Concord and contracts with 10 designated non-profit area agencies. To locate the area agency that serves your region visit: www.dhhs.nh.gov/dcbcs/bds/agencies.htm.

Phone: (603) 271-5034
Website: www.dhhs.state.nh.gov/dcbcs/bds

Under BDS is Special Medical Services which is a NH Title V Program for Children with Special Health Care Needs and administers health programs and services for children ages birth to 21 years who have, or are at risk for a chronic medical condition, disability or special health care need. Programs include care coordination services, support for child development and neuromotor clinics, nutritional and feeding/swallowing consultation, psychological and physical therapy services and support for the NH Family Voices and Partners in Health programs.

Phone: (603) 271-4488
Website: www.dhhs.nh.gov/dcbcs/bds/sms

Bureau of Drug and Alcohol Services (BDAS)

BDAS works in reducing alcohol and other drug problems thereby increasing opportunities for citizens to achieve health and independence. They provide information about treatment and supports for individuals impacted by substance misuse/addiction and other information – i.e., a clearinghouse and lending library.

Phone: (603) 271-6738

Website: www.dhhs.nh.gov/dcbcs/bdas

Bureau of Elderly and Adult Services (BEAS)

BEAS provides a variety of social and long-term supports to adults age 60 and older and to adults between the ages of 18 and 60 who have a chronic illness or disability.

BEAS staff are located at NH DHHS District Offices throughout the state. The main office is located in Concord and is responsible for administrative support and general program and financial planning.

Phone: (603) 271-9203

Website: www.dhhs.nh.gov/dcbcs/beas

Bureau of Homeless and Housing Services (BHHS)

BHHS works with NH communities to develop programs and services for NH's homeless populations. These services are offered at the local level through community partners and service providers. The BHHS office is located in Concord and can provide information on where individuals can access housing/housing assistance programs.

Phone: (603) 271-9196

Website: www.dhhs.state.nh.us/dcbcs/bhhs/contact.htm.

Division of Child Support Services (DCSS)

DCSS helps families establish and enforce child support orders-both medical and financial. DCSS can also establish paternity with or without the help of the courts. They offer a range of services and their office is located in Concord.

Phone: (603) 271-4227

Website: www.dhhs.state.nh.us/dcscs/contact.htm

Division for Children, Youth and Families (DCYF)

DCYF manages child protection and juvenile justice services. These services include permanency, foster care, foster care health programs, adoption, adolescent programs, child development bureau, and the Head Start State Collaborative Office. The main office is in Concord and is responsible for administrative support, general program, and financial planning. DCYF staff are located in the NH DHHS district offices.

Phone: (603) 271-4451

Website: www.dhhs.state.nh.gov/dcyf

Division of Family Assistance (DFA)

DFA administers programs and services for eligible NH residents by providing financial, medical, food & nutritional assistance, help with child care costs and emergency help to obtain and keep safe housing. DFA determines initial and continuing eligibility, the amount of benefits and delivery using federal and NH guidelines and policies. DFA is located in the NH DHHS district offices.

Phone: (603) 271-9700

Website: www.dhhs.nh.gov/DFA

Division of Public Health Services (DPHS)

DPHS is charged with the authority and accountability to enforce laws to protect the public's health in areas as varied as the inspection of food establishments and the prevention of childhood lead poisoning. They respond promptly to public health threats, inquiries and emerging issues (i.e., Suicide Prevention). They also partner with the Bureau of Drug and Alcohol to establish 13 Regional Public Health Networks to partner with their communities to build leadership and address complex public health issues. (To locate the public health network that serves your region visit: www.nhphn.org).

Phone: (603) 271-4501

Website: www.dhhs.nh.gov/DPHS

Office of Minority Health and Refugee Affairs (OMHRA)

OMHRA has three primary areas of responsibility which include providing a sustained focus on the provision of culturally and linguistically appropriate services by NH's residents by DHHS; maintaining communication with racial, ethnic and other medically underserved populations and collaborating and partnering with federal and regional state minority health offices and NH disparity initiatives.

Phone: (603) 271-3986 or TDD Access Relay: (800) 735-2964

Website: <http://www.dhhs.nh.gov/omh/>

Other Resources

Alcohol and Other Substances

F.A.S.T.E.R. (Families Advocating Substance Treatment, Education and Recovery)

If you are a parent concerned about substance use by your child, teen or young adult, you are not alone. New Hampshire has a drug problem. Many families are suffering in silence. Come hear from other parents sharing their stories and gain information, support, and resources to answer your questions and address your concerns. Drug addiction is a preventable disease when information and intervention happens early. Treatment works and recovery is possible. It is okay to ask for help. As a parent, you can play an important role in prevention and in supporting your child's recovery. For locations of peer support groups, you can call NAMI New Hampshire at (603) 225-5359.

New Futures

New Futures is a non-partisan, nonprofit organization that advocates, educates and collaborates with state and local communities to prevent and reduce alcohol and other drug problems in NH.

10 Ferry Street
Concord, NH 03301
Phone: (603) 225-9540
Website: 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.

Treatment Referral Line: (800) 662-4357
Website: findtreatment.samhsa.gov/about.htm
<https://findtreatment.samhsa.gov/>

Education

New Hampshire Department of Education (NH DOE)

The NH DOE offers a wide variety of programs and services in support of New Hampshire's students, teachers, educators, administrators, families and community members. The organization is organized into these Divisions: Career Technology and Adult Learning, Higher Education, Higher Education Commission, Educational Improvements and Program Support.

101 Pleasant Street
Concord, NH 03301
Phone: (603) 271-3494
Website: www.education.nh.gov/

NH DOE – Bureau of Special Education

Special Education provides and promotes leadership, technical assistance and collaboration statewide to ensure all children and youth with disabilities in New Hampshire. Oversees and implements educational programs for New Hampshire students with disabilities. 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) 271-3493
Critical Call Line: (603) 271-3741
Website: www.education.nh.gov/instruction/special_ed

NH DOE – Bureau of Vocational Rehabilitation

The Bureau of Vocational Rehabilitation (BVR) is joint state/federal program that seeks to empower people to make informed choices, build viable careers, and live more independently in the community. They offer School Transition Services for youth with disabilities between the ages of 16 and 21. The main office is in Concord and there are 8 regional offices that serve the citizens of NH. The regional offices locations and contact information are listed on the BVR website page.

21 South Fruit Street, Suite 20
Concord, NH 03301
Phone: (603) 271-3471
Website: www.education.nh.gov/career/vocational

Head Start Programs

Early Head Start is a program for families with infants and toddlers ages birth to three. Head Start is a program that helps eligible young children between the ages of three and five grow up ready to success in school and life. Parents with children in Head Start participate in all aspects of the program. Parents do not pay a fee for Head Start or Early Head Start. Services include center-based, home-based or a combination of both.

Division of Child, Youth, and Families
129 Pleasant Street
Concord, NH 03301
Phone: (603) 271-7190
Website: www.dhhs.state.nh.us/dcyf/headstart

New Hampshire Connections (NHC)

NH Connections supports school district personnel and families of children with disabilities to build and strengthen family-school partnerships in special education. NHC provides research-based best practice resources, direct supports, facilitation, training and assistance on a statewide, regional and individual basis to schools, school districts on creating and maintaining family-school partnerships in special education. NHC trains and supports Parent Leaders in building and maintaining family-school partnerships.

54 Old Suncook Road
Concord, NH 03301
Phone: (603) 224-7005
Website: www.nhconnections.org

Financial and Medical Assistance-Federal Programs

Social Security Administration (SSA)

The SSA administers a wide variety of benefit and recipient financial and medical programs i.e. Supplemental Security Income (SSI), Social Security Disability Insurance Benefits (SSDI), and Social Security Child's Insurance Benefits. There are 6 Social Security Offices, 1 Disability Determination Service, and 1 location for the Office of Disability Adjudication and Review in the State of New Hampshire to serve NH residents.

Website for Types of Benefits: www.ssa.gov/oact/progdata/types.html
Website for Social Security Offices: www.socialsecurityofficelocations.com

Phone numbers for NH Social Security Offices:

Concord – (603) 225-8475 or (888) 397-9798; Keene – (603) 352-3487 or (800) 772-1213;
Littleton – (603) 444-2945 or (800) 772-1213; Manchester – (603) 641-2180 or (800) 772-1213;
Nashua – (603) 880-0295 or (800) 772-1213; Portsmouth – (603) 422-0716 or (800) 772-1213.

Guardianship Rights

Office of Public Guardian

OPG is a private non-profit corporation that provides guardianship and advocacy services to citizens in NH. This is statewide service to incapacitated adults including those with developmental disabilities, mental illness, dementia and traumatic brain injury.

1 Pillsbury Street, Suite 400
Concord, NH 03301
Phone: (603) 224-8041
Website: www.opgnh.com

Granite State Guardianship Services

Granite State Guardianship Services is a private, non-profit agency providing guardianship, protective and fiduciary services to persons with disabilities in New Hampshire.

34 Jefferson Road
Whitefield, NH 03598
Phone: (603) 837-9561
Website: www.gsgs.org

18 Low Avenue
Concord, NH 03301
Phone: (603) 224-0805

HOUSING (federal funding)

New Hampshire Housing Finance Authority (NHHFA)

NHHFA offer safe, fixed rate mortgages to low-and moderate-income home buyers; provide rental assistance to low-income families and individuals; and finance the development of quality, affordable rental housing in New Hampshire. NHHFA receives no state government funding.

Mailing Address:

P.O. Box 5087

Manchester, NH 03108

Phone: (800) 640-7239

TDD: (603) 472-2089

Website: www.nhhfa.org

INDEPENDENT LIVING SUPPORTS

Granite State Independent Living Foundation (GSIL)

GSIL is a statewide non-profit organization that focuses on 4 core services of education, information, advocacy and support for seniors and people with disabilities including mental illness. Through their Home Care Services, Community-Based Disability Supports and Employment Services they assist people with the tools for living life independently.

21 Chenell Drive

P.O. Box 7268

Concord, NH 03302-7268

Phone: (603) 228-9680

Website: www.gsil.org

Granite State Federation of Families for Children's Mental Health (GSFFCMH)

GSFFCMH is a non-profit membership driven organization and is a chapter of the National Federation of Families for Children's Mental Health. Their mission is to provide leadership in the field of children's mental health and develop the necessary human and financial resources to meet the goals. They offer a warm line, training and support to families and professionals, youth support, and participate in a variety of state and local initiatives to provide a voice for families.

497 Hooksett Road

Manchester, NH 03301

Phone: (603) 296-0692

Email: gsffcmh@aol.com

Website: www.gsffcmh.org

Legal and Advocacy Services

Disabilities Rights Center, Inc. (New Hampshire)

A private, nonprofit agency that provides information, referral, legal representation, and advocacy for individuals with disabilities on a wide range of disability related problems.

18 Low Avenue
Concord, NH 03302-3660
Phone: (603) 228-0432
(800) 834-1721 (Voice and TTY)
E-mail: advocacy@drcnh.org
Website: www.drcnh.org

Youth Law Project (YLP)

YLP works with children and teenagers who are facing long term suspensions and expulsions from school, delinquency or CHINS petitions and youth at risk of having such petitions filed against them. YLP does not provide representation in delinquency or CHINS cases, but works closely with the public defenders and court-appointed counsel to determine how best to meet the youth's needs. This is a project under New Hampshire Legal Assistance.

15 Green Street
Concord, NH 03301
Phone: 1-800-639-5290
Website: www.nhla.org

NH Legal Assistance (NHLA)

NHLA is a non-profit law firm offering legal services in civil matters to seniors and eligible low-income persons. There are 6 office locations throughout New Hampshire.

117 No. State Street
Concord, NH. 03301
General Phone: (603) 224-4107
Website: www.nhlegalaid.org

Mental Health Psychiatric Hospital – Public

New Hampshire 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. Most people are admitted to NHH on an involuntary basis; a few individuals are admitted on a voluntary basis. NHH works closely with the community providers. Children and adolescents are admitted and treated within NHH at the Anna Philbrook Unit.

36 Clinton Street
Concord, NH 03301
(603) 271-5300
(800) 735-2964 (TDD)
www.dhhs.state.nh.us/dcbcs/nhh/index.htm

Publications on Mental Health

National Alliance on Mental Illness (NAMI – Arlington, VA)

NAMI is the nation's largest grassroots mental health organization dedicated to building better lives for those who live with mental illness. NAMI advocates for access to services, treatment, supports and research and is steadfast in its commitment to raise awareness and build a community for hope for all of those in need. There are NAMI chapters all over the United States and their territories.

3803 N. Fairfax Dr., Suite 100
Arlington, Va 22203
Phone: (703) 524-7600
Helpline: (800) 950-6264
Website: www.nami.org

National Alliance on Mental Illness New Hampshire (NAMI NH)

Through education, we can help to eradicate stigma. NAMI NH has a Mental Health Resource Center with a wide range of publications, literature, DVD's, etc. that are available for loan. There is also information available through our website.

85 No. State Street
Concord, NH 03301
Phone: (603) 225-5359
Website: www.naminh.org

National Institute of Mental Health (NIMH) – Federal

NIMH's mission is to transform the understanding and treatment of mental illnesses through basic and clinical research, paving the way for prevention, recovery and cure. They offer a wide variety of publications, DVD's, brochures, etc. related to mental health/mental illness that are available to the public usually at no charge.

6001 Executive Boulevard, Room 6200, MSC 9663
Bethesda, MD 20892-9663
Toll Free Phone: 1-866-6-5-6464
TTY: (301) 443-8431 (TTY)
Website: www.nimh.nih.gov

Appendix D. Useful Forms

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.

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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.

Name of Test, Person Administering	Areas Tested	Dates Given	Results/Recommendations (How do results address the referral question?)

***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 _____

Appendix D. Useful Forms _____

Educational Remediation

List special education services, tutoring, speech therapy, or other remediation received.

Dates of Remediation	Type of Remediation	Describe the Experience
---------------------------------	----------------------------	--------------------------------

From: / /

To: / /

From: / /

To: / /

From: / /

To: / /

From: / /

To: / /

From: / /

To: / /

From: / /

To: / /

From: / /

To: / /

From: / /

To: / /

What does your child like best about the school day? _____

What does your child like least about the school day? _____

Child's Medical History

Agencies and Practitioners Contacted

[illegible]

Appendix D. Useful Forms.

Diagnoses

[illegible]

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: / /
			From: / / To: / /
			From: / / To: / /
			From: / / To: / /

Any allergies to medications? _____

Which ones? _____

Appendix D. Useful Forms

Medical Testing

[illegible]

Immunizations and Contagious Diseases

Date	Immunization	Reaction
/ /	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	
/ /		
/ /		

Date	Contagious Disease	Severity (include temperature)
/ /		
/ /		
/ /		
/ /		
/ /		
/ /		
/ /		
/ /		

Appendix D. Useful Forms

Allergy Record

Keep this record up to date, and make copies to distribute during emergency visits.

Child's Full Name

Date of Birth

The above-named child is allergic to the following medications and foods:

Tracking Expenses and Insurance Claims

Dates of Visit / /	Practioner's Name, Specialization, Address, Phone	Purpose of Visit, Referred By	Cost of Visit \$	Date Claim Submitted, Amount Paid \$ / /
/ /			\$	\$ / /
/ /			\$	\$ / /
/ /			\$	\$ / /
/ /			\$	\$ / /
/ /			\$	\$ / /
/ /			\$	\$ / /
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/ /			\$	\$ / /
/ /			\$	\$ / /
/ /			\$	\$ / /
/ /			\$	\$ / /

Medicaid Care Management

A suggested process for making an informed decision

This worksheet is intended to help you through the process of making an informed decision regarding your child's Medicaid and their new Care Management Health Plan.

To talk with a service representative call 1-888-901-4999 and they will assist you to enroll with the Health Plan or your choice.

To learn about each of the Managed Care Plans, visit the NH Department of Health and Human Services website
<http://www.dhhs.nh.gov/ombp/caremgmt/>

If you have an NH Easy account, you can enroll on line with NH Easy (www.nheasy.nh.gov).

You may want to call your child's provider and inquire which Plans they are in enrolled with which will affect your decision—may make it easier.

You still have Medicaid so be sure to keep that card and show it when accessing medical/mental health services.

The Tool

Once you have completed the table below, look at your “must keep” column and which Health Plan lists your child's providers. Think about providers in other columns and decide on a plan that best suits your child's needs.

Child's Providers/ Services	How many times a year does your child see the provider?	Prioritize What is the most important for you and your child? Indicate: 1. Must keep 2. Change Possible 3. Willing to Change	Medicaid Health Plan Check off your providers listed in this Plan's network Well Sense Health Plan	Medicaid Health Plan Check off your providers listed in this Plan's network Healthy Families
Primary Doctor or Pediatrician's Name:				
Specialist Name (i.e. Neurologist, Cardiologists):				
Psychiatrist's Name:				

Child's Providers/ Services	How many times a year does your child see the provider?	Prioritize What is the most important for you and your child? Indicate: 1. Must keep 2. Change Possible 3. Willing to Change	Medicaid Health Plan Check off your providers listed in this Plan's network Well Sense Health Plan	Medicaid Health Plan Check off your providers listed in this Plan's network Healthy Families
Community Mental Health Center:				
Rehabilitative Services (i.e. PT and OT, Speech and Language)				
Other Medical/ Mental Health Providers: List Below				
Pharmacy Name:				
Transportation:				
Other:				
What "extra" benefits offered by the Health Plan would you find helpful? Identify them:				

Adapted with permission from Medicaid Care Management "A Tool for Families Having Children with Special Healthcare Needs" developed by NH Family Voices, Concord, NH.

Appendix D. Useful Forms

Mental Health Emergency Information Sheet

Date Completed: _____

Youth Name: _____ Age: _____ D.O.B: _____

Suicide Attempts: ☐ Yes ☐ No If yes, please explain: _____

Address: _____ Town/City: _____

Telephone Number: _____ Cell Phone Number: _____

Child lives with: Parent(s)/Primary Caregiver's Name: _____

Name of Other Adult(s): _____ Relationship: _____

Siblings: Name: _____ Age: _____ Name: _____ Age: _____

Name: _____ Age: _____ Name: _____ Age: _____

Pets: Name and type of pet(s): _____

Strategies:

What approach or intervention would increase symptoms/behaviors and escalate the situation?

What is helpful to the youth to get himself/herself into control or defuse the situation?

Medications: _____ **Diagnosis:** _____

Name: _____ Dose: _____ Frequency: _____

Name: _____ Dose: _____ Frequency: _____

Name: _____ Dose: _____ Frequency: _____

Prescribing Doctor: (Name and Phone Number):

Mental Health Emergency Service Provider (Name, Location and Phone Number):

Local Police Department (Address, Emergency Number, Non-Emergency Number):

Current Mental Health Providers: (Name, agency, location and phone number)

Insurance Carrier, Policy Number, Owner of Policy, Contact Information:

Family, friends who can assist with childcare, transportation to the hospital: (Name, relationship and telephone number):

Other Notes:

Appendix D. Useful Forms

NAMI New Hampshire

Improving the lives of all persons affected by mental illness.

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 made possible through the support of our members. To become a member, visit our website, or contact NAMI NH at the phone number or e-mail address listed below.

Our Mission

NAMI New Hampshire is a grassroots organization working to improve the quality of life for all by providing support, education and advocacy for people affected by mental illness.

Our Vision

We envision a future where people affected by mental illness have hope, help, and health, and are able to:

- access the supports and evidence-based treatment necessary for recovery,
- have a lifespan that is not cut short by their mental illness or co-morbid conditions, and
- reach their full potential, living in their communities free from discrimination and stigma.

NAMI New Hampshire

85 No. State Street, Concord, NH 03301

Phone: (603) 225-5359

Information and Resource Line: (800) 242-6264

Website: www.naminh.org

Fax: (603) 228-8848

E-mail: info@naminh.org

NAMI New Hampshire

85 North State Street, Concord, NH 03301

Phone: (603) 225-5359 or (800) 242-6264

Fax: (603) 228-8848

E-mail: *info@naminh.org*