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National Alliance on Mental Illness

**Southwestern
Illinois**

Children and Adolescent with Brain Disorders

Information & Resources Guide

2011 Second Edition

National Alliance on Mental Illness (NAMI)

NATIONAL ALLIANCE ON MENTAL ILLNESS SOUTHWESTERN ILLINOIS

Where families are helping families to manage severe mental illness

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Purpose of This Guide

If a child/adolescent in your family has a mental illness, you are not alone. Members of the National Alliance on Mental Illness have learned the hard way about mental illness and services available. We have compiled information in this guide from many different sources, in the hope that it will be helpful to others as they find ways to understand and cope with mental illness in their family.

We acknowledge with sincere gratitude the Madison County Mental Health Board whose grant made the printing of this guide possible and NAMI members who were involved in assembling and editing the text, most notably Jane Roennigke, Vice President and Education Coordinator of NAMI Southwestern IL and Kelli Dickerson, social work practicum student at SIUE. This is the first edition of an Information & Resource Guide for Children & Adolescents with Brain Disorders from NAMI Southwestern IL. Much of the information gathered for this guide is from our NAMI National website.

The NAMI SOUTHWESTERN ILLINOIS Resource Guide is intended as an informational resource only and is not intended as legal and/or medical advice. Information contained within this resource guide is subject to change without notice. NAMI Southwestern Illinois does not endorse, nor is liable for, any use of the services listed.

National Alliance on Mental Illness

The National Alliance on Mental Illness (NAMI) is an organization “dedicated to the eradication of mental illness and to the improvement of the quality of life of those whose lives are affected by these diseases.” There are more than a thousand NAMI affiliates in this country; forty of them are in Illinois. Members include individuals with mental illnesses, as well as family members and friends.

The mission of NAMI is to:

- Promote new and remedial programs/legislation that will provide meaningful assistance for consumers. Press for quality in-patient and out-patient treatment of persons with mental illness. Promote community support programs, including appropriate living arrangements linked with supportive social, vocational rehabilitation, and employment programs. Provide and advocate for family support activities.
- Support and advocate for research into the causes, alleviation, and Eradication of mental illness. Seek improvement of private and governmental funding for mental health facilities and services, care, and treatment, and for residential and research programs.
- Work together with other mental health organizations.
- Promote enforcement of patient and family rights.
- Educate our members and the public about severe mental illnesses so that perceptions change and stigma is eliminated.

Most people who join a NAMI affiliate do so because they need information and ways to cope with the mental illness of their family member. They learn by talking with others, by attending educational meetings and through affiliate newsletters.

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When to Seek Help for Your Child

Parents are usually the first to recognize their child has a problem. The earlier problems are addressed, the sooner they are resolved.

Step 1: Validate your concerns. By talking with your child's teachers, daycare or after-school providers, or a close relative who interacts on a regular basis with your child, you can begin to get a picture of how well your child is functioning. It is important to know how he or she is doing when with others, and how teachers or childcare professionals may compare his or her development with children of the same age.

Step 2: Warning signs of trouble. Based on your child's developmental phase, be aware of warning signs that something may be amiss.

CHILDREN OF ELEMENTARY SCHOOL AGE

- Difficulty in going to sleep, or taking part in activities that are normal for the child's age, or refusal to go to school on a regular basis
- Frequent, unexplainable temper tantrums
- Hyperactive behavior, fidgeting, or constant movement beyond regular playtime activities
- A steady and noticeable decline in school performance
- A pattern of deliberate disobedience or aggression
- Opposition to authority figures, and little or no remorse for breaking rules or norms.
- Persistent nightmares
- Poor grades in school despite trying very hard.
- Pronounced difficulties with attention, concentration, or organization

PRETEENS AND ADOLESCENTS

- Sustained, prolonged negative mood and attitude 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
- Abuse of alcohol, and/or drugs or heavy tobacco use
- Intense fear of becoming obese with no relationship to actual body weight; constant dieting; restrictive eating habits; purging food; or vomiting
- Frequent outbursts of anger or inability to cope with problems and daily activities
- Marked change in school performance
- Marked changes in sleeping and/or eating habits
- Persistent nightmares or many physical complaints
- Threats of self-harm or self-injury; harm or violence toward others
- Sexual acting out
- Threats to run away
- Strange thoughts and feelings and unusual behaviors
- Self-injury, talk of suicide or actual violence requires immediate attention.
If necessary take your child to an emergency room where a psychiatric assessment can be done .

Step 3: Talk to your child's doctor. If you realize your child demonstrates any of the

significant behaviors from the above list, you should bring your concerns to your child's doctor. You may want to make a special appointment to talk about the difficulties your child is experiencing.

Ask your child's primary care physician to make a referral to a mental health professional if he or she shares your concerns. A psychological assessment may be useful in order to determine how best to help your child.

Step 4: Get another opinion. Beware of "it's just a phase" if your instinct tells you your child indeed has a problem. Some family physicians and pediatricians may not recognize symptoms of mental disorders. If you are not comfortable that your concerns are adequately addressed by your child's doctor, you can request a second opinion. This might take the form of a consultation with a child and adolescent psychiatrist or developmental pediatrician. The developmental specialist can allay your fears about the appropriateness of behaviors at any given age. He/she also can confirm your concerns and assist you and your primary care physician in obtaining a complete assessment, and arrange for any interventions that may be appropriate. Trust your instincts!

If you suspect that your child may have a mental health problem, you should seek a comprehensive evaluation by a mental health professional. It is especially helpful when this person is trained to work with children and adolescents. Throughout this assessment process, you should be directly involved and ask questions. It is important that you understand the process your child will undergo during an assessment and that you understand the results of the mental health evaluation. If your child is given a diagnosis be sure to ask for the full range of treatment options—therapy, medications, or a combination of both. If you are not completely comfortable with a particular clinician, treatment option, or are confused about specific recommendations, then consider a second opinion. Assessments are performed by specially trained psychiatrists and psychologists.

Before your child begins any treatment regimen, ask the following of your treating clinician:

- What are the recommended treatment options for my child?
- 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 side effects that might be expected?
- What should I do if the problems get worse or there is no improvement?
- What are the arrangements if I need to reach you after hours or in an emergency?
- Who covers for you when you are away from your office, out of town, or on vacation? Do you have an emergency contact number, or answering service?

You may also need to advocate having your child seen in a timely way, by the most appropriate clinician.

What you need to know about medications. Treatment with psychiatric medications is a serious decision for most of us. Conflicting research and "expert" claims have left us all wondering "what's best for my child?" Medications may be an important part of your

child's treatment for a mental health problem. Psychiatric medication should only be used as one part of a comprehensive treatment plan. Ask your child's physician why other forms of therapy are not prescribed if only medication is offered. Although many types of medications have been tested and proven effective in children, there are just as many medications that have not been thoroughly investigated specifically for use in children under 18. When your doctor prescribes medication, ask him if the medication is indicated by the pharmaceutical company, or the Food and Drug Administration (FDA), specifically for use in children. If the clinician cannot answer yes, then this medication is being prescribed "off label," or in other words, the pharmaceutical company that developed the medication has not yet shown its efficacy in treating youngsters under the age of 18. If this is the case, insist that your doctor share with you the reasons for using the medication in question, and whether another form of treatment would be better prescribed.

Even when well-tested medications are used (and there are many safe medicines approved for use in children with a history of effectiveness), ongoing evaluation and monitoring by a physician is essential. By asking the following questions, children, adolescents, and their parents will gain a better understanding of why the psychiatric medication is being used and what to expect in the short and long term.

- Are there any laboratory tests (e.g. heart or blood test, etc.) which 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 will the decision be made to stop this medication?
- How will the medication help my child and how long before I see any improvement?
- Is this medication addictive? Can it be abused? What precautions need to be taken with this medication?
- Should the medicine be taken with food, or at a particular time of day?
- Has this medication proved helpful to other children with a similar conditions?
- What are the side effects that commonly occur with this medication? What rarer side effects have been reported?
- 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?
- What is the recommended dosage? How often will the medication be taken?
- How long does it take before I'll see some results?
- Are there other medications or foods that my child should avoid while taking the medication?
- Are there any activities or sports that my child should not participate in while taking the medication?
- Will any tests (x-rays, MRIs, lab work) need to be done while my child is taking the medication? How often should I expect these tests to be needed?
- Should my child's teacher or the school nurse be informed to watch for any changes as the child begins treatment?
- When possible, your youngster should be included in the discussion about medications, using words they understand.

Sometimes preteens and adolescents can be embarrassed about taking medications, especially at school. This happens when they are singled out to report to a school nurse, or given their medication in front of others. Discuss these circumstances with your child and tell your doctor if your child mentions concerns of this nature.

An additional source of information is can be found on the NAMI National website <http://www.nami.org>, go to “Support & Programs” tab, then select “Child and Adolescent Action Center”.



Additional NAMI (nami.org) website support sections are available on EDUCATION, TRAINING AND PEER SUPPORT CENTER – CONSUMER SUPPORT – NAMI LEGAL CENTER – MISSING PERSONS SUPPORT – INFORMATION HELPLINE (call 1-800-950-6264).



National Alliance on Mental Illness

Printed from sources within the National Alliance on Mental Illness website

Getting an Accurate Diagnosis for Your Child **10 Steps for Families**

Getting an accurate diagnosis for your child can be challenging. Several factors contribute to this challenge, including the following:

- Symptoms – that often include extreme behaviors and dramatic changes in behavior and emotions – may change and develop over time.
- Children and adolescents undergo rapid developmental changes in their brains and bodies as they get older and symptoms can be difficult to understand in the context of these changes.
- Children may be unable to effectively describe their feelings or thoughts, making it hard to understand what is really going on with them.
- It is often difficult to access a qualified mental health professional to do a comprehensive evaluation because of the shortage of children’s mental health providers and some health care providers are reluctant to recognize mental illnesses in children and adolescents.

Despite these challenges, there is still plenty families can do to help their child get an accurate diagnosis and ultimately receive the most effective treatment, supports, and services. Here are ten steps that families should take to help their mental health services provider make an accurate diagnosis:

1. **Record Keeping:** organize and keep accurate records related to your child’s emotional, behavioral, social, and developmental history. The records should include observations of the child at home, in school, and in the community. They

should be shared with the child's treating provider to help in making a diagnosis. The records should include the following information:

- Primary symptoms, behaviors, and emotions of concern;
- A list of the child's strengths;
- A developmental history of when the child first talked, walked, and developed social skills;
- A complete family history of mental illness and substance use disorders – many mental illnesses run in families.
- Challenges the child is facing in school, in social skill development, with developmental milestones, with behaviors, and with emotions;
- The times of day or year when the child is most challenged;

- Interventions and supports that have been used to help the child and their effectiveness – including therapy, medication, residential or community services, hospitalization, and more;
- Settings that are most difficult for the child (i.e. school, home, social situations);
- Any major changes or stresses in the child's life (divorce, death of a love one, etc);
- Factors that may act as triggers or worsen the child's behaviors or emotions; and
- Significant mood instability or disruptive sleep patterns.

Families know their child best and their expertise is essential in securing an accurate diagnosis for their child.

2. **Comprehensive Physical Examination:** To make an accurate diagnosis, it is important to start the process with the child's primary care physician. A comprehensive physical examination should be done to rule out other physical conditions that may be causing a child's symptoms.
3. **Co-occurring Conditions:** Your child should be evaluated for co-occurring conditions, like learning disabilities, sensory integration problems, and other physical or mental disorders, that may cause behavioral problems or poor school performance. If you suspect that a co-occurring condition is affecting your child's ability to learn, ask the school to perform a psycho-educational evaluation.
4. **Specialists in Children's Mental Health:** After other physical conditions and learning disabilities are evaluated, it is time to meet with a qualified mental health provider. Your child's primary care physician may be able to refer you to a mental health professional. You can also ask for referrals from families involved with NAMI or other advocacy organizations. To find a child psychiatrist, visit the American Academy of Child and Adolescent Psychiatry website (www.aacap.org – click on: *Child and Adolescent Psychiatrist Finder*).
5. **The Diagnostic and Evaluation Process:** A medical diagnostic tool, like a blood test, MRI scan, or x-ray that will diagnose mental illnesses in children has not yet been developed. Your child's diagnosis should be made based on professional observation and evaluation, information provided by your family and other experts, and the criteria found in the latest version of the Diagnostic and Statistical Manual of Mental Disorders. This evaluation should include a comprehensive look at all aspects of your child's life in school, with family, with friends, and in the community. The provider evaluating your child is likely to ask you to fill out a

checklist that provides a detailed profile of your child and the challenges your child is facing.

6. **Adjustments in the Diagnosis:** It may take several visits with a mental health professional before a diagnosis is made. The diagnosis may also change as new symptoms emerge or existing symptoms change. A diagnosis must be confirmed over time and thus an ongoing two-way communication between the treating provider and the family is necessary to track and monitor the child's condition and progress. Families should not hesitate to seek a second opinion if they are not confident in their child's evaluation and the diagnostic process. Getting a second opinion can be challenging because of the shortage of children's mental health providers.
7. **Effective Interventions and Outcomes:** If a diagnosis continues to change or cannot be reached right away, it is still important to focus on effective interventions to address the child's symptoms. The goal should be to achieve the outcomes that are most important to the child and family.
8. **Working with the School:** You should consider meeting with your child's teacher or other school officials to discuss appropriate accommodations and supports for your child. Families should work with the school to identify effective interventions, accommodations, and supports that promote positive behaviors, academic achievement, and prevent challenging behaviors in school. Families should ask their child's treating provider to identify interventions that can be used at school and at home to help your child acquire positive behaviors and academic achievement.
9. **Service and Support Options:** Ask your child's treating provider to recommend effective psychosocial interventions, skills training, support groups, and other options that can help your child cope with symptoms and develop the skills necessary to ultimately lead a full and productive life.
10. **The Importance of Families:** Never underestimate the importance of working with other families. There are many seasoned families who have walked the walk and are happy to share their wisdom and experience with families attempting to secure an accurate diagnosis and effective services for their child.

For some children, having a diagnosis is scary and they may be resistant to accept it. Others are relieved to know that what is happening to them is caused by an illness, that they are not alone, and that there are treatment options that can make them feel and do better. It is important to find ways to use the strengths and interests of your child to help him or her cope with difficult symptoms. Benefits are often derived from aerobic exercise, martial arts, music, and art – whatever it takes to provide your child with a therapeutic outlet. The diagnosis is one piece of a much larger puzzle.

Please visit NAMI's Child & Adolescent Action Center at www.nami.org/caac.

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Childhood Mental Illness

Depending on what criteria for severity are used in diagnosing children with mental illness, anywhere from 6 to 12 percent of children have mental illness.

Many adults with severe mental illness report onset of symptoms of their illness between ages 5 and 9.

Childhood and adolescent mental illnesses include:

- Anxiety Disorder
- Attention Deficit-Hyperactivity Disorder
- Autism
- Bipolar Disorder
- Clinical Depression
- Obsessive-Compulsive Disorder
- Panic Disorder
- Pervasive Developmental Disorder
- Schizophrenia

▶ Early treatment of the major psychiatric disorders can lessen the severity of recurrence over a lifetime.

▶ Pediatricians miss 83% of children with psychiatric diagnoses.

▶ 3 million children have a mental illness diagnosis in a one year period.

▶ 1.4 million of these children receive care in mental health organizations.

▶ Pervasive Development Disorders, including Autism affect 1 to 1.5 of 1000 children.

Neurobiological Brain Disorder Warning Signs

Very Young Children

- Display very little emotion
- No interest in sights, sounds, touch
- Reject being held, playing with others
- Unusually difficult to console
- Unable to calm self
- Extremely fearful, on-guard • Sudden changes in behavior

Preschoolers

- Refusing to play with others
- Inadequate language, communication skills
- Frequent fights with peers, others
- Appears very sad
- Extreme mood swings
- Unusually fearful
- Unusual responses to situations
- Appears withdrawn
- Extremely active
- Loses skills they had earlier
- Sudden behavior changes
- Very accident prone
- Destructive to self, others, objects
- Show extreme immaturity

School-aged Children

- Confusion about what is real or imaginary; déjà vu; preoccupation with Religion, meditation, superciliousness, belief in clairvoyance or sixth sense
- Suspiciousness or paranoid thinking

- Exaggerated self-opinion unrealistic sense of superiority
- Heightened or dulled perceptions, hallucinations; over acuteness of senses to sounds, touch, light, smell
- Odd thinking and speaking process; racing thoughts or slowed-down thoughts; talking about things irrelevant to context or going off the track
- Lack of close friends or confidants other than immediate relatives
- Passively going along with most social activities but in a disinterested or mechanical way
- Flat emotions; decrease in facial expressions, monotone speech; lack of spontaneity and flow of conversation; poor rapport
- Difficulty in abstract thinking
- Difficulty performing functions at work or school; drop in grades; change in eating, sleeping, appearance
- Increased irritability
- Excessive fear of losing parent, cries a lot, nightmares
- Feeling hopeless, overwhelmed; low self-esteem
- Irrational or delusional beliefs not a part of child's culture, do not respond to reason
- Poor concentration, worries about being harmed or harming others
- Performs rituals repeatedly (like washing hands, doing things in rigid manner or order)
- Difficulty making decisions
- Alcohol or substance abuse; aggressive behavior

(Source: Division of DD/MH/SAS, Child and Family Services Section, Prevention, Early Intervention and Family Support Branch)

Abilities Often Impaired in Mental Illnesses

- The ability to stop and think before acting. (impulse control, executive function, ADHD)
- The ability to feel calm and/or safe. (anxiety)
- The ability to feel confident. (depression/anxiety)
- The ability to wait or to be patient. Time seems to pass very slowly. (ADHD, anxiety, mania)
- The ability to "back off" when others request it. (ADHD, mania, anxiety)
- The ability to have thoughts at the same speed as others (mind races from thought to thought) (mania)
- The ability to focus attention on things not of interest. (ADHD, mania, anxiety, depression)
- The ability to transition from one activity to another without emotional and behavioral turmoil. (ADHD, anxiety, many disorders)
- The ability to organize and/or summarize written and/or spoken communication. (Rambling, confusing communication patterns.) (ADHD, mania, schizophrenia, psychosis with depression)
- The ability to feel good. (depression)
- The ability to feel bad. (mania)
- The ability to feel worthwhile. (depression)
- The ability to feel like living. (depression)
- The ability to stop emotional pain. (depression)
- The ability to stop intrusive thoughts, obsessions, auditory hallucinations. (many, if

not most)

- The ability to control movement and voice. (Tourette's)
- The ability to trust other people. (anxiety, paranoia)
- The ability to relax. (anxiety, ADHD, paranoia, mania)
- The ability to function in unstructured, ambiguous social situations Overwhelmed, flooded. (many)
- The ability to feel energetic. (depression)
- The ability to calm down (mania, panic attacks)
- The ability to exercise "good judgment" and "common sense" (mania). To limit one's actions
- Motivation (the association of emotions with actions and memories) is broken. (depression)
- The ability to "read" subtleties of social interactions, facial expressions and body language. (Asperger's Disorder, Autism)
- The ability to slow down. (mania, ADHD)
- The ability to keep track of appointments. ADHD
- The ability to keep track of things. (ADHD, anxiety)
- The ability to be sure that something has been done; that is, the person is compelled to check or wash over and over again, never being "sure." (OCD)
- The ability to compromise. (anxiety including OCD, disorders w/compositionality)
- The ability to see shades of gray. (depression—"all or nothing" thought patterns, schizophrenia, other illnesses)
- The ability to recover quickly from emotional wounds (emotional resiliency). (depression, anxiety)
- The ability to have social "give and take." (many)
- The ability to persist. (depression)
- The ability to get a good night's sleep. (depression, bipolar, ADHD, anxiety)
- The ability to feel rested. (depression)
- The ability to nourish one's body (eating disorders)
- The ability to leave home (agoraphobia), to leave another person (separation anxiety)
- The ability to use one's mind as one wants. The brain hijacks the person's control of his/her thoughts, emotions, and actions. (every mental illness)
- The ability to want to meet other people's expectations (teacher, boss, parent). (compositionality)
- The ability to believe one is meeting other people's expectations (scrupulosity, anxiety)
- The ability to be agreeable. (compositionality)
- The ability to accept work direction. (compositionality, anxiety)
- The ability to let someone else be in control. (anxiety)
- The ability to be flexible and change plans quickly. (anxiety)
- The ability to stop talking. (ADHD, mania)
- The ability to take turns in conversation. (many)
- The ability to think realistically about oneself and one's abilities. (depression/mania, others)
- The ability to experience reality the same way most other people do. (most extreme in schizophrenia, but present in others.)
- The ability to shut out internal auditory hallucinations. (psychosis of depression, bipolar, schizoaffective disorder, schizophrenia)

- The ability to shut out delusions (bipolar and schizophrenia)
- The ability to shut off endless cycles of worry or obsession. (anxiety, esp. OCD)

Back-to-School Strategies for Parents of Children

Living with Mental Illness

For children living with mental illness, going back to school is loaded with potential obstacles and stressors including changing routines, scholastic and social expectations, separation, and excitement.

The start of the school year often triggers anxiety for parents of children with mental illnesses as well. New teachers and environments often mean new challenges, but they can also signal new opportunities for success.

The following are some suggested strategies to consider and adapt to help build a foundation for a successful school year for the child living with mental illness.

1. Address any known problems in a straightforward manner as soon as a school and teachers of any recent medication or treatment plans that are of significance. Communicate your support of the teacher's critical role with your child. Review any special education plans that were drafted the year before, if applicable. Provide information about your child's disorder and be a resource for information for the school and the teachers.
2. Secure arrangements to take the child to school before the first day. Do a walk through of the environment and meet teachers and office staff. Familiarity with his or her physical surroundings will help diminish first day anxieties.
3. Support self-esteem. Identify the child's strengths and hook the child in through existing interests. Keep on the lookout for a developing or possible friendship and encourage a sleep over, movie outing, or gaming day. Set small goals or suggest ideas first and then build to larger expectations, supporting and reinforcing along the way.
4. Help the child organize and structure. Working with the teacher, determine how assignments will be communicated and request an advanced copy of deadlines and assignments. Pop quizzes can be a disaster for a child struggling in his or her recovery; it is OK to request that a heads-up be afforded. If possible, ask the child to share his or her class schedule with you, but realize that sometimes recalling such details can be a challenge. If you have a fax machine, ask the teacher to fax assignment outlines weekly, or secure alternative arrangements to get them delivered to you each week.
5. Ask for and make arrangements to receive weekly behavior/performance updates. The end of a grading period is not the time to find out that the child has missed all homework assignments.

Develop a form with the school's guidance or special education liaison and have this completed by all teachers each week.

Having it faxed or delivered with the child each Friday will help keep you on top of successes and failures so that both can be addressed promptly.

6. Minimize distractions. Some strategies to consider include: take the child to school and avoid the bus for a week or two early in the year. Secure just-late arrival for the child to avoid crowded halls in the mornings. Ask that the child be assigned a seat near the front of the room. Or, for older students, request permission for use of a backpack with

rollers so the child can have all materials available throughout the day, thus avoiding locker visits.

7. Avoid homework hassles. Remember, it is the child's work and grades, not the parents. Reinforce time management; break assignments down into parts with the child, support an organized place for after-school work, and if, necessary, negotiate extended time for assignments. Set homework rules and boundaries early and stick to them.

8. Don't be afraid to raise the bar. With your child's input, determine what expectations you have for educational performance and stick to them.

Confidence, self esteem, and recovery are all supported by success. Avoid automatically rescuing your child from all situations—let the child experience self-reliance where possible and when appropriate.

9. Consistently discipline and support play. Some children respond to "time out," a "thinking room" or other interruption to behavior challenges. Whatever your choice, parent with firm but loving consistency and set and stick to boundaries. Cartoons and video games are a privilege and can be very calming for some children with mental illness by helping them to decompress and cope with a confusing world. If you have other children, the rules should overlap and there should be consistency with expectations around certain behaviors, regardless of a diagnosis, usually including respectfulness, manners, and chores.

10. Learn and express the law. Visit NAMI's Children and Adolescent Action Center Web site for valuable information on children's issues and to subscribe to the free Beginnings magazine. Visit the NAMI Web site to learn about IDEA, the Individuals with Disabilities Education Act. This law mandates a "free and appropriate education" for children with disabilities, including children with mental illness (or emotional disturbance as it is designated in IDEA.)

Seek out and garner the support of other parents through your NAMI affiliate, and learn your child's rights as well as interventions that can be requested to support success.

Most importantly, parents should remember that they are the front line. They know more about their children than anyone else and their instincts are the sharpest. They are also human, have jobs and houses to run, other children to raise, and life stresses to manage. Parenting and personal balance are daily challenges for all, and especially for parents of children living with mental illness. Parents should be encouraged to ask questions, educate themselves, get support from others, remember to play themselves, and most importantly, never give up. Their love and support, regardless of the circumstances, are real and are ultimately all that really count.

Read more on NAMI's efforts to educate schools about mental illness by visiting the NAMI Web site. NAMI has developed an important resource, Parents and Teachers as Allies, which can be ordered from the NAMI Web site.

Attention-Deficit/Hyperactivity Disorder ADD/HD

What is attention-deficit/hyperactivity disorder?

Attention-deficit/hyperactivity disorder (ADHD) is an illness characterized by inattention, hyperactivity and impulsivity. The most commonly diagnosed behavior disorder in young persons, ADHD affects an estimated three percent to five percent of school-age children.

Although ADHD is usually diagnosed in childhood, it is not a disorder limited to children—ADHD often persists into adolescence and adulthood and is frequently not diagnosed until later years.

What are the symptoms of ADHD?

There are actually three different types of ADHD, each with different symptoms: predominantly inattentive, predominantly hyperactive/impulsive and combined.

Those with the predominantly inattentive type often:

- fail to pay close attention to details or make careless mistakes in schoolwork, work or other activities;
- have difficulty sustaining attention to tasks or leisure activities;
- do not seem to listen when spoken to directly;
- do not follow through on instructions and fail to finish schoolwork, chores or duties in the workplace;
- have difficulty organizing tasks and activities;
- avoid, dislike or are reluctant to engage in tasks that require sustained mental effort;
- lose things necessary for tasks or activities;
- are easily distracted by extraneous stimuli; and/or
- are forgetful in daily activities.

Those with the predominantly hyperactive/impulsive type often:

- fidget with their hands or feet or squirm in their seat;
- leave their seat in situations in which remaining seated is expected;
- move excessively or feel restless during situations in which such behavior is inappropriate;
- have difficulty engaging in leisure activities quietly;
- are "on the go" or act as if "driven by a motor";
- talk excessively;

- blurt out answers before questions have been completed;
- have difficulty awaiting their turn; and/or
- interrupt or intrude on others.

Those with the combined type, the most common type of ADHD, have a combination of the inattentive and hyperactive/impulsive symptoms.

What is needed to make a diagnosis of ADHD?

A diagnosis of ADHD is made when an individual displays at least six symptoms from either of the above lists, with some symptoms having started before age seven. Clear impairment in at least two settings, such as home and school or work, must also exist. Additionally, there must be clear evidence of clinically significant impairment in social, academic, or occupational functioning.

How common is ADHD?

ADHD affects an estimated two million American children, an average of at least one child in every U.S. classroom. In general, boys with ADHD have been shown to outnumber girls with the disorder by a rate of about three to one. The combined type of ADHD is the most common in elementary school-aged boys; the predominantly inattentive type is found more often in adolescent girls.

While there is no specific data on the rates of ADHD in adults, the disorder is sometimes not diagnosed until adolescence or adulthood. Half of the children with ADHD retain symptoms of the disorder throughout their adult lives. (It is generally believed that older individuals diagnosed with ADHD have had elements of the disorder since childhood.)

What is ADD? Is it different than ADHD?

This is a question that has become increasingly difficult to answer simply. *ADHD*, or *attention-deficit/hyperactivity disorder*, is the only clinical term for disorders characterized by inattention, hyperactivity and impulsivity used in the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorder, Fourth Edition*, the diagnostic "bible" of psychiatry. However (and this is where things get tricky), *ADD*, or *attention-deficit disorder*, is a term that has become increasingly popular among laypersons, the media and even some professionals. Some use the term *ADD* as an umbrella term—after all, ADHD *is* an attention-deficit disorder. Others use the term *ADD* to refer to the predominantly inattentive type of ADHD, since that type does not feature hyperactive symptoms. Lastly, some simply use the terms *ADD* and *ADHD* interchangeably. The bottom line is that when people speak of ADD or ADHD, they generally mean the same thing. However, only *ADHD* is the "official" term.

Is ADHD associated with other disorders?

Yes. In fact, symptoms like those of ADHD are often mistaken for or found occurring with other neurological, biological and behavioral disorders.

- **Oppositional defiant disorder.** Nearly half of all children with ADHD (especially boys) tend to also have *oppositional defiant disorder*, characterized by negative, hostile and defiant behavior.
- **Conduct disorder.** *Conduct disorder* (marked by aggression towards people and animals, destruction of property, deceitfulness or theft and serious rule-breaking) is found to co-occur in an estimated 40 percent of children with ADHD.
- **Anxiety and depression.** Approximately one-fourth of children with ADHD (mostly younger children and boys) also experience *anxiety* and *depression*.
- **Communication/learning disability.** At least 25 percent of children with ADHD have some type of *communication/learning disability*.
- **Tourette's syndrome.** There is additionally a correlation between *Tourette's syndrome*, a neurobiological disorder characterized by motor and vocal tics and ADHD—a small percentage of those with ADHD also have Tourette's, but at least half of those with Tourette's also have ADHD.
- **Bipolar disorder.** Research is also beginning to show that ADHD-like symptoms are sometimes actually manifestations of childhood-onset bipolar disorder.

What causes ADHD?

First of all, it is important to realize that ADHD is *not* caused by dysfunctional parenting, nor is it due to a lack of intelligence or discipline.

- **Biological basis.** Strong scientific evidence supports the conclusion that ADHD is a biologically based disorder. Recently, National Institute of Mental Health researchers using PET scans have observed significantly lower metabolic activity in regions of the brain controlling attention, social judgment and movement in those with ADHD than in those without the disorder. Biological studies also suggest that children with ADHD may have lower levels of the neurotransmitter dopamine in critical regions of the brain.
- **Toxins.** Other theories suggest that cigarette, alcohol and drug use during pregnancy or exposure to environmental toxins such as lead may be linked to the development of ADHD.
- **Genetic basis.** Research also suggests a strong genetic basis to ADHD—the disorder tends to run in families. In addition, research has shown that certain forms of genes related to the dopamine neurotransmitters system are linked to increased likelihood of the disorder.

While early theories suggested that ADHD may be caused by minor head injuries or brain damage resulting from infections or complications at birth, research found this hypothesis to lack substantial supportive evidence. Furthermore, scientific studies have not verified dietary factors, another widely discussed possible influence for the development of ADHD, as a main cause of the disorder.

How can ADHD be treated? Medications mentioned in this section

Adderall* Amphetamine and dextroamphetamine Atomoxetine* Desoxyn* Dexedrine*
Dextroamphetamine
Methylphenidate Ritalin* Straterra (*Brand name)

Many treatments—some with good scientific basis, some without—have been recommended for individuals with ADHD. The most proven treatments are medication and behavioral therapy.

Medication

Stimulants are the most widely used drugs for treating attention deficit/hyperactivity disorder. Examples of the most commonly used stimulants are methylphenidate (Ritalin), dextroamphetamine (Dexedrine, Desoxyn), amphetamine and dextroamphetamine (Adderall). Some of the stimulant class of medications come in longer acting preparations and can be given once a day. These drugs increase activity in parts of the brain that are underactive in those with ADHD, improving attention and reducing impulsiveness, hyperactivity and/or aggressive behavior. Stimulants have been shown to have the potential for abuse and are classified as controlled substances. The FDA has also approved a non-stimulant medication, Atomoxetine (Straterra), which does not appear to have the same risk of abuse as the stimulants. However, this medication carries a warning that in a small percentage of cases, suicidal thinking can be activated by this medication.

Other medications can be prescribed for ADHD but are done so “off label” which means the FDA has not approved the medication for this particular use in children and adolescents. If the doctor is making that recommendation, ask him or her why and what research and clinical experience inform that recommendation. You may get a second opinion from another doctor if you are not satisfied with the answers.

Every person reacts to treatment differently, so it is important to work closely and communicate openly with your physician. Some common side effects of stimulant medications include weight loss, decreased appetite, trouble sleeping and, in children, a temporary slowness in growth; however, these reactions can often be controlled by dosage adjustments. There is controversy about a serious possible heart complication that can occur in a small percent of people who take stimulants. Tics, or involuntary movement problems, are not common but can be uncomfortable side effects.

It is important to weigh the risks and benefits of these treatments with your doctor and youth. Medication has proven effective in the short-term treatment of about three quarters of individuals with ADHD.

Behavioral Therapy

Treatment strategies such as rewarding positive behavior changes and communicating clear expectations of those with ADHD have also proven effective. Additionally, it is extremely important for family members and teachers or employers to remain patient and understanding.

Children with ADHD can additionally benefit from caregivers paying close attention to their progress, adapting classroom environments to accommodate their needs and using positive reinforcers. There is some evidence that behavioral treatment can lower the

dose of the medications a child requires.

Where appropriate, parents should work with the school district to plan an individualized education program (IEP).

Staying updated

The child and adolescent clinical and research literature is always evolving. The [National Institute of Mental Health](#) and the [American Association of Child and Adolescent Psychiatry](#) are two excellent sources of current information on available treatment options and their potential risks and benefits.

Other Treatments

There are a variety of other treatment options offered (some rather dubious) for those with ADHD. Those treatments *not* scientifically proven to work include biofeedback, special diets, allergy treatment, megavitamins, chiropractic adjustment and special-colored glasses.

Many children with ADHD also have co-occurring learning disabilities. Evaluation of a child's learning style and strengths may be advisable to better match classroom and other supports with their learning style.

Reviewed by Ken Duckworth, M.D., July 2010

Anxiety Disorders in Children and Adolescents

What are anxiety disorders?

Anxiety disorders cause people to feel excessively frightened, distressed, and uneasy during situations in which most others would not experience these symptoms. Left untreated, these disorders can dramatically reduce productivity and significantly diminish an individual's quality of life. Anxiety disorders in children can lead to poor school attendance, low self-esteem, deficient interpersonal skills, alcohol abuse, and adjustment difficulty.

Anxiety disorders are the most common mental illnesses in America; they affect as many as one in 10 young people. Unfortunately, these disorders are often difficult to recognize, and many who suffer from them are either too ashamed to seek help or they fail to realize that these disorders can be treated effectively.

What are the most common anxiety disorders?

- **Panic Disorder** – Characterized by panic attacks, panic disorder results in sudden feelings of terror that strike repeatedly and without warning. Physical symptoms include chest pain, heart palpitations, shortness of breath, dizziness, abdominal discomfort, feelings of unreality, and fear of dying. Children and adolescents with this disorder may experience unrealistic worry, self-consciousness, and tension.
- **Obsessive-compulsive Disorder (OCD)** -- OCD is characterized by repeated, intrusive, and unwanted thoughts (obsessions) and/or rituals that seem impossible to control (compulsions). Adolescents may be aware that their symptoms don't

make sense and are excessive, but younger children may be distressed only when they are prevented from carrying out their compulsive habits. Compulsive behaviors often include counting, arranging and rearranging objects, and excessive hand washing.

- **Post-traumatic Stress Disorder** -- Persistent symptoms of this disorder occur after experiencing a trauma such as abuse, natural disasters, or extreme violence. Symptoms include nightmares; flashbacks; the numbing of emotions; depression; feeling angry, irritable, and distracted; and being easily startled.
- **Phobias** -- A phobia is a disabling and irrational fear of something that really poses little or no actual danger. The fear leads to avoidance of objects or situations and can cause extreme feelings of terror, dread, and panic, which can substantially restrict one's life. "Specific" phobias center around particular objects (e.g., certain animals) or situations (e.g., heights or enclosed spaces). Common symptoms for children and adolescents with "social" phobia are hypersensitivity to criticism, difficulty being assertive, and low self-esteem.
- **Generalized Anxiety Disorder** -- Chronic, exaggerated worry about everyday, routine life events and activities that lasts at least six months is indicative of generalized anxiety disorder. Children and adolescents with this disorder usually anticipate the worst and often complain of fatigue, tension, headaches, and nausea.

Other recognized anxiety disorders include: agoraphobia, acute stress disorder, anxiety disorder due to medical conditions (such as thyroid abnormalities), and substance-induced anxiety disorder (such as from too much caffeine).

Are there any known causes of anxiety disorders?

Although studies suggest that children and adolescents are more likely to have an anxiety disorder if their caregivers have anxiety disorders, it has not been shown whether biology or environment plays the greater role in the development of these disorders. High levels of anxiety or excessive shyness in children aged six to eight may be indicators of a developing anxiety disorder.

Scientists at the National Institute of Mental Health and elsewhere have recently found that some cases of obsessive-compulsive disorder occur following infection or exposure to streptococcus bacteria. More research is being done to pinpoint who is at greatest risk, but this is another reason to treat strep throats seriously and promptly.

What treatments are available for anxiety disorders?

Effective treatments for anxiety disorders include medication, specific forms of psychotherapy (known as behavioral therapy and cognitive-behavioral therapy), family therapy, or a combination of these. Cognitive-behavioral treatment involves the young person's learning to deal with his or her fears by modifying the way he or she thinks and behaves by practicing new behaviors. Ultimately, parents and caregivers should learn to be understanding and patient when dealing with children with anxiety disorders. Specific plans of care can often be developed, and the child or adolescent should be involved in the decision-making process whenever possible. Permission is granted for this fact sheet

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Reviewed January 2

Bipolar Disorder

Children and adolescents with bipolar disorder?

Bipolar disorder can occur in children and adolescents and has been investigated by federally funded teams in children as young as age six.

How common is it in children and adolescents?

Although once thought rare, caseloads of patients examined for federally funded studies have shown that approximately 7 percent of children seen at psychiatric facilities fit the research standards for bipolar disorder.

What are the symptoms of bipolar disorder in children and adolescents?

One of the biggest challenges has been to differentiate children with mania from those with attention deficit hyperactivity disorder. Since both groups of children present with irritability, hyperactivity and distractibility, these symptoms are not useful for the diagnosis of mania. By contrast, elated mood, grandiose behaviors, flight of ideas, decreased need for sleep and hypersexuality occur primarily in mania and are uncommon in ADHD. Below is a brief description of how to recognize these mania-specific symptoms in children.

- ***Elation.*** Elated children may laugh hysterically and act infectiously happy without any reason at home, school or in church. If someone who did not know them saw their behaviors, they would think the child was on his/her way to Disneyland. Parents and teachers often see this as "Jim Carey-like" behaviors.
- ***Grandiose behaviors.*** Grandiose behaviors are when children act as if the rules do not pertain to them. For example, they believe they are so smart that they can tell the teacher what to teach, tell other students what to learn and call the school principal to complain about teachers they do not like. Some children are convinced that they can do superhuman deeds (e.g., that they are Superman) without getting seriously hurt, e.g. "flying" out of windows.
- ***Flight of ideas.*** Children display flight of ideas when they jump from topic to topic in rapid succession during a normal conversation—not just when a special event has happened.
- ***Decreased need for sleep.*** Children who sleep only 4-6 hours and are not tired the next day display a decreased need for sleep. These children may stay up playing on the computer and ordering things or rearranging furniture.
- ***Hypersexuality.*** Hypersexual behavior can occur in children without any evidence of physical or sexual abuse in children who are manic. These children act flirtatious beyond their years, may try to touch the private areas of adults

(including teachers) and use explicit sexual language.

In addition, it is most common for children with mania to have multiple cycles during the day from giddy, silly highs to morose, gloomy suicidal depressions. It is very important to recognize these depressed cycles because of the danger of suicide.

What treatments medications have been shown to be effective and what are their side effects? Medications mentioned in this section: Abilify* Arepepazole Depakote* Lithium Olanzapine Quetiapine Risperidol* Risperidone Seroquel* Topamax* Topiramate Valproic Acid Syprexa*

***Denotes Brand Name.**

First, it is important to recognize that bipolar disorder in children and adolescents is an emerging field and there is much more to learn. A comprehensive evaluation including family history is essential to understanding the diagnosis and the consideration of other possible diagnoses.

Bipolar disorder raises many risks in youth including substance use, suicide and poor school performance. Be sure to ask your clinician about a comprehensive treatment approach. For an example of how expert clinicians conceptualize approaches to treatment for this condition, please review the [Treatment Guidelines by the American Academy of Child and Adolescent Psychiatry from March 2005](#).

There are medications that have been FDA approved for use in teens with bipolar disorder. All other medication use is “off label” which means that it has not been approved by the FDA for this purpose. Those drugs that are FDA approved were studied for effectiveness in short-term studies—which means we do not understand the positive impact and side effects of longer term use.

Antipsychotics

Several of the atypical antipsychotics—aripipazole (Abilify), quetiapine (Seroquel) and risperidone (Risperidol)—have FDA approval for bipolar disorder in youth ages 10 to 17. Olanzapine (Zyprexa) has FDA approval for youths ages 13 to 17 with bipolar 1 disorder.

Lithium

Lithium, which is a mood stabilizer that is not an antipsychotic, also has FDA approval for youths aged 12 to 17. All of these compounds have important side effects that can include weight gain, increased cholesterol and diabetes risk for the antipsychotics. Lithium has risks in thyroid and kidney side effects. More needs to be learned about the safe and effective use of these medications over time in youth with bipolar disorder.

Anticonvulsants

The use of anticonvulsants such as valproic acid (Depakote) and topiramate (Topamax) are not FDA approved for use in youth with bipolar disorder.

Antidepressants

The FDA warning on antidepressants and the increased risk of suicidal ideation is also

worth noting as some youth present first with depressive symptoms.

The medication management of youth bipolar disorder requires a clear understanding of the limited scientific data for longer term use. It is also important to know what side effects need to be monitored in youth.

There are no FDA approved medications for youth under age 10.

Are there any side effects associated with these treatments, including those that may only occur in young people?

Side effects that are particularly troublesome and that are worse in children include the following. Atypical neuroleptics (except aripiprazole) are associated with marked weight gain in many children. One day we hope to have specific genetic tests that will tell us beforehand which people will gain weight on these medications, but right now it is trial and error. The dangers of this weight gain include glucose problems that may include the onset of diabetes and increased blood lipids that may worsen heart and stroke problems later in life. In addition, these drugs can cause an illness called tardive dyskinesia—irreversible, unsightly, repeated movements of the tongue in and out of the mouth or cheek—and some other movement abnormalities. Depakote may also be associated with increased weight and possibly with a disease called polycystic ovarian syndrome (PCOS), which in some cases may be associated with infertility later in life. Lithium has been on the market the longest and is the only medication that has been shown to be effective against future episodes of mania and of depression and of completed suicides. Some people who take lithium over a long time will need a thyroid supplement and in rare cases may develop serious kidney disease.

It is very important that children on these medications be monitored for the development of serious side effects. These side effects need to be weighed against the dangers of bipolar disorder itself, which can rob children of their childhood.

How do children and adolescents with this disease fare over time and as adults?

At this time, regrettably, bipolar disorder in children and youth appears to be more severe and have a much longer road to recovery than is seen with adults. While some adults may have episodes of mania or depression with better functioning between episodes, children seem to have continuous illness over months and years.

Does bipolar disorder in children have an impact on educational achievement?

It is challenging to educate a child whose mood is much too "high" or too "low." Therefore educators need to be aware of the diagnosis and make special arrangements.

Is suicide a risk?

Talking about wanting to die, asking why they were born or wishing they were never born must be taken very seriously. Even quite young children can hang themselves in the shower, shoot themselves or complete suicide by other means.

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Asperger Syndrome

The Diagnostic and Statistical Manual of Mental Disorders (4th Edition), known as DSM IV, published in 1994, defines Asperger syndrome (AS) as marked by “severe and sustained impairment in social interaction” along with “restricted repetitive and stereotyped patterns of behavior.”

As a parent, what behaviors might I suspect as indicative of this disorder?

The more general traits that may be observed include awkwardness in social situations, an intense preoccupation with certain specific (often unusual) topics, self-directed orientation, a lack of understanding of social cues, and clumsiness caused by lack of motor coordination.

What is meant by “severe and sustained impairment in social interaction”?

A child with AS often has problems with normally developed verbal as well as non-verbal interaction tools. The child may, for example, not meet the eyes of a person speaking, seem to lack facial expressiveness, or not use normal body posturing and gestures. This affects social interaction in a negative way.

What are “restricted repetitive patterns of behavior”?

This kind of behavior is demonstrated by a preoccupation with certain actions or objects within a restricted range. Rather than applying an intense interest to a variety of subjects, the child with AS has interests of a rather narrow scope, like aliens or computers, bus routes or sports schedules, maps and charts.

This restricted repetitive behavior also is exhibited through a very rigid, non-negotiable adherence to specific nonfunctional routines or rituals. The child with this disorder may, for example, insist on walking a certain route to school without deviation. The child is inflexible about following a certain sequence of events—he or she may need to walk in a circle before sitting down or dress in a specific order. These nonfunctional routines can be of critical importance to the child with Asperger. Given a choice in clothing, the child might create what seems like a uniform that is worn day after day.

What about relationships with peers?

The child may not make friends easily, or at all, and may not seem interested in sharing experiences or interests with those around him. For example, a child developing normally may show his artwork to people around him or bring a toy to his sister or brother to look at, but a child with AS will not as readily do so.

A child or adolescent with AS may seem unwilling or uninterested in responding to others in a socially or emotionally reciprocal way. For example, the child may ignore or seem to not notice when a person expresses affection toward him or prompts conversation. On the other hand, Asperger individuals may highly desire social interaction, but their poor social skills result in failure which can cause anxiety and depression.

What about the course of Asperger syndrome?

AS usually presents between ages 2 and 6 years, but is often not recognized until later. As far as doctors know, the disorder is present throughout the course of a person life. It has often been diagnosed as late as young adulthood.

Who gets Asperger?

Not much is known about how common the syndrome is because few studies have been done. Prevalence rates are estimated to range from .024 percent to .36 percent based on studies in Canada and Goteborg, Sweden, respectively.

Boys appear to have a higher incidence than girls at a 4:1 ratio. There is likely a genetic component which is thought by some to be related to the genetic deficit in autism. This is presently unclear.

How does one arrive at a diagnosis of Asperger?

The diagnosis is based on the presence of signs and symptoms in the DSM-IV.

Differential diagnosis includes autism, complex learning disabilities, schizophrenia-spectrum disorder and obsessive-compulsive disorder.

What treatments can be considered useful or helpful for the child or adolescent with Asperger?

Because securing educational and related services may be difficult due to the lack of knowledge about Asperger, it is important for the parents and clinician to work closely together to supply the patient and school personnel with the necessary information and help. Educational interventions are often necessary and should be individual accommodations to the persons needs. Because these students generally do well with memory tasks, teaching in a rote fashion may help the individual to retain the information presented.

Deficits in social skills may be remediated in small groups usually led by a mental health professional or speech and language pathologist.

Depending on the presence and extremity of associated symptoms, psych-pharmacological interventions may help. Examples of associated symptoms that may be effectively treated with medication are hyperactivity, impulsivity, inattention, mood instability, temper outbursts, depression, anxiety and obsessive-compulsive symptoms.

Summary:

Early intervention and treatment is the single most important effort a parent can make to influence the outcomes for a child or adolescent with Asperger. Finding a clinician that can make the diagnosis of Asperger may be the more significant hurdle in getting appropriate treatment for your child.

Resources:

Autism and AS, by Uta Frith, Cambridge University Press, London, UK, 1991 (\$17.95)

For more information on the Internet, look for the "Asperger Disorder Homepage" at <http://www.ummed.edu/pub/o/ozbayrak/asperger.html>

What is Autism Spectrum Disorders?

Autism Spectrum Disorders (ASDs) are complex developmental disorders of brain function. Each can affect a child's ability through signs of impaired social interaction, problems with verbal and nonverbal communication, and unusual or severely limited activities and interest. These symptoms typically appear during the first three years of life. There is no cure for ASDs, but with appropriate early intervention, a child may improve social development and reduce undesirable behaviors.

ASDs affect an estimated two to six per 1,000 children and strike males about four times as often as females. They do not discriminate against racial, ethnic, or social backgrounds. ASDs are "spectrum disorders" that affect individuals differently and to varying degrees. The ASDs are Autism (the defining disorder of the spectrum), Asperger Syndrome, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), Rett Syndrome, and Childhood Disintegrative Disorder (CDD). The most severe cases are marked by extremely repetitive, unusual, self-injurious, and aggressive behavior. This behavior may persist over time and prove very difficult to change, posing a tremendous challenge to those who must live with, treat, and teach these individuals. The mildest forms of autism resemble a personality disorder associated with a perceived learning disability.

What are common signs of an ASD?

Children diagnosed with an ASD do not embrace the typical patterns of child development. Some hints of future problems may be apparent from birth, while in most cases, signs become evident when a child's communication and social skills lag further behind other children of the same age. Some parents report the change as being sudden, and that their children start to reject people, act strangely, and lose language and social skills they had previously acquired.

ASDs are defined by a definite set of behaviors that can range from very mild to severe. Children with ASDs may fail to respond to their name and often avoid eye contact. They also have difficulty interpreting tone of voice or facial expressions and do not respond to others' emotions or watch other people's faces for cues about appropriate behavior. Many children will engage in repetitive movements such as rocking and hair twirling, or in self-injurious behavior such as nail biting or head-banging. They tend to speak later than other children and may refer to themselves by name instead of "I" or "me." Some speak in a sing-song voice about a narrow range of favorite topics, with little regard for the interests of the person to whom they are speaking.

In summary, children do not outgrow ASDs, but studies show that early diagnosis and intervention lead to significantly improved outcomes. Signs to look for include:

- Lack of or delay in spoken language (does not babble, point, or make meaningful gestures by one year; does not speak one word by 16 months; does not combine two words by two years; does not respond to name; or loses language or social skill)
- Repetitive use of language and/or motor mannerisms (e.g., hand-flapping, twirling objects)

- Little or no eye contact
- Lack of interest in peer relationships
- Lack of spontaneous or make-believe play
- Persistent fixation on parts of objects
- Does not smile

Symptoms of an ASD do not remain static over a lifetime. About a third of children with an ASD—especially those with severe cognitive impairment and motor deficits—will eventually develop epilepsy. In many children, symptoms of an ASD improve with intervention or as the children mature. Some eventually lead normal or near-normal lives. ASDs in adolescence could worsen behavior problems in some children as they may become depressed or increasingly unmanageable. Parents should be aware and ready to adjust treatment to fit their child’s changing needs.

How is an ASD diagnosed?

Although much about ASDs is not known, the consensus is: the earlier the diagnosis, the earlier interventions and treatment can begin. Evidence over the past decade or more indicate that intensive, early intervention in optimal educational settings for at least two years during the preschool years result in improved outcomes in most young children. Currently, no medical test exists to determine if a child has or will develop an ASD. Therefore, when evaluating a child, clinicians rely on behavioral characteristics to make a diagnosis. Some of the characteristic behaviors of ASDs might be apparent in the first few months of a child’s life, but most often they appear at any time during the early years. A clinical diagnosis would come from an observed problem in at least one of the areas of communication, socialization, or restricted behavior before the age of three.

Diagnosis can be difficult for doctors because ASDs vary widely in severity and symptoms, and may go unrecognized, especially in mildly affected individuals or in those with multiple disabilities. Another consideration is that many of the behaviors associated with autism are shared by other disorders. Therefore, various medical tests may be ordered to rule out or identify other possible causes. For this reason, researchers have developed several sets of diagnostic criteria for ASDs.

They include:

- Absence or impairment of imaginative and social play
- Impaired ability to make friends with peers
- Impaired ability to initiate or sustain a conversation with others
- Stereotyped, repetitive, or unusual use of language
- Restricted patterns of interests that are abnormal in intensity or focus

Diagnosis requires a [two-stage process](#). The first stage involves developmental screening during “well child” check-ups. Several screening instruments have been developed to quickly gather information about a child’s social and communicative

development within medical settings.

The second stage of diagnosis must be done by a multidisciplinary team composed of a psychologist, a neurologist, a psychiatrist, a speech therapist, or other professionals who diagnose children with ASDs.

What are the causes of ASDs?

There is no known direct cause of the disorders, which is one of the reasons why ASDs continue to remain elusive to doctors in the field. ASDs are complex disorders and have remained relatively inaccessible for study. It can be said with great certainty, however, that autism is not the direct cause of a psychological disturbance caused by detached or uncaring “refrigerator” mothers, as once suggested in the 1940s by Dr. Bruno Bettelheim. There is also significant evidence from large-scale studies that refute the proposed link between thimerosal, a mercury-based preservative used in the measles-mumps-rubella (MMR) vaccine and autism.

Researchers believe that it is probably a combination of genetic and environmental factors. Studies of people with ASDs have found abnormalities in several regions of the brain, including the cerebellum, amygdala, hippocampus, septum and mamillary bodies. Neurons in these regions appear smaller than normal and have stunted nerve fibers, which may interfere with nerve signaling. This suggests that autism results from a disruption of normal brain development early in fetal development. Other studies suggest that people with an ASD have abnormalities of serotonin or other signaling molecules in the brain. These findings, however, are preliminary and require further study.

In recent studies it has even been suggested that some people have a genetic predisposition to ASDs. Scientists estimate that families with one child living with an ASD run the risk of approximately 5 to 10 percent of having a second child with one of the disorders—greater than the risk for the general population. Research continues into clues about which genes contribute to this increased susceptibility. Parents and other relatives of an autistic person show mild social, communicative, or repetitive behaviors that allow them to function normally but appear linked to ASDs. There is evidence that those who do not have a history with an ASD have a 0.1 to 0.2 percent change that the family will have a child with an ASD.

How are ASDs treated?

At present, there is no specific cure for ASDs. Therapies or interventions are designed to remedy specific symptoms in each individual. The best-studied therapies include educational/behavioral and medical interventions, but these remedies do not ensure substantial improvement. The lack of proven treatments prompts many parents to pursue their own research, often using “trial and error.” Parents should use caution before subscribing to any particular treatment. Counseling for the families of people with autism also may assist them in coping with the disorder. While the public has become more aware of ASD in recent years, it still remains one of the lowest funded areas of medical research by both public and private sources.

Educational / Behavioral Interventions

Educational and behavioral approaches are often a core feature of the overall treatment

plan for children with an ASD. These strategies emphasize highly structured and often intensive, skill-oriented training that is tailored to the individual child. Therapists work with children to help them develop social and language skills. Recent evidence suggests that early intervention has a good change of favorably influencing brain development. [Applied behavior](#) (ABA) is the most well known of the behavioral approaches.

Medication

Doctors may prescribe a variety of drugs to reduce self-injurious behavior or other troublesome symptoms of ASDs, as well as associated conditions such as epilepsy and attention disorders. Most of these drugs affect levels of serotonin or other signaling chemicals in the brain. The medications most often used in the treatment of ASDs can generally be placed in one of the following groups: antipsychotic drugs, antidepressants, and stimulants.

How is ASD being studied?

There is a growing interest in the scientific field of ASDs as this spectrum of disorders is now affecting 1.5 million American families. The National Institute of Neurological Disorders and Stroke (NINDS), part of the National Institutes of Health (NIH), is the federal government's leading supporter of biomedical research on brain and nervous system disorders, including ASDs. The NINDS conducts research in its laboratories at [NIH](#) and supports research at other institutions through grants. The Children's Health Act of 2000 helped create the Interagency Autism Coordinating Committee (IACC), a committee that includes the directors of five NIH institutes to develop a ten-year agenda for autism research. In November 2003, the committee introduced a roadmap to indicate their research priorities for years 1-3, years 4-6, and years 7-10. The five institutes have also established the Studies to Advance Autism Research and Treatment (STAART) Network, where eight network centers conduct research in the fields of neurobiology, genetics, and psychopharmacology.

The largest collaborative effort to focus on the genetics of autism is being conducted by [the NAAR Autism Genome Project](#). Using the resulting data, scientists will identify genes that demonstrate a link to autism, allowing the medical community to develop treatments. **PDD – Pervasive Developmental Disorders**

Autism is one of five disorders that falls under the umbrella of Pervasive Developmental Disorders (PDD), a category of neurological disorders characterized by “severe and pervasive impairment in several areas of development.”

The five disorders under PDD are:

- Autistic Disorder
- Asperger's Disorder
- Childhood Disintegrative Disorder (CDD)
- Rett's Disorder
- PDD-Not Otherwise Specified (PDD-NOS)

Each of these disorders has specific diagnostic criteria which been outlined in the American Psychiatric Association's Diagnostic & Statistical Manual of Mental Disorders (DSM-IV-TR).

Prevalence of Autism

Autism is the most common of the Pervasive Developmental Disorders, affecting an estimated 1 in 166 births (Centers for Disease Control Prevention, 2004). Roughly translated, this means as many as 1.5 million Americans today are believed to have some form of autism. And this number is on the rise.

Based on statistics from the U.S. Department of Education and other governmental agencies, autism is growing at a startling rate of 10-17 percent per year. At this rate, the ASA estimates that the prevalence of autism could reach 4 million Americans in the next decade.

Autism knows no racial, ethnic, social boundaries, family income, lifestyle, or educational levels and can affect any family, and any child.

And although the overall incidence of autism is consistent around the globe, it is four times more prevalent in boys than in girls.

Learn the Signs

As mentioned previously, autism is a spectrum disorder, and although it is defined by a certain set of behaviors, children and adults with autism can exhibit any combination of these behaviors in any degree of severity. Two children, both with the same diagnosis, can act completely different from one another and have varying capabilities.

You may hear different terms used to describe children within this spectrum, such as autistic-like, autistic tendencies, autism spectrum, high-functioning or low-functioning autism, more-abled or less-abled; but more important than the term used to describe autism is understanding that whatever the diagnosis, children with autism can learn and function normally and show improvement with appropriate treatment and education.

Every person with autism is an individual, and like all individuals, has a unique personality and combination of characteristics. Some individuals mildly affected may exhibit only slight delays in language and greater challenges with social interactions. They may have difficulty initiating and/or maintaining a conversation.

Their communication is often described as talking at others instead of to them. (For example, monologue on a favorite subject that continues despite attempts by others to interject comments).

People with autism also process and respond to information in unique ways. In some cases, aggressive and/or self-injurious behavior may be present. Persons with autism may also exhibit some of the following traits:

- Insistence on sameness; resistance to change
- Difficulty in expressing needs, using gestures or pointing instead of words
- Repeating words or phrases in place of normal, responsive language
- Laughing (and/or crying) for no apparent reason showing distress for reasons not apparent to others
- Preference to being alone; aloof manner
- Tantrums
- Difficulty in mixing with others

- Not wanting to cuddle or be cuddled
- Little or no eye contact
- Unresponsive to normal teaching methods
- Sustained odd play
- Spinning objects
- Obsessive attachment to objects
- Apparent over-sensitivity or under-sensitivity to pain
- No real fears of danger
- Noticeable physical over-activity or extreme under-activity
- Uneven gross/fine motor skills
- Non responsive to verbal cues; acts as if deaf, although hearing tests in normal range.

For most of us, the integration of our senses helps us to understand what we are experiencing. For example, our sense of touch, smell and taste work together in the experience of eating a ripe peach: the feel of the peach's skin, its sweet smell, and the juices running down your face. For children with autism, sensory integration problems are common, which may throw their senses off they may be over or under active. The fuzz on the peach may actually be experienced as painful and the smell may make the child gag. Some children with autism are particularly sensitive to sound, finding even the most ordinary daily noises painful. Many professionals feel that some of the typical autism behaviors, like the ones listed above, are actually a result of sensory integration difficulties.

There are also many myths and misconceptions about autism. Contrary to popular belief, many autistic children do make eye contact; it just may be less often or different from a non-autistic child. Many children with autism can develop good functional language and others can develop some type of communication skills, such as sign language or use of pictures. Children do not "outgrow" autism but symptoms may lessen as the child develops and receives treatment.

One of the most devastating myths about autistic children is that they cannot show affection. While sensory stimulation is processed differently in some children, they can and do give affection. However, it may require patience on the parents' part to accept and give love in the child's terms.

Information from Autism-Society.org

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Depression in Children and Adolescents

How common is depression in children and adolescents?

Studies have shown that on any single day (called "point prevalence" by epidemiologists) about 2 percent of school-aged children and about 8 percent of adolescents meet the criteria for major depression. Looking in the long term, the numbers are higher—for instance, one in five teens have experienced depression at some point. In primary care settings the rates of depression are higher still—as many as 28 percent for adolescents. Preschool depression has begun to attract interest in the literature but much more needs to be learned about how mood disorders may affect this age group.

Which youth get depression?

During childhood, the number of boys and girls affected are almost equal. In adolescence, twice as many girls as boys are diagnosed. Well over half of depressed adolescents have a recurrence within seven years. Several factors increase the risk of depression, including a family history of mood disorders and stressful life events.

Repeated episodes of depression can take a great toll on a young mind. It is prudent to get an evaluation followed by tailored treatment to prevent the social isolation, self-esteem consequences and safety risk of persistent depression.

Do youth with depression need treatment? Will they just "grow out of it"?

Episodes of depression in children appear to last six to nine months on average, but in some children they may last for years at a time. When children are experiencing an episode they do less well at school, have impaired relationships with their friends and family, internalize their feelings and have an increased risk for suicide. To ignore these warning signs and hope for the best while the child tries to cope is a risky decision. There are effective treatments for youth depression.

How can you tell if your child is depressed?

Signs that frequently help parents or others know that a child or teen should be evaluated for depression include:

- feeling persistently sad or blue;
- talking about suicide or being better off dead;
- becoming suddenly much more irritable;
- having a marked deterioration in school or home functioning;
- reporting persistent physical complaints and/or making many visits to school nurses;

- failing to engage in previously pleasurable activities or interactions with friends; and
- abusing substances.

Because the child or teen experiencing depression may not show significant behavioral disturbance—that is, the depression may be taking an internal toll without disrupting the family—parents sometimes "hope for the best" or fail to get a child evaluated.

What are the treatments for children and adolescents with depression?

There are two main groups of treatments for children with depression with well-demonstrated evidence of efficacy:

Psychotherapy (talk therapy)

Pharmacotherapy (medications)

Additionally, in September 2009 a study was published by Fristad, *et al.* demonstrating that family psychoeducation was beneficial for children with depression ages 8–12. This is a key area for further study.

All treatment options have risks and benefits. The best strategy is to educate yourself about the choices you can make, share the decision with your child or teen and evaluate what is best for your child. Untreated depression confers a real risk of suicide, so it is important to consider that no treatment also carries risks.

Exercise and social support are also necessary elements of any good treatment plan to address youth depression. These interventions may fail to address more serious symptoms but remain important components throughout the course of treatment.

Rigorous studies have shown both talk therapy and medications to be useful. Both treatments were more effective than when a placebo alone was given in the NIMH-funded Treatment for Adolescents with Depression Study (TADS). This landmark study also demonstrated that the combination of the two interventions is likely to create even better results than either one alone.

There are two different kinds of psychotherapy that studies have shown to be effective for children and/or adolescents—cognitive behavioral therapy (CBT) and interpersonal therapy (IPT). CBT concentrates on changing the negative attributional bias (seeing every cup as half-empty) associated with major depression. CBT attempts to challenge the automatic negative thinking that may contribute to depression. IPT focuses on a patient's self-concept and relationships with peers and family. More unstructured therapy with a supportive person may also be helpful but is more difficult to study. Ask potential therapists about the kind of psychotherapy they practice and why they feel it might help your child.

Antidepressant therapy can be an effective treatment option for child and adolescent depression, but it also carries risks. Fluoxetine (Prozac) is the only antidepressant specifically approved by the FDA for the treatment of depression in children ages 8 and older. Doctors can prescribe other antidepressant medications “off label” (not specifically approved by the FDA for that condition). If a doctor suggests another medication it is a good idea to ask more questions. Ask why he or she is not recommending the medication approved by the FDA for this condition, and what research and experience are the basis for the recommendation. You may ask for a second opinion from another doctor if you are not sure this is the best course of action.

There are three important considerations with the use of antidepressants in children and adolescents:

Suicidal thoughts. In 2004, the FDA issued a strong “black box” warning about the risk of increased suicidal thoughts and actions in a small percentage of children and adolescents who take antidepressants. While none of the 2200 children and adolescents in antidepressant studies killed themselves, a review of the data determined that the rate of suicidal thoughts was about 4% for those taking the medication, double the rate expected. It is important to have regular care

assessments, monitoring and follow-up, particularly in the first months of medication treatment. Please visit the FDA website for more detail.

In addition, in 2006 the FDA expanded the warning about suicidal thoughts and antidepressants to include adults under the age of 25. All treatment options have risks and benefits. The best strategy is to educate yourself about the choices you can make, to share the decision with your child or teen and to evaluate what is best in the context of a comprehensive care plan.

Bipolar disorder. Children and adolescents who first experience a major depressive episode may, over time, be predisposed to bipolar disorder. Reviewing any family history of bipolar disorder and being mindful of this possibility is a good idea when treating a child or adolescent experiencing a major depressive episode as antidepressants may increase the risk of mania in some youth.

Research on depression in children and adolescents. Research is ongoing in this important area, and more needs to be learned. Ask your caregiver about how the latest research studies have influenced the treatment plan. Look through the [NIMH website](#) for a summary of the latest research. Of future interest are NIMH-funded studies TORDIA (Treatment of SSRI-Resistant Depression in), TASA (Treatment of Adolescent Suicidal Attempters) and ASK (Antidepressant Safety in Kids).

What is the right treatment for my depressed child?

First, be sure that the caregiver has performed an in-depth assessment that looks at the whole person—the environment, school life, medical and family history and current living situation. It is important to have a real understanding of the stresses and strengths a youth brings to the equation. It is also essential to make the youth a part of the emerging plan. There is no “one size fits all” in mental health; interventions need to be tailored to the individual.

Once the diagnosis is made, ask the clinician to collaboratively develop a treatment plan with your child and family. Target symptoms that you and your child are hoping will improve (*e.g.* sleep problems, self-harming statements, school attendance or performance) that will help track your child’s progress. Treatment needs to be specific to your child and his or her world. For example, if there is a co-occurring alcohol problem, that must also be addressed. If there is a learning disability or bullying problem at school, that needs attention. Addressing family stresses or conflict may also be part of helping the youth.

If you have concerns about your child’s safety, be sure to have a plan for responding to these concerns. This should include how to access resources after hours and on weekends.

In general, the youth, family and clinician should together choose a first treatment or treatments and give that regimen an adequate trial determined in concert with the doctor (*e.g.*, eight to 12 weeks). The treatment should be reevaluated at the end of that time if it is not working.

How long should my child stay on treatment?

Treatment duration should be driven by the improvement and severity of the symptoms. Assuming a simple and positive treatment response, medications are typically continued at least six months after response before tapering off. Many therapists will decrease the frequency of psychotherapy sessions but continue some maintenance therapy longer than the initial eight to 12 weeks of treatment. Treatment for a first episode of depression is likely to last at least six to 12 months with either treatment but may be longer.

For recurring depression, many clinicians will recommend a person stay on medication for considerably longer periods, sometimes years, to prevent a recurrence. In that case, one key is to help the youth recognize when their symptoms are recurring or worsening so that additional supports can be activated.

The field of depression treatment for youth is continuously evolving and recent research may hold new information to better guide these decisions. The [NIMH](#) is a good source to summarize these recent findings. The [American Association of Child and Adolescent Psychiatry](#) is another good resource.

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www.fda.gov for all medication and antidepressant warnings and indications.

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Reviewed by Ken Duckworth, M.D., July 2010 (Printed from NAMI (National Alliance on Mental Illness) www.nami.org)

Early Onset Schizophrenia

Schizophrenia is a major psychiatric illness. Symptoms usually begin in late adolescence or early adulthood.

Numerous studies have found that about 1 in every 100 people around the world has the

disorder. However, schizophrenia with an onset in adolescence (prior to age 18) is less common, and an onset of the disorder in childhood (before age 13) is exceedingly rare. It is thought that at most one in every 100 adults with schizophrenia develops it in childhood.

Symptoms and Diagnosis

In both adults and children, the symptoms of schizophrenia can be divided into two broad categories – positive symptoms and negative symptoms.

- **Positive symptoms include:** hallucinations, usually voices which are critical or threatening; delusions, which are firm beliefs that are out of touch with reality and which commonly include the fear that people are watching, harassing, or plotting against the individual; disorganized speech, which is often seen as an inability to maintain a conversation, usually as a result of difficulty staying on topic; or, disorganized or catatonic behavior, which can include behavior that is unusual and bizarre, or can be demonstrated by difficulty planning and completing activities in an organized fashion.
- **Negative symptoms include:** reduction in emotional expression; lack of motivation and energy; or, loss of enjoyment and interest in activities, including social interaction.

Schizophrenia is diagnosed by the presence of two of the symptoms described above. For a diagnosis of schizophrenia, two of these symptoms must be present for at least 6 months and must be accompanied by increased difficulty in daily living in areas such as school, friendships, and self-care.

Hallucinations or delusions in a child should lead to an evaluation by a mental health professional who has experience working with children and adolescents with mental health disorders. A diagnosis of schizophrenia is made through an interview with the child and parents using information obtained from them and from school personnel.

Difficulties in diagnosing schizophrenia

Many of the symptoms seen in people with schizophrenia are also found in people with depression, bipolar disorder, or other illnesses. As a result, studies have found that misdiagnosis is common. This is particularly true with children and adolescents. As such, it is extremely important to rule-out other diagnoses such as depression, bipolar disorder, and substance use before making a diagnosis of schizophrenia.

An additional difficulty in making a diagnosis in children and adolescents relates to the fact that hallucinations are surprisingly common and, in fact, are most often seen in children and adolescents with diagnoses other than schizophrenia. In a large study at the National Institutes of Health, the great majority of those previously diagnosed with schizophrenia did not receive that diagnosis following careful evaluation. In many children with other conditions, the nature of the hallucinations is different. While hallucinations in people with schizophrenia are often pervasive when not well treated, many children with other conditions such as mood disorders and dissociative disorders, report auditory hallucinations when they are under stress. These hallucinations tend to be brief and very intermittent (lasting for only a few minutes). Also, children are very

susceptible to leading questions and therefore should be asked about symptoms in a neutral fashion (i.e., not "Do you hear voices?").

Children with pervasive developmental disorders (autism, Asperger's disorder, or an unspecified pervasive developmental disorder) often have social difficulties, disorganized behavior and language impairments. These developmental disorders can be confused with a diagnosis of schizophrenia.

Prognosis of early onset schizophrenia

The outcome for children with schizophrenia varies greatly and some individuals function well with medication. Earlier onset is often associated with a poorer outcome when it interferes with attending school and completing an education. However, because children typically live at home with the combined social environments of family and school, symptoms are often recognized early. This fact is significant because recent studies have suggested that earlier treatment may reduce the decline in functioning and long-term impairments commonly associated with schizophrenia. As such, accurate and early intervention and diagnosis are critical.

Treatment for schizophrenia

Treatment for schizophrenia includes biological, educational, and social interventions. Medication is the cornerstone of the treatment of schizophrenia, but should be viewed as a means to facilitate psychological and social interventions. Treatment with only medication is not as effective as medication therapy combined with other forms of treatment.

The medications used to treat schizophrenia are termed "anti-psychotics" or "neuroleptics". Although these medications are often effective, they have been associated with significant side effects. The last decade has seen the introduction of a number of new anti-psychotics with reduced side effects. The most commonly used medications used now are: risperidone (Risperdal), olanzapine (Zyprexa), and quetiapine (Seroquel). Other medications include haloperidol (Haldol), thioridazine (Mellaril), and chlorpromazine (Thorazine). For individuals who are not responsive to the previous trials of anti-psychotics, including olanzapine, clozapine (Clozaril) is an important option for children and teenagers, but is not used as a first treatment due to significant side-effects (see below). For some children with refractory psychosis, clozapine proves to be the only medication that helps. We have been able, with careful monitoring, to manage side effects in our children on clozapine, should side effects occur. It is also important that associated symptoms be recognized and treated appropriately. For example, individuals with schizophrenia who develop depression or anxiety should be treated for these symptoms.

Children and adolescents with schizophrenia often need adjustments to their educational programs. Typically this would include smaller classrooms with teachers who are experienced with children and adolescents with psychiatric disorders. Their academic work may also need to be modified in order to accommodate problems sometimes associated with schizophrenia such as reduced concentration and attention.

Social difficulties are commonly seen with early onset schizophrenia. These include

difficulty making and keeping friends, difficulty with interpersonal interactions, and low frustration tolerance. Activities to develop social skills is integral to the treatment of schizophrenia. In addition, family therapy and education about schizophrenia may help family members to cope with the child's illness.

Common side effects of anti-psychotic medications

Every youth will have a different reaction to any medication--be it an antibiotic or an anti-psychotic.

Nonetheless, the most common problem that children and adolescents report when taking the new generation of anti-psychotic medications (olanzapine and risperidone, for example) is weight gain. This can be problematic because teens are particularly sensitive about how they look. Common side effects of the older class of antipsychotics, such as the more commonly-used and less expensive haloperidol (Haldol), include drowsiness; and neuroleptic side effects such as acute extrapyramidal side effects and tardive dyskinesia. Approximately 1% of those taking clozapine (Clozaril) will develop a serious side effect called agranulocytosis; thus, regular monitoring of blood levels is essential.

Research and new treatments

Much research and development of new medications for schizophrenia is underway. Some promising medications have very different mechanisms of action and so may be more effective with fewer side effects. However, the process of drug development and approval is slow and many of these medications are only currently available in research studies. Several centers around the country are involved in research with these new medications.

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Reviewed by Julia Tossell, MD September 2003

Dual Diagnosis

Adolescents with Co-occurring Brain Disorders & Substance Abuse Disorders

Adolescents are often referred to treatment for substance abuse, but are not referred to a qualified mental health professional for appropriate diagnosis and treatment of any underlying cause for their drug and alcohol abuse. However, many teens have symptoms of a mood disorder that may in fact have led to self-medicating with street drugs and alcohol.

Families and caregivers know how difficult it is to find treatment for an adolescent who abuses drugs or alcohol, but who also is diagnosed with a brain disorder (mental illness); i.e., ADHD, depression, or bipolar disorder. Traditionally, programs that treat individuals with brain disorders do not treat individuals with active substance abuse problems, and programs for substance abusers are not geared for people with mental illness. Adolescents are often caught in this treatment or services gap.

Is dual diagnosis common?

The combination of mental illness and substance abuse is so common that many clinicians now expect to find it. Studies show that more than half of young persons with a substance abuse diagnosis also have a diagnosable mental illness.

What causes these disorders?

Mental health and addiction counselors increasingly believe that brain disorders and substance abuse disorders are biologically and physiologically based.

What kind of treatment works?

Families and caregivers may feel angry and blame the adolescent for being foolish and weak-willed. They may feel hurt when their child breaks trust by lying and stealing. But it's important to realize that mental illness and often substance abuse are disorders that the adolescent cannot take control of without professional help.

Teens with difficult problems such as concurrent mental illness and substance abuse disorders do not respond to simplistic advice like "just say no" or "snap out of it." Psychotherapy and medication combined with appropriate self-help and other support groups help most, but patients are still highly prone to relapse.

Treatment programs designed primarily for substance abusers are not recommended for individuals who have a diagnosed mental illness.

Their reliance on confrontation techniques and discouragement of use of appropriate prescription medications tend to compound the problems of individuals with mental illness. These strategies may produce stress levels that make symptoms worse or cause relapse.

What is a better approach?

Increasingly, the psychiatric and drug counseling communities agree that **both disorders must be treated at the same time**. Early studies show that when mental illness and substance abuse are treated together, suicide attempts and psychotic episodes decrease rapidly.

Since dually diagnosed clients do not fit well into most traditional 12-step programs, special peer groups based on the principle of treating both disorders together should be developed at the community level. Individuals who develop positive social networking have a much better chance of controlling their illnesses. Healthy recreational activities are extremely important.

What's the first step in treatment?

The presence of both disorders must first be established by careful assessment. This may be difficult because the symptoms of one disorder can mimic the symptoms of the other. Seek referral to a psychologist or psychiatrist. Local NAMI affiliates are happy to refer families to mental health professionals their members recommend. **(Call the NAMI HelpLine at 1-800/950-6264 for a local contact).**

Once a professional assessment has confirmed a dual diagnosis of mental illness and substance abuse, mental health professionals and family members should work together on a strategy for integrating care and motivating the adolescent.

What do model programs for treating mental illness and substance abuse look like?

There is a growing number of model programs. Support groups are an important component of these programs. Adolescents support each other as they learn about the negative role that alcohol and drugs has had on their lives. They learn social skills and how to replace substance use with new thoughts and behaviors. They get help with concrete situations that arise because of their brain disorder (mental illness).

Look into programs that have support groups for family members and friends.

If your teen has a substance abuse disorder ...

- * Don't regard it as a family disgrace. Recovery is possible just as it is with other illnesses.**
- * Encourage and facilitate participation in support groups during and after treatment.**
- * Don't nag, preach, or lecture.**
- * Don't use the "if you loved me" approach. It is like saying, "If you loved me, you would not have tuberculosis."**
- * Establish consequences for behaviors. Don't be afraid to call upon law enforcement if teens engage in underage drinking on your premises. You can be held legally responsible for endangering minors if you do not take timely action.**
- * Avoid threats unless you think them through carefully and definitely intend to carry them out. Idle threats only make the person with a substance abuse disorder feel you don't mean what you say.**
- * During recovery, encourage teens to engage in after-school activities with adult supervision. If they cannot participate in sports or other extracurricular school activities, part-time employment or volunteer work can build self-esteem.**
- * Don't expect an immediate, 100-percent recovery. Like any illness, there is a period of convalescence with a**

brain disorder. There may be relapses and times of tension and resentment among family members.

*** Do offer love, support, and understanding during the recovery.**

Reviewed by Patrick C. Friman, Ph.D., A.B.P.P., Director of Clinical Services & Research at Father Flanigan's Boys' Home and associate professor, Creighton University School of Medicine.

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Obsessive-compulsive Disorder

The National Institute of Mental Health estimates that more than 2 percent of the U.S. population, or nearly one out of every 40 people, will suffer from OCD at some point in their lives. The disorder is two to three times more common than schizophrenia and bipolar disorder.

What is Obsessive-compulsive disorder?

Obsessions are intrusive, irrational thoughts -- unwanted ideas or impulses that repeatedly well up in a person's mind. Again and again, the person experiences disturbing thoughts, such as "My hands must be contaminated; I must wash them"; "I may have left the gas stove on"; "I am going to injure my child." On one level, the sufferer knows these obsessive thoughts are irrational. But on another level, he or she fears these thoughts might be true. Trying to avoid such thoughts creates great anxiety.

Compulsions are repetitive rituals such as hand washing, counting, checking, hoarding, or arranging. An individual repeats these actions, perhaps feeling momentary relief, but without feeling satisfaction or a sense of completion. People with OCD feel they must perform these compulsive rituals or something bad will happen.

Most people at one time or another experience obsessive thoughts or compulsive behaviors. Obsessive-compulsive disorder occurs when an individual experiences obsessions and compulsions for more than an hour each day, in a way that interferes with his or her life.

OCD is often described as "a disease of doubt." Sufferers experience "pathological doubt" because they are unable to distinguish between what is possible, what is probable, and what is unlikely to happen.

Who gets OCD?

People from all walks of life can get OCD. It strikes people of all social and ethnic groups and both males and females. Symptoms typically begin during the teenage years or young adulthood.

What causes OCD?

A large body of scientific evidence suggests that OCD results from a chemical imbalance in the brain. For years, mental health professionals incorrectly assumed OCD resulted from bad parenting or personality defects. This theory has been disproven over the last 20 years. OCD symptoms are not relieved by psychoanalysis or other forms of "talk therapy," but there is evidence that behavior therapy can be effective, alone or in combination with medication. People with OCD can often say "why" they have obsessive thoughts or why they behave compulsively. But the thoughts and the behavior continue.

People whose brains are injured sometimes develop OCD, which suggests it is a physical condition. If a placebo is given to people who are depressed or who experience panic attacks, 40 percent will say they feel better. If a placebo is given to people who experience obsessive-compulsive disorder, only about two percent say they feel better. This also suggests a physical condition.

Clinical researchers have implicated certain brain regions in OCD. They have discovered a strong link between OCD and a brain chemical called serotonin. Serotonin is a neurotransmitter that helps nerve cells communicate.

Scientists have also observed that people with OCD have increased metabolism in the basal ganglia and the frontal lobes of the brain. This, scientists believe, causes repetitive movements, rigid thinking, and lack of spontaneity. People with OCD often have high levels of the hormone vasopressin.

In layperson's terms, something in the brain is stuck, like a broken record. Judith Rapoport, M.D., describes it in her book, *The Boy Who Couldn't Stop Washing*, as "grooming behaviors gone wild."

How do people with OCD typically react to their disorder?

People with OCD generally attempt to hide their problem rather than seek help. Often they are remarkably successful in concealing their obsessive-compulsive symptoms from friends and co-workers. An unfortunate consequence of this secrecy is that people with OCD generally do not receive professional help until years after the onset of their disease. By that time, the obsessive-compulsive rituals may be deeply ingrained and very difficult to change.

How long does OCD last?

OCD will not go away by itself, so it is important to seek treatment. Although symptoms may become less severe from time to time, OCD is a chronic disease. Fortunately, effective treatments are available that make life with OCD much easier to manage.

Is age a factor in OCD?

OCD usually starts at an early age, often before adolescence.

It may be mistaken at first for autism, pervasive developmental disorder, or Tourette's syndrome, a disorder that may include obsessive doubting and compulsive touching as symptoms.

Like depression, OCD tends to worsen as the person grows older, if left untreated. Scientists hope, however, that when the OCD is treated while the person is still young, the symptoms will not get worse with time.

What are other examples of behaviors typical of people who suffer from OCD?

People who do the following may have OCD:

- * repeatedly check things, perhaps dozens of times, before feeling secure enough to go to sleep or leave the house. Is the stove off? Is the door locked? Is the alarm set?
- * fear they will harm others. Example: A man's car hits a pothole on a city street and he fears it was actually a body.
- * feel dirty and contaminated. Example: A woman is fearful of touching her baby because she might contaminate the child.
- * constantly arrange and order things. Example: A child can't go to sleep unless he lines up all his shoes correctly.
- * are excessively concerned with body imperfections -- insist on numerous plastic surgeries, or spend many, many hours a day body-building.
- * are ruled by numbers, believing that certain numbers represent good and others represent evil.
- * are excessively concerned with sin or blasphemy.

Is OCD commonly recognized by professionals?

Not nearly commonly enough. OCD is often misdiagnosed, and it is often underdiagnosed. Many people have dual disorders of OCD and schizophrenia, or OCD and bipolar disorder, but the OCD component is not diagnosed or treated. Researchers believe OCD, anxiety disorders, Tourette's, and eating disorders such as anorexia and bulimia can be triggered by some of the same chemical malfunctioning of the brain.

Is heredity a factor in OCD?

Yes. Heredity appears to be a strong factor. If you have OCD, there's a 25-percent chance that one of your immediate family members will have it. It definitely seems to run in families.

Can OCD be effectively treated?

Yes, with medication and behavior therapy. Both affect brain chemistry, which in turn affects behavior. Medication can regulate serotonin, reducing obsessive thoughts and compulsive behaviors.

Anafranil (clomipramine): A *tricyclic antidepressant*, Anafranil has been shown to be effective in treating obsessions and compulsions. The most commonly reported side effects of this medication are dry mouth, constipation, nausea, increased appetite, weight gain, sleepiness, fatigue, tremor, dizziness, nervousness, sweating, visual changes, and sexual dysfunction. There is also a risk of seizures, thought to be dose-related. People with a history of seizures should not take this medication. Anafranil should also not be taken at the same time as a *monoamine oxidase inhibitor (MAOI)*.

Many of the antidepressant medications known as *selective serotonin reuptake inhibitors (SSRIs)* have also proven effective in treating the symptoms associated with OCD. The

SSRIs most commonly prescribed for OCD are Luvox (fluvoxamine), Paxil (paroxetine), Prozac (fluoxetine), and Zoloft (sertraline).

Luvox (fluvoxamine): Common side effects of this medication include dry mouth, constipation, nausea, sleepiness, insomnia, nervousness, dizziness, headache, agitation, weakness, and delayed ejaculation.

Paxil (paroxetine): Side effects most associated with this medication include dry mouth, constipation, nausea, decreased appetite, sleepiness, insomnia, tremor, dizziness, nervousness, weakness, sweating, and sexual dysfunction.

Prozac (fluoxetine): Dry mouth, nausea, diarrhea, sleepiness, insomnia, tremor, nervousness, headache, weakness, sweating, rash, and sexual dysfunction are among the more common side effects associated with this drug.

Zoloft (sertraline): Among the side effects most commonly reported while taking Zoloft are dry mouth, nausea, diarrhea, constipation, sleepiness, insomnia, tremor, dizziness, agitation, sweating, and sexual dysfunction.

SSRIs should never be taken at the same time as MAOIs.

How long should an individual take medication before judging its effectiveness?

Some physicians make the mistake of prescribing a medication for only three or four weeks. That really isn't long enough. Medication should be tried consistently for 10 to 12 weeks before its effectiveness can be judged.

What is behavior therapy, and can it effectively relieve symptoms of OCD?

Behavior therapy is not traditional psychotherapy. It is "exposure and response prevention," and it is effective for many people with OCD. Consumers are deliberately exposed to a feared object or idea, either directly or by imagination, and are then discouraged or prevented from carrying out the usual compulsive response.

For example, a compulsive hand-washer may be urged to touch an object he or she believes is contaminated and denied the opportunity to wash for several hours. When the treatment works well, the consumer gradually experiences less anxiety from the obsessive thoughts and becomes able to refrain from the compulsive actions for extended periods of time.

Several studies suggest that medication and behavior therapy are equally effective in alleviating symptoms of OCD. About half of the consumers with this disorder improve substantially with behavior therapy; the rest improve moderately.

Will OCD symptoms go away completely with medication and behavior therapy?

Response to treatment varies from person to person. Most people treated with effective medications find their symptoms reduced by about 40 percent to 50 percent. That can often be enough to change their lives, to transform them into functioning individuals.

A few consumers find that neither treatment produces significant change, nor a small number of people are fortunate to go into total remission when treated with effective medication and/or behavior therapy.

For further information:

Call the **NAMI HelpLine** at **1-800-950-6264** to request a free copy of, "Expert Consensus Treatment Guidelines for Obsessive-Compulsive Disorder: A Guide For Patients and Families," or download this guide from www.psychguides.com.

The Boy Who Couldn't Stop Washing, by Judith L. Rapoport, M.D. New American Library, 1977.

Obsessive-Compulsive Disorder: The Facts, by Padmal de Silva and Stanley Rachman. Oxford University Press, 1998.

Polly's Magic Games: A Child's View of Obsessive-Compulsive Disorder, by Constance H. Foster. Illustrated by Edwin A. Chase. Dilligaf Publishing, 1994.

Tormenting Thoughts and Secret Rituals: The Hidden Epidemic of Obsessive-Compulsive Disorder, by Ian Osborn, M.D. Delacorte Press, 1999.

Organizations:

National Institute of Mental Health
Phone: 301-443-4513
Web site: www.nimh.nih.gov

Obsessive-Compulsive Foundation
Phone: 203-315-2190
Web site: www.ocfoundation.org

Fact sheet information from Teri Pigott, M.D., Georgetown University and the National Institute of Mental Health, and Mary Lynn Hendrix, National Institute of Mental Health, and reviewed by Jack D. Maser, Ph.D., chief, Anxiety Disorders Program, National Institute of Mental Health.

Printed from NAMI website (National Alliance on Mental Illness) website nami.org

Eating Disorders

What is anorexia nervosa?

Anorexia nervosa is a serious, occasionally chronic, and potentially life-threatening eating disorder defined by a refusal to maintain minimal body weight within 15 percent of an individual's normal weight. Other essential features of this disorder include an intense fear of gaining weight, a distorted body image, denial of the seriousness of the illness, and amenorrhea (absence of at least three consecutive menstrual cycles when they are otherwise expected to occur).

There are two subtypes of anorexia nervosa. In the restricting subtype, people maintain their low body weight purely by restricting their food intake and, possibly, by excessive exercise. Individuals with the binge eating/purging subtype also restrict their food intake, but also regularly engage in binge eating and/or purging behaviors such as self-induced vomiting or the misuse of laxatives, diuretics, or enemas. Many people move back and

forth between subtypes during the course of their illness. Starvation, weight loss, and related medical complications are quite serious and can result in death. People who have an ongoing preoccupation with food and weight even when they are thin would benefit from exploring their thoughts and relationships with a therapist. The term anorexia literally means loss of appetite, but this is a misnomer. In fact, people with anorexia nervosa often ignore hunger signals and thus control their desire to eat. Often they may cook for others and be preoccupied with food and recipes, yet they will not eat themselves. Obsessive exercise that may accompany the starving behavior can cause others to assume falsely that the person must be healthy.

Who develops anorexia nervosa?

Like all eating disorders, anorexia nervosa tends to occur in pre- or post-puberty, but can develop at any time throughout the lifespan. Anorexia nervosa predominately affects adolescent girls and young adult women, although it also occurs in boys, men, older women and younger girls. One reason younger women are particularly vulnerable to eating disorders is their tendency to go on strict diets to achieve an "ideal" figure. This obsessive dieting behavior reflects today's societal pressure to be thin, which is seen in advertising and the media. Others especially at risk for eating disorders include athletes, actors, dancers, models, and TV personalities for whom thinness has become a professional requirement. People with anorexia nervosa will often mention that the sense of control they develop over eating and weight helps them feel as if other aspects of their life are under control.

The presence of depression and anxiety disorders may increase the risk of developing anorexia nervosa.

How many people suffer from anorexia nervosa?

Conservative estimates suggest that one-half to one percent of females in the U.S. develop anorexia nervosa. Because more than 90 percent of all those who are affected are adolescent and young women, the disorder has been characterized as primarily a woman's illness. It should be noted, however, that males and children as young as seven years old have been diagnosed; and women 50, 60, 70, and even 80 years of age have fit the diagnosis. Some of these individuals will have struggled with eating, shape or weight in the past but new onset cases can also occur.

How is the weight lost?

People with anorexia nervosa usually lose weight by reducing their total food intake and exercising excessively. Many persons with this disorder restrict their intake to fewer than 1,000 calories per day. Most avoid fattening, high-calorie foods, and often eliminate meats. The diet of persons with anorexia nervosa may consist almost completely of low-calorie foods and or beverages like lettuce and carrots, popcorn, and diet soft drinks.

What are the common signs of anorexia nervosa?

The hallmark of anorexia nervosa is a preoccupation with food and a refusal to maintain

minimally normal body weight. One of the most frightening aspects of the disorder is that people with anorexia nervosa continue to think they look fat even when they are bone-thin. Their nails and hair become brittle, and their skin may become dry and yellow. People with anorexia nervosa often complain of feeling cold (hypothermia) because their body temperature drops. They may develop lanugos (a term used to describe the fine hair on a new born) on their body.

Persons with anorexia nervosa develop odd and ritualistic eating habits such as cutting their food into tiny pieces, refusing to eat in front of others, or fixing elaborate meals for others that they themselves don't eat. Food and weight become obsessions as people with this disorder constantly think about their next encounter with food. Generally, if a person or their family fears he or she has anorexia nervosa, a doctor knowledgeable about eating disorders should make a diagnosis and rule out other physical disorders.

Other psychiatric disorders can occur together with anorexia nervosa, such as depression, anxiety disorders and substance abuse disorders.

What are the causes of anorexia nervosa?

Although the precise causes of anorexia nervosa are unknown, we do know that it is caused by a combination of genetic and environmental factors. Scientists have studied the role of personality, genetics, environment, and biochemistry of people with these illnesses. Certain personality traits common in persons with anorexia nervosa are perfectionism, neuroticism (anxiety-proneness), low self-esteem, and social isolation (which usually occurs after the behavior associated with anorexia nervosa begins). Many people who develop anorexia nervosa had been good students and athletes.

Eating disorders also tend to run in families, with female relatives most often affected. Relatives of someone with anorexia nervosa are over 10 times more likely to have an eating disorder themselves than relatives of someone without anorexia nervosa. The heritability of anorexia nervosa has been estimated to be over 50%. Behavioral and environmental influences also play a role in vulnerability to the illness. Stressful life events or transitions may precipitate the illness. In studies of the biochemical functions of people with eating disorders, scientists have found that the neurotransmitters serotonin and norepinephrine are decreased in those with anorexia nervosa who are at a low weight. People with anorexia nervosa also tend to have higher than normal levels of cortisol (a brain hormone released in response to stress) and vasopressin (a brain chemical found to be abnormal in patients with obsessive-compulsive disorder).

Are there medical complications?

The starvation experienced by persons with anorexia nervosa can cause damage to vital organs such as the heart, kidneys, and brain. Pulse rate and blood pressure drop, and people suffering from this illness may experience irregular heart rhythms or heart failure. Nutritional deprivation along with purging causes electrolyte abnormalities such as low potassium and low sodium. Nutritional deprivation also leads to calcium loss from bones, which can become brittle and prone to breakage (osteoporosis). Nutritional deprivation also leads to decreased brain volume. In the worst-case scenario, people with anorexia

can starve themselves to death. Anorexia nervosa has the highest mortality rate of any psychiatric illness. The most frequent causes of death are suicide and complications of the malnutrition associated with the disorder.

Is treatment available?

Recovery from anorexia nervosa is possible. In long term follow-up studies, about half of individuals fully recover from the illness, a small percentage continued to suffer from anorexia, and the remainder continue to have other eating disorders. For some, anorexia nervosa can be relatively short-lived, whereas for others it can become a chronic and debilitating illness.

We do not yet know predictors of clinical course.

Luckily, most of the complications experienced by persons with anorexia nervosa are reversible when they restore their weight. People with this disorder should be diagnosed and treated as soon as possible because eating disorders are most successfully treated when diagnosed early. Some patients can be treated as outpatients, but some may need hospitalization to stabilize their dangerously low weight. Weight gain of one to three pounds per week is considered safe and desirable. The most effective strategies for treating a patient include weight restoration, individual, family, and group therapies along with psychiatric medications as needed.

To help people with anorexia nervosa overcome their disorder, a variety of approaches are used. Some form of psychotherapy is needed to deal with underlying emotional issues. Cognitive-behavioral therapy is sometimes used to change unhealthy thoughts and behaviors. Group therapy is often advised so people can share their experiences with others. and dieting may be identified and interventions instituted Family therapy is important particularly if the individual is living at home and is a child or young adolescent. A physician or advanced-practice nurse is needed to prescribe medications that may be useful in treating the disorder or associated depression or anxiety. Be sure to check with your doctor before taking any psychiatric medications as they can impact weight and have varied risks and benefits. Finally, a nutritionist is necessary to advise the patient about proper diet and eating regimens. Where support groups are available, they can be beneficial to both patients and families. It is also important to realize that some people require a coordinated team of professionals from many disciplines to maximize their chance of recovery.

What about prevention?

New research findings are showing that some of the "traits" in individuals who develop anorexia nervosa are actual "risk factors" that might be treated early on. For example, anxiety, low self esteem, body dissatisfaction, before an eating disorder develops. Advocacy groups have also been effective in reducing dangerous media stories, such as teen magazine articles on "being thin" and pro-anorexia (pro-ana) websites that may glamorize such risk factors as dieting.

From further fact sheets on other Eating Disorders see NAMI website nami.org.

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Berkman ND, Lohr KN, Bulik CM. Outcomes of eating disorders: a systematic review of the literature. *Int J Eat Disord*. 2007 May;40(4):293-309. Review. PMID: 17370291 [PubMed - indexed for MEDLINE]

Bulik CM, Berkman ND, Brownley KA, Sedway JA, Lohr KN. Anorexia nervosa treatment: a systematic review of randomized controlled trials. *Int J Eat Disord*. 2007 May;40(4):310-20. Review. PMID: 17370290 [PubMed - indexed for MEDLINE]

Suicide in Youth

How many young people make serious suicide attempts or commit suicide?

Each year in the U.S., approximately 2 million U.S. adolescents attempt suicide, and almost 700,000 receive medical attention for their attempt (AACAP, 2001). According to the Youth Risk Behavior Surveillance System, in 2001, 2.6% of students reported making a suicide attempt that had to be treated by a doctor or nurse. With respect to suicide, it is estimated that each year in the U.S., approximately 2,000 youth aged 10 – 19 complete suicide. In 2000, suicide was the 3rd leading cause of death among young people aged 15 to 24 years of age, following unintentional injuries and homicide (CDC Wonder).

- The suicide rate among children aged 10-14 was 1.5/100,000, or 300 deaths among 19,895,072 children in this age group.
- The suicide rate among adolescents aged 15-19 was 8.2/100,000, or 1,621 deaths among 19,882,596 adolescents in this age group.
- The suicide rate among young people aged 20-24 was 12.8/100,000, or 2,373 deaths among 18,484,615 people in this age group.

What leads to suicide in children and adolescents?

Suicide is the result of many complex factors. More than 90% of youth suicide victims have at least one major psychiatric disorder, although younger adolescent suicide victims have lower rates of psychopathology (Gould et al., 2003). It is important to note that while the majority of suicide victims have a history of psychiatric disorder, especially mood disorders, very few adolescents with psychiatric disorder will go on to complete suicide.

Other important risk factors for suicide and suicidal behavior include:

- Prior suicide attempt
- Co-occurring mental and alcohol or substance abuse disorders
- Family history of suicide
- Parental psychopathology

- Hopelessness
- Impulsive and/or aggressive tendencies
- Easy access to lethal methods, especially guns
- Exposure to the suicide of a family member, friend, or other significant person
- History of physical or sexual abuse
- Same-sex sexual orientation (only been shown for suicidal behavior, not suicide)
- Impaired parent-child relationships
- Life stressors, especially interpersonal losses and legal or disciplinary problems
- Lack of involvement in school and/or work (“drifting”)

Is there some way that family or other adults can identify a young person at risk?

Yes, people can be educated about the warning signs of suicidal behavior. Some of the key risk factors to look for are listed above. The single biggest risk factor is serious current suicidality, either suicidal ideation with intent to commit suicide, or a recent attempt. Other warning signs include (abstracted from AACAP Teen Suicide Fact Sheet):

- Change in eating and sleeping habits
- Withdrawal from friends, family, and regular activities
- Violent actions, rebellious behavior, or running away
- Drug and alcohol use
- Unusual neglect of personal appearance
- Marked personality change
- Persistent boredom, difficulty concentrating, or a decline in the quality of schoolwork
- Frequent complaints about physical symptoms, often related to emotions, such as stomach aches, headaches, fatigue, etc.
- Loss of interest in pleasurable activities
- Not tolerating praise or rewards

For adolescents who are already receiving psychiatric treatment, family

Psycho-education may be an effective approach to help parents and family members to understand better the problems of their adolescent.

The goals of such education are to increase compliance with treatment, promote a partnership with the parents so that they can monitor the patient with regard to recurrences, and to help the family learn how to cope with a child with a psychiatric illness.

Is there some way that suicide can be prevented in young people? Yes, suicide can be prevented. As noted above, most suicides occur with at least some outward warning. One of the most effective suicide prevention strategies is educating people about how to identify and effectively respond to the warning signs of suicidal behavior, thus increasing the referral of at-risk youth. Screening for psychopathology among adolescents may be one way to detect youths at risk for suicide. However, because suicidal tendencies tend to wax and wane, screenings may have to be repeated. Treatment of parental psychopathology may also attenuate risk in psychiatrically ill youths.

One of the primary goals of effective suicide prevention strategies among young people

is to reduce suicide risk factors. Psychopathology, particularly mood disorders, conduct/antisocial disorders, and substance abuse, is strongly associated with youth suicide. Importantly, these mental disorders are all treatable. Therefore, it is imperative that psychiatric disorders in young people be accurately recognized and effectively treated.

According to one recent case-control study (Brent et al., 1999) the effective targeting of a handful of risk factors, namely past suicide attempt, psychopathology in the adolescent, parental psychopathology, and gun in the home, is likely to result in a substantial reduction in the suicide rate among youth.

Tourette's Syndrome

Tourette's disorder, or Tourette's syndrome (TS) as it is frequently called, is a neurologic syndrome. The first indication a parent has that their child may have TS. Involuntary sounds, such as throat clearing and sniffing, or tics of the limbs may be an initial sign in other children.

Are any other symptoms associated with Tourette's? Approximately 50 percent of patients meet criteria for attention deficit hyperactivity disorder (ADHD) and this may be the more impairing problem. Approximately one-third of patients meet criteria for obsessive-compulsive disorder (OCD) or have other forms of anxiety. Learning disabilities are common as well as developmental stuttering. Social discomfort, self-consciousness and depressed mood frequently occur, especially as children reach adolescence.

What causes these symptoms? Although the cause has not been definitely established, there is considerable evidence that TS arises from abnormal metabolism of dopamine, a neurotransmitter.³ Other neurotransmitters may be involved.

Can TS be inherited? Genetic studies indicate that TS is inherited as an autonomic dominant gene but different family members may have dissimilar symptoms. A parent has a 50 percent chance of cs with varying degrees of attention deficit-disorder and OCD.

Are boys or girls more likely to have TS? The sex of the child can influence the expression of the TS gene. Girls with the gene have a 70 percent chance of displaying symptoms, boys with the gene have a 99 percent chance of displaying symptoms. Ratios of boys with TS to girls with TS are 3:1.

How is Tourette's syndrome diagnosed? No blood analysis, x-ray or other medical test exists to identify TS. Diagnosis is made by observing the signs or symptoms as described above. A doctor may wish to use a CAT scan, EEG, or other tests to rule out other ailments that could be confused with TS. Some medications cause tics, so it is important to inform the professional doing the assessment of any prescribed, over-the-counter, or street drugs to which the patient may have been exposed.

What are the benefits of seeking early treatment of TS symptoms? When a child's behavior is viewed as disruptive, frightening, or bizarre by peers, family, teachers, or friends, it provokes ridicule and rejection. Teachers and other children can feel threatened and exclude the child from activities or interpersonal relationships. A child's socialization difficulties will increase as he reaches adolescence. Therefore, it is very important for the child's self-esteem and emotional well-being that treatment be

sought as early as possible.

What treatments are available for TS? Not everyone is disabled by his or her symptoms, so medication may not be necessary. When symptoms interfere with functioning, medication can effectively improve attention span, decrease impulsivity, hyperactivity, tics, and obsessive-compulsive symptomatology. Relaxation techniques and behavior therapy may also be useful for tics, ADD symptoms, and OCD symptoms.

How does TS affect the education of a child or adolescent with TS? TS alone does not affect the IQ of a child. Many children who have TS, however, also have learning disabilities or attention deficits. Frequently, therefore, special education may be needed for a child with TS. Teachers should be given factual information about the disorder and, if learning difficulties appear, the child should be referred to the school system for assessment of other learning problems.

What is the course of TS? Some people with TS show a marked improvement in their late teens or early twenties. However, tics as well as ADD and OCD behavior, may wax and wane over the course of the life span.

1 According to the Diagnostic and Statistical Manual of Mental Disorders (4th Edition), or DSM-IV

2 This is a change from the former edition, DSM-III-R, that set maximum age of onset at 21 years of age.

3 A biochemical substance that transmits nerve impulses from one nerve cell to another at a synapse.

Reviewed by Charles T. Gordon, III, M.D.

Internet Resource List for Children's Mental Health

NAMI Child & Adolescent Action Center

Federal Agencies

- Center for Mental Health Services (CMHS)
Children, Adolescents and Family Resources

Web address: www.mentalhealth.org

- Centers for Disease Control and Prevention (CDC)
The CDC has data and statistics on suicide and increasingly has information available on mental illnesses.

Web address: www.cdc.gov

- Centers for Medicare & Medicaid Services (CMS)
CMS administers the Medicare, Medicaid and SCHIP (State Children's Health Insurance Program) programs.

Web address: www.cms.hhs.gov

- Department of Education (DOE) – Office of Special Education and Rehabilitative Services (OSERS)

OSERS web site includes a wide array of information for families, school districts and states in three main areas: special education, vocational rehabilitation and research.

Web address: www.ed.gov (click on “offices” and then click on Office of Special Education and Rehabilitative Services, listed under “Program Offices.”)

- InsureKidsNow

The U.S. Department of Health and Human Services has created a national

campaign to link the nation’s 10 million uninsured children – from birth to 18 years – to free and low-cost health insurance.

Web address: www.insurekidsnow.gov/

- Maternal and Child Health Library (MCH)

The Maternal Child Health Library (MCH) has an on-line web site designed to help service providers and families find available national, state, and local resources that can address child and family needs, including mental health resources. To learn more about locating services for your child or understanding which services to look for, visit Knowledge Path: Locating Community-Based Services to Support Children and Families at Website address:

www.mchlibrary.info/KnowledgePaths/kp_community.html

- National Institute of Mental Health (NIMH)

The mission of NIMH is to diminish the burden of mental illness through research. Web address: www.nimh.nih.gov

- Office of Juvenile Justice and Delinquency Prevention (OJJDP)

OJJDP’s mission is to provide national leadership, coordination, and resources to prevent and respond to the needs of individuals in the juvenile justice system. OJJDP supports states and local communities in their efforts to develop agency also works to improve the juvenile justice system.

Web address: www.ojjdp.ncjrs.org

- Office of the U.S. Surgeon General

In 1999, Surgeon General David Satcher displayed true leadership in issuing A

Comprehensive Report on mental health – chapter 3 covers children and adolescents. Web address: www.surgeongeneral.gov/sgooffice.htm

President’s New Freedom Commission on Mental Health

The Commission was created to examine the current gaps in mental illness treatment services and to make recommendations to the President on ways in which the federal government can help states increase access to care and improve quality in their public programs.

Web address: www.mentalhealthcommission.gov

Children’s Mental Health and Advocacy Organizations

- Autism Society of America

Information and resources on autism.

Web address: www.autism-society.org

- Bazelon Center for Mental Health Law

The Bazelon Center for Mental Health Law works on a broad array of children's mental health issues.

Web address: www.bazelon.org

- Child and Adolescent Bipolar Foundation (CABF)

The Child and Adolescent Bipolar Foundation (CABF) is a parent-led, web-based membership organization of families raising children diagnosed with, or at risk for, early-onset bipolar disorder. The web site includes information and resources on early-onset bipolar disorder.

Web address: www.bpkids.org

- Children and Adults with Attention-Deficit/Hyperactivity-Disorder (CHADD) CHADD is a national organization representing individuals with AD/HD in providing education, advocacy and support to individuals and families. The organization is composed of dedicated volunteers from around the country who play an integral part in the organization by providing resources and encouragement to families, educators and professionals.

Web address: www.chadd.org

- Children's Defense Fund (CDF)

CDF's mission is to provide a strong, effective voice for all the children of America who cannot vote, lobby, or speak for themselves. CDF addresses the needs of poor and minority children and those with disabilities. CDF's mission is also to educate the nation about the needs of children and encourages preventive investment before they get sick or into trouble, drop out of school, or suffer family breakdown.

Web address: www.childrensdef

- Child Welfare League of America (CWLA) CWLA

is the nation's oldest membership-based child welfare organization committed to engaging people everywhere in promoting the well-being of children, youth, & their families, and protecting every child.

Web address: www.cwla.org/default.htm

- Council for Children with Behavioral Disorders (CCBD)

The Council for Children with Behavioral Disorders (CCBD) is the official division of the Council for Exceptional Children (CEC) committed to promoting and facilitating the education and general welfare of children and youth with emotional or behavioral disorders. Web address: www.ccbd.net/index.cfm

You may also be interested in accessing the web site for the Council for Exceptional Children which includes information related to special education.

Web address: www.cec.sped.org

- Federation of Families for Children's Mental Health

The Federation of Families is dedicated to providing education, resources and information to children with mental health needs and their families.

Web address: www.ffcmh.org

National

- Henry J. Kaiser Family Foundation

The Kaiser Family Foundation is an independent foundation focusing on the major health care issues facing the nation. The Foundation is an independent voice and source of

facts and analysis for policymakers, the media, the health care community, and the general public. The Kaiser Foundation has excellent resources on the Medicaid program. Web address: www.kff.org

- John D. and Catherine T. MacArthur Foundation

The MacArthur Foundation is a grant-making institution dedicated to helping groups and individuals foster lasting improvement in the human condition. The Foundation seeks the development of healthy individuals and effective communities and has funded projects focused on children's mental health and juvenile justice reform. The Foundation pursues its mission by supporting research, policy development, dissemination, education and training, and practice. Web address: www.macfound.org

Professional Organizations

- American Academy of Child & Adolescent Psychiatry (AACAP)

Web address: www.aacap.org

- American Academy of Pediatrics

Web address: www.psych.org

- American Psychiatric Association (APA)

Web address: www.psych.org

- American Psychological Association (APA)

Web address: www.apa.org

- American School Counselors Association (ASCA)

Web address: www.schoolcounselor.org/index.cfm

- American School Health Association (ASHA)

Web address: www.ashaweb.org

- Coalition for Juvenile Justice (CJJ)

The Coalition for Juvenile Justice (CJJ) provides information and resources on delinquency prevention and juvenile justice issues. CJJ's annual report for 2000, entitled *Handle With Care: Serving the Mental Health Needs of Young Offenders*, focused on the mental health needs of youth in the juvenile justice system. More information about the publication is available on CJJ's web site.

Web address: www.juvjustice.org/

- National Association of State Directors of Special Education

(NASDSE) Web address: www.nasdse.org

- National Association of State Mental Health Program Directors (NASMHPD) Child, Youth and Families Division

Web address: www.nasmhpd.org (click on "Divisions/Councils/Affiliations", then click on "Children.")

- National Association of School Psychologists (NASP)

Web address: www.nasponline.org/index2.html

- National Governor's Association (NGA)

The NGA has developed a series of fact sheets and resources on mental health issues. To access these resources, click on "NGA Center for Best Practices",

then in "Areas of Interest" click on "Health Division" then click on "Mental Health."

Web address: www.nga.org

Other Organizations Focusing on Children,

Adolescents and Families

- Center for Effective Collaboration and Practice

The Center offers a broad array of information, reports and publications addressing children's mental health, with a particular emphasis on the systems of care model. Web address: www.cecp.air.org

- Columbia University TeenScreen Program The Carmel Hill Center at Columbia University operates the TeenScreen® Program and the Positive Action for Teen Health (PATH) initiative. The

TeenScreen program creates partnerships with communities across the nation to implement early-identification programs for suicide and mental illness in youth.

The program staff includes mental health, public policy, and training experts that are available to help schools, mental health professionals, parents, community groups, and policymakers to raise awareness about the problem of youth depression and suicide risk, the benefits of mental health screening, and to help implement screening programs.

Web address: www.teenscreen.org

- Juvenile Bipolar Research Foundation
Foundation to support expanded research of early onset bipolar disorder.

Information for parents and professionals.

Web address: www.bpchildresearch.org

- Multisystemic Therapy (MST)

Multisystemic therapy is an innovative method for delivering mental health and substance abuse services to children and their families. MST is an intensive family- and community-based treatment that addresses the multiple determinants of behavior in youth. The multisystemic approach views individuals as being nested within a complex network of interconnected systems that encompass individual, family, and extrafamilial (peer, school, neighborhood) factors. It is increasingly being recognized as an evidence-based best-practice approach to

treatment for youth with mental illnesses and substance use disorders. Web address: www.mstservices.com

Academic Centers Focusing on Children's Mental Health

- Center for the Advancement of Children's Mental Health

Peter Jensen, M.D. directs this center dedicated to a variety of issues related to children and adolescents with mental illnesses. Dr. Jensen's center is located at Columbia University. Web address: www.kidsmentalhealth.org

- Center for the Promotion of Mental Health in Juvenile Justice

The Center for the Promotion of Mental Health in Juvenile Justice is dedicated to providing expert guidance to juvenile justice settings regarding best practices for mental health assessment and referral. This center is located at Columbia University. Web address: www.promotementalhealth.org

- Florida Mental Health Institute at the University of South Florida
 - The Research and Training Center for Children’s Mental Health
- The goal of the RTC is to improve services for children and adolescents with serious emotional disabilities (SED) and their families by strengthening the knowledge base for effective services and systems of care. Web address:
www.rtckids.fmhi.usf.edu/
- Georgetown University Child Development Center—National

Technical Assistance Center for Children’s Mental Health

Since 1984, the technical assistance center has been dedicated to working in partnership with families and many other leaders across this country to reform services for children and adolescents who have, or are at risk for, mental health problems and their families.

Web address: www.georgetown.edu/research/gucdc/cassp.html

- New York University Child Study Center

Web address: www.aboutourkids.org

- Portland Research and Training Center, Portland State

University – The Research and Training Center for Children’s

Mental Health

The Center promotes effective community-based, culturally competent, family-centered services for families and their children who are, or may be affected by mental, emotional or behavioral disorders. The web site includes publications and an excellent newsletter – Focal Point.

Web address: www.rtc.pdx.edu

WEBSITES and RESOURCES

- American Psychological Association www.apa.org
- American Foundation for Suicide Prevention <http://www.afsp.org>
- Anxiety Disorders Association of America <http://www.adaa.org>
- Big Step (early onset bipolar disorder) www.bipolar-children.bigstep.com
- Child & Adolescent Bipolar Foundation (CABF) www.bpkids.org
- Children and Adults with Attention-Deficit/Hyperactivity-Disorder <http://www.chadd.org>
- CIVITAS Child Trauma Programs <http://www.civitas.org>
- Council for Children with Behavioral Disorders (CCBD) www.ccbd.net/index.cfm
- Depression and Bipolar Support Alliance (DBSA) <http://www.dbsalliance.org>
- Exceptional Parent <http://www.eparent.com>
- Family Voices <http://www.familyvoices.org>
- Federation of Families for Children’s Mental Health <http://www.ffcmh.org>
- IL Dept. of Human Services Office of Mental Health www.dhs.state.il.us/mhdd/omh
- Juvenile Bipolar Research Foundation <http://www.bpchildresearch.org>
- U. S. Department of Education <http://www.ed.gov>
- Madison County IL Mental Health Board www.madisoncountymentalhealthboard.org
- Mental Health Ministries <http://www.mentalhealthministries.net>
- National Information Center for Children and Youth with Disabilities (NICHCY)

<http://www.nichcy.org>

National Institute of Mental Health (NIMH) <http://www.nimh.nih.gov>

National Mental Health and Education Center <http://www.naspcenter.org/index2.html>

National Mental Health Association (NMHA) <http://www.nmha.org>

NAMI Southwestern Illinois (NAMISWI) <http://www.namiswi.org>

NAMI of Illinois <http://www.illinois.nami.org>

National Mental Health Services Knowledge Exchange Network (KEN)

<http://www.mentalhealth.org>

National Mental Health Consumers' Self-Help Clearinghouse <http://www.mhselfhelp.org>

Obsessive Compulsive Foundation, Inc. <http://www.info@ocfoundation.org>

OCD Resource Center <http://www.ocdresource.com>

Parents and Children Coping Together <http://www.pacct.net>

St. Elizabeth's Hospital Behavioral Healthcare Services www.steliz.org/behavioral.htm

U. S. Department of Education <http://www.ed.gov>

Voices for Children <http://www.voices4kids.org>

ADDITIONAL RESOURCES

American Academy of Pediatrics.....(847) 981-7667

American Association of Suicidology.....(202) 237-2280

American Mental Health Counselors Association.....(800) 326-2642

American Psychiatric Association.....(202) 682-6220

American Social Health Association.....(919) 361-8400

American Trauma Society.....(800) 556-7890

Autism Society of America.....(800) 3-AUTISM

Brain Aneurysm Foundation.....(617) 723-3870

National Coalition Against Domestic Violence.....(303) 839-1852

1) Piecing It All Together: How Children's Mental Health & Mental Illness Affect Family, School, and community.

Annual Conference held usually during the month of March at Southern Illinois University Edwardsville. Parents, Foster Parents, School Professionals and Mental Health Professionals come together to get the latest research, treatment, and information on Children's Mental Health & Mental Illness. NAMI Illinois sponsors this conference with the collaboration of many agencies in our area. Call the NAMI IL office for more information or to get a flyer.

National Alliance on Mental Illness (NAMI)

- National Office
3803 N. Fairfax Dr., Suite 100

Arlington, VA 22203

(703) 524-7600 Informational Helpline (800) 950-6264 <http://nami.org>

- State Office
218 West Lawrence
Springfield, IL 62704
(217) 522-1403 (800) 346-4572 <http://illinois.nami.org>
- NAMI Southwestern IL Affiliate Office
2100 Madison Avenue, 4th Floor
Granite City, IL 62040
(618) 798-9788 <http://namiswi.org>

Federal Resources:

Does your child qualify for Social Security and Medicaid?

Many families do not realize that mental illness qualifies as a disability and that their child may be eligible for income assistance and health care.

There are two federal disability programs; SSI (Supplemental Security Income) and SSDI (Social Security Disability Income). Apply at the local Social Security office. Bring along your child's Social Security number; birth certificate or other proof of age and citizenship; information about the home where he/she lives; possible work history; any sources of financial support; child's Individualized Education Plan and names, addresses and phone numbers of doctors, hospitals, clinics, and institutions where treatment has been received with dates of treatment. If you do not have all of the things listed, apply anyway. For more information or to find the number of your local Social Security office, call 1-800-772-1213. Have the Social Security number with you when you call.

To be eligible for SSI based on disability, the person must:

- Have a physical or mental impairment which prevents the child from performing normal activities of daily living, or which prevents an adult from doing any substantial gainful work, and has lasted or is expected to last at least a year or to result in death.
- Have little or no income or resources, or in the case of a child under 18 living with his family, his or her family has little or no income or resources.

To be eligible for Social Security Disability Income (SSDI), a person must:

- Have worked and paid Social Security taxes (RCA) long enough to be covered under Social Security, or be an unmarried son or daughter (with rare exceptions) who became disabled before age 22, who has a parent eligible for retirement/disability/death benefits.

The disabled child does not have to be dependent or be financially supported by the parent.

- Have a physical or mental impairment that prevents the person from doing any substantial gainful work and has lasted or is expected to last for at least one year.

Since benefits are retroactive only to the day of application, apply as early as possible and follow up persistently. If benefits are denied, the ruling may be appealed by requesting: (1) reconsideration, (2) a hearing before an administrative law judge, (3) a

review of the decision by the Appeals Council, or (4) civil action in federal district court. You have 60 days to appeal between each of these steps.

While waiting for a decision on eligibility for SSI or SSDI, a disabled person living in Madison County may qualify for: Township Assistance (contact local township supervisor), food stamps, or assistance with emergency food and shelter through the Crisis Food Center (618-462-8201), Catholic Charities (618-877-1184 / 618-462-0634) Community Care Center of Protestant Welfare (618-876-8770), or the Salvation Army (618-451-7957 or 618-465-7764).

Illinois Resources:

NAMI Illinois
217 West Lawrence
Springfield, IL 62704
(217) 533-2403 or (800) 346-4572
<http://illinois.nami.org>

Encompasses 41 affiliate groups:

Northern Illinois Affiliates:

- 1) NAMI Barrington Area 847-496-1415
- 2) NAMI Northwest Suburban 847-899-0195
- 3) NAMI Cook County North Suburban 847-716-2252
- 4) NAMI DeKalb, Kane South and Kendall Counties 630-896-6264
- 5) NAMI Livingston/McLean 309-212-0581
- 6) NAMI DuPage County 630-752-0066
- 7) NAMI Elk Grove/Schaumburg 630-529-3037
- 8) NAMI Greater Chicago 312-563-0445
- 9) NAMI Grundy County 815-941-3140
- 10) NAMI Hanover Township 630-736-2823
- 11) NAMI Hanover Township 630-736-2822
- 12) NAMI Kane County 847-683-2371
- 13) NAMI Kankakee 815-935-8886
- 14) NAMI Lake County 847-249-1515
- 15) NAMI McHenry County 815-444-8300
- 16) NAMI McComb West Central Illinois
- 17) NAMI Metro Suburban 708-524-2582
- 18) NAMI Northwestern Memorial 312-404-3038
- 19) NAMI North Central Illinois 815-433-0430
- 20) NAMI Northwest Suburban 847-945-8873

- 21)NAMI Northern Illinois 815-332-4744
- 22)NAMI Rock Island/Mercer Counties 309-793-4993
- 23)NAMI Sauk Valley 815-244-1405
- 24)NAMI Southwest Suburban 708-425-0925
- 25)NAMI Will County 815-483-6904
- 26) **Central Illinois Affiliates:**
- 27)NAMI Champaign 217-367-6577
- 28)NAMI University of Illinois Campus Champaign 630-768-0983
- 29)NAMI Greater Decatur 217-877-0284
- 30)NAMI Morgan/Scott Counties
- 31)NAMI Quincy 217-222-1124
- 32)NAMI Springfield 217-522-0048
- 33)NAMI Tri-County (Peoria area) 309-274-2481
- 34)NAMI Vermilion County 217-662-2865
- 35)**Southern Illinois Affiliates:**
- 36)NAMI Jackson County 618-453-1509
- 37)NAMI Southwestern Illinois 618-798-9788
- 38)NAMI Southern Illinois University 618-528-0170
- 39)NAMI Mt. Vernon 618-242-1792
- 40)NAMI Southeastern Illinois (Harrisburg) 618-252-5400x2370
- 41)NAMI Metropolis-Southern Most Illinois 618-524-5626

Health Insurance: All Kids Program

All Kids Program is a complete healthcare program for every child in Illinois. Illinois is the first state in the nation to ensure that every child, regardless of medical conditions or income, has access to healthcare.

What Does All Kids Cover?

The All Kids program offers many Illinois children comprehensive healthcare that includes doctors visits, hospital stays, prescription drugs, vision care, dental care and medical devices like eyeglasses and asthma inhalers.

How does it Work?

All Kids will cost most families a lot less than private insurance. For instance, a family of four that earns \$45,000 to \$67,000 a year will pay \$40 a month for each child plus a \$10 co-pay for each doctor visit. All Kids has an annual limit on the total co-pays most families have to pay for their children’s healthcare. Total costs for each family vary by income and number of children.

Who is Eligible?

Children age 18 or younger who live with their families in Illinois and who need health insurance can get All Kids.

What if my children have health insurance? If your family has health insurance and your monthly income qualifies for FamilyCare/All Kids Share, Premium Level 1 or Rebate, you can choose the plan that is best for your family. FamilyCare/All Kids Share and All Kids Premium provide a medical card to help cover services for your children that your plan does not cover. FamilyCare/All Kids Rebate reimburses the policyholder for a portion of the premium they pay for health insurance. If you want to apply for the FamilyCare/All Kids Rebate plan, have your employer or insurance agent complete Part B of the Rebate Form.

What about KidCare?

For information on the Illinois' KidCare program call 1-866-255-5437 or visit the AllKids website at <http://www.allkids.com/>.

What if I need transportation to get medical treatment? The State of Illinois provides transportation assistance, call 1-877-725-0569.

How do I enroll my Child?

You can apply online or download an application.

For more information call toll-free 1-866-ALL-KIDS (1-866-255-5437). Persons who use a TTY can call 1-877-204-1012.

The program officially begins on July 1, 2006. This information is from the State of Illinois website: www.allkidscovered.com/

Local numbers to get information regarding health insurance:

Dept of Human Services in Madison County, call (618) 258-1660

Need help with prescription drug coverage?

Call the above number for the Dept. of Human Services. You can also check with your local community mental health center. IMPACT in Alton at (618) 462-1411 can also direct you to resources.

Illinois Regional Offices of Education

Illinois State Board of Education

100 North First Street

No. Name Superintendent Superintendent Telephone Springfield, Illinois 62777-0001

Madison -- Robert Diaber

618-692-6200 x4530 Fax 618-692-7180

P.O. Box 600, Room 438

Asst. Andre Reinking

Edwardsville, IL 62025

St. Clair County -- Brad Harriman

618-825-3900 Fax 618-825-3999

1000 South Illinois St.,

Asst. Susan Sarfaty

Belleville, IL 62223

618/397-8930 or 800/942-7827

For additional information on Regional Superintendent office directory visit their website at <http://www.iarss.org/directory/>

ILLINOIS STARNET INFORMATION

For information regarding early childhood special education services, please contact Pamela Reising Rechner at preising@isbe.net.

STARNET provides training and technical assistance to early childhood special education preschool staff and families of young children.

Family Matters Parent Training and Information Center (866) 436-7842 www.fmptic.org

Family Matters offers support, advocacy, information and education to parents to a 26 county region of South Central Illinois. In 2002, they received a grant from the U.S. Department of Education to offer Parent Training and Information which included providing information, referrals, linkages, and training to parents, students with disabilities and special education professionals. This serves the entire state of Illinois outside of the Chicago area.

The mission of Family Matters Parent Training and Information Center is to build upon families' strengths, empower parents and professionals to achieve the strongest possible outcomes for students with disabilities, and to enhance the quality of life for children and young adults with disabilities.

The Family Matters PTIC can assist you to learn about early intervention services for children from birth to three years of age, can inform you about special education services for school aged children, can help with transition issues for students who will be leaving the educational system and are preparing for the world of work, adult services or college, and can provide information about resources, best practices, specific disabilities, and training opportunities and conferences.

IL Department Of Human Services Mental Health Network Agency List

Agency/Name/Address Executive Name

Tri-County Counseling Center Ms. Carol Schaffener
220 East County Road P.O. Box 381 Jerseyville, IL 62052 (618)498-9587
Chestnut Health Systems Mr. Orville Mercer
50 Northgate Industrial Dr. Granite City, IL 62040 (618)877-4420

Child Center for Behavioral Dev Ms. Carolyn Birth
353 N. 88th St. Centerville, IL 62203 (618)398-1152

WellsSpring Resources Ms. Karen Sopronyi,
2615 Edwards St. Alton, IL 62002 618)462-4883

Comprehensive MH St. Clair Marsha Johnson
3911 State St. East St. Louis, IL 62205 (618) 482-7330

Human Service Center Metro-East Mr. Theo Wells 10257 State Route 3 Red Bud, IL
62278 (618) 282-6233

Human Support Services Mr. James Poschel 988 North Market Waterloo, IL 62298
618) 939-8644

Seeking Treatment and Crisis Intervention

When the need for treatment is evident, family members may be at a loss as to what to say or do in order to succeed in getting the help that is needed. Here are some suggestions:

- Understand it is neither your fault nor the fault of the person who is in crisis.
- be informed as to what resources are available.
- Evaluate the situation, have the person's written medical and behavior information available.

Contact the nearest NAMI affiliate to your area for additional resources or questions. If a NAMI affiliate is not in your area, please contact the NAMI Illinois state office at (217) 522-1403 or (800) 346-4572

Crisis Intervention

In the Event of a Mental Health Emergency, contact: In Madison and St. Clair Counties when you dial 911, ask for a CIT (Crisis Intervention Team) officer who is specifically trained to help deal with a mental health emergency.

****Consult ahead of time with the social worker, psychiatrist, and/or your local mental health center or CIT officer so you will know how to obtain services when you need them. You may also call NAMI Southwestern Illinois at 618-798-9788 for assistance with taking these steps.**

If you need to call for help in a crisis, have with you written information about the family member's diagnosis, medications and a description of the specific behavior that precipitated the crisis. It may be useful to have several copies to give to the police and to the mental health professionals.

HOTLINE PHONE NUMBERS FOR THE TWELVE COUNTIES WITHIN THE NAMI SOUTHWESTERN ILLINOIS SERVICE AREA:

- **BOND COUNTY** – Prairie Counseling Center (618)664-1455 (8:30am – 4:00pm)then
(618)397-0963 (4:00pm – 8:30am)
- **CALHOUN / JERSEY COUNTY** – WellSpring Resources (618)639-2016
(call 24 hrs. 7 days/wk.)
- **CLINTON COUNTY** – Community Resource Center (618)533-1391
(call 24 hrs. 7 days/wk.)
- **GREENE / MACOUPIN COUNTY** – Locust Street Resource Center (217)854-3166 (weekdays only) (217)854-3135 (after hours and weekend calls go to Police Dept.

& police Dept. will notify a crisis worker.)

- **MONROE / RANDOLPH / WASHINGTON COUNTY** – Call For help (618)397-0963
(call 24 hrs. 7 days/wk.)
- **MONTGOMERY COUNTY** – County Health Dept. – Hillsboro 1-800-324-5052
(call 24 hrs. 7 days/wk.)
- **SAINT CLAIR COUNTY** – Call for Help (618)397-0963
(call 24 hrs. 7 days/wk.)
- **EASTERN SAINT CLAIR COUNTY** – Chestnut Health Systems (618)877-0316
(call 24 hrs. 7 days/wk.)
- **NORTHERN MADISON COUNTY** – WellSpring Resource Center (618)465-4388
(call 24 hrs. 7 days/wk.)
- **SOUTHERN MADISON COUNTY** – Chestnut Health Systems (618)877-0316
(call 24 hrs. 7 days/wk.)

Local Psychiatric Hospital

▪ Gateway Regional Medical Center Behavioral Health Services
2100 Madison Ave., Granite City, IL 62040 618-798-3000

For Children & Adolescents offers:

- ▶ Traditional Outpatient Therapy for all ages.
- ▶ Partial Hospitalization Program – ages 3 to 17
Offered Monday through Friday
- ▶ Inpatient Hospitalization

Has an Adolescent Unit and a Children’s Unit

If you are needing help for your child, contact:

The Resource Center (618) 798-3888

Have the following information available:

- ▶ Patient Name
- ▶ Parent/Legal Guardian’s Name
- ▶ Patient Address & Phone Number
- ▶ Reason for referral
- ▶ Medical Insurance

Resource Center will schedule an appointment for an assessment.

School Advocates:

COMMUNITY & RESIDENTIAL Services Authority (crsa.illinois.gov)

We are responsible for identifying and addressing barriers facing parents, professionals and providers when trying to get needed services and programs for individuals, through the age of 21, with a behavior disorder or a severe emotional disturbance and their family.

- **IMPACT, INC.** 2735 East Broadway, Alton, IL (618) 462-1411. Covers several counties.
- **LINC, INC.** 120 East A Street, Belleville, IL 62220 (618) 235-9988. Covers several counties.

Parent Resources

- **PTIC**, Parent Training and Information Center, (866) 436-7842
 - **SASS** (Screening and Assessment Support Services) Call your local community mental health provider and ask for the nearest SASS program.
- For Madison County, Community Counseling Center in Alton, Illinois (618)462-2331. Parent Resource Individual available. Will also help with ICG Grants.

- **STARNET**, (618) 397-8930, Birth to 8 years old. Early Intervention resources
- **Illinois Family Partnership Network** Covers the whole state. Call main number and get local representatives. (312) 516-5559

MADISON AND ST. CLAIR COUNTY RESOURCES

ABUSE and NEGLECT:

- Child Abuse and Neglect Hotline.....800.252.2873
- Court Appointed Special Advocates (CASA).....618.234.4278
- IL Dept. of Children and Family Services (Belleville).....618.394.2150

CHILDREN and YOUTH:

- Alternatives for AT-Risk Students.....618.398.5280
- Belleville Area Special Services Cooperative (BASSC).....618.355.4700
- Big Brothers/Big Sisters of St. Clair County.....618.398.3162
- Call For Help, Inc(Information and Referrals).....618.397.0996
- Call For Help, Inc(24 hour suicide crisis and intervention).....618.397.0963
- Children’s Center for Behavioral Development.....618.398.1152
- Children’s Home and Aid Society (C.H.A.S.I.) of Belleville618.398.6700
- CHASI Child Care Resource & Referral.....800.467.9200
- Cahokia Area Joint Agreement for Special Education.....618.332.3700
- ESL Area Joint Agreement for Special Education.....618.583.8200

Hoyleton Youth and Family Services (for teen mothers).....618.398.0900
 Illinois Center for Autism.....618.398.7500
 IL Department of Children and Family Services (East618.258.1660
 IL Department of Children and Family Services (Belleville).....618.394.2150
 IL Department of Human Services (St. Clair County).....618.257.7400
 Judevine Center for Autism (St. Louis, MO).....314.849.4440
 Lincoln’s Challenge (for high school drop-outs).....800.851.2166
 Madison Co. Regional Office of Education.....618.692.6200 x 4530
 Mamie O. Stookey School618.234.6876
 Promise Center for the Developmentally Disabled.....618.274.3500
 Riverbend Head Start.....618.463-5950
 School Violence Prevention Hotline (St. Clair County).....877.724.5847
 St. Clair County Even Start Program.....618.397.8930 x 179
 St. Clair County Regional Office of Education.....618.397.8930
 STARNET Region IV Belleville).....618.397.7827
 Southwestern Illinois Special Services Cooperative618.355.4700
 SIUE Head Start Programs.....618.482.6955
 Success By 6 Parent Helpline (MO).....314.539.4064
 Volunteers of America (foster care/counseling).....618.271.9833
 Youth Crisis Hotline.....800.448.4663

COUNSELING and MEDICAL CARE:

Barnes-Jewish Health Systems (St. Louis, MO).....314.747.3000
 BJC Children’s Hospital (St. Louis, MO).....314.454.6000
 Behavioral Health Alternatives.....618.251.4073
 Call For Help, Inc.....618.397.0996
 Cardinal Glennon Children’s Hospital (Saint Louis ,MO).....314.577.5600
 Catholic Social Services Diocese of Belleville.....618.277.9200
 Chestnut Health System (Granite City.....618.877.4420
 Chestnut Health System (Belleville).....618.233.0330
 C.H.A.S.I. (maternity and parent education).....618.398.6700
 Wellspring Resources.....618.465.4388
 Comprehensive Mental Health Center of St. Clair County, Inc. ..618.482.7330
 Cornell Interventions.....618.271.4542

Depressive-Bipolar Support Alliance.....	618.234.0156
East Side Health District (ESL area).....	618.271.8722
Family to Family (NAMI).....	618.798.9788
Gateway Regional Medical Center.....	618.798.3000
GROW in Illinois (support group).....	618.332.3664
Human Service Center (Red Bud).....	618.282.6233
IL Department of Children & Family Services (Belleville).....	618.394.2150
IL Department of Public Health – Region IV (Glen Carbon).....	618.656.6680
IL Office of Mental Health Help Line.....	800.843.6154
IL Office of Rehabilitation Services.....	618.466.8409
Lutheran Child & Family Services.....	618.234.8904 x21
Memorial Hospital (Belleville).....	618.257.5805
Mental Health Center of St. Clair County.....	618.274.7154
NAMI CUPFUL (East St. Louis).....	314.868-8031
NAMI SOUTHWESTERN ILLINOIS.....	618.798.9788
Obsessive Compulsive Disorders.....	800.397.0900
Provident, Inc.....	800.782.1008
RAVEN (Rape and Violence End Now).....	314.725.6137
SIUE Community Nursing Services.....	618.482.6959
Southwestern Illinois Visiting Nurse Association.....	618.236.5800
St. Clair County Health Department.....	618.233.7703
St. Elizabeth’s Hospital.....	618.234.2120
Shriners Hospital for Children (St. Louis, MO).....	314.432.3600
Touchette Regional Hospital.....	618.332.3060
Violence Prevention Center of Southwestern Illinois.....	618.236.2531

DISABILITY SERVICES and ADAPTATIONS:

Alternative Transportation System (Belleville only).....	618.239.0749
Developmental Disability Services of the Metro East.....	618.236.7957
Equip for Equality.....	800.758.0464
IMPACT (Alton).....	618.462.1411
LINC, INC. (Living Independently Now Center.....	618.235.9988
Madison County Mental Health Board 708	618.692.6200 x 4359
St. Clair Associated Vocational Enterprises, Inc. (SAVE).....	618.234.1992

St. Clair County Mental Health Board (708).....618.277.6022
Specialized Living Centers (Swansea).....618.233.6161

SUBSTANCE ABUSE and PREVENTION:

Al-Anon.....618.398.9470
Alcoholics Anonymous.....618.398-9544
ARTS.....618.482-7385
Chestnut Health System (Granite City).....618.877.4420
Emotions Anonymous.....618.345.2167
Gateway East Health Services, Inc.....618.874.0095
Gateway Foundation, Inc.....618.234.9002
Narcotics Anonymous.....618.398.9409
National Council on Alcohol/Drug Abuse (St. Louis area).....314.962.3456
Obsessive Compulsive Anonymous.....618.233.0330
Peter’s Place (ministry for young men with dual diagnosis)618.624.7345
Provident, Inc.....618.235.5656
Recovery, Inc.....618.632.2601
SMARTS (residential services).....618.482.71
St. Elizabeth’s Hospital Chemical Dependence Prog.....618.234.2120x1555
.....St. Elizabeth’s Hospital Chemical Dependence Hotline...800.800.9011
T.A.S.C.,INC.(Treatment Alternatives to Street Crimes)..... 800.582.9458
Youth DUI Prevention.....,.....618.397.8930

