

Taking Charge

An Introductory Guide to Choosing the Most Effective Services for the Mental, Behavioral, and Emotional Health of Youth Within a System of Care

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THIS GUIDE AS YOUR MAP

This guide provides a “roadmap” or path to help youth and families move through the process of seeking help. It is not meant to be a stand-alone document; rather, it is one tool among many designed to help youth and families become better partners with their mental health providers in deciding the best course of treatment. The guide gives examples of the emotional and behavioral disorders that are most commonly diagnosed in adolescents and provides an overview of the various intervention options available. The guide closes with a vignette (an example scenario) presenting a conversation that could take place between a family worried about their child abusing substances and a healthcare provider. This guide is designed to help provide youth and families with information as they begin to seek treatment in a system of care. A system of care is “a comprehensive spectrum of mental health and other necessary services, which are organized into a coordinated network to meet the multiple and challenging needs of children and adolescents with severe emotional disturbances and their families” (Pires, 2002). An array of services and supports make up a system of care; included in this is effective and evidence-based clinical treatment. A critical principle in system of care is that services, supports, and treatments should be family driven and youth guided. Thus families and, whenever possible, youth must be given the necessary information to make informed decisions and “take charge.”

The journey that is examined in this guide usually begins when a family seeks help for a young person based on concerns about his or her ability to get along with others, express emotions appropriately, or control behaviors. Once a youth and family have entered a system of care, the youth and family members will speak with a mental health professional. After an initial screening, the professional, family, and youth—if appropriate—will decide whether further screenings or evaluations are needed.

The results of additional evaluations will help the professional make a potential diagnosis (or diagnoses). As a team, the mental health professional, family, and youth will then choose a treatment that meets the needs of the youth and his or her family. This guide walks youth and families through the steps to selecting an effective treatment plan. It poses questions and makes observations. A number of family advocacy groups and resources are available to help youth and families who are entering systems of care. Everyone involved in the journey should expect to be treated with respect, have their privacy and confidentiality protected, and have all their questions answered. We hope this guide will provide information and support to youth and families. They are part of a team that is family driven and youth guided, and no one has to make the journey alone.

SIGNS AND SYMPTOMS

Most families begin their journey into a system of care when they notice a change in their child's mood, attitude, or behavior. Some of the most common signs and symptoms that family members, other adults, and peers often cite to describe the changes they see in a young person include:

- Aggressiveness (verbal or physical)
- Academic difficulties
- Impulsiveness
- Substance abuse
- Disinterest in usually enjoyable activities
- Poor social skills
- Hyperactivity
- Frequent disobedience
- Concerns about sexual identity
- Suicidal thoughts
- Risk-taking behavior
- Irritability
- Depression

When talking to a healthcare professional, it is extremely important for the family and youth to describe all of the young person's symptoms, in order to present the most accurate picture of the youth. The more a family and youth are treated and function as true partners in this process, the more accurate the diagnosis (or diagnoses) and treatment intervention can be.

SCREENING AND ASSESSMENT

An assessment is an evaluation aimed at collecting more detailed information about a young person, such as how the youth functions at home, in school, and in the community. The initial assessment is often called a screening. It is a shorter, more general evaluation. If concerns are identified and confirmed, a more in-depth assessment may be done. Assessments are typically conducted by a health professional (for example, a mental health or substance abuse counselor, psychologist, nurse, or doctor) who is skilled in asking questions and figuring out what the answers mean. Comprehensive assessments often include questions in these areas:

- Substance use (risky behaviors)
- Mental health
- Physical health
- Education
- Family history
- Job training or employment
- Living arrangements
- Community
- Financial factors

After the assessment, the youth and family should be given a written report of the findings for their records. The next step is a discussion of the results between the health professional and the youth and family.

DIAGNOSIS AND TREATMENT

Families should be encouraged to ask questions and provide information so that they fully understand and are in agreement with their child's diagnosis (or diagnoses). The most common diagnoses among youth who are evaluated in system of care communities are:

- Oppositional/defiant disorder
- Depression
- Substance abuse
- Conduct disorder
- Attention deficit and hyperactivity disorder (ADHD)

Far less common but important diagnoses include anxiety, post traumatic stress, and bipolar disorder. Children will often show symptoms of more than one of these disorders and be given two or more diagnoses. This is called comorbidity. If the diagnoses involve a substance use disorder and a mental health disorder, they are also referred to as co-occurring. If the diagnoses involve a developmental disability and an emotional disorder, the youth is usually described as having a dual diagnosis.

Many older adolescents have multiple disorders simultaneously, creating the need for a team of providers that understands how to treat all the disorders. The treatment or treatments decided upon by the youth, family, and provider should reflect the symptoms, the diagnosis, and what the youth, family, and provider think will work best for everyone involved in the treatment process. Effective treatment plans include having everyone agree on how best to motivate, monitor, and model the desired change and help the youth avoid the triggers and behaviors that might lead back to the problem behaviors.

CHOOSING THE RIGHT INTERVENTION

Treatment interventions can be broken down into two broad categories: effective practices and evidence-based interventions.

Effective Practices

Effective practices, or "best practices," are treatment interventions that families and service providers believe can help youth and their families but generally have not gone through repeated studies by clinical researchers. These treatment interventions are delivered according to the community's cultural values and standards for care. An example of an effective practice is systemic family therapy, in which the entire family is treated, as opposed to just the youth. It is considered an effective practice because many families, youth, and health professionals describe it as an intervention that works.

Evidence-Based Interventions

Evidence-based interventions are interventions that have undergone a series of standardized clinical research trials and have been shown to be effective with different groups of people who are similar in terms of their diagnoses and often are of the same age, race/ethnicity, and gender. Clinical research trials are studies which are conducted, evaluated, and published using standard methods and reviewed by expert researchers in the field. A very common example of a research trial involves youth who have the same symptoms or diagnoses and are from similar backgrounds. The youth are divided into two groups, and one group receives the treatment being studied while the other group does not. The outcomes for the two groups are compared to see whether the outcomes for the group receiving treatment are significantly better. Then the study is repeated to see if the same results occur. An example of an evidence-based intervention is videotape parent modeling, an intervention that provides videotapes of parents modeling different responses to children's behaviors. It is considered an evidence-based intervention because when it has been replicated using the same standardized approach, the outcomes have been better for the families who received the intervention.

Medication

Depending on the diagnosis, medication prescribed by a physician (preferably a child psychiatrist) can be an evidence-based intervention. The most commonly prescribed medications in systems of care, listed in order of usage, are antidepressants, psycho stimulants, anti psychotics, anticonvulsants, and antihypertensives. Medication is often paired with an effective evidence-based psychosocial intervention. The table on the following page presents an alphabetized list describing the evidence-based interventions that are most widely used for the most common childhood/adolescent diagnoses. It is followed by a chart of the most common diagnoses found in systems of care and the possible intervention options for each.

Evidence-Based Interventions

- **Adolescent community reinforcement approach (ACRA)**—a behavioral treatment integrated with case management and counseling based in the community. The goal of ACRA is to find and use positive rewards that exist naturally in the community to motivate behavior change.
- **Anger coping therapy**—an intervention that attempts to provide youth with more appropriate ways to think and behave when they are angry.
- **Behavior therapy**—an intervention that teaches and uses reinforcers (for example, praise, money, computer time) to encourage positive behaviors and discourage negative ones.
- **Cognitive behavioral therapy (CBT)**—a treatment that helps individuals change their negative or destructive cognitions (thoughts) and behaviors into more positive and appropriate ones. CBT can be used to help change a number of conditions, including depression, inappropriate anger, oppositional behaviors, substance abuse, and anxiety. The treatment can involve assertiveness and relaxation training, modeling, and role play.
- **Delinquency prevention program**—an early intervention targeting aggressive children. A multidisciplinary team implements a home-based training for parents on effective child rearing and a school-based training for children, focusing on social skills.
- **Family therapy**—a treatment involving all family members. Family therapy can occur in the home or other settings. It seeks to change existing unhealthy, negative situations and interactions and prevent the onset of new ones.
- **Functional communication training**—an intervention based on strategies that teach a child to use verbal and positive alternative communication methods to make requests for immediate needs. Such training teaches young people to use their words instead of aggressive, unsafe, or challenging behavior.
- **Interpersonal psychotherapy (IPT)**—improves communication skills and increases self-esteem by working through the relationships and social interactions that a person has with family members and friends. The treatment helps the person identify and develop more adaptive methods for dealing with interpersonal issues.
- **Motivational enhancement therapy (MET)**—a therapy aimed at empowering the individual to make change. MET is based on the principle that people can understand and change unhealthy behavior more easily if they are involved in a therapeutic relationship that (a) is not confrontational, but respectfully honest; (b) helps to explain and address inconsistencies in behavior; (c) provides accurate feedback; and (d) helps develop and encourage healthy choices as alternatives to unhealthy behavior.
- **Multi-systemic therapy (MST)**—an intensive, short-term, home- and family-focused treatment approach for youth with severe emotional disturbances. MST intervenes directly in the youth's family, peer group, school, and neighborhood by identifying and working to change factors or issues that contribute to the youth's problem behaviors. The main goal of MST is to have parents and community organizations learn to manage and motivate the positive changes in the youth so that his or her healthy behavior will persist after brief (3 to 4 months) and intensive treatment.
- **Pharmacotherapy**—medication prescribed by a physician (preferably a child psychiatrist). The physician is often part of the system of care team or hopefully works closely with the team and helps to monitor the dose and side effects according to the outcome.
- **Rational emotive therapy**—an approach that helps youth realize that the things they think and say to themselves, and not what actually happens to them, are what causes their positive or negative emotions. The therapy helps create a new way of thinking, feeling, and acting.
- **Videotape parent modeling**—an intervention in which parents meet in groups led by a mental health provider to watch videotapes about how to handle their child's behavior. After watching the video, parents discuss and practice the skills for handling behavior in positive ways.

Common Diagnoses and Intervention Options

Diagnosis

Anxiety disorder

Intervention Options

- Cognitive behavioral therapy
- Behavior therapy
- Pharmacotherapy (a common medication used is the class of drug known as selective serotonin reuptake inhibitor, or SSRI)

Attention deficit and hyperactivity disorder

- Behavior therapy
- Videotape parent modeling
- Pharmacotherapy (stimulants such as Adderal, Ritalin, and some atypical drugs like Wellbutrin).

Bipolar disorder

- Pharmacotherapy (medication management needs to be carefully evaluated by the child psychiatrist): mood stabilizers (children and adolescents generally are treated with lithium, but valproate and carbamazepine also are used)

Depression (unipolar)

- Cognitive behavioral therapy
- Interpersonal psychotherapy for adolescents (nonspecific individualized approach that aims to change the underlying emotions and dysfunctional behavior patterns through the relationship with the therapist)
- Pharmacotherapy (medication management needs to be carefully evaluated by the child psychiatrist)

Disruptive behavior disorder
(oppositional or defiant conduct)

- Anger coping therapy
- Delinquency prevention program
- Multi-systemic therapy
- Cognitive behavioral therapy (problem-solving skills training)
- Rational emotive therapy
- Videotape parent modeling
- Pharmacotherapy (psycho stimulants, mood stabilizers, and anti psychotics)

Post-traumatic stress disorder

- Cognitive behavioral therapy

Substance use disorder (abuse/dependence on nicotine, alcohol, marijuana, or other legal/illegal substances)

- Adolescent community reinforcement approach
- Cognitive behavioral therapy
- Family therapy
- Motivational enhancement therapy
- Cognitive behavior therapy and motivational enhancement therapy combined
- Multi-systemic therapy

Questions

Important questions for a family or youth to ask a system of care provider concerning treatment options may be:

- How do I know if a particular treatment is the best for my child and my family?
- What kinds of problems are the treatments designed to help?
- What training and experience does the provider have with the treatment?
- What will be required of my child and family if we choose this treatment?
- How long will the treatment take, and where do we receive it?
- Where do I find out more about medications?

SUBSTANCE ABUSE VIGNETTE

What follows is a dialogue that may occur between a family with a youth who is abusing substances and their system of care provider. If the youth has a diagnosis other than substance abuse, the conversation will follow a similar path, but the specific questions asked, treatment interventions suggested, and community support offered will be targeted for that particular diagnosis. Here is how the question-and-answer session might look with the family asking the questions (Q) and the provider supplying the answers (A):

Q. I don't feel like I know my child anymore. He is moody all the time. His grades are dropping, and he doesn't seem to be putting any effort into school. I don't even recognize his friends. What's wrong with my child?

A. If a youth has a substance abuse problem, a family may observe the following changes in appearance and behavior:

- Mood—more irritable or depressed
- Energy—overall low energy level; often tired, unable to wake up
- Peer group—old friends are not as important as new friends; family often has not met new friends or does not approve of new friends
- Health—frequent headaches, colds, runny nose, lowered resistance to sickness, and increased absence from school due to illness
- Attitude—negative attitude about spending time with the family; no longer makes it to family events, such as dinner at home
- Academic interest and performance—interest in school drops off, and school is said to be “boring”; increased truancy and lower grades
- Dress and cleanliness—change in dress; decreased interest in appearance

Q. How do I know these changes aren't just typical adolescent behavior or something like “hormones”?

A. It is possible that your child's behaviors do not represent a serious problem, but it is also important to trust your own instincts. If there is significant evidence of a number of the signs and symptoms listed above, and if behavior changes have also been reported by others with whom your child interacts, then there is reason to seek help. If the child displays multiple symptoms, it is best to act immediately. You do not want to wait until the problem intensifies.

Q. I think my child needs help. Where do we begin?

A. In most cases, it is best to enter the system of care with an introduction and orientation for the entire family to explain the steps and clear up any trust and confidentiality issues. As part of the initial assessment, it is recommended that the healthcare professional spend time with each family member individually before discussing next steps. Spending time alone with your child can help the professional build trust and learn more about the youth's problems and concerns.

Q. What kinds of questions will the health professional ask my family?

A. The professional should ask a variety of questions of the family, including:

When did you first notice the changes? Has the family seen any physical evidence of substance use/abuse (such as drug paraphernalia, cigarette packs, alcohol bottles)? The health professional should ask questions designed for the age of the child being interviewed. Most often the professional will ask a set of short questions to “screen” the youth and see if he or she needs a more comprehensive assessment. Substance use screening and assessment tools developed specifically for adolescents between 12 and 18 years old include: the CRAFFT (Knight et al., 2002); the Massachusetts Automated Youth Screening Instrument, 2nd Edition (MAYSI-2) (Grisso & Barnum, 2000); and the Global Appraisal of Individual Needs, AIN Quick Version (GAIN-Q) and Full Version (Dennis et al., 2002). Others can be found in the Substance Abuse and Mental Health Services Administration's (SAMHSA's) Treatment Improvement Protocol (TIP) Series publications, numbers 31 (Screening and Assessing Adolescents With Substance Use Disorders) and 32 (Treatment of Adolescents With Substance Use Disorders).

The assessment period may vary depending on the tools chosen by the healthcare provider. However, the assessment process should continue throughout the treatment stages. If substance use disorder is suspected, the professional can also recommend initial and followup urine tests. These tests check for any drugs left in the body. Although often seen as a violation of privacy, urine tests help determine what drugs are involved at the start of treatment and can actually help many youth refuse and stay off drugs during and after treatment.

Q. How long will the initial assessment process take?

A. Most initial assessments take anywhere between 1 to 3 hours. However, the assessment process should continue throughout the treatment stages, because the understanding of the problem will change as your child goes through the treatment.

Q. What kind of diagnosis should I expect?

A. When a child is diagnosed with a substance use problem, he or she should be diagnosed for either a specific substance (for example, nicotine, alcohol, or marijuana) or for a combination of substances. The problem may be diagnosed as abuse, meaning the substance is causing impairment at school, in family activities, with the law, or in other areas of life. However, if alcohol or other drugs are needed “just to function,” “to wake up,” or “to feel okay about everyday activity,” the diagnosis will be dependence, suggesting that the youth's body now craves the substance, as a result of regular use. For many youth, the acknowledged frequency and type of substance use can vary dramatically based on their ability to access the substance(s) and their willingness to give an accurate account of their usage. Therefore, it is best for the healthcare professional to start with a “working diagnosis” and re-assess frequently.

Q. How will the treatment intervention be selected?

A. The treatment intervention will, whenever possible, be selected with input from the family, youth, and mental health provider. Remember, the specific treatment intervention is only one piece of a broad treatment plan. Regardless of the intervention chosen, everyone involved needs to understand the treatment plan so they can help the youth avoid the triggers that cause and support his or her substance use. In other words, your family, including you and your child, should be able to identify the people, places, and emotions that create “risky situations” so that they can be avoided. For substance abuse, the most common interventions are (a) family alcohol and drug education and/or family therapy; (b) motivational enhancement therapy; (c) cognitive behavioral therapy; and (d) adolescent community reinforcement approach.

Q. How will I know when my child’s treatment intervention is over?

A. Effective and evidence-based treatments vary in length and number of sessions. It is typical for the active treatment phase to last between 3 and 6 months. Sessions may occur once a week, though more intensive options require meetings up to three times per week. When the active phase of treatment is over, the continuing care and followup phase begins. The continuing care phase often includes a self-help group, family groups, and followup assessments (including urine tests) to reinforce and help maintain the positive changes that occurred in treatment. If the treatment has not been successful, it may be suggested that families try either a more intense intervention (with longer duration and more frequent sessions) or another effective or evidence-based intervention option.

THE OPEN ROAD THAT LIES AHEAD

This guide has attempted to lead youth, families, and professionals through the various stages of seeking health treatment within a system of care—from identifying signs to seeking an evaluation, to getting a diagnosis, to, finally, exploring treatment options. However, it is important to realize that beginning treatment will not make the problem disappear instantly. Families will need support throughout the process, and they can encourage each other and help each other along the way. Youth and families should be encouraged to turn to people in their community. In fact, that is what a system of care is all about. In the system of care, there will be families who have gone through the process and can help guide and support others. There are also family and youth organizations that can provide support, education, and advocacy. Remember, there is a community of families and professionals who want to help every child and family get through this rough time, move ahead in the right direction, and stay on the path to recovery. In journeying to recovery, a youth and family might follow these steps:

Step 1 Identify signs that are of concern.

Step 2 Seek an evaluation to assess a possible diagnosis.

Step 3 Explore treatment options that best fit the youth’s diagnosis and needs.

Step 4 Choose and use the most effective treatment option.

Step 5 Evaluate how effective the treatment is with the professional.

Step 6 Continue monitoring and motivating positive emotional and behavior change. If lapse or relapse occurs, plan to reengage in the same or new treatment and refer for additional supports.

RESOURCES

The resources below provide information and help concerning child and family mental health and substance abuse interventions.

- **Technical Assistance Partnership for Child and Family Mental Health (TA Partnership)**

<http://www.tapartnership.org>

The TA Partnership’s Web site is a dynamic resource offering information and links for all topics related to developing systems of care. It also includes a searchable consultant pool, technical assistance, a monthly newsletter, a calendar of events, and electronic registration pages for Webinars and system of care community meetings. The site also provides contact information for resource specialists and other supports for system of care communities.

- **Youth Involvement in Systems of Care: A Guide to Empowerment**

<http://www.tapartnership.org/youth/youthguide.asp>

Youth Involvement in Systems of Care: A Guide to Empowerment provides a valuable resource to youth, youth coordinators, family members, professionals, and other adults working with young people. It aims to educate all professionals and adults who work with young people on the importance of engaging and empowering youth. This guide will help build the foundation and framework for youth involvement and enhanced opportunities for young people to contribute to system change.

- **Chestnut Health Systems: Lighthouse Institute Publications**

<http://www.chestnut.org/li/bookstore>

This Web site offers many important references on adolescent substance abuse treatment, including program development, program and clinical management tools, assessment tools (for example, GAIN), and manuals for implementing effective interventions. The site also contains manuals from both the five-volume Cannabis Youth Treatment Series and adolescent treatment models.

- **Evidence-Based Treatment for Children and Adolescents** <http://www.effectivechildtherapy.com>
This Web site provides the general public and practitioners with the most up-to-date information about mental health treatment interventions for children and adolescents. Effective and scientifically evaluated treatment interventions are defined and listed for the treatment of many common childhood mental disorders. The site is maintained and sponsored by the Society of Clinical Child and Adolescent Psychology and the John D. and Catherine T. MacArthur Foundation.
- **National Institute on Drug Abuse (NIDA)** <http://www.nida.nih.gov>
The NIDA Web site hosts an enormous quantity of educational information on the effects of drugs and effective treatment. Of special note is the publication *Principles of Drug Addiction Treatment: A Research-Based Guide* (National Institutes of Health, 1999).
- **National Institute of Mental Health (NIMH)** <http://www.nimh.nih.gov>
The NIMH Web site contains valuable and timely information on research for mental health disorders and effective and evidence-based interventions. News bulletins and links to information and organizations related to many of the common mental health diagnoses (such as anxiety, ADHD, depression, and bipolar disorder) can also be found on the site.
- **Substance Abuse and Mental Health Services Administration (SAMHSA)** <http://www.samhsa.gov>
The SAMHSA Web site provides vital resources for the substance abuse and mental health field, including information on funding, policy, treatment, and other initiatives. Of special note are links to the National Mental Health Information Center (<http://mentalhealth.samhsa.gov>) and the Treatment Improvement Exchange (<http://www.treatment.org>).

The resources below are the most well-known advocacy groups for families.

- **Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD)** <http://www.chadd.org>
CHADD is the national organization representing individuals with ADHD, providing education, advocacy, and support. The Web site includes research and resource information, public policy updates, a professional directory, and discussion boards.
- **Depression and Related Affective Disorders Association (DRADA)** <http://www.drada.org>
DRADA serves individuals affected by a depressive illness, while also helping family members, healthcare professionals, and the general public. DRADA assists self-help groups, provides education and information, and lends support to research programs. The organization promotes public knowledge of signs, symptoms, and resources available to persons affected by these illnesses in hopes of eliminating the stigma attached to mood disorders.
- **Federation of Families for Children's Mental Health** <http://www.ffcmh.org>
The Federation of Families for Children's Mental Health is a national family-run organization dedicated to helping children with mental health needs and their families achieve a better quality of life. The organization provides advocacy, technical assistance, and an annual conference. The Web site provides resources related to policy, evaluation, and systems of care.
- **National Alliance for the Mentally Ill (NAMI)** <http://www.nami.org>
NAMI is a support and advocacy organization for families and friends of people who have severe mental illnesses. NAMI is dedicated to the eradication of mental illnesses and the improvement of the quality of life of all whose lives are affected by these diseases. The Web site includes resource information about mental illness, contact information for state and local programs, discussion groups, and advocacy and news updates.
- **National Youth Leadership Network (NYLN)** <http://www.nyln.org>
NYLN is the national voice for young leaders with disabilities. It aims to ensure that all youth who have disabilities are given opportunities to be involved in their communities, develop their leadership skills, and have their voices heard. The organization's Web site includes numerous resources, information on upcoming events, and contact information for youth experts on a variety of issues.

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