NAMI IOWA
Children's
Mental Health Resources

an introduction to
mental health services, resources, and support
for families of children and teens in Iowa

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NAMI IOWA Children’s Mental Health Resources

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To request information on mental illness or to schedule an educational presentation, contact:

NAMI IOWA
National Alliance on Mental Illness-Iowa
Des Moines, Iowa
www.namiiowa.org  info@namiiowa.com
NAMI IOWA Information

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Welcome to NAMI IOWA

NAMI IOWA (National Alliance on Mental Illness-Iowa) is a nonprofit, tax-exempt organization which offers mutual support, education about mental illness, and advocates for the needed services. There are many forms of mental illness; for example, bipolar (manic depression), major depression, schizophrenia, and neurobiological disorders of children.

We are pleased to welcome you and hope that we can be of help to you. Members of NAMI IOWA are families and caring friends of persons with a mental illness (adults, adolescents, or children), and persons who have such an illness. These consumers of mental health services are valued members of NAMI IOWA.

Mental illness can strike a person in childhood, adolescence or adulthood. It can be a devastating experience for the individual and the family. Physically, emotionally, and financially the impact is enormous. Medical and social services are complex and frightening to approach, difficult to comprehend, and hard to access. Adjusting to living with the illness requires effort on the part of the consumer, the family, and friends.

NAMI IOWA offers a range of education, support, and advocacy programs aiming to:

Provide a caring, supportive environment in sharing meetings.

Present informative programs on topics related to serious mental illnesses.

Advocate for a comprehensive state mental health system that provides effective services for mentally ill persons in their communities, including: adequate housing, rehabilitative services, and sufficient income, schooling, and employment options.

Counteract the stigma which remains associated with these illnesses.

Encourage the support of research in the causes and treatments of mental illness.

Provide printed materials and a library of books, CDs, DVDs, audios, and videos.

NAMI IOWA, affiliated with the National Alliance on Mental Illness, operates through its local affiliates throughout the state of Iowa, and from the state office in Des Moines. Local affiliates in the greater Des Moines area and other population centers of the state bring NAMI IOWA within the reach of most Iowans.

Local affiliate meetings are usually of two types: (1) a sharing meeting for informal, supportive conversation, and the exchange of information by members; and (2) an educational program with a speaker who may be a mental health professional, a public official, or other person whose activity touches on the needs of persons with a mental illness. These meetings, usually held monthly, are open to all interested persons without requirement of membership.

NAMI IOWA Mission Statement

NAMI IOWA is a non-profit, statewide grassroots organization.

Our mission is to raise public awareness and concern about mental illness, to foster research, to improve treatment and to upgrade the system of care for the people of Iowa.

We work to support our mission through education, advocacy and support.
NAMI IOWA Education Programs

One in four families includes a member who has a mental illness and forty percent of people with serious mental illnesses continue to live with their families through their adult years. Families can be the first line of defense against relapse. Through education and support, consumers and family members are better equipped to effectively manage the ups and downs of mental illnesses, serious emotional disorders, and behavior challenges.

**Basics**
Basics is an educational program for parents and other primary caregivers of children and adolescents who have living with mental illness. The course provides learning and practical insights for families. The parent classes are taught by parents and other primary caregivers who have lived similar experiences with their own children. The course is provided free of charge.

**Parents & Teachers as Allies**
This two-hour in-service for teachers, administrators, school health professionals and others in the school community focuses on helping school professionals and families better understand the early warning signs of mental illnesses in children and adolescents. Participants learn how best to intervene so that youth with mental health treatment needs are linked with services. It also covers the lived experience of mental illness and how school personnel can effectively communicate with families about mental health related concerns. The course is provided free of charge.

**Family-to-Family**
The Family-to-Family course consists of a series of classes for family members of adults with serious and persistent mental illness as well as those whose behaviors suggest such a diagnosis. It is designed to help families face the challenges of brain disorders and find support, resources, and coping strategies. The course is provided free of charge.

**Peer-to-Peer**
Peer-to-Peer is for any adult with serious mental illness who is interested in establishing and maintaining wellness. It is an education course on the topic of recovery that meets for ten weeks, two hours each week. The course uses a combination of lecture, interactive exercises, and structured group processes. Peer-to-Peer is designed to offer an opportunity for growth and support. The course is provided free of charge.

**Provider Education**
The Provider Education Course consists of a series of classes for line personnel at public agencies who work directly with persons with mental illness. It is designed to help the providers learn to understand the day-to-day hardships of brain disorders; and to use this as a basis in developing staff skills and competency. Through learning of the bio-psycho-social aspects and developing understanding of clinical intervention and strategies of secondary intervention a mutually beneficial empowerment structure is demonstrated to all. The course is arranged through a contractual agreement and a fee is charged. Materials are copyrighted by NAMI.

For more information about NAMI IOWA education programs, contact:
NAMI IOWA (Des Moines) www.namiiowa.org email: info@namiiowa.com
Tel: (515)254-0417 or (800)417-0417
NAMI IOWA Background

What is NAMI? NAMI is a grassroots organization which was founded in 1979 by family members in Madison, Wisconsin. It is a self-help organization made up of families of persons with mental illness, consumers of mental health services, and friends. The need is great and support for one another is so important when working with family members. The organization has grown to over 1,200 self-help support groups nationwide with more than 220,000 members.

What is available in Iowa? NAMI IOWA was formed in 1984. There are 20 affiliates and support groups plus other information contacts located around the state. The office staff provides families with support, education, and information services, as well as working to positively impact public policy decisions that affect mental health consumers and their families.

Who are the seriously mentally ill adults? One out of every four families has a member who suffers from a serious mental illness. It affects the rich and the poor, the urban dweller and the rural population, people from all walks of life.

Who are the children with severe emotional disorders (SED)? They are young people who have a functional impairment which substantially interferes with, or limits, the child's or teen's ability to function in family, school, or community activities; or from achieving or maintaining one or more developmentally appropriate social, behavioral, cognitive, communicative, or adaptive skills.

What is mental illness? Mental illness is a "no fault" brain disease. The brain is part of the body; it too can become ill. Progress continues to be made in research of the brain. We can be proud that the University of Iowa is in the forefront of this research.

Are effective medications available to treat mental illnesses? Yes, many people experience significant benefit when treated with the right medication. At this time there are medications that reduce the symptoms markedly for most people, but do not cure the illness. However, there is no "one size fits all", and a medicine that works well for one person may not work well for another.

Why is mental illness a major issue? Mentally ill persons occupy more hospital beds than persons suffering from cancer, lung and heart diseases combined. These are widespread illnesses that wishful thinking cannot drive away. In Iowa, we have more people with mental illnesses housed in our prisons than in our care facilities. Mental health advocates believe that with effective services, people with mental illnesses can live safely and with dignity in our communities, rather than in our prisons and homeless shelters.

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Benefits of NAMI IOWA Membership

Through NAMI IOWA, members have access to...

Automatic membership at both the Iowa and national levels in NAMI (National Alliance on Mental Illness) and NAMI’s national quarterly newsletter, The Advocate, which brings informative and timely articles concerning the latest research regarding neurological brain disorders, the status of major legislation at the federal level and in state and local governments, provocative editorials, book reviews, and more! Also available, NAMI Beginnings a national publication that presents the latest research, treatments, medications, and the personal experiences of families coping with brain disorders.

Legislative Alerts: Keeping you abreast of current legislative activities in federal and state government; and alerting you whenever immediate action needs your voice to influence a vote which may impact the lives of persons suffering from neurobiological brain disorders.

Stigma Alerts: A notice of current or pending media pieces which misrepresent or discriminate against persons suffering from mental illness.

Handbook and other literature with clear, concise descriptions of mental illnesses including: schizophrenia, major depression, bipolar disorder, schizoaffective disorder, and anxiety disorders, among others.

Staff members dedicated to the special concerns of families dealing with mental illness.

Toll-free Helpline offering information, support, and referral services: (800) 417-0417.

Notification of regional conferences with programs designed to enhance members' knowledge in the area of mental health education, advocacy, and research.

Notification of NAMI's national convention where you can meet and talk with leading researchers and experts in the mental health field.

Technical assistance from NAMI IOWA staff in the areas of building affiliate membership, fundraising, state and local advocacy efforts, media relations, and public education.

Our education programs: Family-to-Family, Peer-to-Peer, Provider Program, Basics, and Parents & Teachers as Allies.

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Section I.

Your Family at Home
# Section I. Your Family at Home

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To parents and other caregivers:

This handbook is a resource for Iowa caregivers of children who have severe mental and emotional disorders. It is comprehensive and family friendly because it was written with and for families.

Parenting typical children brings challenges, responsibilities, heartache, fear, joy, and personal growth. Parenting children with mental and emotional disorders can bring all of these things, but also confusion, powerlessness, and isolation. Parents of typical children are often guided by their own life experiences and have access to information about raising children from their parents, friends, neighbors, magazines, and books. Parents caring for children with mental or emotional illness have had to evolve their own information, skills, strategies, and supports frequently at great personal and social costs.

As parents who have come before you, we want you to know that you are not alone. With an appreciation for the uniqueness of your child, this handbook is meant to be a resource that we hope will assist you in acknowledging your special challenges, as well as in understanding and negotiating the complex system of services and supports from service providers, schools, and communities.

Colleen Robinson
What Happens to Families When Mental Illness Hits

A crisis is defined as a disruption in the family from an uncontrollable life event. The occurrence of a mental illness definitely fits the definition of a crisis. When this occurs, families may display the following responses:

Psychological stress – people must modify their identity, image, and roles

Narrow, fixed spans of attention

Feel alienated and alone

Loss of identity

Reduced capacity to make decisions

Perform their usual social roles in an unsatisfactory way

Shock

Denial

Helpless confusion

Try to escape the situation

The family experiences grief and loss.

People grieve the loss of the person they once knew before the mental illness. There is a loss of hopes and dreams for the individual. Some people experience a complete loss of the life they once knew. A job may come to an end, family relationships change, and friends may distance themselves after symptoms appear.

Unfortunately, people coping with mental illness may continually go through grieving periods. Mental illness is commonly a cyclic illness. Individuals may go through times when they are relatively symptom free and other periods when the illness dominates their lives. This cyclic pattern produces a continuous grieving cycle. When the individual shows symptoms, the grieving process may begin all over for families.

Families blame themselves and feel guilty regarding the illness.

Parents review and criticize their parenting style. They also trace their family histories for evidence of mental illness. If illness is found in their family, they blame themselves for passing on mental illness to their child.
Families experience stigma surrounding the illness of their family member.

Many times families are embarrassed about having mental illness affect their family. Embarrassment also occurs from the behavior of the ill member. Families have difficulty getting support from others due to the general lack of understanding about mental illness.

An overall lack of power is felt by families.

They may feel responsible for their family member, but see themselves as having little power to influence outcomes. Part of the lack of power comes from having limited understanding and knowledge about mental illness and available services.

There is a threat to a family’s integrity and optimism.

Hopes and dreams for the individual who is ill are shattered. Families become angry about the unfairness of life. Many times anger is directed at God or some other higher power. Families begin to question their basic understanding of the order of life.

Ways to Cope

Educate yourself about mental illness, treatments, and services.

Take care of yourself.

Acknowledge fears you are having.

Be honest about your feelings and share them with someone.

Learn and practice relaxation techniques.

Get involved with a local affiliate of NAMI.

Suggested Readings

*Surviving Schizophrenia: A Family Manual*, by Torrey, M.D., E. Fuller
*Surviving Mental Illness*, by Hatfield and Lefley
*When Someone You Love Has a Mental Illness*, by Woolis, Rebecca

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Parents’ Bill of Rights

Culture is the underlying structure and meaning that defines people's perceptions, interpretations and behaviors. Family culture can be seen in a family's relationships, routines, expectations, boundaries, and activities. If family culture means "The way we do things around here," then families of children with special needs develop a unique culture.

Regular family routines like laundry, grocery shopping, meal time, attending school events, religious or social activities, family reunions, and family vacations look different in families of children with special needs.

Parents are very aware of their responsibility to provide for their sons and daughters, but are seldom aware of the rights they have as caregivers. Parents have created their own Bill of Rights.

You have the right to:

Accept that you are doing the best you can, and that it’s good enough

Have needs that are as important as the needs of your child

Have your own hobbies and interests (When I go back to doing the things I used to enjoy, like artwork and model building, I get out of my negative mood.)

Enjoy being alone at times, and let your child have his or her own privacy

Tell your child that his or her behavior is unacceptable

Get angry once in a while

Say that you don’t want to talk about your problems (I’m tired of talking about my son or daughter.)

Not tell the whole truth to everyone (Fine when someone asks how it’s going)

Devote as much time as you want to the cause of the disabled, or get away from it for a while

Have a vacation away from your child every year, have dates, celebrations, weekends away, and time together with your partner to enhance your relationship

Be gentle with yourself!

Important!

Parents who do not enjoy some of these rights are probably unhappy or tense most of the time. Parent martyrs are seldom appreciated by anybody, least of all by their son or daughter with SED (serious emotional disorder).
Adapting Family Environment

Build daily invisible RAMPS to allow success to grow

R  **Respect** the child’s differences to allow self-respect to grow.

A  **Anchor** with predictability to allow trust to grow.
If you say something is going to happen, make sure it happens.
If you communicate with the teacher through a notebook, check it daily.
If you want a household chore to look a specific way when it’s finished, check it every time.

M  **Medication** allows focusing, concentration, and attention to grow.
When your child asks, “Why do I have to take medicine?” Answer honestly.
Our brain processes information by moving the messages it receives along certain paths to other parts of our brain to tell it what to do. These messages travel from one nerve cell to another nerve cell by chemicals along the path. Sometimes the chemicals don’t work properly so the messages get confused about where to go. Medication gives the brain what it needs to keep the messages moving along the right path.

P  **Pictures** allow task completion to grow.
Use charts, calendars, step-by-step job cards or “walk through” verbally with active feedback about your expectation before your child starts the job.
**Example:** “Brush your teeth” means:

```
1. get your toothbrush
2. get the toothpaste
3. put toothpaste on
4. brush
5. rinse
6. spit
7. rinse
8. clean-up
```

S  **Structure** allows a sense of security to grow.
Establish and enforce routines. Routines help explain “change” when you need flexibility later.
**Examples:**
Morning routine: make bed, eat breakfast, brush teeth, and get dressed for school
After school routine: homework, household chores, music practice, and help with supper
**Bedtime routine:** bath, snack, brush teeth, story time
Adapting Parenting Style

Accept that your child may require different parenting skills than other children.

Separate the child from the behavior.

Set realistic and attainable expectations. You are not "lowering" or "compromising" your expectations; your child simply needs different expectations to be successful.

Measure success in "baby steps".

Tolerate your conflicting feelings; e.g., frustrations with baby steps.

Maintain the environment that works. This may require daily intense "eyes-on" supervision of every task.

Build into your week respite breaks.

Learn creative parenting strategies.

Seek information and learn the terminology of the different systems that provide services for your child.

Write questions and concerns down when you think of them and discuss them with the "experts" in your child's life.

Keep a file or three ring binder for medical reports, treatment plans, medication logs, school plans, etc.

Be resilient to the barriers of stigma, the lack of knowledge of "experts" and outdated policies within each "service system".

Develop a firm belief in commitment to your child's healthy growth and development.

Keep your sense of humor.

Your family has a lot to focus on; get through each day one step at a time.
Finding Informal Supports

Maintaining a highly structured family environment and adapting your parenting style every day is demanding. It requires giving your child consistent and patient directions and redirection for each and every daily task. It requires defining and "policing" each and every boundary consistently and patiently.

Providing this intense level of daily care is stressful to the whole family. Although every parent reacts somewhat differently to the stress of living with a child with special needs, a sense of isolation or grief is experienced by almost every parent.

Common feelings:

Denial
"This can't be happening to my child... to my family." Denial is a very common first response to finding out your child has special needs.

Anger
Denial quickly becomes anger for many parents. It is common to direct our anger toward self, spouse, medical or educational professionals.

Fear
Fear is another immediate response that many parents feel. Fear of the future, the unknown, and other people's reactions are most common.

Guilt
Many parents feel guilty and ask themselves if their child is suffering because of something that they did (or didn't) do. It is important to continuously remind yourself and surround yourself with others who understand that brain disorders are not the result of poor parenting!

Confusion
Parents must negotiate confusing systems of care to gain an accurate diagnosis and find appropriate treatment for their child. Parents are immediately faced with new terminology and acronyms for topics that were previously foreign.

Powerlessness
There is no way to change the fact that your child has a disability. In addition, you are forced to seek the recommendations and opinions of professionals that you previously do not yet have a trusting relationship with.

Disappointment
It is normal to feel disappointed.

Moving Back and Forth within the Stages

The emotional reactions listed above seem to flow in a logical order from one to the other. That's not the way you will feel them. Don't expect the stages to happen in that order. In
Finding Informal Supports continued:

addition, after you have worked your way through a stage, and for instance are no longer feeling extreme anger or guilt about your child’s condition, you might start having those feelings again a few weeks or months later. And sometimes, you will experience more than one stage at the same time, or emotions that seem totally contradictory (acceptance, and some guilt too perhaps). None of these stages is wrong or right; they are the normal reactions that anyone feels when faced with serious illness and a critical disruption in life.

Talk about your feelings with your spouse or significant people in your life.

Surround yourself with people who:
Recognize that your child needs accommodations.
Respect your adaptive home environment and parenting style.
Support your child’s successes.

Seek other parents who have children with special needs. They are a source of information, support, resources, understanding, and hope.

Participate in a support group.

Find support within yourself by remembering and then enjoying your talents and hobbies.

Variations within Your Family

There is no “best way” to go through the stages in the adjustment process. You will go through the process your way. Other members of your family will go through it their way. Don’t expect other family members to be having the same feelings you are having while you are having them.

For example, a mother might be having unrealistic hopes and working feverishly to find a “cure” for her son’s disorder; while the sister is feeling the anger-guilt-shame stage, aware mostly of the embarrassment her brother is causing her at school; and the grandfather is experiencing the deep grief of the loss of the grandson and family as they were before. Knowing where you are in the process can help you to be gentler with yourself and more understanding of others who might be at a different stage in the process.

Advice from Other Families

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

Learn all you can about the disorder that your child has.

Remember that other family members (partners, brothers, sisters, aunts, grandparents, and friends) are affected too, and they probably are feeling strong emotions, as you are.

Take the lead in keeping communication open by talking with them about this. Grandparents, aunts, and uncles might be your greatest source of strength and help.
Respite Care

Respite care services provide temporary relief for the usual caregiver, including all necessary care that the usual caregiver would provide during that time period. The purpose of respite care is to enable the member (the child or teen needing supervision and other services) to remain in the family home.

**Specialized respite:** Respite is provided on a staff-to-member ratio of one-to-one or higher for individuals with specialized medical needs requiring monitoring or supervision provided by a licensed registered nurse or licensed practical nurse.

**Basic individual respite:** Respite is provided on a staff-to-member ratio of one-to-one or higher for individuals without specialized medical needs requiring monitoring or supervision provided by a licensed registered nurse or licensed practical nurse.

**Group respite:** Respite is provided on a staff-to-member ratio of less than one to one.

Respite periods usually last a few hours, a day, or a weekend. There are different models of respite care, some in the home, some in the community, and some in other people’s homes.

By having periods of relief, or knowing that they are available when needed, your family’s level of stress can be significantly reduced. Therefore, you are better able to care effectively for your child and cope with ongoing family issues. Using respite services does not indicate that you are not able to care for your child. Caring for a child with SED is a very intense, high-pressure activity. Regularly scheduled and anticipated breaks can only enhance your effectiveness.

If your friends and relatives cannot provide the type of support you need, talk with your mental health provider. He or she may be able to provide information about respite services available in your area. Sometimes we are not aware that we need relief until we find ourselves screaming at our child or bursting into tears over a small problem. Of course, this happens to all of us at some time or other. It is best, however, to monitor our stress levels and those of other family members, so we can seek respite before we reach the breaking point. Do not force yourself to hang in there until you can take another moment. Schedule some respite as soon as you feel some pressure starting to build in yourself or the family.

**Direct Family Access Respite**

**www.irccc.com  Tel:(800)255-3140 (toll free) IA Respite & Crisis Care Coalition**

The Direct Family Access Program, developed in 2001, assists families who need respite care, but are not eligible for respite services from any other source. This program is for families who know someone who is willing to provide the care, but they need a way to pay for the care. No agency is involved. Families can apply for up to $500 to provide respite care for an individual who has a disability. Funds are distributed on a first-come, first-serve basis to those eligible.

Go to the website to fill out an application or call the toll free number. You will be notified if funds are available. Then contact the desired provider, negotiate payment arrangements, and arrange for services. You are also responsible for negotiating their pay rates, hours worked, etc.
Respite Care continued...

After the care is provided, a simple one-page payment voucher is completed and signed by both the family member and the person who provided the respite care. Payment is made directly to the family member/caregiver, who then reimburses the individual who provided the respite care.

Easter Seals Camp
www.ia.easterseals.com
Easter Seals offers families caring for an individual with a disability in the home a safe, supervised alternative - respite. Studies have shown that when families use respite care, it increases the likelihood that a family member with a disability will remain in the home, rather than require placement outside the home. The break from daily responsibilities gives families an opportunity to focus on other areas of their lives. Traditional camp activities such as archery, swimming, horseback riding, wheelchair sports, and hiking are available to all campers.

Emergency Shelters
Contact: Shelter services vary among communities.
Although young people may be court-ordered to be placed in an emergency shelter, some shelters also provide emergency respite for families who need to have their child or teen out of their home. Shelter care provides 24 hour supervision, crisis intervention services and behavioral assessments. Services are purchased from private and public providers.

Crisis Planning

What is a mental health crisis?

Your child will, of course, have good days and bad days, and some of the bad days will be pretty scary for both of you. But how can you tell the difference between a "bad day" and what an emergency team considers a "mental health crisis"? The information below defines a child or adolescent experiencing a mental health crisis.

When your child or adolescent is experiencing a mental health crisis, you are not able to control his or her behavior...

_and at least one of the following is true:

He or she is at serious risk of hurting herself or himself.

He or she is at serious risk of hurting others.

Call for help if you feel threatened too. It is not okay to live in your own home in a state of fear for your safety.

Crisis Planning continued...

He or she is experiencing disorganized and dangerous thinking.

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

What is a crisis prevention plan?

A crisis prevention plan is a written plan designed to prevent crises. It helps the child realize that extreme negative behavior is disruptive and destructive to family life and it does not get his or her needs met. Writing a plan allows a family to set aside a time when things are calm to talk about how they can do things differently.

Who can facilitate writing the plan?

Parents or any significant person in the child's life who can help the child understand the following:

Behavior is a way of communication.

Negative behavior may indicate there is something negative to communicate.
The feelings of being “overloaded” with the stresses of daily life are valid and need to be communicated.

The inability to express those feelings causes frustration.

There are better and constructive ways of communicating those “overloaded” and frustrating feelings.

**How does the plan work?**

The plan only works with commitment from both the child and the parents.

**How do you write the plan?**

The child and parents must set aside time to do the following:

Identify potential triggers or stressors that may cause an “overloaded” feeling in the child.

Have the child describe what’s going on in his or her mind when the “overloaded” feeling starts.

Identify constructive ways to “de-escalate” those feelings.

Identify someone both the child and parents agree on, who can mediate if necessary.

*Crisis Planning continued...*

**A Wrap Workbook for Kids: Wellness Recovery Action Plan**, by Mary Ellen Copeland is a good resource. More information is available at [www.mentalhealthrecovery.com](http://www.mentalhealthrecovery.com)

**If a crisis may require professional intervention, implement the following steps:**

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

   Although services in different regions differ, emergency mental health evaluations are usually conducted by the regional community mental health center emergency team. This would ordinarily be done at the mental health center, in the emergency room of the local hospital, or occasionally, in your home.

   If your child is in treatment with a private mental health provider, rather than the community mental health center, your provider should provide the evaluation. Ask your provider now about their procedure for handling mental health crises.

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

   You can contact your insurance provider for authorization at this point. Your choice of treatment facility may be limited due to restrictions in the insurance policy; sometimes an insurance reviewer will question the need for hospitalization.
Gathering information now

Now is the time to gather information about the organizations and facilities you will be working with when a crisis arises. Having the information you need at your fingertips and being familiar with the places you and your child might have to go, will allow you to swing into action immediately, even though you might feel shaken by the situation.

Procedures and Terminology of Crisis Organizations

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

Follow these steps now to become familiar with the procedures and terminology used by these organizations before a crisis arises:

Talk with your private insurance carrier (if you have one).

Find out if there are any restrictions on who you can use to provide emergency services in step 1 above, or which hospital or facility you can use to provide psychiatric services in step 2 above.

Crisis Planning continued...

Talk with one or more of your child’s mental health providers.

Alert them to any restrictions that your insurance carrier might have and then find out the names, locations, and phone numbers of the following:

The emergency services that conduct psychiatric evaluations. (This could be your child’s therapist/case manager, depending on time of day and their availability.)

The facility to which your child might be admitted.

Call your child’s therapist or case manager.

Work with them to develop a plan for handling a mental health crisis for your child, as follows:

Find out if there are any circumstances under which emergency services will come to your home to conduct the evaluation, or if you always have to transport your child to them or the local hospital.

Find out if there is any situation for which you should call your local police department.

Ask for driving directions to the emergency services location.
Find out the probable facilities that your child would be admitted to if he or she had to be hospitalized.

Ask for driving directions to the hospital.

Ask them to tell you about their crisis procedure.

Ask if there is any other information they think you should know.

Language and terminology can be different at different facilities, so be alert for different words being used for the same thing by emergency services and the hospital.

A transportation plan

If you need to transport your child to receive an evaluation or hospitalization, there are some decisions to make, some information to gather, some people to contact, and some trips to make now, before the crisis—here are those decisions:

Ideally, you should have at least one other person to drive, or manage your child while you drive. Who will be that other person? Depending on your family and neighborhood situation, consider these options: a neighbor, taxi, ambulance, or the local police are possibilities for helping you transport your child to the required facility.

Crisis Planning continued...

Please be prepared that if your child is being transported by police officers, they might decide to hand-cuff or otherwise restrain your child during transport. It is also possible that you will not be allowed to ride in the vehicle in which the police are transporting your child.

In the event that you will not be using a taxi, ambulance, or the police, and will be driving yourself and your child, use the directions you obtained in the previous procedure to make a "dry run" trip now to the crisis services location, and from there to the psychiatric hospital, before a crisis arises.

A “dry run” trip checklist:

Become familiar with the routes and the length of both trips.

Locate parking and find the correct entrance.

Go inside and find the admitting desk and waiting area.

Speak with someone at the admitting desk and ask for any hints on what to expect. Find out if your child would be entering through this same entrance during an emergency.
You might need help getting your child safely from the car to the emergency room. Who will assist you if no one is able to come with you and your child? Speak to your child’s therapist and ask for advice on handling this part of the trip.

Will you need to arrange for the care of other children while you are transporting your child in crisis? If yes, what are your options: parents, in-laws, siblings, neighbors, regular baby sitters? Call two or three of these people (in case you call one and get no answer on the day of the crisis) and ask them if it’s okay to rely on them for this help.

If your child will be transported by ambulance, you will be following the ambulance in your car.

**Contact information**

Compile names, locations, and phone numbers of the following organizations and people; and keep the list where it is easy to reach as you make the calls:

Mental health emergency services

Local police department

Your child’s mental health professional (psychiatrist, psychotherapist, case manager, social worker)

Nearest NAMI family partner and/or local affiliate contact person (This is a support person from your local NAMI group.)

Nearby family, friends, and neighbors who have volunteered to help in a crisis

**Crisis Planning continued...**

**Medical information**

To aid the professionals who will be working with your child, it is ideal to have a 3x5 card with the following medical information already written down:

Your child’s diagnosis or diagnoses

Medications, including dosages, schedule of how often to take, and whether to take with or without food

Name and phone number of your child’s prescribing doctor, if taking medications, or professional who is most familiar with your child’s emotional disorder (therapist, case manager, primary care physician, etc.)

Name and 800 number of your child’s insurance carrier, and your child’s policy number. Keep this in a place where you are sure to have it when you arrive at the emergency service location or the hospital (in your wallet, in the glove compartment, etc.) The written information can be passed from one professional to another, if necessary, without loss of accuracy. Some parents recommend keeping two copies of this card in case one is misplaced during the crisis.
Try to review and update the information on the index cards twice a year.

**Rehearsing the call to emergency services**

On the day or night of the crisis, when you talk to the emergency clinician, try to focus on why your child is not safe. The emergency services clinician is there to help you and your child, and will be able to help you better if you provide the kind of information that is needed.

**What to tell the emergency services clinician**

When calling, use all of the following that apply to your child’s situation.

Describe your child’s current actions and their impact. The actions should clearly show how your child is: 1) a danger to self, 2) a danger to others, 3) and/or experiencing disorganized and dangerous thinking.

Give clear examples as to why your child is not safe and why family members or community members are not safe, if your child is a danger to self or to others.

Give your child’s diagnosis, if he or she has one.

Explain how these actions have escalated over the past three days, which indicates that this is not typical behavior for your child.

**Crisis Planning continued...**

Share the recent concerns of other individuals in your child’s life, such as school teachers, guidance counselors, neighbors, friends, etc.

If your child has a past history of hospital-level care, be certain to tell the emergency team.

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*To request information on mental illness or to schedule an educational presentation, contact:*

**NAMI IOWA**
National Alliance on Mental Illness-Iowa
Des Moines, Iowa
www.namiowa.org info@namiowa.com
Section II.

Working with the Treatment System
Section II. Working with the Treatment System

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Mental Health Treatment Professionals

The different roles of various professional mental health providers can be confusing to families who are new to accessing services for their children, especially when hearing the terms "counselor" or "therapist" used to refer to a variety of professionals. Following is a brief description of some of the professionals who work within the mental health treatment system.

Psychiatrist
Psychiatrists are physicians who have specific training in the assessment, diagnosis, treatment, and prevention of mental illnesses. Psychiatrists attend medical school and receive an M.D. or osteopathic school and receive a D.O. After medical training, they complete additional years of residency training in mental health. In addition to this, some receive additional training in a specific area of interest such as geriatric psychiatry, child and adolescent psychiatry, addictions or other areas. Unlike psychologists, psychiatrists are able to prescribe medications.

Psychologist
Psychologists must complete graduate training in psychology in order to be licensed in the state of Iowa. Unlike psychiatrists, they are not authorized to prescribe medications. However, psychologists do provide assessment, diagnosis, and therapy.

Counselors
Licensed counselors typically have two to three years of graduate training in counseling methods. Specialty areas include marriage and family counseling, school counseling, community counseling, and substance abuse counseling.

Social Workers, LCSW
Licensed clinical social workers (LCSW) have approximately two years of graduate training in therapy, completion of an internship, and supervised experience in the field. Other social workers may have a Master's degree in social work as well as supervised clinical experience.

Advanced Psychiatric Nurses
Advanced psychiatric nurses hold a Master's degree or higher in psychiatric-mental health nursing. They are able to assess patients, diagnose disorders, provide psychotherapy, and prescribe medications in some states. Advanced psychiatric nurses work as clinical nurse specialists or nurse practitioners and work in diverse settings including hospitals, private clinics, mental health settings, emergency psychiatric settings and substance abuse treatment centers.

Primary Care Physician/Family Practice Doctor

Pediatrician
Pediatricians are medical doctors who specialize in treating children.
**Getting an Accurate Diagnosis for Your Child in 10 Steps**

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

**10 Steps**

(1) **Record Keeping:** organize and keep accurate records related to your child’s emotional, behavioral, social, and developmental history; including observations of the child at home, in school, and in the community. Share the records with the child’s treating provider to help in making a diagnosis.

Include the following information in the records:

- 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.
(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 can determine if there are other physical conditions that may be causing a child’s symptoms.

(3) **Co-occurring Conditions:** Co-occurring conditions may include 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. Don’t hesitate to seek a second opinion if you are not confident in your 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 is to achieve the outcomes that are most important to the child and family.

(8) **Working with the School:** Consider meeting with your child’s teacher or other school officials to discuss appropriate accommodations and supports for your child. Families can work with the school to identify effective interventions, accommodations, and supports that promote positive behaviors, academic achievement, and prevent challenging behaviors in school. Ask your 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 treatment provider to recommend psychosocial interventions, skills training, support groups, and other options that can help your child cope with symptoms and develop skills necessary to lead a full 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.

NAMI IOWA (Source: adapted from Visions for Tomorrow, NAMI Texas)

**Approaches to Counseling and Therapy**

Mental health professionals use a variety of approaches to give people tools to deal with ingrained, troublesome patterns of behavior and to help them manage symptoms of mental illness. The best therapists will work with your family to design a treatment plan that will be most effective for your child. This sometimes involves a single method, or it may involve elements of several different methods, often referred to as an "eclectic approach" to therapy.

The goals of treatment are to reduce symptoms of emotional disorders, improve personal and social functioning, develop and strengthen coping skills, and promote behaviors that make a person's life better. Biomedical therapy, psychotherapy, and behavioral therapy are basic approaches to treatment that may help a person overcome problem. There are many specific types of therapies that may be used alone or in various combinations.

**Biomedical therapies**

Treatment with medications has benefited many patients with emotional, behavioral, and mental disorders and is often combined with other therapy. The medication that a psychiatrist or other physician prescribes depends on the nature of the illness being treated as well as on an assessment of the patient's general medical condition. During the past 35 years, many psychotherapeutic medications have been developed and have made dramatic changes in the treatment of mental disorders. Today there are specific medications to alleviate the symptoms of such mental disorders as schizophrenia, bipolar disorder, major depression, anxiety, panic disorder, and obsessive-compulsive disorder.

**Psychotherapy**

Psychotherapy refers to a variety of techniques and methods used to help children and adolescents who are experiencing difficulties with emotion and behavior. Psychotherapy may involve an individual child, group, or family. Psychotherapy is often used in combination with other treatments (medication, behavior management, or work with the school). The relationship that develops between the therapist and the patient is very important. The child or adolescent
must feel comfortable, safe, and understood. Psychotherapy helps children and adolescents receive emotional support, resolve conflicts with people, understand feelings and problems, and try out new solutions to old problems. Goals for therapy may be specific (change in behavior, improved relations with friends or family), or more general (less anxiety, better self-esteem). The length of psychotherapy depends on the complexity and severity of problems.

**Behavioral therapy**

Behavioral therapy uses learning principles to change troublesome thinking patterns and behaviors systematically. The individual can learn specific skills to obtain rewards and satisfaction. Such an approach may involve the cooperation of important persons in the individual's life to give praise and attention to desirable changes. Behavioral therapy includes an array of methods such as Stress Management, biofeedback, and relaxation training.

**Psychodynamic therapy**

Psychodynamic therapy helps the child look inward, to reflect on his experiences, feelings and reactions. Its aim is for the youngster to gain insight into and understanding of his behavior and emotions, especially those of which he may not have been conscious, and to change them in some fundamental way. Some therapists are nondirective, meaning that they may encourage a child to play and talk about whatever comes to mind while they listen for clues as to what may be at the root of the youngster's difficulties. This type of therapy is sometimes necessary to understand a child's deeper and more personal problems. Central to this approach is providing the child with an opportunity to form a relationship with the therapist. In this context the therapist can observe the child's problems firsthand and work with the youngster to overcome them. Other therapists are more directive and guiding, leading youngsters into discussions of specific problematic issues. Psychodynamic treatment may be lengthy and expensive and requires a highly skilled therapist, such as a child psychiatrist, psychologist or trained social worker. It may be more effective with older children who are reflective and insight-oriented.

**Family-system therapy**

Family-system therapy looks at the family structure and its subunits (marital, sibling, parental). The child's behavioral problem is seen as a reflection of a dysfunction or stress within the family. The child's behavior is considered to be the symptom of a larger problem within the family. While the child is identified as the patient, in fact the whole family is the patient. The aim is to change and improve the child's and the family's relationships, communication and behavior. Therapy can last several sessions or many years and requires a trained family therapist.

**Cognitive-behavioral therapy**

Cognitive-behavioral therapy helps the child look outward and develop better ways of acting and reacting. Its aim is to change the child's behavior, to allow him to see the world differently and think about and be aware of his actions and how they affect him and others. It uses behavior-modification techniques to change his expectations and responses, and it uses rewards and punishment. Role playing, storytelling, interactive games, talking, thinking and problem-solving are used to help the child explore his feelings and perceptions, consciously think about his behavior, and then devise more effective behavior. This type of therapy also requires a change in parental behavior. It is usually carried out by pediatricians, psychiatrists, psychologists or social workers and can last for varying lengths, but usually several months.
(Source: The Family Guide to Systems of Care for Children with Mental Health Needs is a publication of the Caring for Every Child’s Mental Health Campaign, a national public education initiative emphasizing attention to children’s and adolescents’ mental health. This campaign is managed by the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services. The content and format of the guide was determined by families from across the country, and it was written by a diverse team of experts led by the Federation of Families for Children’s Mental Health. The initial text for the guide was developed by Families and Communities Equal Success of Stark County, OH. Rhode Island Parent Support Network of Warwick, RI, field-tested the guide’s content, relevance, usefulness, and format. In 2005, the guide was updated to reflect the current state of the science in mental health service delivery, as well as to ensure that it supports the recommendations called for in the report of the President’s New Freedom Commission on Mental Health.)

**Family Guide to Systems of Care for Children with Mental Health Needs**

You may have decided to read this guide because you are concerned that your child needs help getting along with others, controlling his or her behavior, or expressing emotions. Depending on your child’s needs and your family’s situation, you might look for help from schools, health clinics or hospitals, health insurance providers, community mental health centers, social service programs, and, possibly, the courts. When different agencies work together and include you and your family as a team, this is the beginning of developing a system of care.

Working with several different providers can be confusing, even overwhelming, unless they partner with you as a team to focus on your goals, strengths, and needs. In a system of care, each family defines its own strengths, the things it wants to change, and the kinds of help and support needed to reach the family’s goals.

Families who have received help from systems of care participated with the Federation of Families for Children’s Mental Health in creating this guide. In seeking appropriate care for their children, family members reported having felt overwhelmed, alone, intimidated, or even blamed. They found strength by sharing their experiences with other families. They have used their experiences to help develop this guide.

**Finding Services for Your Child**

Get help early. If you have concerns about your child’s behavior or emotions, tell your doctors, teachers, counselors, social workers, spiritual advisers, friends, and relatives who know about child and adolescent development and mental health. Ask for their help to find out what the problem is and where to get services.

Explore all options available to meet your child’s and family’s needs. Check your library, the health department, and the social service section of the telephone book for places that might offer the kinds of help you are looking for. A large amount of information can be found on the Internet. Many family-run organizations have resource centers and advocates or mentors who know about available services in your community.
What you need to know
You are the expert when it comes to your child. You know your child better than anyone else.

You know:
How your child responds to different situations;
Your child’s strengths and needs;
What your child likes and dislikes;
What has worked to help your child; and
What has not worked.

You are the person who decides what services and supports your child and family will receive. Include your child in the decision-making process. Your child needs to understand what is going on in order to actively participate in his or her care.

Every child is different, yet there are children similar to yours. You are not alone. Other families have faced similar problems, shared the same experiences, and are willing to help you.

What to ask
What do I need to know and to do to help my child?
What agencies in the community have programs or services that can help my child and other members of my family? How do I get services from them?
How will my child’s health, growth and development, social interaction, and ability to learn be affected by the problems we face?
What has helped other children like mine?

What you can expect
You will hear and learn many new words and technical terms. Ask for definitions and explanations.
Because systems of care are youth-guided and family-driven, your entire family may be asked to participate in the services you are offered.
There may be waiting lists for some services. Find out how to get some help while you are waiting for a particular service.

What you can do
Gather all the information you have about your child. Keep track of everything and start a notebook or file to organize:
Reports of tests and evaluations;
Service plans and information about the providers, programs, and services you are using;
Instructions from doctors, teachers, social workers, and others working with your child and family;
Changes in your child’s behavior;
Medications note dates that medications are prescribed and changed, and any differences in your child’s physical and/or mental health;
Appointments, conversations, and meetings, including notes of what was discussed;
Requests you have made for supports such as child care, transportation, and flexibility in scheduling appointments; and
Letters about meetings and services note the date they were received.
Ask for information and written materials in the language you speak and ask for explanations of anything you don’t understand.

Find other parents or family-run organizations where you can get information and support by sharing ideas and experiences.

### Preparing for the First Visit

The first step to getting involved with the system of care usually is called an initial referral or intake. This is when you and the staff of the program or service find out about each other. This first visit may be at your home, at your child’s school, or at an agency office. This meeting could last a while—maybe as long as 2 hours.

**What you need to know**

Most programs and services have eligibility criteria. You may be asked to bring your child to the first visit. Someone may want to talk with your child alone. Do not agree to this before both you and your child feel comfortable and have agreed to participate in the program. Most programs have a handbook that explains how they do their work. The intake worker should give you one. People who work in systems of care really do want to help your child and family. They will encourage you to speak up and ask questions on behalf of your child and family.

**What to ask**

What services and supports are available, and when and where can we get them? How is eligibility for services determined? How much do services cost and where can I get help to pay for them? Who will watch my children while I complete the paperwork and go to meetings? How often will my child and family get services and how long can we continue? How do I get help if there is a crisis, especially at night, weekends, or when the office is closed? How do I find respite care and other support to help me care for my child at home?

**What you can do**

Schedule the first visit at your (and your child’s) convenience.

**Bring:**

Someone you trust with you (e.g., a parent advocate) to the first visit, and other meetings. Your folder or notebook of information and some identification, such as driver’s license, social security number, or birth certificate; and Proof of medical insurance, a Medicaid card, or evidence of your need for financial assistance (such as a pay stub or rent receipt).

Write down your questions before you go to the meeting.

Answer questions honestly and give accurate information about your child’s strengths and needs. Remember that there is no such thing as a dumb or foolish question. Request information, and ask anything you want to know more about or do not understand.
Family Guide to Systems of Care for Children with Mental Health Needs cont…

Write down the answers to your questions and the names and phone numbers of people you want to get in touch with, and of those who will be working with your child and family.

Get a brochure or write down information about the agency’s services, fees, payment options, procedures, and appeal process.

Request a written explanation if you are told that your child and family are not eligible for services.

Do your own homework. Get another opinion, and ask for a referral to another service or program that could help you.

What you can expect
You will be asked many questions about your child and family. The intake worker will want to know things such as:
- What things your child does well;
- What you think the problems are and how they affect your family;
- What you want help with;
- What kind of insurance you have or how the services will be paid for; and
- Who or what has been helpful in the past.

You will be asked to sign many forms such as:
- Permission for your child to be tested;
- Permission to gather or release information; and
- Agreement to accept and pay for services.

It is okay if you feel tired and a bit stressed when the first visit is over.
Set a date to meet with your service planning team.

Partnering With Service Providers

Your child and family will be working with individual service providers and a service planning team. Building partnerships among families, individual providers, and service planning teams is hard work. Everyone has to be courteous and honest to gain the respect and confidence of others.

You are the customer and the client. Tell your service planning team and service providers what services and supports you need. Be clear about your family’s strengths, your needs, and what you think will help your child and family the most.

You and your system of care service planning team will work together to write a service plan specifically designed for your child and family, including:
- Goals to achieve;
- Services and supports provided as close to home as possible;
- Services and supports that match your family’s lifestyle and culture; and
- Regular progress reports and an ongoing communication plan for the service providing team.
A service coordinator or case manager can help organize services so they are easy for you to use, and can help provide your family with guidance and support. In some systems of care, you can be your family’s service coordinator.

All providers may not agree or recommend the same services and supports for you and your family. You can disagree with a provider, get a second opinion, or reject a provider’s advice. Providers and services that are considerate and respectful of your family’s language, spiritual beliefs, and cultural values must be accessible to you.

**What to ask**
How will the services and supports in the plan help my child and family?
What are the service provider’s qualifications? Does he or she have special training and a track record of working with children and families like mine?
Can I call service providers at any time of the day or night if there is a crisis?
How do I change services or providers if things aren’t working out as planned?

**What you can expect**
You have the opportunity to speak up, be listened to with respect, and not be judged.
Most service providers will talk to you and your child in a clear, courteous, respectful, and sensitive manner in the language you use at home. Ask for an interpreter if you need one — do not let your children translate for you.
Service providers who work with your child may have a different view of your child and family from yours. Carefully consider the evidence for what they are saying before reacting. Most service providers are just as eager to see progress as you are. Insist that service providers meet when and where your child and family feel comfortable. Service providers may ask for your feedback and suggestions. Be honest when you reply. Most service providers will help you advocate for the services and supports that will help your child and family achieve goals that you set. You may be asked to sign something that says you agree to the service plan and are accepting the services offered. You can refuse to sign if you do not agree with the plan. Ask for a copy of the service plan if it is not given to you.

**What you can do**
Pick your service planning team members carefully, and be an active participant on the team.

**Choose people who:**
Respect and trust you;
Know your child and family and have been supportive;
Have a track record of success managing the kinds of problems you are facing; and
Know about services in the community.

Share the future you envision for your child and explain how others can help achieve it.

Let service providers know your child’s and family’s strengths, needs, wants, and expectations, and tell them about your family’s preferences and priorities. You could talk with someone you trust before the meeting so you are confident about what you say.
Write down short and long-term goals for your child and family, and watch for progress.

Tell your service coordinator or case manager as soon as you realize that some part of the plan isn’t working as you expected. Meet with your service planning team again as needed.

**Rights and Responsibilities**

In a system of care, your child and family have specific rights and responsibilities. Other families, as well as advocates and providers, can tell you about these and can help you understand how and when to use them. Become a strong advocate for your child and family. Exercise your rights.

**What you need to know**

Discrimination in the provision of services on the basis of race, religion, ethnicity, gender, religion, age, or disability is illegal.

If your child is being evaluated for special education, you have special rights and responsibilities. Ask the school to tell you about them and get a copy of them in writing.

You can choose providers who respect and value your language, culture, and spiritual beliefs. Services and supports need to be provided in your community, so your child and family can be involved with others from your neighborhood.

You can refuse any service offered to you without being penalized. Get help from family advocates if you are penalized for making a legitimate complaint or refusing services that you believe could harm your child or family.

Responsible providers will notify you before they change or stop providing any service. Ask for a written notice and explanation of the change if you are not given one.

**What to ask**

How do I review and get copies of my child’s and family’s records?

How is my child’s and family’s privacy protected, and who has access to confidential records?

How do I get help exercising my rights especially if I want to file a complaint?

**What you can expect**

Schools and agencies will give you a guide that explains all of your rights. The guide should be in the language you understand best, or a professional or advocate who speaks your language can interpret and explain it to you.

You will be told details of what confidential information will be disclosed to others and under what circumstances. Make sure you review information before giving permission for anything to be released to another school, provider, or agency.

You can exercise any and all of your rights without punishment in any form. If you experience otherwise, seek help from an organized advocacy group or family-run organization.

Expect to be treated with courtesy, consideration, and respect.

**What you can do**

Get to know and understand your rights and all the terms or conditions that apply to the services your child and family are using.

Read everything carefully. Be sure that you understand and really do agree with anything that you are given before you sign it.
Remember that although you may be under a great deal of stress, you are your child’s best advocate. Clearly, you should listen to the advice of others on your service planning team who know something about your child’s needs. Ultimately, you must decide what help is needed, where you want to go for it, and when and how often you need to have a service.

Take control of the flow of information about your child and family. Carefully consider what reports go to which person, agency, school, and so forth. Think about this before you sign permission for information to be collected or given out.

Resolve disputes promptly. If you disagree with a decision, speak first to the person most immediately involved. If that doesn’t solve the problem, speak to your service coordinator or the provider’s supervisor before you file a complaint.

Request help from advocates who know the rules, understand the system of care, and have experience with the providers who are working with you and your family.

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**Paying for Mental Health Services**

**Private Health Insurance**

Most health insurance plans provide fairly easy access to a pediatrician, but offer limited access to mental health professionals, and possibly no access to long-term care. Sometimes it isn’t enough for a pediatrician or primary care provider to write a referral to see a mental health professional. You may also have to call a “gatekeeper” employed by your insurance company, who screens patients for this type of care. In general, private health insurance covers less than the services provided in the public health system, although you will probably have to wait for services to be available in the public system. Don’t let a gatekeeper get between your child and early and appropriate treatment. If treatment is denied or delayed, file an appeal if necessary.

**Public Health Benefit Programs**

**Child Health Program (CHP) (primarily for children from birth to age 10)**

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

Some community health agencies offer Child and Family Health such as assistance with health care enrollment, referrals, case management, care coordination, and education and counseling relative to a child and family. These services may be provided in person or by telephone.
Paying for Mental Health Services cont...

**Medicaid**

This program allows eligible children who need mental health care to receive preventive and all medically necessary health care through the Early Periodic Screening, Diagnosis, and Treatment (EPSDT) program. While private health insurance might not include all the mental health care services your child needs, EPSDT provides any health care service that is medically necessary and approved by Medicaid. In Iowa the EPSDT program is called Care for Kids.

The Iowa Department of Human Services (DHS) determines financial and non-financial eligibility. (Medicaid Administration determines eligibility based on developmental disabilities.)

There are three types of criteria that DHS evaluates to determine eligibility for Medicaid: income, other financial resources, and non-financial criteria (food stamps, child care assistance, etc.). **Regarding income eligibility, remember that it is your child’s income that is being evaluated, not yours. Do not assume that your child is not eligible for Medicaid based on your own income level.**

DHS coordinates eligibility for medical coverage for Iowa children under the age of 19. Some of the medical services provided to eligible children by the Medicaid program include: hospital, physician, prescription drugs, physical and speech therapy, medical transportation, medical supplies, durable equipment, psychotherapy, interpreter, EPSDT, services for persons with developmental disabilities and acquired brain disorders, and services at community mental health centers.

**To find out if your child is eligible for any of the services provided under Medicaid, contact the Medicaid Program in your District Human Services office. To contact the EPSDT Care for Kids program coordinator for your county: [www.idph.state.ia.us](http://www.idph.state.ia.us) Tel: (800)369-2229.**

**Social Security Benefits**

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

If you think your child is eligible for Social Security benefits, apply for benefits at your regional Social Security Administration Office.

**Supplemental Security Income Benefits (SSI)**

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

**To qualify for SSI, your child must:**

Be under age 18

Be in a low-income family (your income level depends on the number of people in your home, your type of monthly income, and your family’s assets)

Have a disability that “severely limits his or her ability to function when compared to other children of the same age”
Paying for Mental Health Services cont…

The SSI benefit includes a monthly check, adjusted for your family’s income. After your child reaches 18, he or she may apply for SSI as a disabled adult, at which time your income is no longer counted. Begin the application process at least six months prior to your child’s 18th birthday. If you think your child might be eligible for the SSI program, apply at your local Social Security Administration Office.

**Transitional Assistance (TANF)**
The Transitional Assistance for Needy Families (TANF) program provides assistance and work opportunities to needy families by granting federal funds to states. The states then develop and implement their own welfare programs.

Iowa operates a TANF program that includes cash assistance and Medicaid benefits for low-income families who are deprived of the ability to support themselves. All able-bodied parents must participate in a job-seeking program or risk losing a portion of their support and/or medical insurance. If your child is between the ages of 16 and 18, receives TANF benefits, and is not in school, he or she must also participate in the work program. Medicaid may continue for up to a year after a person’s eligibility has ceased because they are working.

When a child is moved out of his or her parent’s home into foster care, institutional care, or group placement, state and federal dollars go to support the child in that care. It is common for a child in a residential treatment facility to be required to give his or her SSI check to the facility to cover some of the cost of the care.

The Iowa Family Assistance Program provides cash assistance to eligible families headed by adults who are permanently disabled, have long-term obstacles to employment, or are over age 60. The program also provides cash assistance for children living with a non-parent caretaker relative, such as an aunt, grandparent, or adult sibling.

Parents of families eligible for TANF cash assistance are eligible for Medicaid. TANF families are also eligible for Emergency Assistance that helps eligible families get and keep safe and secure housing. Most families can only receive TANF cash assistance for a maximum of 60 months in their lifetime. Every month of TANF financial assistance, whether received in Iowa or another state, counts toward the 60-month lifetime limit.

If you think you might be eligible for TANF, apply at your DHS district office.

The Children’s Mental Health Waiver (CMH)
The CMH Waiver exists to meet the needs of children under age 18 with serious emotional disturbance (SED). Many children with serious emotional disturbances must leave their homes to seek support in a medical institution. The parents of eligible children ‘waive’ using services in an institution and choose instead to use services and individual supports to keep their children in their own home. The child, his or her family, chosen providers, the targeted case manager, and others come together to form an interdisciplinary team (IDT), which meets to plan the interventions and supports a child and family need to safely maintain the child’s physical and mental health in the family’s home. They guide the implementation of CMH Waiver services.
Paying for Mental Health Services cont…

To enable children to remain in their own homes and communities, the CMH Waiver offers a range of services that may include: environmental modifications, adaptive devices and therapeutic resources, family and community support services, in-home family therapy, respite.

**The following requirements must be met for a child to be eligible for CMH Waiver services:** *These requirements are found in IAC 441-83.122(249A)*

**Age:** The child must be under 18 years of age.

**Diagnosis:** The child must be diagnosed with a serious emotional disturbance. For the initial application to the HCBS CMH Waiver program, documentation that substantiates a mental health diagnosis of serious emotional disturbance (SED), as determined by a mental health professional, must be current within the 12-month period before the application date. A mental health professional must complete an annual evaluation that substantiates a mental health diagnosis of serious emotional disturbance.

**Level of Care:** The child must be medically certified in need of a level of care that, but for the waiver, would be provided in a psychiatric hospital serving children under the age of 21. The Iowa Medicaid Enterprise (IME) medical services unit shall certify the consumer’s level of care annually based on the Children’s Mental Health Waiver Assessment (form 470-4211).

**Financial Eligibility:** The child must be eligible for Medicaid under an SSI, SSI-related, FMAP, or FMAP-related coverage group; or be eligible under the special income level (300 percent) coverage group; or become eligible through application of the institutional deeming rules; or would be eligible for Medicaid if in a medical institution. For this purpose, deeming of parental or spousal income or resources ceases in the month after the month of application.

**Choice of Program:** The child must choose HCBS CMH Waiver services over institutional care. This is indicated by the signature of the child’s parent or legal guardian on the Children’s Mental Health Waiver Assessment (form 470-4211).

**Need for Service:** The child must have service needs that can be met under the CMH Waiver, as documented in the service plan developed in accordance with IAC 441-83.127(249A). The child must be a recipient of targeted case management services or be identified to receive targeted case management services immediately following program enrollment.

**Other Medicaid Home and Community Based Services Waivers (HCBS):**

**Medical Assistance-Iowa**
The HCBS program helps people in need of additional health care while they remain at home. Home and community-based services are alternatives to institutional care. Inspired over 25 years ago by a child from Iowa named Katie Beckett, young people, older adults and persons with disabilities benefit in their own homes from supports offered through Iowa’s various HCBS waiver programs.
Paying for Mental Health Services cont…

The Centers for Medicare and Medicaid Services (CMS) provide the funding for HCBS services, with two-thirds coming from federal Medicaid dollars and the remainder from the county or the state. Medicaid covers basic health care services plus services to promote self-care and/or family care. A child, adult, or elderly person may be eligible if program guidelines are met.

HCBS waivers include: Ill and handicapped, AIDS/HIV, Mentally retarded, Elderly, Brain injury

How to apply for a waiver program:
A person must first apply for and be denied Supplemental Security Income (SSI), before being considered for the HCBS Waiver program. To apply for SSI, call (800)772-1213.

Once you are denied SSI, contact the Department of Human Services (DHS) and ask for a Medical Assistance application. You will need to provide your SSI denial statement to DHS. Complete the Medical Assistance application and return it to DHS as soon as possible. Your application will be processed based on the date it is received.

The UI Hospitals and Clinics Child Health Specialty Clinics, phone: (319)353-6172, also have an agreement with DHS to assist the Iowa Model Waiver program.

Services for Your Child at Home

Wraparound
(Source: Guidebook for Caregivers of Children and Adolescents with Serious Emotional Disorders, New Hampshire)

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

Many different kinds of planning meetings have been called “wraparound.” This can be confusing for families, youth, and service providers alike. Wraparound is an ongoing and circular process in which the child, family, and their team identify the children and family’s strengths, supports, and most important, needs. With guidance of a trained facilitator, they work together, taking action steps and finding creative solutions. Wraparound is not a one-time meeting or event and does not solve all issues immediately. There is no attachment of “blame or shame” if a plan does not work out the first time; the team keeps “working until it works.” Once action steps are identified and implemented, the family evaluates whether its needs were met or if the team needs to identify new ideas and new possible strategies.

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

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

By providing supervision, skill development and support to the family, a non-residential alternative to traditional out-of-home care is provided which allows the youth to remain in the family home.

**Child Welfare Services at Home**

The state of Iowa initiated a process to maximize federal financial reimbursement for child welfare and juvenile justice services by distinguishing the treatment portion of certain child welfare services from the supervision and maintenance portion of those services.

**Treatment services**

**Family Preservation Services**
Case Management
Time-limited services from community providers to stabilize crisis

**Family Centered Services**
Case Management
Rehabilitative services from community providers

Children in child welfare are monitored (case managed) by state social workers. These workers are often listed in the county section of the phone book and located in county offices but they work for the State of Iowa Department of Human Services (DHS).

The case manager can authorize the following rehabilitative treatment services (RTS):
- psychosocial evaluation
- social skills development
- family skills development
- restorative living skills development
- behavioral management for foster children
Out-Patient Mental Health Services

Community Mental Health Centers (CMHC)
Each of the regional CMHCs in Iowa provides outpatient mental health services to qualifying individuals regardless of their ability to pay. To be eligible for services, your child must be assessed and found to be in need of the services provided at the center.

CMHC services may include the following:
Assessment (part of the intake procedure).
Individual, group, and family counseling.
Evaluation and testing.
Case management, including coordinating community-based support and treatment (wraparound services).
Medication administration and monitoring.
Mental Illness Management Services (MIMS).
Limited emergency mental health services (24 hours/day).

CMHCs are staffed by a variety of practitioners, including nurse practitioners, clinical social workers, clinical psychologists, psychiatric nurses, and mental health counselors. The centers differ from each other in staffing, the way services are provided, and the role that families play in the treatment process. If you find that you are not being included as a partner on your child’s treatment team, step forward and speak to your child’s case manager or therapist about becoming a part of the team. Be certain that you receive a copy of the treatment plan after you sign it.

Community mental health services accept private insurance as well as Medicaid and Medicare. CMHC’s also offer a sliding scale of fees based on your family’s ability to pay.

In-Patient Mental Health Services

Psychiatric In-Patient Hospital Units for Children (Short Term)
Children admitted to inpatient programs are usually those who are either in immediate danger of harming themselves or others, or they have severe disabilities or medical factors that complicate the mental health disorder and place them at significant risk.

Psychiatric Medical Institutes for Children (PMIC)
The PMIC system is intended to serve children who need an intensive treatment program for an extended period of time. Each of the twelve facilities in Iowa determines its own criteria for eligibility, service descriptions, and direct-care provider requirements. Ordinarily, a child admitted to a PMIC facility will have one-hundred percent of the costs paid by Medicaid.

Parents are not required to terminate their parental rights or to relinquish custody in order for a child who has an emotional, behavioral, or mental health disorder to obtain treatment in a PMIC. 
Relinquishment of a child’s custody shall not be a condition of the child receiving services. 
(source: Iowa Code Title IV. Public Health...Psychiatric Medical Institutions for Children, Chapter 135H.6(11)
In-patient Mental Health Services continued:

Residential Treatment Facilities for Children (Group Care)
Group care provides highly structured 24-hour treatment services and supervision for children who cannot be served at a less restrictive level of care due to the intensity or severity of their emotional/behavioral problems. Various levels of care are available. Services include counseling and therapy, social skills development, restorative living skills development, family skills development, and supervision.

Residential treatment is available both for children who have been adjudicated for delinquent acts and for children who have not but whose emotional/behavioral problems require 24-hour supervision in a setting away from the family home. Costs for care in a residential treatment facility, as differentiated from a PMIC, will usually be paid by the family. If a child is placed in a residential treatment facility by the juvenile court, Medicaid may cover the cost of treatment but the parents will likely be responsible for the costs of room and board. In order for a child to be placed in a residential treatment facility, the county attorney would need to file a petition with the juvenile court.

NAMI IOWA

To request information on mental illness or to schedule an educational presentation, contact:

NAMI IOWA
National Alliance on Mental Illness-Iowa
Des Moines, Iowa
www.namiiowa.org  info@namiiowa.com
Section III.

Medications for Children & Adolescents
Section III. Psychiatric Medications for Children & Adolescents

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Psychiatric Medications for Children & Adolescents

Psychiatric medications may be part of your child’s treatment. A comprehensive evaluation will be conducted prior to any medication trial. Most medication studies and research have been with adults. Treating children with medication has been described by some as a “soft science,” which means finding the right medication for your child may take several trials. Usually each medication is started with a low dose and may take several days or weeks to see any effect.

It is important for the child’s caregiver to keep a written log to help the physician or Advanced Registered Nurse Practitioner (ARNP) know whether to increase or discontinue the medication. All prescriptions must be taken as directed and results reported to the doctor.

Questions to Ask Your Doctor

What is the medication name? Is it known by other names?

What is known about its helpfulness with other children who have a condition that is similar to my child’s?

How will the medication help my child?

How long before I see improvement?

What are the most common side effects? What are the rare side effects?

Is the medication addictive?

What is the recommended dosage and how often is it taken?

Are there any laboratory tests that need to be done before my child begins taking this medication?

Will a child and adolescent psychiatrist be monitoring my child’s response to medication and make dosage changes if necessary? How often will progress be checked and by whom?

Are there any other medications or foods that my child should avoid while taking the medication?

Are there any activities that my child should avoid while taking the medication?

How long will my child need to take this medication? How will the decision be made to stop this medication?
Questions to Ask Your Doctor continued...

What do I do if a problem develops (e.g., if my child becomes ill, doses are missed, or side effects develop)?

What is the cost of the medication (generic vs. brand name)?

Does my child’s school nurse need to be informed about this medication?

______________________________________________________________________________

Taking Medication

When the decision is reached that a child should take medication, active monitoring by all caretakers (parents, teachers, and others who interact with the child) is essential. Children should be watched and questioned for side effects because many children, especially younger ones, do not volunteer information. Monitor the child to see that the medication is being taken at the proper dosage and on schedule. (Source: Medications, NIMH. Sept. 2002)

Always consult with your child's medical provider if you have any questions or concerns involving medications.

Never increase, decrease or stop a medication abruptly without first consulting your child's medical provider.

Common Stimulant Related Side Effects: (Source: Visions for Tomorrow, NAMI Texas)

Loss of appetite-Give stimulant with meals; add calorie-enhanced snacks (ice cream); if taking Cylert, ask doctor about checking liver function with blood test.

Difficulty falling asleep-Ask doctor about administering earlier in the day; changing to short-acting forms; or using low-dose clonidine, Benadryl, Periactin, Remeron, melatonin at bedtime.

Dizziness-Check blood pressure; drink more fluids; ask doctor about changing to longer-acting form.

Rebound Phenomena-Ask doctor about overlapping stimulant dosing by 30 minutes; change to a long-acting form; combine long-/short-acting forms; use additional treatment of low-dose clonidine or tricyclic antidepressants.

Irritability-Evaluate when it occurs so doctor will have necessary information to reduce dose; assess for another problem such as depression, use adjunctive treatment (antidepressants, lithium, and anticonvulsants).

Sadness, moodiness, agitation-Inform doctor who may re-evaluate diagnosis; reduce dose; change to a long-acting form; consider additional agent.
Taking Medication continued...

Growth problems—Compare with parental height history; refer to pediatrician; add calorie-enhanced snacks; discuss weekend “medication vacation” or changing to non-stimulant treatment (nortriptyline, clonidine; Tenex, Wellbutrin) with doctor.

**Potential Drug Interactions of Stimulants with Commonly Used Drugs:**
(Source: Wilens, Timothy., M.D. Straight Talk about Psychiatric Medications for Kids)

- Decongestants—May increase effectiveness of both medications
- Pseudoephedrine (Actifed, Sudafed)—Start with lower doses of decongestant
- Antihistamines (Benadryl, Dimetapp)—May diminish effectiveness of stimulant
- Tricyclic Antidepressants—May increase effects of medication; check blood level and antidepressant
- Anticonvulsants—May increase or decrease efficacy
- Prozac, Wellbutrin, Serzone—No noted interaction
- Antibiotics—No noted interaction
- Antipsychotics, Anxiety—No noted interaction

______________________________________________________________________________
(Source: The Facts for Families series developed by the American Academy of Child and Adolescent Psychiatry (AACAP) and The New York University Child Study Center.)

**Types of Medication**

Following is a brief overview of common types of psychiatric medications.
For more information: www.nami.org

**Antidepressant Medication:**
Antidepressant medications are commonly used in the treatment of depression, school phobias, panic attacks, post traumatic stress disorder, obsessive compulsive disorder, and other anxiety problems. In addition, eating disorders, bed wetting, and attention deficit disorders may be treated with antidepressant medications.

Common side effects may include sedation, headaches, dry mouth, GI upset, constipation, blurry vision, EKG changes.

Selective Serotonin Reuptake Inhibitors (SSRI)—Common side effects may include GI upset, insomnia or sedation, and headaches.
Types of Medications continued...

Monoamine Oxidase Inhibitors (MAOI)

Atypical Antidepressants-Side effects may include sleep disturbance, sedation, GI upset, and hypertension (with Effexor).

Antipsychotic Medication:
Antipsychotic medications are commonly used to treat psychotic symptoms and disorganized thinking. Antipsychotic medications may also assist with muscle twitching and symptoms of Tourette’s syndrome. Antipsychotic medication may also be used to treat high levels of aggression, bipolar disorder, posttraumatic stress disorder, and severe anxiety disorders. Common side effects include sedation, movement disorder, weight gain, and cognitive blunting.

Mood Stabilizers and Anticonvulsant Medications:
Mood stabilizers may be helpful in treating bipolar disorder, aggressive behavior, impulse control disorders, and sever mood symptoms in schizoaffective disorder and schizophrenia. Common side effects include GI upset, dizziness, weight gain, enuresis, tremors, and sedation.

Anti-Anxiety Medications/ Anxiolytics:
Anti-anxiety medications are helpful in the treatment of severe anxiety and sleep problems. There are several types of anti-anxiety medication including benzodiazepines, antihistamines, and atypicals. Side effects include sedation, cognitive blunting, dizziness, and the potential for addiction.

Sleep Medications:
Sleep medication may be used for a short time to assist with sleep problems. Examples include tricyclic antidepressants, Desyrel (trazodone), Ambien (zolpidem), and Benadryl (diphenhydramine).

Alpha Agonists:
Catapres (clonidine) & Tenex (guanfacine) are both being used to treat symptoms of attention deficit disorders, aggression, and tics. Tenex is also used to treat severe flashbacks in children with post traumatic stress disorder.

Free or Reduced-Cost Medications

If your child needs medication and you cannot afford the prescription, there are free and reduced prescription medications available to those who qualify. The Partnership for Prescription Assistance helps qualifying patients without prescription drug coverage get the medicines they need for free or nearly free. Their mission is to increase awareness of patient assistance programs and boost enrollment of those who are eligible. They offer a single point of access to more than 475 public and private programs, including nearly 200 offered by pharmaceutical companies. Contact: www.pparx.org, Tel:(888)477-2669; or consult your pharmacist or prescribing physician to find out more about programs that may assist your family.
Section IV.

NAMI IOWA Fact Sheets
Childhood Disorders
& Behavior Challenges
Section IV. NAMI IOWA Fact Sheets
Childhood Disorders & Behavior Challenges

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95  Tourette’s Disorder
Childhood Disorders & Behavior Challenges

Neurobiological Brain Disorders

Neurobiological disorders are a class of severe and persistent brain disorders described by educators and community providers as serious emotional disorders (SED) or behavior disorders (BD).

Neurobiological disorders can significantly interfere with the learning process, interpersonal relationships, adjusting to changes, thinking and feeling. They can reduce a young person's capacity to cope with the ordinary demands of everyday life. Children and adolescents with neurobiological disorders often benefit from special accommodations at home and in school.

Families may encounter other terms that are sometimes used to refer to children and adolescents who have childhood disorders and behavior challenges. In addition to neurobiological disorder, or serious emotional disorder, or behavior disorder, parents may hear the term mental illness. Mental illness is a broad term that generally refers to the many diagnoses listed in the Diagnostic and Statistical Manual, the source professionals refer to when determining a person's diagnoses.

The symptoms listed on the following NAM IOWA fact sheets were either taken directly from or based on criteria of the Diagnostic and Statistical Manual IV (DSM-IV) [published by the American Psychiatric Association (1994) Washington, DC, Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition] and the National Institute of Mental Health.
Anxiety Disorders in Children and Adolescents

Anxiety disorders are the most prevalent mental illness in America. As many as one in ten children and adolescents are affected.

Anxiety disorders cause people to feel excessively frightened, distressed, and uneasy during situations in which most others would not experience these symptoms. The reason for anxiety is usually from an ill-defined, irrational, distant, or unrecognized source of danger.

Anxiety disorders in children can lead to poor school attendance, low self-esteem, deficient interpersonal skills, alcohol abuse, and adjustment difficulty.

Symptoms

| Feeling shaky | Fatigue |
| Jumpiness    | Twitching |
| Muscle aches | Impatience |
| Trembling    | Irritability |
| Tension      | Upset stomach |
| High heart rate | Fear a bad thing will happen |
| Worry        | Difficulty concentrating |

Causes

Studies suggest that anxiety disorders tend to have both a biological and an environmental link. It has not been established; however, which plays the greater role in the development of these disorders.

Abnormalities in parts of the brain have been suggested as a cause of anxiety disorders; although no definite area in the brain has been proven to cause the disorders.

Scientists at the National Institute of Mental Health and elsewhere have found that some cases of OCD occur following infection or exposure to streptococcus bacteria. Further research is being done in this area in order to pinpoint who is at greatest risk.

Treatments

Medication is an effective treatment for anxiety disorders. Medications serve the purpose of reducing anxiety, relaxing muscles, and inducing sleep. It may take up to six or seven weeks before the medication shows its effectiveness.

Psychotherapy, in the form of behavior therapy or cognitive-behavioral therapy, is an equally important and effective treatment for anxiety disorders. Cognitive-behavioral therapy involves teaching a young person to modify the way he/she thinks and behaves by practicing new behaviors. This enables the child to better deal with fears.

Parents and caregivers should learn to be understanding and patient when dealing with children with anxiety disorders.
Anxiety Disorders Fact Sheet continued…

Common types of Anxiety Disorders

**Generalized Anxiety Disorder (GAD):** GAD is characterized by chronic, exaggerated worry about everyday, routine life events and activities that lasts at least six months. Usually the worst is anticipated and often there are complaints of fatigue, tension, headaches, and nausea.

**Obsessive Compulsive Disorder (OCD):** OCD is characterized by repeated, intrusive, and unwanted thoughts (obsessions) and/or rituals that seem impossible to control (compulsions). Younger children are not as aware that their symptoms are excessive. They instead may only feel distressed when they are prevented from carrying out their compulsive habits. Adolescents may be aware that their symptoms do not make sense and are excessive. Compulsive behaviors often include counting, arranging and rearranging objects, and excessive hand washing.

**Posttraumatic Stress Disorder (PTSD):** PTSD is characterized by nightmares, flashbacks, numbing of emotions, depression, feeling angry, irritable and distracted, and being easily startled. Symptoms of this disorder may occur after experiencing a trauma such as abuse, natural disasters, or extreme violence.

Suggested Readings

*Mending Minds*, by Heston, Leonard
*Triumph Over Fear*, by Ross, Jerilyn
*Obsessive Compulsive Disorder: A Guide*, by University of Wisconsin
*Obsessive Compulsive Disorders*, by Levenkron, Steven
*The Boy Who Couldn’t Stop Washing*, by Rapoport, Judith

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**NAMI IOWA**
National Alliance on Mental Illness-Iowa
Des Moines, Iowa
www.namiiowa.org info@namiiowa.com
Asperger’s Syndrome (AS)

AS is different than Autism in that a child with AS does not experience a significant delay in cognitive development or in the development of language skills. In addition, a child with AS can be quite imaginative; whereas, children with Autism tend to be concrete thinkers.

It appears that boys are more likely to have AS than girls.

AS typically presents between ages two and six, but is often not recognized until later.

Symptoms

Very rigid adherence to specific non-functional routines or rituals (i.e., walks a certain route to school)

Lack of facial expressiveness

Lack of eye contact when spoken to

Self-directed orientation

Intense preoccupation with certain specific (often unusual) topics

Lack of understanding of social cues

Preoccupation with certain actions or objects with a restricted range (i.e., interests of a narrow scope)

Lack of the use of normal body posture and gestures

Awkwardness in social situations

Clumsiness caused by lack of motor coordination

Failure to develop peer relationships

Causes

The cause of AS is presently unclear, but it appears to have a somewhat later onset than Autism. Motor delays or motor clumsiness may be seen in the preschool period.

Treatments

Medication may be helpful depending on the presence and extent of symptoms. For example, symptoms such as hyperactivity, impulsivity, mood instability, temper outbursts, anxiety, depression, and obsessive-compulsive symptoms may be treated effectively with medication.

Psychotherapy in the form of group therapy led by a mental health professional may be helpful in treating the social skills deficits associated with AS.

Educational interventions and accommodations should be closely coordinated between the parents and school personnel.
Asperger’s Fact Sheet continued…

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 AS. Finding a clinician who can make the diagnosis of AS may be a significant hurdle in getting appropriate treatment for your child.

Suggested Readings

Autism and AS, by Frith, Uta
Asperger’s Syndrome: A Guide for Parents and Professionals, by Attwood, Tony & Wing, Lorna
One Small Starfish: A Mother’s Everyday Advice, Survival Tactics & Wisdom for Raising a Special Needs Child, by Addison, Anne

For more information

www.aspergers.com

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www.namiowa.org info@namiowa.com
Attention-Deficit/Hyperactivity Disorder (AD/HD)

In a classroom of 30 children or youth, it is likely that at least two students are affected by AD/HD. This surprisingly common condition makes it hard for children and youth to control their behavior (sit still, think before speaking or acting, etc.) and/or to pay attention. If left untreated, it can lead to school or job difficulties, depression, relationship problems, and substance abuse.

AD/HD often co-occurs with other disorders such as the following: learning disabilities, oppositional defiant disorder, conduct disorder, anxiety or mood disorders, language and communication disorders, and Tourette's disorder.

What Is ADHD?

Types of AD/HD include the hyperactive-impulsive type, the inattentive type, and a type that is a combination of both. The severity of AD/HD varies among children, even siblings, so no two children will have exactly the same symptoms. Also, you may hear that girls have lower rates and less severe cases of the disorder than boys. More research is needed on this subject, but girls may have lower rates of the hyperactive type.

Hyperactive-Impulsive:

Feeling restless, often fidgeting with hands or feet, or squirming while seated

Running, climbing, or getting up in situations where quiet behavior is expected

Blurtling out answers before hearing the whole question

Having difficulty waiting in line or taking turns

Inattentive:

May appear to not be listening or easily distracted by irrelevant sights and sounds

Often failing to pay attention to details, and making careless mistakes

Rarely following instructions carefully, and often losing or forgetting things like toys, pencils, books, or other tools needed for a task

Often skipping from one uncompleted activity to another

Experts believe that in some cases, heredity plays a role in whether or not a child has AD/HD. Symptoms of AD/HD are first seen in children before age 6 and may cause problems at home, at school, or in relationships. Sometimes, it is hard to tell if a child has AD/HD because symptoms
may be mistaken for typical childhood behaviors or other mental health issues, and AD/HD often occurs at the same time that other conditions are present. Equally important are the roles that a family’s culture and language play in how causes and symptoms are perceived and then described to a mental health care provider. Misperceptions and misunderstandings can lead to delayed diagnoses, misdiagnoses, or no diagnoses which are serious problems when a child needs help. It is important that only qualified health care or mental health care providers diagnose AD/HD, and that supports be in place to bridge differences in language and culture.

Symptoms

To be diagnosed with AD/HD, a child must have at least six of the symptoms listed below, lasting at least six months, with some having started before age seven. These behaviors must also significantly interfere with at least two areas of life, such as school and home.

Fidgets with hands or feet
Squirms in seat or feels restless
Has difficulty remaining seated when required to do so
Easily distracted
Difficulty awaiting turn in games or group situations
Blurs out answers to questions before they have been completed
Difficulty following through on instructions from others
Shifts from one uncompleted activity to another
Difficulty playing quietly
Talks excessively
Interrupts or intrudes on others
Does not seem to listen to what is being said to him/her
Loses things necessary for tasks or activities
Engages in physically dangerous activities without considering possible consequences
Difficulty sustaining attention in tasks or play activities

Causes

AD/HD is a biological disorder that appears to be genetically or developmentally based.

The symptoms frequently begin at birth, as seen in feeding or sleeping problems.

Researchers believe that there may be either a chemical or electrical problem in the brain caused by abnormalities in the development of the brain or genetic differences. For example, it appears that a lower level of activity in some parts of the brain may cause inattention.

Environmental factors such as viruses, harmful chemicals, alcohol, drugs, and tobacco during pregnancy are also considered as possible causes of AD/HD. These factors may affect normal brain development, which lead to the development of symptoms associated with AD/HD.
Treatments

If AD/HD is suspected, an assessment or evaluation may initially be done by a school psychologist, family physician, or pediatrician. This individual may then refer a family to a specialist, such as a psychiatrist and/or psychologist.

Medications such as Ritalin, Cylert, Dexedrine, and Adderall are commonly used for treatment. These stimulants increase activity in the parts of the brain that are underactive in youth with AD/HD. Approximately two-thirds of children with AD/HD will respond to one of these medications.

Behavioral therapy in combination with medication has also been shown to be effective in treating AD/HD. This approach often involves strategies such as rewarding positive behavior changes and communicating clear and consistent expectations. It is important to initiate a consistent behavior management program in all areas of life (i.e., school and home).

It may be necessary and beneficial to provide a child with AD/HD with special accommodations at school that help him/her to succeed. For example, a teacher may seat the child in an area with few distractions or may allow the child extra time on tests. If accommodations in a regular education classroom are not effective, a special education classroom should be made available.

Educating parents and children is very valuable in helping to manage this disorder.

Suggested Reading

Survival Strategies for Parenting Your ADD Child, by Lynn, G. T.
The Hyperactive Child, Adolescent, and Adult: ADD thru the Lifespan, by Wenderg, Paul H.
Maybe You Know My Kid: A Parent’s Guide to Identifying, Understanding, and Helping your Child with ADHD, by Fowler, M.
Shelly the Hyperactive Turtle, by Moss D.
Learning to Slow Down and Pay Attention, by Nadeau, K., & Dixon, E. (ages 6-12)
The “Putting on the Brakes” Activity Book for Young People with ADHD, by Quinn M.D., Patricia O. & Stern, M.A., Judith (ages 8-12)

Other Resources

Attention Deficit Information Network (Ad-IN)
www.addinfonetwork.com Tel: (781)458-9895

Children and Adults With Attention-Deficit/Hyperactivity Disorder
www.chadd.org Tel: (301)306-7070

NAMI (National Alliance on Mental Illness)
www.nami.org Tel: (800)950-6264 (toll-free)
AD/HD Fact Sheet continued…

National Institute of Mental Health
National Institutes of Health
www.nimh.nih.gov
Tel: (866)615-6464 (toll-free; English/Spanish)  TTY: 301.443.8431

National Mental Health Information Center
Substance Abuse and Mental Health Services Administration
www.mentalhealth.samhsa.gov
Tel: (800)789-2647 (toll free; English/Spanish) TDD: 1.866.889.2647

National Resource Center on AD/HD
www.help4adhd.org
Tel: (800)233-4050 (toll-free)

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Autism

Autism occurs in approximately 4.5 out of 10,000 live births. Approximately 15 to 20 out of 10,000 children have autistic-like behaviors.

As with many other developmental disabilities, autism is more prevalent in males than females.

Autism can manifest itself very differently in different individuals. Some individuals may be antisocial, some asocial, and others social. Likewise, some may be aggressive toward themselves and/or aggressive toward others.

Some individuals may have little or no language skills, some repeat or echo words or phrases, others may have normal language skills.

Many individuals with autism have an impairment of one or more of their senses. This impairment may cause their senses to be hypersensitive, hyposensitive, or may result in the person experiencing interference, such as a continual ringing or buzzing in the ears. This affects the ability to process incoming sensory information properly.

Symptoms

According to the *Diagnostic and Statistical Manual for Mental Disorders-IV*, at least six of the symptoms listed below must be present with onset prior to age three in order to be diagnosed with autism. In addition, there needs to be a delay in social interaction, social communication, or symbolic or imaginative play.

**Social Interaction:**
Marked impairment in the use of multiple nonverbal behaviors
Lack of spontaneous seeking to share interests and achievements with others
Failure to develop age-appropriate peer relationships
Lack of emotional reciprocity

**Communication:**
Delay in or lack of spoken language development
Lack of spontaneous age-appropriate make-believe or social imaginative play
Marked impairment in conversational skill
Stereotyped and repetitive use of language

**Stereotyped patterns of behavior:**
Preoccupation with at least one stereo-typed and restricted pattern of interest to an abnormal degree
Stereotyped and repetitive motor mannerisms
Inflexible adherence to nonfunctional routines or rituals
Preoccupation with parts of objects
Autism Fact Sheet continued…

Causes

Some evidence suggests a genetic influence in autism. Twin studies have shown a greater prevalence among siblings who are identical twins than those who are fraternal twins.

Researchers have found abnormalities in the neural structure of the brain. For example, studies have shown that areas of the limbic system and cerebellum are significantly underdeveloped and smaller in autistic individuals. Studies have also shown abnormalities in brain chemistry. It appears that autistic individuals have elevated levels of serotonin in their blood and cerebral spinal fluid compared to those without Autism.

Treatments

Some individuals are given medications to improve their general well-being. However, a medication that specifically and consistently targets the symptoms of autism has not been found.

Behavior modification, such as positive reinforcement and time-out, has been shown to be effective with some children in increasing appropriate behaviors and decreasing inappropriate behaviors. Communication skills and social behavior are primarily targeted to be increased, while self-injurious behaviors are targeted to be decreased.

Other areas of treatment that have received attention include sensory integration training, auditory integration training, visual training, and changing the individual's diet in order to eliminate particular foods.

Suggested Reading

Nobody Nowhere, by Williams
Thinking in Pictures, by Gandin, Temple

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www.namiowa.org   info@namiowa.com
Bipolar Disorder in Children and Adolescents

Bipolar disorder, also known as manic-depressive illness, is a disorder of mood involving episodes of serious mania and serious depression. It affects approximately 1 percent of the general population. Both men and women are equally affected.

About one-third of depressed people are diagnosed as having bipolar disorder, but experts believe that about one-half of all depressed people are actually bipolar.

Severe and frequent manic symptoms have been correlated with increased psychosocial impairment among children and adolescents. Manic symptoms not only interfere with daily activities, they also have long-term consequences which may include interference with the mastery of developmental tasks such as regulating emotions, acquiring competencies, and establishing and maintaining social relationships.

Bipolar Disorder Sub-Types (I and II):

In Bipolar I Disorder, a person experiences one or more manic episodes or mixed episodes (symptoms of mania and depression mixed together in one single episode) of bipolar disorder. Often these individuals will also have had one or more major depressive episodes. People with this sub-type may have some free intervals when no symptoms are experienced.

Bipolar II Disorder is characterized by the occurrence of one or more major depressive episodes accompanied by at least one hypomania episode (mania without psychotic symptoms). Symptom-free intervals may also exist in this sub-type of bipolar disorder.

Symptoms

**Depression:**
Persistent sad or "empty" mood
Changes in appetite, weight, or sleep patterns
Decreased energy
Feelings of hopelessness, loss, or guilt
Thoughts of death or suicide
Difficulty thinking or remembering
Loss of interest in ordinary activities
Irritability
Excessive crying

**Mania:**
Excessive "high" mood
Increased energy and activity
Decreased need for sleep
Unrealistic beliefs in one's abilities and powers
Extreme irritability or distractibility
Uncharacteristically poor judgment
Racing thoughts
Obnoxious or provocative behavior
Drug and/or alcohol abuse
Bipolar Fact Sheet continued…

Causes

Bipolar Disorder is a biological brain disease that appears to be genetically-based and tends to run in families.

Bipolar Disorder is a disorder of mood caused by a chemical imbalance in the frontal lobe of the brain. During a manic episode, there is increased activity in the frontal lobe; during a depressive episode, there is decreased activity in the frontal lobe of the brain.

Treatments

A full physical examination, intake of family history, and psychological evaluation should be completed by a mental health professional or family physician before any treatment takes place.

Intervention should involve a bio-psychosocial approach which incorporates both school intervention and education of the child or adolescent and his/her family about the illness.

Medications, such as Lithium and Depakote, are usually very effective in controlling mania, and preventing the recurrence of both manic and depressive episodes, and are used for treating both adolescents and adults. However, adolescents tend to alternate more quickly between depressive and manic episodes (i.e., rapid cycling) than adults; this has been associated with poor response to Lithium. Antidepressant medications may be used to supplement the treatment of depressive episodes.

Psychotherapy is often used in combination with medication therapy and usually takes the form of interpersonal therapy, behavior therapy, and/or cognitive therapy. Psychotherapy helps the adolescent to understand himself/herself, adapt to stresses, rebuild self-esteem, and improve relationships. Stressful life events may act as precipitants for recurrent episodes and therefore need to be reduced.

Suggested Reading

*Handbook of Lithium Therapy*, by Johnson, F. Neil  
*Helping the Depressed Person Get Treatment*, by Sargent  
*Learning to Cope with Depression & Manic Depression*, by Copeland, Mary Ellen  
*Lithium & Manic Depression: A Guide*, by Lithium Information Center/University of Wisconsin  
*Moodswing*, by Fieve M.D., Ronald  
*Suicide: Why?*, by Wrobleski, Adina  
*Schizophrenia & Manic Depressive Disorder*, by Torrey, Bowler, Taylor, Gottensman

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Brain Injury (BI)

**Healthy Brain:** Before we can understand what happens when a brain is injured; we must realize what a healthy brain is made of and what it does. The brain is enclosed inside the skull. The skull acts as a protective covering for the soft brain. The brain is made of neurons (nerve cells). The neurons form tracts that route throughout the brain. These nerve tracts carry messages to various parts of the brain. The brain uses these messages to perform functions. The functions include our thought processes, physical movements, personality changes, behavioral changes, and sensing and interpreting our environment. Each part of the brain serves a specific function and links with other parts of the brain to form more complex functions.

**Traumatic Brain Injury (TBI):** Damage to living brain tissue caused by a blow or jolt. It is usually characterized by a period of altered consciousness (amnesia or coma) that can be very brief (minutes) or very long (months/indefinitely). The specific disabling condition(s) may be orthopedic, visual, aural, neurological, perceptive/cognitive, or mental/emotional in nature. The term does not include brain injuries that are caused by insufficient blood supply, toxic substances, malignancy, disease-producing organisms, congenital disorders, birth trauma or degenerative processes.

**Injured Brain:** The functions of the neurons, nerve tracts, or sections of the brain can be affected by injury. If the neurons and nerve tracts are affected, they can be unable or have difficulty carrying the messages that tell the brain what to do, resulting in thinking changes, physical changes, and personality and behavioral changes. These changes can be temporary or permanent, and may cause impairment or a complete inability to perform a function.

**Acquired Brain Injury:** The implication of this term is that the individual experienced normal growth and development from conception through birth, until sustaining an insult to the brain at some later time which resulted in impairment of brain function.

**Closed Brain Injury:** This occurs when the head accelerates and then rapidly decelerates or collides with another object (for example the windshield of a car) and brain tissue is damaged, not by the presence of a foreign object within the brain, but by violent smashing, stretching, and twisting of brain tissue. Closed brain injuries typically cause diffuse tissue damage that results in disabilities which are generalized and highly variable.

**Mild Brain Injury:** A patient with a mild traumatic brain injury has had a traumatically-induced physiological disruption of brain function, as manifested by at least one of the following:

- Any period of loss of consciousness
- Any loss of memory for events immediately before or after the accident
- Any alteration in mental state at the time of the accident (e.g., feeling dazed, disoriented, or confused)
Brain Injury Fact Sheet continued…

Focal neurological deficit(s) which may or may not be transient; but where the severity of the injury does not exceed the following: a) loss of consciousness of approximately 30 minutes or less; b) an initial Glasgow Coma Scale score of 13-15 after 30 minutes; c) Post Traumatic Amnesia not greater than 24 hours.

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Bullying

Bullying is physical or psychological intimidation or aggression that occurs repeatedly over time, typically to someone who is weak and vulnerable, creating an ongoing pattern of harassment and abuse. One in three children is affected by bullying. Although boys are more likely to engage in and to be victims, girls are more likely to bully as a group. Girls are also less likely to be physically intimidated and are more apt to be belittled about their looks with verbal abuse and gossip, or to be ostracized or rejected.

Bullying often leads to more violent behavior when the child grows up. One out of four elementary school bullies has a criminal record by age 30; 60 percent of bullies in grades 6 through 9 have a criminal record by age 24.

Approximately 66 percent of students involved in school shootings report feeling persecuted, bullied, or threatened by other students. Frequently bullied children are more likely to be depressed and suicidal.

What are the warning signs?

Torn or damaged clothing

Child loses things without a proper explanation

Does not bring friends home or rarely spends time with friends after school

Has unexplained bruises, injuries, cuts, and scratches

Chooses an illogical route home from school

Loses interest in school and grades decline

Seems unhappy, distressed, depressed, or has unexpected mood shifts with sudden outbursts of irritation or anger

Often little appetite, headaches or stomachaches, especially before school

Sleeps restlessly with nightmares and possibly cries in his/her sleep

Takes or asks for money from family members

Seems fearful about attending school

What are the characteristics of a bully?

These are general characteristics. Use with caution.

Has a more favorable view of violence than others

Is aggressive, nasty, spiteful, and generally in opposition

Has a marked need to dominate or control others

Seems likely to insult, push around, or tease other children

Is often hot-tempered, impulsive and has low frustration tolerance

Finds it difficult to conform to rules

Is good at talking himself/herself out of difficult situations

Appears to be tough or to show little sympathy toward those who are bullied

Is likely to engage in other anti-social behavior
Bullying Fact Sheet continued…

What are the characteristics of the victim?
These are general characteristics. Use with caution.

Submissive or passive victim:
Doesn’t do well in sports
Quiet, careful, sensitive, shy, cries easily
Poor self-esteem (negative self-image)
Avoids fighting and is weaker than the bully, particularly boys
Has few or no friends and relates better to adults than to kids

Provocative victim:
Is quick-tempered, may try to fight back if victimized
Is often clumsy, restless, immature, unable to concentrate, and considered difficult
May be hyperactive and have reading/writing problems
May be disliked by adults because of irritating behavior
May try to bully weaker and smaller students

Where does bullying take place?
Two to three times more children are bullied at school, as compared to those who are bullied on the way to school
Approximately 40-75 percent of bullying takes place during breaks in the schoolyard, corridors, at recess, bathrooms
Bullying also occurs on public playgrounds and at sports and youth clubs

What can parents do if you suspect your child is being bullied?
Contact school personnel immediately
Talk to other parents
Help your child keep a detailed record of incidents of harassment or bullying, including how the incidents are communicated to school personnel
Talk with your child about strategies for dealing with the bully

What can parents do if your child is the bully?
Make it quite clear that you take bullying seriously and will not tolerate this behavior
Set up consistent rules for family interactions; praise your child when rules are followed, and enforce a negative consequence if rules are broken
Spend 15 minutes or more of quality time with your child every day, monitor and supervise activities, and know how his/her time is spent
Help your child find a positive way to use his/her energy and need to dominate
Maintain contact with school personnel to see if behavior improves
If behavior doesn’t improve, get in touch with a mental health professional for more help
Be careful that you don’t encourage or model bullying with your own behavior and messages

What can a bystander/witness do?
Don’t join in; walk away and get help
Be a friend; listen to victim; let victim know you are there to talk
Report the incident to a teacher, counselor, or other adult
Let the bully know he/she is wrong
Bullying Fact Sheet continued…

What can be done to prevent bullying?
Create a safe climate and encourage all children to report bullying incidents
Set firm limits against unacceptable behavior
Use non-physical, non-hostile negative consequences if rules are broken
Be authoritative (not authoritarian) with children at home and in school
Initiate conversation about bullying and discuss; stress your strong disapproval
Encourage children to report incidents
Work with children to develop assertiveness and conflict resolution skills

Suggested Reading
Bullies & Victims: Helping Your Child Survive the Schoolyard Battlefield, by Fried, Suellen and Paula
The Bullying Prevention Handbook: A Guide for Principals, Teachers, and Counselors, by Hoover, John H. and Oliver, Ronald
Keys to Dealing with Bullies, by McNamara, Barry E. and Francine J.
Bullying at School: What We Know and What We Can Do (Understanding Children’s Worlds,) by Olweus, Dan
Bullyproof: A Teacher’s Guide on Teasing and Bullying for Use with Fourth and Fifth Grade Students, by Stein, Nan; Sjostrom, Lisa; and Cappello, Dominic
Nobody Knew What to Do: A Story About Bullying, by McCain, Becky Ray; Whitman, Albert & Company (ages 4-8).
The Hundred Dresses, by Estes, Eleanor (ages 9-12)
Changing Perspectives: Paving the Path to Bully-Free Schools, Iowa Department of Education
Blueprints for the Violence Prevention: Book Nine, by Olweus, Dan; and Limber, Sue; and Mahalic, Sharon

Websites
www.bullying.org dedicated to letting victims of bullying tell their stories and allowing others to respond
www.greatschools.net/cgi-bin/showarticle/ia/215/?&page=1 What You Can Do to Stamp Out Bullying
www.stopbullyingnow.org provides information on bullying prevention
www.clemson.edu/olweus Olweus Bullying Prevention Program, a comprehensive, school-wide program designed for use in elementary, middle, or junior high schools
www.cfchildren.org (Committee for Children) learn how you can promote the safety, well-being, and social and academic development of children, including Steps to Respect: A Bully Prevention Program
www.mentalhealth.samhsa.gov/publications/allpubs/SVP-0051/ (15+ make Time to Listen: Take Time to Talk about Bullying)

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Conduct Disorder

Children with conduct disorder repeatedly violate the personal or property rights of others and the basic expectations of society. A diagnosis of conduct disorder is likely when symptoms continue for 6 months or longer. Conduct disorder is known as a "disruptive behavior disorder" because of its impact on children and their families, neighbors, and schools.

Conduct disorder affects 1 to 4 percent of 9- to 17-year-olds, depending on exactly how the disorder is defined (U.S. Department of Health and Human Services, 1999). The disorder appears to be more common in boys than in girls and more common in cities than in rural areas.

Another disruptive behavior disorder, called oppositional defiant disorder, may be a precursor of conduct disorder. A child is diagnosed with oppositional defiant disorder when he or she shows signs of being hostile and defiant for at least 6 months. Oppositional defiant disorder may start as early as the preschool years, while conduct disorder generally appears when children are older. Oppositional defiant disorder and conduct disorder are not co-occurring conditions.

Symptoms

Aggressive behavior that harms or threatens other people or animals

Destructive behavior that damages or destroys property

Lying or theft

Truancy or other serious violations of rules

Early tobacco, alcohol, and substance use and abuse; and precocious sexual activity.

Children with conduct disorder or oppositional defiant disorder also may experience:

Higher rates of depression, suicidal thoughts, suicide attempts, and suicide

Academic difficulties

Poor relationships with peers or adults

Sexually transmitted diseases

Difficulty staying in adoptive, foster, or group homes

Higher rates of injuries, school expulsions, and problems with the law.
Who is at risk for conduct disorder?

Research shows that some cases of conduct disorder begin in early childhood, often by the preschool years. In fact, some infants who are especially "fussy" appear to be at risk for developing conduct disorder.

Other factors that may make a child more likely to develop conduct disorder include:

- Early maternal rejection
- Separation from parents, without an adequate alternative caregiver
- Early institutionalization
- Family neglect
- Abuse or violence
- Parental mental illness
- Parental marital discord
- Large family size
- Crowding
- Poverty

Treatment

Although conduct disorder is one of the most difficult behavior disorders to treat, young people often benefit from a range of services that include:

- Training for parents on how to handle child or adolescent behavior
- Family therapy
- Training in problem solving skills for children or adolescents
- Community-based services that focus on the young person within the context of family and community influences
Conduct Disorder Fact Sheet continued...

What can parents do?

Some child and adolescent behaviors are hard to change after they have become ingrained. Therefore, the earlier the conduct disorder is identified and treated, the better the chance for success. Most children or adolescents with conduct disorder are probably reacting to events and situations in their lives. Some recent studies have focused on promising ways to prevent conduct disorder among at-risk children and adolescents. In addition, more research is needed to determine if biology is a factor in conduct disorder.

Parents or other caregivers who notice signs of conduct disorder or oppositional defiant disorder in a child or adolescent should:

Pay careful attention to the signs, try to understand the underlying reasons, and then try to improve the situation.

If necessary, talk with a mental health or social services professional, such as a teacher, counselor, psychiatrist, or psychologist specializing in childhood and adolescent disorders.

Get accurate information from libraries, hotlines, or other sources.

Talk to other families in their communities.

Find family network organizations

To request information on mental illness or to schedule an educational presentation, contact:

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National Alliance on Mental Illness-Iowa
Des Moines, Iowa
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Co-Occurring Disorders in Adolescence (Substance Abuse)

Families know how difficult it is to find treatment for an adolescent who is a substance abuser and who also has a mental illness or other brain disorder (i.e., AD/HD, depression, bipolar disorder). Although studies have shown that more than half of young people who are substance abusers also have a diagnosable mental illness, adolescents who are referred to treatment for a substance abuse problem might not receive referral to a mental health professional for appropriate diagnosis and treatment of a possible underlying cause.

Recommendations for Family Members

Get involved and stay involved:
- Listen to what your child is saying, walk in his/her shoes for a while
- Support your child in treatment
- Praise your child for making progress
- Participate in evaluating the program and treatment

Educate:
- Offer what you know to other families
- Make sure that your child has a voice in decisions about treatment
- Respect your child's and your own openness and readiness for disclosure
- Read everything, and talk with other families who have been through this

Cause

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

Treatments

Families and caregivers may feel angry and consider the adolescent foolish and weak. They may feel hurt when the child breaks their trust by lying and stealing. Teens with the difficult problems of co-occurring mental illness and substance abuse disorders do not respond to simplistic advice such as "just say no" or "snap out of it." It is important to realize that mental illnesses, and often substance abuse, are disorders that the adolescent cannot effectively manage without professional help.

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.

Treatment programs designed primarily for substance abusers are not recommended for individuals who have a diagnosed mental illness. Since people with co-occurring disorders do not fit well into most traditional 12-step programs, a better choice is involvement in special peer
groups based on the principle of treating both disorders together.

Working with an effective therapist, receiving appropriate medication, and participating in support groups can be of great help, but patients may still relapse. An individual who develops a positive social network has a much better chance of controlling the disorders and participating in healthy recreational activities.

Programs for treating mental illness and substance abuse

Support groups are an important component of these programs. Adolescents support each other as they learn about the negative role that alcohol and/or drugs has had on their lives. They learn social skills, how to replace substance use with new thoughts and behaviors, and receive help with concrete situations that arise. Look into programs that also have support groups for family members and friends.

Resources

Federation of Families for Children’s Mental Health, 1101 King Street Suite 420, Alexandria VA, (703) 684-7710

Patrick Friman, Ph.D., A.B.P.P., Director of Clinical Services & Research, Father Flanagan’s Boys’ Home, and Associate Professor, Creighton University School of Medicine.

To request information on mental illness or to schedule an educational presentation, contact:

NAMI IOWA
National Alliance on Mental Illness-Iowa
Des Moines, Iowa
www.namiiowa.org info@namiiowa.com
Depressive Disorders in Children and Adolescents

One out of every ten high school students reports feeling depressed. Clinical depression is more than being temporarily down or blue. It is a physical illness involving a chemical imbalance in the brain. Depression affects the total person—behavior, mood, and thoughts as well as one's physical health, academic or work performance, and the ability to handle everyday situations. The gender ratio (female: male) of major depression among pre-adolescent children is 1:1 and among adolescents it is 5:1.

The most common method of suicide is by the use of firearms. It is estimated that for each completed suicide, ten attempts are made. Although more boys than girls commit suicide, at a ratio of 4:1, girls make more suicide attempts.

Symptoms

<table>
<thead>
<tr>
<th>Sad, empty mood</th>
<th>Irritability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss of interest in ordinary activities</td>
<td>Fatigue</td>
</tr>
<tr>
<td>Sleep and/or eating disturbance</td>
<td>Feelings of aloneness</td>
</tr>
<tr>
<td>Psychomotor retardation or agitation</td>
<td>No plan for the future</td>
</tr>
<tr>
<td>Difficulty concentrating</td>
<td>Acting out</td>
</tr>
<tr>
<td>Difficulty making decisions</td>
<td>Truancy</td>
</tr>
<tr>
<td>Hopelessness, worthlessness</td>
<td>Feelings of guilt</td>
</tr>
<tr>
<td>Decreased school performance</td>
<td>Skipping school, dropping clubs</td>
</tr>
<tr>
<td>Suicidal ideation, attempt or plan</td>
<td>Change in appearance</td>
</tr>
</tbody>
</table>

Causes

Depressive illnesses are biological brain diseases that appear to be genetically-based and tend to run in families.

Depression is a disorder of mood caused by a chemical imbalance in the frontal lobe of the brain.

Factors that can influence the onset of a depressive episode include a stressful environment, low self-esteem, pessimistic thinking, and being easily overwhelmed.

Treatments

A full physical examination, intake of family history, and psychological evaluation should be completed by a mental health professional or family physician before any treatment takes place.

Medications, such as Prozac, Zoloft, Norpramine, Pamelor, and others, are primary choices of treatment for those diagnosed with severe depression. Medication provides for a quicker recovery and is the most cost-effective treatment as well.
Depressive Disorders Fact Sheet continued...

Psychotherapy is often used in combination with medication therapy and may take the form of play therapy, family therapy, interpersonal therapy, behavior therapy, and/or cognitive therapy. Psychotherapy is often the primary mode of treatment for those diagnosed with mild and moderate forms of depression.

Prevalence of Major Depression

Preschoolers 0.3 percent
Pre-adolescent children 1.8 percent
Adolescents 4.7 percent

Suggested Reading

What's Wrong With My Child? by Gattozzi, Ruth
Coping With Mental Illness in the Family, by Hatfield, Agnes
Is Your Child Depressed? by Herskowitz, Joel
Helping Your Depressed Child, by Kerns, Lawrence
Children and Adolescents With Mental Illness/A Parent's Guide, by McElroy, Evelyn
High Times/Low Times: The Many Faces of Adolescent Depression, by Meeks, John

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National Alliance on Mental Illness-Iowa
Des Moines, Iowa
www.namiiowa.org info@namiiowa.com
Fetal Alcohol Effects

Prenatal alcohol exposure is the most common cause of birth defects in the United States. According to the American College of Obstetrics and Gynecology, pregnant women should not drink any alcohol. Women who are thinking of becoming pregnant need to be aware of the very serious negative effects of alcohol on the developing baby (fetus). Exposure to alcohol during pregnancy damages the brain and behavior of children, effects that are 100 percent preventable. Drinking even one alcoholic beverage per day during pregnancy puts the developing baby at risk of serious birth defects as small amounts of alcohol can cause permanent harm to the child.

Infants may have slow growth and delays in development, unusual facial features, irritability, brain and neurological disorders, mental retardation and problems with attachment to parents. Toddlers and school age children may have learning problems, poor frustration tolerance, poor social boundaries and reading difficulties. Adolescents may have continued learning problems, depression, anxiety and sexually inappropriate behavior.

Fetal Alcohol Effects (FAE) describes the negative effects caused by drinking alcohol while pregnant. Fetal Alcohol Syndrome (FAS) is a more specific set of symptoms caused by drinking alcohol while pregnant. FAS is diagnosed when the child has been prenatally exposed to alcohol, has facial deformities, and slow or delayed growth.

Brain and neurological problems

Children who are suspected of having FAS should be carefully evaluated by a pediatrician, child and adolescent psychiatrist or other experienced clinician. Fetal alcohol exposure is frequently missed as the cause of a child’s behavior problems. The effects of alcohol on the developing brain during pregnancy cannot be reversed. However, early intervention can reduce the severity of the disability and improve the child’s chance for success. Early intervention for FAE or FAS includes occupational therapy, special education and speech therapy evaluations.

Resources

National Organization on Fetal Alcohol Syndrome www.nofas.org
National Institute on Alcohol Abuse and Alcoholism pubs.niaaa.nih.gov/publications/brochure.htm
SAMHSA ï FASD Center for Excellence www.fasdcenter.samhsa.gov/index.cfm
SAMHSA ï FASD Information in Spanish www.fasdcenter.samhsa.gov/fasdsp/index.cfm

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Intellectual and Developmental Disabilities

Intellectual disability is the currently preferred term for the disability that was previously referred to as mental retardation. The term intellectual disability covers the same population of individuals who were diagnosed previously with mental retardation in number, kind, level, type, and duration of the disability and the need of people with this disability for individualized services and supports. Every individual who is or was eligible for a diagnosis of mental retardation is eligible for a diagnosis of intellectual disability.

Causes

The causes of MR/ID (mental retardation/intellectual disability) can be divided into biomedical, social, behavioral, and educational risk factors that interact during the life of an individual and/or across generations from parent to child. However, doctors can identify a specific cause in only about one third of people with mild MR/ID and in two thirds of people with moderate to profound MR/ID.

Biomedical factors: related to biologic processes, such as genetic disorders or nutrition.

Social factors: related to social and family interaction, such as child stimulation and adult responsiveness.

Behavioral factors: related to harmful behaviors, such as maternal substance abuse.

Educational factors: related to the availability of family and educational supports that promote mental development and increases in adaptive skills.

Inter-generational factors: factors present during one generation can influence the outcomes of the next generation. By understanding inter-generational causes, appropriate supports can be used to prevent and reverse the effects of risk factors.

How is intellectual disability diagnosed?

Step 1: Administer one or more standardized intelligence tests.

Step 2: Describe the person’s strengths and weaknesses across four dimensions (i.e., intellectual and adaptive behavior skills; psychological/emotional considerations; physical/health/etiological considerations; environmental considerations

Strengths and weaknesses may be determined by formal testing, observations, interviewing key people in the individual's life, interviewing the individual, interacting with the person in his or her daily life or a combination of these approaches.

Step 3: An interdisciplinary team determines needed supports across the four dimensions. Each support identified is assigned one of four levels of intensity - intermittent, limited, extensive, or pervasive. The first three, intermittent, limited and extensive supports, may not be needed in all life areas for an individual.
Interruption support: support provided on an "as needed basis", such as support needed in order to find a job. Intermittent support may be needed occasionally by an individual over the lifespan, but not on a continuous daily basis.

Limited support: support that may occur over a limited time span, such as during transition from school to work or in time-limited job training. This type of support has a limit on the time that is needed to provide appropriate support for an individual.

Extensive support: assistance that an individual needs on a daily basis that is not limited by time. This may involve support in the home and/or support in work.

Pervasive support: constant support across environments and life areas and may include life-sustaining measures. A person requiring pervasive support will need assistance on a daily basis across all life areas.

What does the term "mental age" mean when used to describe the person's functioning?

The term mental age is used in intelligence testing. It means that the individual received the same number of correct responses on a standardized IQ test as the average person of that age in the sample population.

Saying that an older person with mental retardation is like a person of a younger age or has the "mind" or "understanding" of a younger person is incorrect usage of the term. The mental age only refers to the intelligence test score. It does not describe the level and nature of the person's experience and functioning in aspects of community life.

References

*Children with Disabilities (4th edition)*, by Batshaw, M.L.
*Children with Mental Retardation: A Parents' Guide*, edited by Smith, R.
www.aamr.org/Policies/faq_intellectual_disability.shtml

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**NAMI IOWA**
National Alliance on Mental Illness-Iowa
Des Moines, Iowa
www.namiowawa.org info@namiowawa.com
Obsessive Compulsive Disorder (OCD)
in Children and Adolescents

OCD is an anxiety disorder characterized by obsessions (repeated involuntary thoughts, urges, impulses, or worries) and compulsions (purposeless repetitive behaviors).

Approximately 1 million children and adolescents in the United States suffer from OCD. In other words, OCD affects about 3 to 5 youngsters per average-sized elementary school and about 20 teenagers in a large high school.

OCD is as or more prevalent than many other better known childhood illnesses such as attention deficit/hyperactivity disorder and diabetes.

The symptoms of OCD may have their onset in children as early as age three or four, but very young children and their parents may not recognize the symptoms.

OCD in children often exists concurrently with motor tics and/or Tourette’s disorder.

OCD affects children and adolescents during a very important period of social development. It often affects their schoolwork, home life, and friendships. While young children may be unable to understand that their thoughts and actions are unusual, many adolescents feel embarrassed. Not wanting to be “different” from their peers, they worry about their uncontrollable behavior.

Children and adolescents often involve family members in their rituals. For example, they may insist that their laundry be washed several times, demand that parents check their homework repeatedly, or become outraged if household items are in disarray.

Symptoms

Common obsessions:
Fear of contamination/serious illness
Fixation on lucky/unlucky numbers
Fear of danger to self or others
Need for symmetry or exactness
Repeated doubt

Common compulsions:
Cleaning/washing
Touching
Counting/repeating
Arguing/organizing
Checking/questioning
Hoarding

Causes

OCD is not caused by bad parenting or an individual weakness in the person with OCD. Research has shown that OCD tends to run in families and it appears that a biological imbalance of the brain chemical serotonin can be passed on to succeeding generations. Thus, the tendency to develop OCD may be inherited, but the actual disorder may not be.
OCD Fact Sheet continued…

Treatments

OCD will continue for years if left untreated. The symptoms may become less severe at times, but generally OCD is a chronic illness.

A primary form of treatment for OCD is medication. Medications that regulate serotonin reduce obsessive thoughts and compulsive behaviors. However, medication is not completely effective for everyone with OCD.

Behavior therapy is commonly used in combination with medication. This type of therapy exposes a person to a feared object or thought. The person is then discouraged from carrying out the usual compulsive response.

The most effective way to treat OCD is to use both medication and therapy.

Medications:
Clomipramine (Anafranil) is usually the first choice of medication.
Fluoxetine (Prozac)

Medications may take up to ten weeks to take effect. If the medications most commonly used in treating OCD are not working, other medications such as Lithium, Fenfluramine, Buspirone, and other antipsychotic medications may be beneficial.

Between 50 and 80 percent of patients with OCD improve with medication. However, they still may have some obsessive and compulsive behaviors remaining.

Suggested Reading

*The Boy Who Couldn’t Stop Washing*, by Rapoport, Judith
*Obsessive Compulsive Disorders*, by Levenkron, Steven
*Obsessive Compulsive Disorder: A Guide*, by University of Wisconsin

Other Resources:

OC Foundation – PO Box 70, Milford CT 06460-0070 or www.ocfoundation.org
The OC Foundation publishes an excellent newsletter and has information about support groups. They also publish a newsletter for support group leaders.

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Oppositional Defiant Disorder (ODD)

Oppositional defiant disorder (ODD) usually becomes evident before age eight. Onset is typically gradual, occurring over the course of months or years. It is typically seen in more males than females before puberty, but the rates of occurrence are equal during adolescence.

Many of the symptoms of ODD are seen in children and adolescents with mood disorders and psychotic disorders; therefore, care should be taken in making a diagnosis.

Attention deficit/hyperactivity disorder, learning disorders, and communication disorders are commonly seen in children with ODD. These behaviors must be seen more frequently than is typically observed in individuals of comparable age and developmental level and must lead to significant problems in social or school functioning.

Symptoms

The diagnosis of ODD differs from conduct disorder in that it excludes symptoms of violations of personal rights and social rules. The symptoms of ODD focus more on annoying, difficult, and disruptive behavior. Symptoms must be displayed regularly for at least six months.

Disobedient and hostile behavior toward authority
Stubbornness
Resistance to directions
Unwillingness to compromise, give in or negotiate with adults or peers
Deliberate or persistent testing of limits by ignoring orders, arguing and failing to accept blame for misdeeds
Losing temper
Arguing with adults
Refusing to follow rules
Deliberately doing things to annoy others
Blaming others for his/her own mistakes or bad behavior
Being easily annoyed by other people
Being angry or resentful
Being spiteful or vindictive

Causes

The cause of oppositional defiant disorder is unclear. Research has shown that ODD is more common in children who have at least one parent with a history of a mood disorder, ODD, attention deficit/hyperactivity disorder, substance abuse, or antisocial personality disorder. Also, this disorder is commonly seen in children whose parents have serious marital discord.

Treatments

An effective medical treatment for ODD has not been found. Current treatments emphasize teaching the individual appropriate social skills, family therapy, placement outside the home, limit setting, consistency, and behavior management.
ODD Fact Sheet continued…

Treatment may include the management of other occurring disorders, such as attention deficit/hyperactivity disorder or mood disorders, with appropriate medications.

Suggested Reading

*Educational Rights of Children with Disabilities*, by Ordover, Eileen & Boundy, Kathleen
*High Risk, Children Without a Conscience*, by Magid, Ken & McKelvey, Carole
*Kids Out of Control*, by Cohen, Alan
*Neurobiological Disorders in Children and Adolescents*, by Peschel & Howe
*What’s Wrong With My Child? How to Understand and Raise a Behaviorally Difficult Child*, by Gattozzi, Ruth

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www.namiowa.org info@namiowa.com
Posttraumatic Stress Disorder (PTSD)
In Children and Adolescents

A child or adolescent who experiences a catastrophic event may develop ongoing difficulties known as Posttraumatic Stress Disorder (PTSD). The event usually involves a situation where someone's life has been threatened or severe injury has occurred.

A child's risk of developing PTSD is related to the seriousness of the trauma, whether the trauma is repeated, the child's proximity to the trauma, and relationship to the victim. Children who experience repeated trauma may develop a kind of emotional numbing to deaden or block the pain and trauma. This is referred to as dissociation.

Sexually traumatic events may include developmentally inappropriate sexual experience without threatened or actual violence or injury.

**Symptoms**
The symptoms of PTSD may last from several months to years.

A child with PTSD may re-experience the traumatic event by:
Having distressing dreams/nightmares
Developing repeated physical or emotional symptoms when the child is reminded of the event

Children with PTSD may also show the following symptoms:
Worry about dying at an early age
Loss of interest in activities
Headaches and stomachaches
Show more sudden and extreme emotional reactions
Problems falling or staying asleep
Problems concentrating
Disorganized or agitated behavior
Repeated enactment of the trauma through play

**Treatments**

**Medications:** anti-depressants and anxiety-reducing medications can ease the symptoms of depression, sleep problems, nightmares, flashbacks, and help to control anger

**Psychotherapy:** allows the child to speak, draw, play, or write about the event

**Supportive psychotherapy and psycho-education:** for families and caregivers

**Cognitive-behavioral therapy**

**Support group**

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Reactive Attachment Disorder (RAD)

Reactive Attachment Disorder (RAD) is a psychological and neurological disorder that occurs during the first three years of life when a child does not attach and bond properly to the primary caregiver, resulting in on-going rage, fear of attaching to anyone, lack of trust, an unusual effort to control everything in his/her life, a lack of self-worth, and an inability to fully comprehend cause and effect.

A child who has an attachment disorder will typically fail to develop a conscience. A common manifestation is continual lying, against all odds and for no apparent reason. It is an extraordinary kind of lying because it makes no sense. This trait seems to be related to the control issue these children have. They believe telling the truth to adults will give those adults some kind of control over them and that this adult control must be avoided in order to survive.

Types of RAD
Inhibited type: the child fails to initiate and to respond to most social interaction in a developmentally appropriate way
Disinhibited type: there is a pattern of thinly distributed attachments. This child exhibits indiscriminate sociability or lack of selectivity in the choice of attachment figures.

Symptoms (Often the following behaviors are not seen by anyone but the parents.)
Severe need for control over everyone and everything, bossy
Argumentative, often over ridiculous things
Difficulty with eye contact, especially with parents, will look into your eyes while lying to you
Superficially charming and engaging
Demanding/clingy, often at inappropriate times
Indiscriminate affection
Impulsive
Hyper vigilant, hyperactive
Cruelty to animals and/or people
No conscience, shows no remorse
Destructive to property and self
Speech and language problems
Fascinated with fire, blood, gore, weapons, evil
Food issues; i.e., hoarding, gorging, refusing to eat, eating strange things
Very concerned about tiny hurts but brushes off large injuries

Causes
Abuse and/or neglect in the first three years of life
Multiple primary caregivers
Separation from birthmother
Many foster care placements
Unresolved, ongoing pain; i.e., ear infections
Maternal substance abuse
Maternal depression
Lack of attunement between mother and child
Young or inexperienced mother with poor parenting skills
**Course**

By definition, the onset of RAD begins before five years of age. The course appears to vary depending on individual factors in child and caregivers, the severity and duration of the psychosocial deprivation, and the nature of the intervention. Considerable improvement or remission may occur if an appropriate environment is provided. Otherwise, this disorder follows a continuous course.

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Des Moines, Iowa  
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Schizophrenia (Childhood Schizophrenia)

Schizophrenia is rare in children prior to the age of seven or eight. However, cases of schizophrenia have been seen in children as young as five years old. It is not caused by bad parenting or a personal weakness. Rather, it is a biological illness of the brain.

If a child has a parent with schizophrenia, there is a risk of developing the illness. Research has found that at-risk children who develop schizophrenia show increased incidence of early neurosensory, neuromotor, and attention deficits.

The symptoms of schizophrenia in children are sometimes mistakenly viewed as symptoms of autism. For this reason, some children with schizophrenia will be incorrectly diagnosed as autistic. A child with the diagnosis of autism may actually have schizophrenia if the child has well developed speech, normal or borderline IQ, and shows symptoms of schizophrenia.

Schizophrenia is not an intellectual disability. An intellectual disability is a developmental disability present from birth that affects oneÁE intellectual capacity (formerly known as mental retardation). On the other hand, schizophrenia is a mental illness typically having its onset in adolescence or early adulthood. It is a disease of the brain which affects a personÁE ability to think, feel, and relate to the environment.

Schizophrenia affects 1 percent of the general population. It is twice as common as AlzheimerÁE disease, five times more common than Multiple Sclerosis, and sixty times more common than Muscular Dystrophy.

**Symptoms**

For a diagnosis of schizophrenia to be made, individuals must have two or more positive symptoms, or a combination of one positive symptom and one or more negative symptoms for at least one month. Social or occupational dysfunction needs to be present. Signs of the illness must persist for at least six months. During this time some symptoms may subside; however, positive symptoms may be exhibited in a less severe form.

**Symptoms commonly seen in children:**
- Inappropriate giggling
- Incongruity of affect
- Blunting of affect
- Rages
- Delusions and hallucinations (less elaborate than adults)
- Self-directed aggression
- Ambivalence
- Perplexity
- Visual hallucinations

**General symptoms:**
- Lack of fluency of speech/thought
- Lack of motivation and drive
- Lack of capacity to enjoy
- Lack of emotional expression
- Hallucinations
- Delusions
- Disorganized speech
- Disorganized behavior
Schizophrenia (childhood) Fact Sheet continued…

Causes

Research studies suggest there is a genetic link in schizophrenia. The probability of developing schizophrenia as the offspring of two parents, neither of whom has the disease, is 1 percent. The probability of developing schizophrenia as the offspring of one parent with the disease is approximately 13 percent. The probability of developing schizophrenia as the offspring of both parents with the disease is approximately 35 percent.

Research has demonstrated that people with schizophrenia have functional (including brain chemicals) and structural differences in the brain. It is clear that genetics is not completely responsible for causing schizophrenia. Environmental influences appear to play a role as well. Some environmental influences that have been suggested to be a possible contributor to the development of the illness are birth injury and prenatal complications, viral illnesses in the mother during pregnancy, or other toxins during pregnancy. Overall, Schizophrenia appears to be caused by a combination of genetic and environmental factors.

Treatments

Medication, known as antipsychotic, is the primary form of treatment

Social and occupational rehabilitation are often used in conjunction with medication

Support groups for individuals affected by schizophrenia and their family members are helpful in facilitating recovery

Suggested Reading

*Surviving Schizophrenia: A Family Manual*, by Torrey, M.D., E. Fuller
*The Broken Brain*, by Andreasen, M.D., Nancy
*Schizophrenia and Manic Depressive Disorder*, by Torrey, Bowler, Taylor & Gottesman
*Schizophrenia: Symptoms, Causes and Treatments*, by Bernheim
*Coping With Mental Illness in the Family*, by Hatfield, Agnes

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Separation Anxiety Disorder

Separation anxiety disorder is distinguished from generalized anxiety disorder in that the anxiety concerns separation from home and attachment figures. The disorder is estimated to occur in 4 percent of children and young adolescents, and, based on clinical samples, occurs equally in males and females. Serious long-term effects such as anxiety and panic disorder may occur if professional assistance is not received. Although symptoms of separation anxiety can be associated with pervasive developmental disorders, schizophrenia, or other psychotic disorders, a diagnosis of separation anxiety disorder is not given when it occurs with one of these disorders.

Symptoms must be displayed for at least four weeks with onset before the age of 18 years.
- Stomachaches
- Headaches
- Nausea and vomiting
- Feeling unsafe alone in a room
- Clinging behavior
- Excessive worry and fear about parents or about harm to oneself
- Shadowing parent around the home
- Difficulty sleeping and frequent nightmares
- Exaggerated, unrealistic fears of animals, monsters, burglars
- Fear of being alone in the dark
- Cardiovascular symptoms such as palpitations, dizziness, and faintness (rare in young children)

Causes
Separation anxiety disorder may develop after some life stress (e.g., death of a relative or pet, illness of the child or relative, change of schools, move to a new neighborhood, immigration). It is found to be more common in first-degree biological relatives than in the general population and may be more frequent in children of mothers with panic disorder.

Treatment
Medication in conjunction with play therapy, cognitive-behavioral therapy, family therapy

Suggested Reading
Educational Rights of Children with Disabilities, by Ordover, Eileen & Botmdy, Kathleen
High Risk, Children Without a Conscience, by Magid, Ken & McKelvey, Carole
Neurobiological Disorders in Children and Adolescents, by Peschel & Howe
What's Wrong With My Child? How to Understand and Raise a Behaviorally Difficult Child, by Gattozzi, Ruth
It’s Nobody’s Fault, by Koplewicz, Harold

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Des Moines, Iowa
www.namiiowa.org info@namiiowa.com
Teenage Suicide

In Iowa, an average of two young people take their lives every month; 9 percent of suicides involving guns are committed by teenagers; more 10 to 19 year olds are killed by suicide than by homicide, and fewer are killed by suicide than by traffic accidents.

Most everyone at some time in his or her life will experience periods of anxiety, sadness, and despair. These are normal reactions to the pain of loss, rejection, or disappointment. However, those who have serious mental illnesses often experience much more extreme reactions that can leave them mired in hopelessness. About 90 percent of teenagers who commit suicide suffer from a psychiatric disorder such as depression, anxiety, or substance abuse. When all hope is lost, some feel that suicide is the only solution. It is not.

Of those people who commit suicide, 75 percent tell someone before it happens. It cannot be stressed more strongly that any talk of death or suicide should be taken seriously. Many signs may go unrecognized. Putting one's affairs in order is an obvious sign that suicide is planned. This may involve giving or throwing away favorite belongings.

Symptoms
While suffering from one of these symptoms does not necessarily mean that a person is suicidal, it is always best to communicate openly with a loved one who has one or more of these behaviors, especially if they are unusual for that person.

<table>
<thead>
<tr>
<th>Extreme personality changes</th>
<th>Loss of interest in activities that used to be enjoyed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Significant loss or gain in appetite</td>
<td>Difficulty falling asleep or wanting to sleep all day</td>
</tr>
<tr>
<td>Fatigue or loss of energy</td>
<td>Neglect of personal appearance or hygiene</td>
</tr>
<tr>
<td>Feelings of worthlessness, guilt</td>
<td>Aggressive, destructive or defiant behavior</td>
</tr>
<tr>
<td>Sadness, irritability or indifference</td>
<td>Withdrawal from family and friends</td>
</tr>
<tr>
<td>Trouble concentrating</td>
<td>Hallucinations or unusual beliefs</td>
</tr>
<tr>
<td>Extreme anxiety or panic</td>
<td>Drug or alcohol abuse</td>
</tr>
<tr>
<td>Poor school performance</td>
<td></td>
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</tbody>
</table>

Causes
The overwhelming majority of those who commit suicide have a mental or substance-related disorder. This can make it very difficult to cope with crippling stressors, to see that life can turn around, and to recognize that suicide is a permanent solution to a temporary problem. It is understood that low levels of the brain chemical serotonin may cause impulsive behavior, and research indicates that those who have attempted suicide may have lower than normal levels.

While the reasons that teens commit suicide vary widely, there are some common situations and circumstances that seem to lead to such extreme measures. These include major disappointment, rejection, failure, a loss such as breaking up with a girlfriend or boyfriend, failing a big exam, or witnessing family turmoil. Although not actually the "causes" of suicide, these can be triggers for suicide in a person suffering from a mental illness or substance-related disorder.
What to do if warning signs are seen:
Take threats seriously.
Seek professional help. Call the doctor, hospital, mental health center, or suicide-prevention.
If confided in, discuss openly.
Gently and respectfully acknowledge feelings and problems.
Stay calm and concerned, listening with interest and support.
Remove all weapons which are accessible.
Make sure the person is not left alone.

What not to do if warning signs are seen:
Do not minimize or ignore statements about wanting to die.
Do not be dismissive, never say Òeverything will be alrightÓ or Òsnap out of it.Ó
Do not give advice, be judgmental, or increase guilt.
Do not debate whether suicide is right or wrong.
Do not swear secrecy.
Do not delay dealing with the situation.

Resources
American Academy of Child & Adolescent Psychiatry, Washington DC
Tel: (202)966-7300  www.aacap.org

American Association of Suicidology, Washington DC
Tel: (202)237-2280  www.suicidology.org

American Foundation for Suicide Prevention, New York NY
Tel: (888)333-AFSP (toll free) or (212)363-6237  www.afsp.org

SA/VE (Suicide Awareness/Voices of Education), Minneapolis MN
Tel: (952)946-7998  www.save.org

SPAN (Suicide Prevention Advocacy Network), Marietta GA
Tel: (888)649-1366 (toll free)  www.spanusa.org

Yellow Ribbon Suicide Prevention Program, Westminster CO
Tel: (303)429-3530  www.yellowribbon.org

Suggested Reading
Night Falls Fast: Understanding Suicide, by Jamison, Kay Redfield
His Bright Light: The Story of Nick Traina, by Steel, Danielle
Suicide: Why? by Wrobleski, Adina
Tourette’s Disorder

Tourette’s Disorder is a neurobiological illness which typically begins to appear between the ages of 2 and 15, with a general age of onset at 7 years.

The disorder is approximately 3 times more common in males than in females and occurs in approximately 4 to 5 individuals per 10,000.

Research indicates that Tourette’s is genetically-based and tends to run in families.

The duration of the disorder is usually life-long, though periods of remission lasting from weeks to years may occur.

About 50 percent of children diagnosed with the disorder have diagnosable learning disabilities.

Motor tics commonly involve eye blinking, touching, squatting, deep knee bends, retracing steps, and twirling when walking.

Vocal tics typically include various words or sounds such as clicks, grunts, yelps, barks, sniffs, snorts, and coughs. Coprolalia, a vocal tic involving the uttering of obscenities, is present in a few individuals (less than 10 percent).

Diagnostic criteria for Tourette’s Disorder (DSM-IV)

Both multiple motor and one or more vocal tics have been present at some time during the illness, although not necessarily at the same time.

The tics occur many times a day (usually in bouts) nearly every day or intermittently throughout a period of more than 1 year, and during this period there is never a tic-free period of more than 3 consecutive months.

The disturbance causes marked distress or significant impairment in social, occupational, or other important areas of functioning.

The onset is before age 18 years.

The disturbance is not due to the direct physiological effects of a substance (e.g., stimulants) or a general medical condition (e.g., Huntington’s Disease or Post-viral Encephalitis).

Symptoms

Motor tics
Self-mutilation
Impulsivity
Aggressive behavior
Hyperactivity and distractibility
Tourette’s Fact Sheet continued…

Mimicking the movements of others
Compulsive thought patterns
Coprolalia (vocal tics)

Cause

Research suggests that Tourette’s is genetically-based. However, not all individuals with a genetic vulnerability to the disorder will develop it. In about 10 percent of those with Tourette’s, there is no evidence of a family pattern.

Treatment

Medications may take the form of antidepressants, anticonvulsants, vitamins, anti-Parkinsonians, or stimulants.

Studies have found that with the use of nicotine patches, tics can be reduced an average of 50 percent. However, after 16 weeks the reduction may not be as noticeable.

Behavior therapy and/or psychotherapy are often used in combination with medication.

Evaluation, diagnosis, and treatment can be sought through a child psychiatrist, family physician, mental health center, or a mental health specialist. A complete evaluation should consist of an intake of family history, physical evaluation, and psychological evaluation.

Suggested Reading
Coping With Mental Illness in the Family, by Hatfield, Agnes
Children and Adolescents With Mental Illness/A Parent’s Guide, by McElroy, Evely
Educational Rights of Children with Disabilities, by Ordover, Eileen & Boundy, Kathleen
Neurobiological Disorders in Children and Adolescents, by Peschel & Howe
When Someone You Love Has Mental Illness, by Woolis, Rebecca

To request information on mental illness or to schedule an educational presentation, contact:

NAMI IOWA
National Alliance on Mental Illness-Iowa
Des Moines, Iowa
www.namiowa.org info@namiowa.com
Section V.

Your Child's Academic Performance
Section V. Your Child's Academic Performance

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Improving Communication – Tips for Parents

Listen. Don't put up walls by assuming you won't like what you hear. Try to keep an open mind even if your views differ from those of the educators. The better you hear and understand their point of view, the better equipped you are to challenge it if you disagree.

Boil it down to the essentials and build from there. If you try to deal with too many issues, none get the attention they need, so prioritize. Focus on the most crucial points now and work your way down the list over time.

Put the really important stuff in writing. Taking the time to write a formal letter to make a request helps you organize your thoughts and evidence, creates a clear record and lets educators know this is an issue you take very seriously.

Ask for clarification whenever you need it. Be persistent in asking questions and expecting good answers. It is very difficult to be comfortable in your own decisions or confident in the opinions of others if you do not understand what they are proposing for your child and why.

Expect and be open to full explanations of the reasons educators have for recommending a particular course of action for your child. If they have a well-developed plan for how they believe your child should be taught, they will be able to explain the plan to you in a way that makes it understandable.

Know your own emotional triggers. Do your best to think through situations that you know are upsetting to you and plan for how you can respond or calm yourself in the moment. Write down key points ahead of time so that if your emotional buttons get pushed you have something in mind to fall back on and help keep you focused.

Ask for time for careful consideration of the options when you feel you need it. Educators often complain that parents agree with them at meetings and then go home and change their minds. If you feel you need more time to make a decision, don't allow yourself to be pressured into instant action.

Give educators a chance. You will probably never get what you consider to be the perfect plan for your child, but recognize when it's time to give a reasonable plan a try. Just because you accept an offer, it doesn't mean you can't ask to make changes or try something else if it proves less than successful. Acknowledge their effort.

Give things time to work. If you are frustrated by your child's lack of progress or have reservations about a proposed program, it's hard to wait to see improvement, but few techniques or strategies show dramatic change overnight. Most programs need time to test their effectiveness for an individual child. If the approach to learning is changed too often, your child may just become confused and you may not be able to identify what works and what doesn't.
Parent & Educator Coordinators (PEC)

Families with children who have special learning needs, age birth to twenty-one, are encouraged to contact their local parent & educator coordinator (PEC). Each Area Education Agency (AEA) has a PEC on staff who brings the perspective of a parent with a child having special needs. They may be parents of children who have physical disabilities, intellectual disabilities, or emotional disabilities. Therefore areas of expertise vary. Educators and others who work with children with special needs may also contact the PEC for information and resources.

What the PEC can do for parents and educators:

Link families and educators with needed services and resources

Assist parents as they prepare to meet with school personnel

Attend IEP meetings

Assist parent-educator support groups

Conduct workshops on various subjects for families and educators

Provide books, pamphlets and video/audio tapes on issues regarding special education, parenting and disabilities

Network with other agencies and programs working with parents and educators

Connect families and educators with similar needs and interests

Inform and encourage state and local educational groups to support home-school relationships

To reach your PEC, contact the local Area Education Agency. An AEA directory can be found at: www.iowaaea.org

Training-in-a-Box

Training-in-a-Box kits include information about particular disorders or other topics of interest to parents and teachers of children with special needs. The kits are available for lending to parents and teachers from the Media Library of each of the local Area Education Agencies (AEA).

A kit typically includes books, pamphlets, articles, handouts, and a video. The kits have been developed through a joint effort of the Iowa Department of Education and the Child and Adolescent Educational Services Department at the University of Iowa.

Training-in-a-box topics include:

- Anxiety disorders
- Attention Deficit/Hyperactivity Disorder
- Asperger's
- Bipolar Disorder
Training-in-a-Box continued...

<table>
<thead>
<tr>
<th>Disorder</th>
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<tbody>
<tr>
<td>Brain Injury</td>
<td>Crisis &amp; Severely Disruptive Behaviors/Adolescence</td>
</tr>
<tr>
<td>Depression</td>
<td>Crisis &amp; Severely Disruptive Behaviors/Childhood</td>
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<tr>
<td>Eating Disorders</td>
<td>Obsessive-Compulsive Disorder</td>
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<tr>
<td>Oppositional Defiant Disorder</td>
<td>Prenatal Drug Effects</td>
</tr>
<tr>
<td>Reactive Attachment Disorder</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>Tourette's Disorder</td>
<td>Serious Emotional Instability &amp; Self-Mutilation</td>
</tr>
</tbody>
</table>

To request a Training-in-a-Box kit, contact the Media Library at your local Area Education Agency, or the Parent & Educator Coordinator (PEC). An AEA directory can be found at: www.iowaea.org

Parent Training and Information Center of Iowa (PTI)

PTI assists parents to better understand their children's disabilities and educational development and to ensure access to appropriate educational services. PTI provides advocacy, technical assistance, information, and training to families of children with special needs, including:

Information about disabilities

Information about family support resources

Information and training on the Individuals with Disabilities Education Act (IDEA)

Skill-building to empower parents to participate effectively in the Individualized Education Plan (IEP) process for their child

Skill-building to empower parents to participate in school improvement and education policy reform activities

The PTI of Iowa is a statewide service of ASK (Access for Special Kids) Family Resource Center, a nonprofit organization dedicated to helping families of children with disabilities.

Contact: PTI at ASK Family Resource Center, Des Moines Tel:(515)243-1713 or (800)450-8667 TDD:(800)735-2942 www.askresource.org

Know Your Rights

You have the right to request an evaluation.

You have the right to agree to the method of evaluation.

You have the right to participate in making decisions about your child.

You have the right to examine all of your child's educational records.
Know Your Rights continued…

You have the right to receive copies of your child's records (a small fee may be charged).

You have the right to receive all written and oral communications in your primary language.

You have the right to challenge school decisions about your child.

You have the right for your child to be educated in the least restrictive environment (LRE) possible.

Suggested Reading

*Educational Rights of Children with Disabilities*, by Ordover, Eileen L. & Boundy, Kathleen
*Children and Adolescents with Mental Illness, A Parents Guide*, edited by McElroy, Evelyn

Resources

Iowa Department of Education, www.iowa.gov/educate

Ask Family Resource Center, www.askresource.org

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NAMI IOWA (sources: Ask Family Resource Center www.askresource.org & Iowa Protection and Advocacy Services, Inc. www.ipna.org)

**A Brief Overview of Federal Laws Affecting Children with Disabilities**

Every public school in Iowa must provide a free, appropriate education to each child in their district, including each child who has a disability. Two federal laws that pertain are the Individuals with Disabilities Education Improvement Act (IDEA 2004) and Section 504 of the Rehabilitation Act of 1973.

In addition to providing a free appropriate education, requirements include the identification of every child with a disability who needs more than the regular school program to learn, testing and evaluation of the child’s educational needs, and the requirement that students who have disabilities and students who do not have disabilities are able to attend school together.

**IDEA (Individuals with Disabilities Act)**

The IDEA is an education law which provides schools with funds for special education services. It applies specifically to pre-school, elementary, and secondary education, creating an affirmative duty for schools to provide a free and appropriate public education including specialized instruction and related services to eligible students with disabilities.

**Who is covered by the IDEA?**

Students, ages 3-21 years, who need special education and related services to learn

**How do you know if a child needs education services?**

The child must be evaluated and found to need special education.
IDEA continued…

**What type of education must be provided under the IDEA?**
The child must have a written individual education plan (IEP) and be placed in the least restrictive environment (LRE) possible.

The child should be placed in the program that will best fit his or her educational needs, and educated as much as possible in the regular school programs, including extracurricular activities and field trips.

**What is a parent's role?**
A parent should take part in any decisions made about the child, discuss plans for special education, help to prepare the IEP, share information about the child and stay informed of any changes in the child's school program.

**What if the parent and the educators disagree?**
Read the *Procedural Safeguards Manual for Parents' Rights*. This is available from the school and is also available online at the Iowa Department of Education website under Parent Information. [www.iowa.gov/educate](http://www.iowa.gov/educate)

Consult with your PEC (parent & educator coordinator) or with PTI (Parent Training and Information Center of Iowa). See PEC and PTI information found elsewhere in the "Your Child's Academic Performance" section of this resource book.

It is always best to try the least confrontational methods first. However, when those have been tried and the parent and the educators still do not agree about what is best for the child, parents have the right to: request mediation; ask the Iowa Department of Education, through a Complaint, to help reach an agreement; ask for a due process hearing to present the issues; appeal a due process hearing decision to the Iowa Department of Education; and appeal the state's decision by filing a civil lawsuit.

**504 Plans (Section 504 of the Rehabilitation Act of 1973)**

A 504 plan is an attempt to remove barriers so that students can participate freely in classroom learning and school activities. Reasonable accommodations are to be provided to the student to ensure non-discrimination. The "504" in 504 plans refers to Section 504 of the Rehabilitation Act and the Americans with Disabilities Act (ADA), federal law that specifies that no one with a disability may be excluded from participating in federally funded programs or activities, including elementary, secondary or postsecondary schooling. A 504 plan outlines accommodations to be provided to a student who has a physical or mental impairment. There are procedural safeguards afforded to all 504 students and the 504 plan is legally binding.

**Who is covered by Section 504?**
Students who do not need special education but who do need accommodations
The law applies to students from preschool through college. Parents with a physical or mental disability must also have their needs met, such as an interpreter at a teacher conference for a parent who is hearing impaired.
The child must have a physical or mental problem which limits a major life activity such as: caring for one's self, doing manual tasks, walking, seeing, speaking, breathing, learning or working. These are generally referred to as living, learning, and working. The problem does not have to affect a child's ability to learn.

**How do you know if a child needs education services?**
The child must be evaluated and found to have a disability; and the child would benefit from accommodations to the regular school program.

**What type of education must be provided?**
The student's needs must be met through accommodations in the regular school program, extracurricular activities, and field trips.

**What is a parent's role?**
A parent should take part in any decisions made about the child including sharing information about the child, helping to prepare the 504 plan, and staying informed of any changes in the child's school program.

**What if the parent and educators disagree?**
Read the *Procedural Safeguards Manual for Parents' Rights*. This is available from the school and is also available online at the Iowa Department of Education website under Parent Information. [www.iowa.gov/educate](http://www.iowa.gov/educate)

Consult with your PEC (parent & educator coordinator) or with PTI (Parent Training and Information Center of Iowa). See PEC and PTI information found elsewhere in the "Your Child's Academic Performance" section of this resource book.

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**Comparing IDEA and Section 504**

<table>
<thead>
<tr>
<th><strong>IDEA</strong></th>
<th>The Individuals with Disabilities Education Act of 2004 is a federal public education law. The first such law was enacted in 1975.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Section 504</strong></td>
<td>Section 504 of the Rehabilitation Act of 1973 is a federal anti-discrimination law.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>IDEA</strong></th>
<th>Entitlement: entitles eligible children with disabilities to be offered special education and related services</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Section 504</strong></td>
<td>Civil rights law: prohibits discrimination on the basis of disability</td>
</tr>
</tbody>
</table>

| **IDEA** | Provides specialized instruction and related services to eligible students |
| **Section 504** | Provides accommodation and some modification to meet disability-related needs |
Comparing IDEA and Section 504 continued…

<table>
<thead>
<tr>
<th>IDEA</th>
<th>Section 504</th>
</tr>
</thead>
<tbody>
<tr>
<td>Applies from birth to age 21; no provisions for post-secondary education</td>
<td>Applies to all ages and to areas other than education, but contains specific provisions applicable only to elementary and secondary education; other rules apply only to post-secondary education</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>IDEA</th>
<th>Section 504</th>
</tr>
</thead>
<tbody>
<tr>
<td>Requires the provision of a &quot;free and appropriate public education&quot; (FAPE)</td>
<td>Requires the provision of a &quot;free and appropriate public education&quot; (FAPE)</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>IDEA</th>
<th>Section 504</th>
</tr>
</thead>
<tbody>
<tr>
<td>Requires eligibility determination that the child (1) has a disability fitting the IDEA definition, and (2) requires specialized instruction to benefit from education</td>
<td>Requires eligibility determination that the child (1) has a disability that substantially limits one or more major activities, and (2) needs accommodation to prevent discriminatory treatment</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>IDEA</th>
<th>Section 504</th>
</tr>
</thead>
<tbody>
<tr>
<td>Evaluation is needed to determine eligibility and appropriate supports/services</td>
<td>Evaluation is needed to determine eligibility and appropriate accommodations</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>IDEA</th>
<th>Section 504</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eligibility process can be accessed by a request from parent (a formal written request is strongly recommended)</td>
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</table>

<table>
<thead>
<tr>
<th>IDEA</th>
<th>Section 504</th>
</tr>
</thead>
<tbody>
<tr>
<td>Procedural protections insure strong parental involvement and consent</td>
<td>Parental involvement important and encouraged; less emphasis on procedural safeguards than IDEA</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>IDEA</th>
<th>Section 504</th>
</tr>
</thead>
<tbody>
<tr>
<td>Needs and services determined by IEP team including parents (and student as appropriate)</td>
<td>Needs and accommodations determined by multi-disciplinary team including parents and student, if appropriate</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>IDEA</th>
<th>Section 504</th>
</tr>
</thead>
<tbody>
<tr>
<td>Documented in a written plan called an IEP: Individualized Education Plan</td>
<td>Documented in a written plan called a 504 or Accommodation Plan</td>
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</table>

<table>
<thead>
<tr>
<th>IDEA</th>
<th>Section 504</th>
</tr>
</thead>
<tbody>
<tr>
<td>Uniform system of procedural and substantive safeguards and due process rights mandated by federal law</td>
<td>Each school or AEA is responsible for adopting its own due process procedures that meet the non-discrimination standard</td>
</tr>
</tbody>
</table>
Comparing IDEA and Section 504 continued…

| IDEA | Services can be delivered in a wide variety of settings from a general education classroom to a home, hospital, or residential setting |
| Section 504 | Services usually delivered in a general education classroom |

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**Behavioral Intervention Plans (BIP)**

A BIP is a plan developed by educators and parents to help a child control his or her behavior. Such a plan may include the child's course of study, where the child sits in the classroom, changes in classroom environment, or other "interventions". Behavior can be a child's way of communicating unmet needs. If teachers and parents can determine what the child is trying to communicate through certain behaviors, they may be able to help the child learn more appropriate and effective ways to communicate, and to eliminate or reduce the behaviors.

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**Individualized Education Plan (IEP)**

An IEP (Individualized Education Plan) is a written plan for meeting the educational needs of a child who has a disability that meets the legal criteria for federally funded special education services. The disability must affect the child's ability to learn. Services provided under an IEP are commonly referred to as special education services.

A team of people who are familiar with the child's needs meet with the parents and teacher to develop a plan that spells out specific goals for the child’s educational progress. The plan includes information concerning how the child is performing at the present time, a statement of measurable goals, and a statement of specific education services to be provided. The plan is revisited periodically to record progress.

From age 14 and up the IEP must include information on "transition" services and information on the student's legal rights that transfer to him or her at the age of eighteen. See Transitioning out of High School information found elsewhere in the "Your Child’s Academic Performance" section of this resource book.

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**NAMI IOWA** (sources: Iowa Protection and Advocacy Services, Inc. [www.ipna.org])

**Before the IEP Meeting**

Review your child's school work and observe your child at school or home.

Review your child's records and note important information.

Talk to your child, teachers, and others on the team.

Request a draft IEP and any evaluations/assessments needed.

Be familiar with the general education curriculum and expectations for typical peers.
Before the IEP Meeting continued…

Think about how your child's disability will impact his or her experiences in the general education environment, both curricular and extra-curricular activities.

Make sure that both you and the school team are clear about the purpose of the meeting.

Let the team know in advance if you are requesting something different and find out if they will accept or reject your request.

Prepare a written statement to share with the team. Be clear about your vision for your child and share information about your child's talents, interests, and needs.

It is good to have an objective set of eyes and ears at the meeting. Consider inviting a support person to accompany you. If you do invite a support person to attend, be sure to inform the teacher who is making the meeting arrangements.

Get organized, have all your things ready to take to the meeting, including your file.

Read the *Procedural Safeguards Manual for Parents' Rights* before the meeting. This is available from the school; and is also available online at the Iowa Department of Education website under Parent Information. [www.iowa.gov/educate](http://www.iowa.gov/educate)

Find out who will be at the meeting. If it is important to you that a particular person attends, and you learn that he or she has been invited but will not be there, inform the teacher who is making the arrangements that the meeting needs to be rescheduled.

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**NAMI IOWA** (sources: Iowa Protection and Advocacy Services, Inc. [www.ipna.org](http://www.ipna.org))

**At the IEP Meeting**

If it is important to you that a particular person attends, and you learn that he or she has been invited but will not be there, inform the teacher who has made the arrangements that the meeting needs to be rescheduled.

Consider having your child present for at least part of the meeting, as appropriate.

Think of the school team as your allies. You are all working together for the good of your child.

Make sure you understand everything that is said. Ask for definitions and explanations.

Don't be afraid to ask questions: who, what, when, where, how.

Before signing the IEP, read it carefully and make sure it accurately reflects what was discussed and agreed to at the meeting.

After the IEP meeting, continue to be an active participant on the team, attend school meetings, volunteer. Ongoing communication and positive relationships are critical for success.
Transitioning Out of High School

Children and youth with disabilities are entitled to special education services until they graduate from high school; quit school; or until they reach the age of 21, have an IEP and have not yet graduated from high school. If your child has an IEP and quits school, he or she may return to school up to the age of 21.

Federal education law requires that transition planning must begin by age 16 for every young person who has a disability, as defined under the IDEA. However, in Iowa transition planning begins at age 14. Transition planning requires the IEP to specify the services that a student needs in order to prepare for life after leaving the public school system. These services must be designed to help the student achieve real-life outcomes, such as employment, post-secondary education, independent living, adult services, and community participation. These outcomes are generally referred to as living, learning, and working.

A representative of any agency that is likely to be responsible for providing or paying for the transition services should be invited to the IEP meeting. The services must be based on the needs of the individual student and reflect his or her preferences and interests. For example, your child may be planning to attend college. The transition plan should identify what it will take to make sure your child has every opportunity to achieve that goal.

When setting up a transition plan, use the following two guidelines:

Know what you want.
Consult with each of the professionals on the IEP team separately to hear his or her opinion of what’s best for your child. Then with your child, decide on specific goals.

Consider the school staff to be your allies.
Work toward communicating openly and effectively with your child’s IEP team.

If your child will require help in independent living, adult services, community participation, or if he or she plans to get further education, then the IEP should reflect those needs.

Note: When your child is a high-school senior, request an evaluation if you believe he or she will need to continue receiving services after high school. Otherwise, you will be required to pay for an independent evaluation after your child finishes high school.

Vocational Rehabilitation
Transition services might require contact with vocational rehabilitation, and the vocational assessment process should start as early as age 14.

If your child has a disability that is a barrier to getting a job and keeping it, your child’s transition plan may include vocational rehabilitation services from Vocational Rehabilitation. This agency (under the Department of Education) helps people with physical, mental, emotional, and learning disabilities help themselves to get and keep a job.
Sample Letter: Requesting an IEP Meeting

(Always keep a copy of your letter for your own files.)

Your Street Address
City, State Zip Code
today's date

Name of School
Street Address
City, State Zip Code

Re: (Child's Name)
(School), (Grade)

Dear (Principal's name):

(In this paragraph say who you are, give your child's full name, and his or her current class placement. Say something positive about your child's situation here.)

(Briefly, explain why you are writing.) I recently reviewed my child's IEP which was developed in (month, year) and I believe that it is (out of date, needing revision).

I request that an IEP meeting be held as soon as possible to review and, if necessary, to revise my child's IEP. Please contact me (give your daytime telephone number) so that the meeting can be scheduled at a mutually agreeable time and place.

Thank you for your attention to this matter. I look forward to hearing from you within the next week.

Sincerely,
(Your name)

cc: your child's teacher
others?

(Note: The "cc:" at the bottom of the letter means you are sending a copy of your letter to the people listed after the cc. For example, if you write to the Director of Special Education about a problem at your child's school, you should copy the principal. If you write to the principal about a problem, you should copy your child's teacher or other staff involved with your child. This follows the "chain of command." It also lets people involved know your concerns and that you are taking steps to resolve these concerns.)
Sample Letter: Requesting Your Child's School Records

(Always keep a copy of your letter for your own files.)

Your Street Address
City, State Zip Code
today's date

Name of School
Street Address
City, State Zip Code

Re: (Child's Name)
(School), (Grade)

Dear (Name):

Please send me a complete copy of my child's educational records, including all evaluations, test results, reports, assessments, grades, notes by teachers or other staff members, and memorandum. I understand that I am eligible to obtain a copy of these records according to the Family Education Rights and Privacy Act (FERPA).

Please let me know if there is a cost associated with these copies. I am happy to pick them up.

I would like to have these records by (a week or two from the date of your letter). I need these in order to prepare for a meeting scheduled on (the date of your next meeting).

If you have any questions about this request, please contact me at your earliest convenience. The best way to reach me is by calling me at (home? work? my cell?) The number is (daytime phone number).

Thank you for your prompt attention to this important matter.

Sincerely,
(Your Name)

cc: (child's teacher)

Note: The "cc:" at the bottom of the letter means you are sending a copy of your letter to the people listed after the cc.
Section VI.

Hospitalization & Juvenile Court
Section VI. Hospitalization & Juvenile Court

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113 Voluntary Hospitalization

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117 Involuntary Hospitalization (Mental Health Commitment)

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Hospitalization & Juvenile Court

(sources: Juvenile Justice Plan 1997 www.iowa.gov/dhr/cjjp; Mental Health Commitment in Iowa, Iowa Protection & Advocacy Services, Inc.; excerpts from Iowa Code: www.legis.state.ia.us)

Editor's Note: References and excerpts from the Iowa Code and other information contained in this document are not offered as legal advice, but are intended as an introduction to the topic.

Definition of "Seriously Mentally Impaired"

When applying for either voluntary hospitalization or involuntary hospitalization for treatment of mental illness, it is necessary to provide information that shows your child or teen has a serious mental impairment, as defined in the Iowa Code.

Iowa Code 229.1 Definitions.

17. "Seriously mentally impaired" or "serious mental impairment" describes the condition of a person with mental illness and because of that illness lacks sufficient judgment to make responsible decisions with respect to the person's hospitalization or treatment, and who because of that illness meets any of the following criteria:

a. Is likely to physically injure the person's self or others if allowed to remain at liberty without treatment.

b. is likely to inflict serious emotional injury on members of the person's family or others who lack reasonable opportunity to avoid contact with the person with mental illness if the person with mental illness is allowed to remain at liberty without treatment.

c. Is unable to satisfy the person's needs for nourishment, clothing, essential medical care, or shelter so that it is likely that the person will suffer physical injury, physical debilitation, or death.

Voluntary Hospitalization

Iowa Code 229.2 Application for voluntary admission - authority to receive voluntary patients.

1. An application for admission to a public or private hospital for observation, diagnosis, care, and treatment as a voluntary patient may be made by any person who is mentally ill or has symptoms of mental illness.

In the case of a minor, the parent, guardian, or custodian may make application for admission of the minor as a voluntary patient.
Voluntary Hospitalization continued...

a. Upon receipt of an application for voluntary admission of a minor, the chief medical officer shall provide separate prescreening interviews and consultations with the parent, guardian or custodian and the minor to assess the family environment and the appropriateness of the application for admission.

b. During the interview and consultation the chief medical officer shall inform the minor orally and in writing that the minor has a right to object to the admission. If the chief medical officer of the hospital to which application is made determines that the admission is appropriate but the minor objects to the admission, the parent, guardian or custodian must petition the juvenile court for approval of the admission before the minor is actually admitted.

c. As soon as is practicable after the filing of a petition for juvenile court approval of the admission of the minor, the juvenile court shall determine whether the minor has an attorney to represent the minor in the hospitalization proceeding, and if not, the court shall assign to the minor an attorney. If the minor is financially unable to pay for an attorney, the attorney shall be compensated by the county at an hourly rate to be established by the county board of supervisors in substantially the same manner as provided in section 815.7.

d. The juvenile court shall determine whether the admission is in the best interest of the minor and is consistent with the minor's rights.

e. The juvenile court shall order hospitalization of a minor, over the minor's objections, only after a hearing in which it is shown by clear and convincing evidence that:

(1) The minor needs and will substantially benefit from treatment.

(2) No other setting which involves less restriction of the minor's liberties is feasible for the purposes of treatment.

f. Upon approval of the admission of a minor over the minor's objections, the juvenile court shall appoint an individual to act as an advocate representing the interests of the minor in the same manner as an advocate representing the interests of patients involuntarily hospitalized pursuant to section 229.19.

2. Upon receiving an application for admission as a voluntary patient, made pursuant to subsection 1:

a. The chief medical officer of a public hospital shall receive and may admit the person whose admission is sought, subject in cases other than medical emergencies to availability of suitable accommodations and to the provisions of sections 229.41 and 229.42.

b. The chief medical officer of a private hospital may receive and may admit the person whose admission is sought.
Voluntary Hospitalization continued...

Iowa Code 229.41 Voluntary admission.

Persons making application pursuant to section 229.2 on their own behalf or on behalf of another person who is under eighteen years of age, if the person whose admission is sought is received for observation and treatment on the application, shall be required to pay the costs of hospitalization at rates established by the administrator. The costs may be collected weekly in advance and shall be payable at the business office of the hospital. The collections shall be remitted to the department of human services monthly to be credited to the general fund of the state.

Iowa Code 229.42 Costs paid by county.

If a person wishing to make application for voluntary admission to a mental hospital established by chapter 226 is unable to pay the costs of hospitalization or those responsible for the person are unable to pay the costs, application for authorization of voluntary admission must be made through a central point of coordination process before application for admission is made to the hospital. The person's county of legal settlement shall be determined through the central point of coordination process and if the admission is approved through the central point of coordination process, the person's admission to a mental health hospital shall be authorized as a voluntary case. The authorization shall be issued on forms provided by the administrator. The costs of the hospitalization shall be paid by the county of legal settlement to the department of human services and credited to the general fund of the state, provided that the mental health hospital rendering the services has certified to the county auditor of the county of legal settlement the amount chargeable to the county and has sent a duplicate statement of the charges to the department of human services. A county shall not be billed for the cost of a patient unless the patient's admission is authorized through the central point of coordination process. The mental health institute and the county shall work together to locate appropriate alternative placements and services, and to educate patients and family members of patients regarding such alternatives.

All the provisions of chapter 230 shall apply to such voluntary patients so far as is applicable.

The provisions of this section and of section 229.41 shall apply to all voluntary inpatients or outpatients receiving mental health services either away from or at the institution.

If a county fails to pay the billed charges within forty-five days from the date the county auditor received the certification statement from the superintendent, the department of human services shall charge the delinquent county the penalty of one percent per month on and after forty-five days from the date the county received the certification statement until paid. The penalties received shall be credited to the general fund of the state.

Iowa Code 229.4 Right to release on application.

A voluntary patient who requests release or whose release is requested, in writing, by the patient's legal guardian, parent, spouse or adult next of kin shall be released from the hospital forthwith, except that:
Voluntary Hospitalization continued...

1. If the patient was admitted on the patient's own application and the request for release is made by some other person, release may be conditioned upon the agreement of the patient.

2. If the patient is a minor who was admitted on the application of the patient's parent, guardian or custodian pursuant to section 229.2, subsection 1, the patient's release prior to becoming eighteen years of age may be conditioned upon the consent of the parent, guardian or custodian, or upon the approval of the juvenile court if the admission was approved by the juvenile court; and

3. If the chief medical officer of the hospital, not later than the end of the next secular day on which the office of the clerk of the district court for the county in which the hospital is located is open and which follows the submission of the written request for release of the patient, files with that clerk a certification that in the chief medical officer's opinion the patient is seriously mentally impaired, the release may be postponed for the period of time the court determines is necessary to permit commencement of judicial procedure for involuntary hospitalization. That period of time may not exceed five days, exclusive of days on which the clerk's office is not open unless the period of time is extended by order of a district court judge for good cause shown. Until disposition of the application for involuntary hospitalization of the patient, if one is timely filed, the chief medical officer may detain the patient in the hospital and may provide treatment which is necessary to preserve the patient's life, or to appropriately control behavior by the patient which is likely to result in physical injury to the patient or to others if allowed to continue, but may not otherwise provide treatment to the patient without the patient's consent.

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Emergency Hospitalization

Iowa Code 229.22 Hospitalization – emergency procedure.

1. The procedure prescribed by this section shall not be used unless it appears that a person should be immediately detained due to serious mental impairment, but that person cannot be immediately detained by the procedure prescribed in sections 229.6 or 229.11 because there is no means of immediate access to the district court.

2. In the circumstances described in subsection 1, any peace officer who has reasonable grounds to believe that a person is mentally ill, and because of that illness is likely to physically injure the person’s self or others if not immediately detained, may without a warrant take or cause that person to be taken to the nearest available facility... A person believed mentally ill, and likely to injure the person's self or others if not immediately detained, may be delivered to a hospital by someone other than a peace officer. Upon delivery of the person believed mentally ill to the hospital, the examining physician may order treatment of that person, including chemotherapy, but only to the extent necessary to preserve the person's life or to appropriately control behavior by the person which is likely to result in physical injury to that person or others if allowed to continue... If the examining physician finds that there is reason to believe that the person is seriously mentally impaired, and because of that impairment is likely to physically injure the person's self or others if not immediately detained, the examining physician shall at once communicate with the nearest available magistrate...
3. The chief medical officer of the hospital shall examine and may detain and care for the person taken into custody under the magistrate's order for a period not to exceed forty-eight hours from the time such order is dated, excluding Saturdays, Sundays and holidays, unless the order is sooner dismissed by a magistrate. The hospital may provide treatment which is necessary to preserve the person's life, or to appropriately control behavior by the person which is likely to result in physical injury to the person's self or others if allowed to continue, but may not otherwise provide treatment to the person without the person's consent. The person shall be discharged from the hospital and released from custody not later than the expiration of that period, unless an application for the person's involuntary hospitalization is sooner filed with the clerk pursuant to section 229.6...

4. The cost of hospitalization at a public hospital of a person detained temporarily by the procedure prescribed in this section shall be paid in the same way as if the person had been admitted to the hospital by the procedure prescribed in sections 229.6 to 229.13.

Involuntary Hospitalization
(Mental Health Commitment)

Mental Health Commitment proceedings involve the placement of a child in a hospital or other treatment facility for mental illness or a substance abuse problem. Involuntary hospitalization for minors is handled in juvenile court, a division of the district court for your county.

The clerk of district court, or other staff person in the office of the clerk of district court, will be able to answer your questions about the commitment process and help you fill out the paperwork. Information concerning involuntary hospitalization: Iowa Code 229.

Iowa Code 229.6 Application for order of involuntary hospitalization

Proceedings for the involuntary hospitalization of an individual may be commenced by any interested person by filing a verified application with the clerk of the district court of the county where the respondent is presently located, or which is the respondent's place of residence. The clerk, or the clerk's designee, shall assist the applicant in completing the application. The application shall:

1. State the applicant's belief that the respondent is seriously mentally impaired.

2. State any other pertinent facts.

3. Be accompanied by:

   a. A written statement of a licensed physician in support of the application; or

   b. One or more supporting affidavits otherwise corroborating the application; or
Involuntary hospitalization (Mental Health Commitment) continued...

c. Corroborative information obtained and reduced to writing by the clerk or the clerk's
designee, but only when circumstances make it infeasible to comply with, or when the clerk
considers it appropriate to supplement the information supplied pursuant to, either paragraph
"a" or paragraph "b" of this subsection.

Delinquency Cases

Delinquency cases involve acts that would be considered criminal acts if committed by an adult.
Delinquency cases are handled in juvenile court, a division of the district court for your county.

Delinquency cases are handled in the same manner as criminal cases with a few key differences.
In a juvenile court delinquency case a child is adjudicated to be a delinquent rather than
convicted of a crime. After being adjudicated delinquent, the child is not "sentenced", he receives
a disposition. An adult criminal will generally be sentenced to a discreet period of years for
probation or incarceration. The child in a delinquency disposition is given a rehabilitative plan
which is usually not time limited. The focus in the juvenile case is to provide the child services
that will prevent future delinquencies. In a delinquency case there is no right to a jury trial.

Intake

The first step of most delinquency proceedings is "intake." This is the preliminary screening of a
complaint by a juvenile court officer and the child's parents. The purpose of intake is to
determine whether the court should take action in the case. From intake the case may proceed in
two directions, either to informal adjustment or to the filing of a delinquency petition. If a child
has been apprehended or detained by law enforcement, the matter may go straight to the filing of
a petition without the intake procedure. The petition is generally filed by the county attorney.

Informal Adjustment

If informal adjustment is selected by the juvenile court officer as the appropriate disposition, the
child and the child's parents must agree to the terms required in an informal adjustment
agreement. The agreement always requires that the child admit the charges. In addition, the
typical agreement requires (1) non-judicial probation in which the child is to abide by conditions
of behavior imposed under the probation or (2) treatment services. Typically, if a child obeys the
conditions of the informal adjustment a petition is not filed and the child is released from the
oversight of the juvenile court.

Formal Proceedings

The filing of a petition triggers formal court proceedings. The petition contains allegations of the
child's delinquent acts. After the filing of the petition there will be one or more hearings--a
waiver hearing and an adjudicatory hearing.

Depending on the nature of the alleged delinquent act there may be a detention hearing to
determine if the child should be placed or retained in detention.
Delinquency Cases continued...

Most petitions proceed to adjudicatory hearings. An adjudicatory hearing is a court hearing to determine if the allegations in the petition are supported by evidence. The case is presented by the county attorney. The child has the right to be represented by counsel. If the child cannot afford counsel, counsel will be provided at state expense. Both sides present evidence. If the child is found not to have committed the alleged delinquent acts, the petition is dismissed and the child is no longer under the jurisdiction of the court. If the child is found to have committed the acts, the child is adjudicated a delinquent. A disposition hearing follows a determination of delinquency. At the disposition hearing the court determines the appropriate consequences or treatment for the child.

In cases involving violent criminal behavior by older adolescents there may be a waiver hearing. Iowa law provides that some people under 18 years of age may be tried as adults. A juvenile judge may "waive" a child to adult court if the child is over 14 years of age, and there are no reasonable prospects to rehabilitate the child in juvenile court. Additionally, if a child sixteen or over and commits a "forcible felony", that child is automatically waived to adult court. Once waived to adult court, the child is no longer under the jurisdiction of the juvenile court and is subject to the same criminal procedures and penalties as adults.

Court Ordered Services

Community-Based/In Home Services

Community-based delinquency services include day treatment programs, life skills services, and tracking and monitoring services. "Trackers" work under the supervision of local juvenile court officers. They contact a given juvenile several times in a single day, making it possible for youth to remain in the community. Services may include: tracking and monitoring, skills development, school-based supervision, community service.

Short-Term/Out of Home Services

Emergency Shelters

Many youth in shelter care have behavioral or emotional problems. Shelter care provides 24 hour supervision, crisis intervention services and behavioral assessments. Shelter care services are purchased from private and public providers.

Juvenile Detention Centers

The eight judicial districts have centers to hold youth charged with committing a delinquent act while they wait for adjudication and/or disposition. Average length of stay is one week.
Court Ordered Services continued...

**Long Term/Out of Home Services**

If a child has an emotional, behavioral, or mental health disorder, the psychiatric institution shall not require court proceedings to be initiated to terminate parental rights or to transfer legal custody of the child for the purpose of obtaining treatment. *Relinquishment of a child's custody shall not be a condition of the child receiving services.* (source: Iowa Code Title IV. Public Health...Psychiatric Medical Institutions for Children, Chapter 135H.6(11)

**Psychiatric Medical Institutes for Children (PMIC)**

Each PMIC facility in Iowa determines its own criteria for eligibility, service descriptions, and direct-care provider requirements. The PMIC system is intended to serve children who need an intensive treatment program for an extended period of time. PMIC stays may be funded either privately through your health insurance or publicly through your local Iowa DHS social worker and/or court system. Care in a psychiatric medical institute for children is available both for children who have been ordered by the court to receive services as well as for children whose parents voluntarily place their children in the treatment facilities.

**Residential Treatment Facilities for Children (Group Care)**

Group care provides highly structured 24-hour treatment services and supervision for children who cannot be served at a less restrictive level of care due to the intensity or severity of their emotional/behavioral problems. Group care services include counseling and therapy, social skills development, restorative living skills development, family skills development, and supervision. Residential treatment is available both for children who have been ordered by the court to receive services as well as for children whose parents voluntarily place their children in the treatment facilities.

**Psychiatric Medical Institutions for Children (PMIC's)**

Each PMIC facility in Iowa determines its own criteria for eligibility, service descriptions, and direct-care provider requirements. The PMIC system is intended to serve children who need an intensive treatment program for an extended period of time. PMIC stays may be funded either privately through your health insurance or publicly through your local Iowa DHS social worker and/or court system.

**Juvenile Corrections Institutions**

The Department of Human Services administers two state juvenile corrections institutions: the Boys State Training School in Eldora for delinquent boys and the Iowa Juvenile Home in Toledo for delinquent girls.
Child in Need of Assistance (CINA)

Child in Need of Assistance (CINA) cases most typically involve abused, abandoned, or neglected children, and sometimes lead to termination of parental rights. CINA proceedings are handled in juvenile court, a division of the district court for your county.

The CINA law, Iowa Code Chapter 232, is primarily for the protection of children who have been abused. Among other things, it provides for parents giving up their parental rights and the child being placed in the custody of the state. The law includes several statutory grounds; however, the most commonly used grounds for adjudication are the provisions defining physical abuse, sexual abuse and neglect.

Previously, the inability of a family to pay for a child's needed mental health treatment was also deemed to be grounds for a CINA proceeding. However, it is currently (2009) not required that parents in Iowa give up their parental rights in order for their children to receive needed mental health treatment and services in a Psychiatric Medical Institute for Children (PMIC). (Iowa Code Title IV. Public Health...Psychiatric Medical Institutions for Children Chapter 135H.6 lists among requirements of licensure for a PMIC facility that there may not be a requirement that parents relinquish parental custody in order for a child to receive services.) Parents may voluntary place children needing in-patient psychiatric services in a PMIC facility. Ordinarily, a child who is admitted to one of the twelve PMIC facilities in Iowa will have one-hundred percent of the costs paid by Medicaid.

Costs for care in a residential treatment facility, as differentiated from a PMIC, will usually be paid by the family. If a child is placed in a residential treatment facility by the juvenile court, Medicaid may cover the cost of treatment but the parents will likely be responsible for the costs of room and board. In order for a child to be placed in a residential treatment facility, the county attorney would need to file a petition with the juvenile court.
To request information on mental illness or to schedule an educational presentation, contact:

NAMI IOWA
National Alliance on Mental Illness-Iowa
Des Moines, Iowa
www.namiiowa.org info@namiiowa.com
Section VII.

Resources
Section VII. Resources

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150  Websites for Children and Teens
151  Miscellaneous Mental Health Related Resources
152  Information for Foster and Adoptive Parents
153  Resources and Organizations Focused on Specific Disorders
Suggested Reading

General

Stop Pretending; Sones, Sonya; poems tell the story of what it meant for a 13-year-old girl to see her beloved older sister transformed by mental illness from her best friend into a stranger, going from disbelief and denial to acceptance and healing. *(for pre-teens, teens, and anyone who has a sibling with a mental disorder)*

When Madness Come Home; Secunda, Victoria; personal experiences of siblings, offspring, parents, and spouses of people who have mental illnesses. *(for people who have a sibling, parent or partner suffering from a mental illness)*.

The Face at the Window; Hanson, Regina & Linda Saport (Illustrator); tells a reassuring story about the rift mental illness imposes between people and how the gift of kindness can work to bridge this distance as a young Jamaican girl learns about mental illness through her neighbor Miss Nella’s strange behavior. *(for children)*

Catch a Falling Star: A Tale from the Iris the Dragon Series; Grass, Gayle & Coral Nault (Illustrator); a fairy tale about a young boy named Fish who begins to experience early warning signs of mental illness and through the help and companionship of a Renaissance Dragon called Iris is able to confront his fears and learn to express his worries to his parents. *(for children)*

More Than a Mom: Living a Full and Balanced Life When Your Child has Special Needs; by Baskin, Amy & Heather Fawcett; teaches mothers how to pay attention to their own needs while meeting the demands of a child with mental health or learning issues.

That's My Child: Strategies for Parents of Children with Disabilities; by Capper, Lizanne. How to navigate resources to help disabled children: organizations, state and federal law (especially IDEA), and school systems.

Transition to Adulthood: A Resource for Assisting Young People with Emotional or Behavioral Difficulties; by Clark (Ph.D.), Hewitt B. & Maryann Davis (Ph.D.); offers guidance in advocating for appropriate services, provides information on best practices and model programs.

The Early Intervention Dictionary: A Multidisciplinary Guide to Terminology, Third Edition; Coleman (M.Ed.), Jeanine G.; defines educational terms commonly used by the many different professionals involved in the early intervention field, updated version includes research, educational approaches, treatments and changes in the field.

Crazy: A Father’s Search through America’s Mental Health Madness, Earley, Pete; contains two stories, one about Earley’s son, the other about Earley’s investigation inside the Miami-Dade County jail where he was given complete, unrestricted access.

Childhood Revealed: Art Expressing Pain, Discovery & Hope; Goodman, Robin F., Harold S. Koplewicz & Margery D. Rosen; current, practical information on treatment and prognosis for various disorders; also words and artwork from the children themselves.
Suggested Reading continued…

*The Explosive Child*; Greene (Ph.D.), Ross W.; offers a framework for creating a more "user friendly" home where rages and meltdowns are less likely to happen, also information about psychopharmacology and therapeutic remedies.

*It's Nobody's Fault*; Koplewicz (M.D.), Harold S.; explains that mental illnesses are chemical brain disorders and nobody's fault; includes diagnosis, treatment, and prognosis of 13 disorders.

*Your Child: What Every Parent Needs to Know, What’s Normal, What’s Not, and When to Seek Help*; Pruitt (M.D.), David; guide to emotional, behavioral and cognitive development from infancy through pre-adolescence; guidance for day-to-day interactions; sleep problems; self-esteem; when behaviors call for professional help and where to find it.

*After the Tears: Parents Talk about Raising a Child with Disability*; Simmons, Robin; how parents first confronted their shattering experience and then recovered to emerge stronger, healthier and better able to cope and help their children.

*Is it “Just a Phase”? How to Tell Common Childhood Phases from More Serious Problem*; Swedo, Dr. Susan & Dr. Henrietta Leonard; common problems of development; and emotional and psychiatric illnesses that are beyond “just a phase”, advances in diagnosis and treatment.

*Nature Lessons*; Brasfield, Lynette; a novel is about a forty-year-old woman struggling to come to terms with the legacy of growing up with a mother who suffers from a mental illness, her dysfunctional relationships, and the impact of her mother’s mental illness on her life. The story weaves back and forth between 1960s apartheid South Africa and post-apartheid 1995 and provides glimpses into a spectrum of racial perspectives over time.

*I’m Not Alone: A Teen’s Guide to Living with a Parent Who has a Mental Illness*; Sherman (Ph.D.), Michelle D. & DeAnne M. Sherman; interactive workbook focuses on the teenager’s experience of living with a parent who has bipolar disorder, major depression or schizophrenia; helps teens understand mental illness, sort through their feelings, learn coping skills, deal with their friends, identify resources and find hope; includes clear information and opportunities for self-expression. *(for teens)*

*Finding My Way: A Teen’s Guide to Living with a Parent Who has Experienced Trauma*; Sherman (Ph.D.), Michelle D. & DeAnne M. Sherman; interactive manual for teenagers who have a parent who has experienced trauma; clearly explains PTSD and other common responses to trauma; reviews co-occurring problems (including addictive behavior); describes treatment options; teaches teens coping skills, how to identify resources and deal with friends. *(for teens)*

*Our Special Dad; Sobkiewicz, Tootsie, and Our Special Mom; Sobkiewicz, Tootsie*; interactive storybooks about problems faced by a child when a parent has a mental illness; conveys the message to children that they are not responsible for the parent’s illness and that the illness is not contagious, the parent’s erratic and sometimes unkind behavior should not be interpreted as lack of love. *(primary school age)*
Suggested Reading continued…

**Anxiety Disorders**

*What You Must Think of Me: A Firsthand Account of One Teenager’s Experience with Social Anxiety Disorder*; Ford, Emily with Michael Liebowitz & Linda Wasmer Andrews; a memoir of how the author managed the obstacles of social anxiety and eventually overcame them; provides medical and scientific information about the causes, diagnosis, treatment and self-management of the disorder; advice on dealing with social anxiety in school and work, seeking professional help and handling difficult social situations. *(for teens)*

*Help for Worried Kids;* Last (Ph.D.), Cynthia G.; strategies for preventing episodes, how to intervene when one is in progress, tips on how to keep anxiety from worsening as child matures.

*Helping Anxious Child: A Step-by-Step Guide for Parents;* Rapee (Ph.D.), Ronald M., Susan H. Spence (Ph.D.), Vanessa Cobham (Ph.D.) & Ann Wignall (M.S.); relaxation techniques, stress management, deductive thinking, how to teach social skills, includes case studies.

*Worried No More: Help and Hope for Anxious Children;* Wagner (Ph.D.), Aureen Pinto; focuses on coping with disasters, tragedies, panic, phobias, worry, school refusal, separation anxiety, excessive shyness, obsessions and compulsions; includes how-to steps, forms and tools.

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

*A Bird’s-Eye View of life with ADD and ADHD: Advice from Young Survivors;* Dendy (M.S.), Chris Zeigler & Alex Zeigler; offers advice based upon first-hand experience; written by twelve teens and a young adult. *(for children and teens)*

*Lucky Horseshoes: A Tale from the Iris the Dragon Series;* Grass, Gayle & Linda Crockett (Illustrator); a story of Skippy, a young girl with AD/HD, who overcomes her difficulties with school and home as she learns to work through her challenges with the help of a Dragon named Iris and a colt named Ben; explains through Skippy’s experiences that AD/HD is treatable and that there are accommodations that can help children succeed and enjoy school. *(for children)*

*The Best of Brakes: An Activity Book for Kids with ADD;* Quinn (M.D.), Patricia O. & Judith M. Stern (M.A.); includes games, puzzles, activities, tips, resources; suggestions for solving problems and getting organized; real kids going through familiar experiences; and ideas that make life more manageable and more fun. *(for pre-teens)*

*Taking ADD to School: A School Story about Attention Deficit Disorder and/or Attention Deficit Hyperactivity Disorder (ADHD);* Weiner, Ellen & Terry Ravanelli (illustrator); the story of Ben, who recalls the difficulty he had in second and third grade and how treatment for his attention problems with medicine and help from his parents, teachers and doctor led to his improvement in school. *(for children)*

Suggested Reading continued...

_Eddie Enough!_; Zimmett, Debbie & Charlotte Murray Fremaux; story about Eddie, a third-grade boy who is *too much* at times even for his peers as he can’t get organized, sit still or even walk around his classroom without knocking something over, typical problems of a youngster with AD/HD, until he gets better when he sees his doctor, is tested and gets treated. *(ages 5-10)*

_One Small Starfish: A Mother’s Everyday Advice, Survival Tactics & Wisdom for Raising a Special Needs Child;_ Addison, Anne; about raising a child diagnosed with AD/HD and Asperger Syndrome; includes practical strategies, communication tools and data gathering techniques.

_Taking Charge of ADHD: The Complete Authoritative Guide for Parents, Revised Edition;_ Barkley (Ph.D.), Russell A.; current research; also strategies to help parents manage AD/HD at home and at school.

_Willie: Raising and Loving a Child with Attention Deficit Disorder;_ Colin, Ann; author describes her son's symptoms and her experiences in seeking a diagnosis, from a neurologist, psychologists, school personnel and a psychiatrist to at last finding a treatment that helped.


_Making the System Work for your Child with ADHD: How to cut through red tape and get what you need from doctors, teachers, school and healthcare plans;_ Jensen (M.D.), Peter S.; for anyone who is the primary caregiver and responsible for getting help for a child with ADHD

_ADHD A Complete and Authoritative Guide;_ Rieff (M.D.), Michael I. & Sherill Tippins; information on: evaluation and diagnosis, coexisting conditions, behavior therapy, academics, medication, unproven treatments, the teenage years, and effective parenting skills.

**Autism and Asperger Syndrome**

_Taking Autism to School;_ Edwards, Andreanna & Tom Dineen (Illustrator); includes topics such as echolalia, schedules, sensory issues, and medications related to autism. *(for ages 5-10)*

_Your Life is Not a Label;_ Newport, Jerry & Ron Bass; an encouraging and educational guide for regarding Asperger Syndrome or high-functioning autism, provides advice about how to maximize their potential and minimize their grief and worries about their illness; emphasizes living independently and learning to accept the illness. *(for teens)*

_Special Children, Challenged Parents: The Struggles and Rewards of Raising a Child with a Disability;_ Naseef (Ph.D.), Robert A.; written by a father of a child with autism who is also a psychologist specializing in counseling families of children with special needs.

_Aspurger’s Syndrome: A Guide for Parents and Professionals;_ Attwood (Ph.D), Tony; strategies to reduce conspicuous or debilitating characteristics.
Suggested Reading continued…

_The Asperger Parent: How to Raise a Child with Asperger Syndrome and Maintain Your Sense of Humor_; Cohen, Jeffrey; offers essential information and emotional support for parents.

_Asperger Syndrome: A Practical Guide for Teacher_; Cumine, Val; guide to effective classroom practice for teachers; theory, case studies and examples of successful interventions.

_Asperger Syndrome_; Klin (Ph.D.), Ami, Fred Volkmar (M.D.) & Sara S. Sparrow (Ph.D); effects on social, communication and behavioral development; identifies challenges faced at home, in school, the workplace, and other everyday settings.

_Asperger Syndrome and Difficult Moments: Practical Solutions for Tantrums, Rage, and Meltdowns_; Myles, Brenda Smith & Jack Southwick; strategies that promote social skills development, including self-awareness, self-calming and self-management.

_Asperger Syndrome: A Guide for Educators & Parents_; Myles (Ph.D.), Brenda & Richard Simpson; focus on social skills and language needs; addressing child’s needs in the classroom; planning strategies for post-secondary schooling.

_A Parent’s Guide to Asperger Syndrome and High-Functioning Autism: How to Meet the Challenges and Help Your Child Thrive_; Ozonoff, Sally, Geraldine Dawson & James McPartland; strategies for handling common challenging behaviors at home, suspected causes of the disorders, treatments, strategies for getting appropriate educational services.

**Bipolar Disorder**

_Brandon and the Bipolar Bear: A Story for Children with Bipolar Disorder_; Anglada, Tracy; provides a rare glimpse into the feelings and fears of a child with bipolar disorder. Brandon learns that he is not the only one who struggles with inner turmoil and that he is not to blame. He learns from his doctor what his illness is about and the important role of heredity. See www.bipolar-children.Bigstep.com for ordering information. (for ages 4-11)

_The Life of a Bipolar Child: What Every Parent and Professional Needs to Know_; Carlson, Trudy; about the author’s son from his emerging bipolar disorder, the effects of his illness on functioning through each year of school, until his death by suicide at age fourteen.

_If Your Adolescent Has Depression or Bipolar Disorder_; Evans, Dwight L. (M.D.) & Linda Wasmer Andrews; includes warning signs, getting a diagnosis, treatments, coping at home and school, and prevention strategies; provides practical advice, resources and tools.

_Raising a Moody Child: How to Cope with Depression and Bipolar Disorder_; Fristad (Ph.D.), Mary A. & Jill Goldberg Arnold (Ph.D.); includes how to teach kids skills to manage their moods using a coping toolkit; keep challenging conduct from turning home and school into a battleground; deal with stress; professional treatment; and common diagnostic errors.
Suggested Reading continued…

*Bipolar Disorder in Childhood & Early Adolescence*, New Edition; Geller (M.D.), Barbara & Melissa P. Delbello (M.D.); provides an understanding of the clinical perspective with an overview of theory and research, addresses diagnosis and assessment and the life course of the disorder; describes how the illness presents itself differently in children than in adults.

*The Ups and Downs of Raising a Bipolar Child: A Survival Guide for Parents*; Lederman, Judith & Candida Fink (M.D.); detailed practical advice and guidance, how the disorder is diagnosed, special education services, sibling issues.

*Understanding the Mind of Your Bipolar Child: The Complete Guide to the Development, Treatment, and Parenting of Children with Bipolar Disorder*; Lombardo, Gregory T.; diagnosis; developmental issues; disorders that go hand-in-hand with bipolar disorder (AD/HD and oppositional defiant disorder); treatment options, including psychotherapy and medication.

*The Bipolar Teen: What You Can Do to Help Your Child and Your Family*; Miklowitz, David J. (Ph.D.) & Elizabeth L. George (Ph.D.); helps parents distinguish between the typical ups and downs of teen life and the symptoms of mania or depression and how parents can strike a healthy balance between medication and psychotherapy.

*The Bipolar Child: The Definitive and Reassuring Guide to Childhood's Most Misunderstood Disorder*, Third Edition; information about adolescence, hospitalization, insurance and the psychological impact the illness has on the child; from recent advances in neuroscience and genetics what is known and not known about the illness; diagnosis; finding good treatment; medications; how to effectively advocate for the child at school, includes an IEP.

*Acquainted with the Night: A Parent’s Quest to Understand Depression and Bipolar Disorder in His Children*; Raeburn, Paul; personal story of the great pain, joy and hope that the author and his family endured in the course of his son’s bipolar illness and then his daughter’s depression.

*Bipolar Disorders: A Guide to Helping Children and Adolescents*; Waltz, Mitzi; covers diagnosis, insurance, family life, medications, talk therapies, school, improving sleep patterns and diet, preventing seasonal mood swings, special education and suggestions for helping the child make a successful transition to adulthood.

*SSometimes My Mommy Gets Angry*; Campbell, Bebe Moore; a story about a young girl who learns how to cope with difficult moments in her mother’s struggle with bipolar disorder; narrated from a child's perspective, it presents symptoms and coping strategies in a simple and easy-to-understand way. *(for children)*

**Depression**

*The Storm in my Brain - Kids and Mood Disorders (Bipolar Disorder and Depression)*; from Depression and Bipolar Support Alliance (DBSA) www.dbsalliance.org and The Child and Adolescent Bipolar Foundation (CABF) www.hpkids.org; speaks to children about how it feels to have a mood disorder, includes colorful artwork created by young people living with depression and bipolar disorder, offers tips for parents and teachers. *(for children)*
Suggested Reading continued…

*Depression: Challenge the Beast within Yourself and Win-I Did. Here’s my Story;* Irwin, Cait; inspiring story written by a high-school senior about how depression affected her life and that of friends and family. *(for pre-teens and teens)*

*Monochrome Days: A Firsthand Account of One Teenager’s Experience with Depression;* Irwin, Cait with Dwight Evans (M.D.) & Linda Wasmer Andrews; a first-person account of living with and recovering from depression at a young age; provides information on depression, treatment, the science behind the illness, hospitalizations, medications, and how to deal with the illness at school and at home. *(for teens)*

*Mind Race: A Firsthand Account of One Teenager’s Experience with Bipolar Disorder;* Jamieson, Patrick E. (Ph.D.) with Moira A. Rynn (M.D.); a novel that offers advice and resources; provides information on causes, treatment, symptoms and tips on how to manage daily life with bipolar disorder; includes information on hospitalization, living with mood-stabilizing medications, and how to talk to family and friends about mental illness. *(for teens)*

*Darcy Daisy and the Firefly Festival: Learning about Bipolar Disorder and Community;* Lewandowski (Ph.D.), Lisa & Shannon M.B. Trost (B.S.); helps children understand what bipolar disorder is, the importance of community acceptance, the need for good Information, and the harm that results from rumors and gossip. *(for children)*

*Detour by Lizzie Simon;* an account of the author’s journey during which she interviewed other young people with bipolar disorder and discusses her feelings of having been different for most of her life and her need for finding others similar to herself. *(for young adults)*

*When Nothing Matters Anymore: A Survival Guide for Depressed Teens;* Cobain, Bev; for teens who feels hopeless, helpless, and alone; clear, encouraging and matter-of-fact; *(age 13 and up)*

*The Adolescent Depression Workbook;* Copeland (M.S.), Mary Ellen & Stuart Copans (M.D.); practical steps for reflection and recovery, enables teens to assess how they feel and determine what to do to return to enjoying a rich, full life. *(for teens)*

*Help Me, I’m Sad: Recognizing, treating, and preventing childhood and adolescent depression;* Fassler (M.D.), David & Lynne S. Dumas; how to recognize warning signs of depression, case histories illustrate what childhood-onset depression looks like at different ages.

*More than Moody: Recognizing and Treating Adolescent Depression, Reissue Edition;* Koplewicz (M.D.), Harold S.; differences between normal teenage angst and depression; warning signs, risk factors and key behaviors; anti-depressants and cognitive behavior therapy.

*Helping Your Teenager Beat Depression;* Manassis (M.D.), Katharina & Anne Marie Levac (RN); how parents can be active partners in their child’s treatment; overview of teenage mood problems; cognitive behavioral therapy (CBT); includes case studies, exercises and checklists.

*A Mood Apart;* Whybrow (M.D.), Peter C.; an understanding and compassionate exploration of depression and bi-polar disorder.
Suggested Reading continued…

*Adolescent Depression;* Mondimore (M.D.), Francis Mark; includes descriptions of the many forms of depression and the many ways in which it can appear; summarizes symptoms, treatments, complications, and causes; how it relates to other problems such as drug abuse, ADHD, and eating disorders and other self-injurious behavior.

*Screaming for a Vine;* Williamson, Violet; about the author’s daughter Amy, her symptoms of paranoia and clinical depression in day-to-day living and helpful insights learned along the way; includes Amy’s poems and journal entries; a good resource for families new to a diagnosis.

*Parenting Well when You are Depressed;* Nicholson (Ph.D.), Joanne, Alexis Henry (Sc.D.), Jonathan Clayfield (M.A.) & Susan Phillips; offers strategies, action plans and resources to help depressed parents provide for their children’s healthy development.

*Mommy Stayed in Bed this Morning;* Weaver, Mary Wenger; viewed through the eyes of David, a preschooler, the book portrays symptoms of his mother’s depression and therapeutic interventions; helps children recognize their fears and anxieties and then points to ways for them to discover health and wholeness. *(for children)*

Sad Days, Glad Days; Hamilton, Dewitt; beautifully and sensitively illustrated introduction to a parent’s depression. *(for ages 5-9)*

*Out of the Darkened Room: When a Parent is Depressed: Protecting the Children and Strengthening the Family;* Beardslee (M.D.), William; offers advice on prevention strategies, communication on the subject of mental illness in the family; lessons to help families when a parent suffers from depression or other mental illness; focuses on the family member with depression and provides potential suggestions on how best to help the children in the family.

**Drug Abuse and Co-Existing Disorders**

*Lives at Risk: Understanding and Treating Young People with Dual Diagnosis;* Ryglewicz, Hilary & Bert Pepper; about co-existence of mental illness and drug abuse, integrates personality theory and brain studies in a bio-psychosocial model, written for treatment professionals.

**Eating Disorders**

*Next to Nothing: A Firsthand Account of One Teenager’s Experience with an Eating Disorder;* Arnold, Carrie with Timothy Walsh; The author in this memoir recounts the tale of how she experienced anorexia as a teenager, was able to seek help, and what finally brought her to recovery. She also offers practical advice and guidance to young adults who have recently been diagnosed with an eating disorder, or who are at risk for developing one. *(for teens)*

*Helping Your Teenager Beat an Eating Disorder;* Lock, James (Ph.D.) & Daniel Le Grange (Ph.D.); strategies for parents and information regarding research into treatment methods.
Suggested Reading continued…

*If Your Adolescent Has an Eating Disorder: An Essential Resource for Parents;* Walsh, Timothy B. (M.D.) & V.L. Cameron; includes warning signs, getting a diagnosis, treatments, coping at home and school, and prevention strategies; combines scientific expertise and research findings with the practical wisdom of parents.

**Medications**

*Psychiatric Medications for Children: Medication and Treatment for Children & Youth with Emotional and Behavioral Challenges;* Perrin (M.D.), Mark; about mental health care for children, effective treatments as well as the benefits and risks of medications.

*Helping Parents, Youth & Teachers Understanding Medications for Behavioral & Emotional Problems: A Resource Book of Medication Information Handouts, Second Edition;* Dulcan (M.D.), Mina & Claudia Lizarralde (M.D.); the handouts cover medications for pediatric behavioral and emotional disorders including anticonvulsants, stimulants, antianxiety medications, SSRIs and more; available in print and on CD-ROM.

*Child and Adolescent Clinical Psychopharmacology Made Simple;* Preston (Psy.D.), John, John H. O’Neal (M.D.) & Mary C. Talaga (PH.D.); fact sheets on medications include diagnosis, treatment and follow up.

*The Straight Talk about Psychiatric Medications for Kids, Revised Edition;* Wilens (M.D.), Timothy E.; answers to frequently asked questions; explains which medications may be prescribed and why; the effects on children’s health, emotions and school performance.

**Obsessive-Compulsive Disorder (OCD)**

*You Do That Too?;* Benson, Jose Arturo; A fictional adolescent with a real problem is the focus of this story. Along with illustrations, the book describes the nature of OCD and offers possible remedies. While focusing mainly on teenagers, this book can be helpful to readers of all ages.

*Kids Like Me: Children's Stories about Obsessive-Compulsive Disorder;* Foster, Constance H., tells the story of five children with OCD; explains what OCD is and the main differences and typical symptoms of children with OCD. *(for children)*

*Polly’s Magic Games: A Child’s View of OCD;* Foster, Constance H. & Edwin A. Chase; tells the story of Polly and Annie friendship when they were ten years old and the struggle of Polly to fit in at school and not be different from her peers; explains common signs and treatment options for the disorder. *(for ages 8-12)*

*Kissing Doorknobs;* Hesser, Terry Spencer; story about 14-year-old Tara who is diagnosed with OCD when she starts kissing the front doorknob every time she wants to leave the house; explains what OCD feels like, the effects it has on family and friends, and explores both Tara’s confusion and fear and her parent’s anxiety and agony. *(for pre-teens and teens)*
Suggested Reading continued...

_Blink, Blink, Clop, Clop: Why Do We Do Things We Can't Stop? An OCD Storybook_; Moritz, E. Katia (Ph.D.) & Jennifer Jablonsky; provides a description of OCD and its most common symptoms by using animals as the main characters. (for children)

_The Secret Problem_; Wever, Chris & Neal Phillips (Illustrator); explains OCD and its treatment utilizing a cartoon format. (for children)

_Up and Down the Worry Hill: A Children's Book about Obsessive-Compulsive Disorder and Its Treatment_; Wagner (Ph.D.), Aureen Pinto & Paul A. Jutton (Illustrator); a story about Casey in his initial struggle with OCD, his sense of hope when he learns about treatment, his relief that neither he nor his parents are to blame, and eventually his victory over OCD. (for children)

_School Personnel: A Critical Link in the Identification and Management of OCD in Children and Adolescents_; Adams, Gail & Marcia Torchia; recognizing OCD in the school setting; current treatments; role of school personnel in identification, assessment and educational interventions.

_Freeing Your Child from Obsessive-Compulsive Disorder: A Powerful, Practical Program for Parents of Children and Adolescents_; Chansky (Ph.D.), Tamar; describes the illness as a brain hiccup, a misfiring, a mechanical glitch that can be fought and defeated.

_OCD in Children & Adolescents_; March (M.D.), John S. & Karen Mulle; manual of a cognitive-behavioral treatment program; goes through psychoeducation, cognitive training, mapping OCD and graded exposure and response prevention in 13 to 20 clearly prearranged and structured treatment sessions; includes rating scales, patient handouts and tips and resources for parents.

_Talking Back to OCD_; March (M.D.), John S. & Christine M. Benton; teaches children and adolescents skills they can use to take charge of their illness, shows parents how to provide encouragement and support, explains each component of recovery and helps parents and children gain control of the mental illness.

_Obsessive-Compulsive Disorders: A Complete Guide to Getting Well and Staying Well_; Penzel (Ph.D.), Fred; how to choose the most effective therapies and medications, and how to avoid relapses and setbacks; discusses treatment for children, offers advice for families.

_What to do When you Child has Obsessive-Compulsive Disorder: Strategies and Solutions_; Wagner (Ph.D.), Aureen Pinto; a step-by-step approach for parents and children to use to regain control from OCD.

_Obsessive Compulsive Disorder: Help for Children and Adolescents_; Waltz, Mitzi; includes an overview of OCD, how it is diagnosed, family issues, treatment options, dealing with insurance problems and the healthcare system, school and transition planning.
Suggested Reading continued...

**Sensory Processing Disorder**

*Out of Sync Child*, Revised Edition; Kranowitz (M.A.), Carol Stock; recognizing and coping with sensory processing disorder; information on vision and hearing deficits, motor skill problems, nutrition and picky eaters, AD/HA, autism, and other related disorders.

*Out of Sync Child Has Fun*; Kranowitz (M.A.), Carol Stock & T.J. Wylie (Illustrator); presents activities that parents of kids with sensory processing disorder can do at home with their child to strengthen their child's abilities, and have some fun together along the way.

**Suicide**

*My Uncle Keith Died*; Loehr, Carol Ann & James Miojonnier (Illustrator); a tool to explain depression and suicide to a child who has lost someone to suicide; includes information about how depression can lead to suicide, the difference between sadness and depression and how to help a friend who is depressed. *(for children)*

*Will’s Choice*; Griffith, Gail; personal story about the author’s son’s near fatal suicide attempt and their journey as a family to heal together, interspersed with the information and practical advice on the risk of suicide and adolescent depression.

*Night Falls Fast: Understanding Suicide*, New Edition; Redfield (Ph.D.), Kay Jamison; depiction of the psychological suffering of those who attempt or commit suicide, the causes, and the potential for prevention.

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**Parent and Teacher Education**

**NAMI IOWA – Visions for Tomorrow (VFT)**
An educational program for people who are raising or working with children and adolescents who have mental illnesses and behavioral challenges. Classes and workshops help parents, foster parents and others face day-to-day challenges; learn the facts; and find support, resources, and strategies to cope.

**NAMI IOWA – Parents & Teachers as Allies**
A two-hour in-service for teachers, administrators, and others in the school community, focusing on helping school professionals and families better understand early warning signs of mental illnesses in children and how best to intervene to link them with services and how school personnel can best communicate with families about related concerns.

**For information on Visions for Tomorrow and Parents & Teachers as Allies contact:**
www.namiioawa.org  email: info@namiioawa.com  Tel:(800) 417-0417 (toll free outside metro Des Moines area) or (515)254-0417
Parent and Teacher Education continued…

Disability Resource Library (Iowa City IA)
Resources available from Iowa's University Center for Excellence on Disabilities at the University of Iowa Children's Hospital
www.healthcare.uiowa.edu/CDD (click on "Disability Resource Library")
Email: disability-library@uiowa.edu  Tel: (800)272-7713

Family Directions of Iowa, Inc. (West Des Moines IA)
Provides parents with expert education and advocacy to build healthy families and strengthen parent and child relationships Through the Parents Anonymous model.
www.familydirectionsiowa.org  Tel: (515)255-9490

Possibilities (Iowa City IA)
Possibilities includes descriptions and contact information for various education and training events of interest to parents. It is a free quarterly publication of the Center for Disabilities and Development Iowa's University Center for Excellence on Disabilities at the University of Iowa Children's Hospital.
To subscribe: Email: michael-hoening@uiowa.edu or Tel: (319)353-6448

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Infant and Toddler Resources

Better Kid Care (Pennsylvania)
Early childhood education, information, and support from Penn State
www.betterkidcare.psu.edu

Care for Kids Program (EPSDT)
In Iowa, the EPSDT program is called Care for Kids, and the services are free to Medicaid enrolled children. This program allows eligible children who need mental health care to receive preventive and all medically necessary health care through the Early Periodic Screening, Diagnosis, and Treatment (EPSDT) program, including oral health care. EPSDT provides any health care service that is medically necessary and approved by Medicaid.

To learn if your child is eligible for any of the services provided under Medicaid, contact the Department of Human Services in your district. Eligibility determinations are based on developmental disabilities. To contact the EPSDT Care for Kids program coordinator for your county: www.idph.state.ia.us  Tel:(800)369-2229

(The Iowa Department of Human Services contracts with the Iowa Department of Public Health to assure that children have access to EPSDT Care for Kids services throughout the state of Iowa. Iowa's Child Health Screening Centers provide EPSDT Care for Kids services locally.)
Healthy Opportunities for Parents to Experience Success (HOPES) (pre-natal to age 4)
Healthy Families Iowa (HFI)
Healthy Opportunities for Parents to Experience Success - Healthy Families Iowa (HOPES-HFI) is a researched-based home visiting program for families that begins during pregnancy or at the birth of a child and can continue for up to age 4. The program follows the national Healthy Families America model of home visiting. This standard tool is used to identify level of risk and screens for the family conditions and characteristics that impact child growth, development, and health. Examples include family coping skills, parenting skills, and family functioning. Families identified as "high-risk" are offered HOPES-HFI services and voluntarily agree to participate.
www.pcaiowa.org (Available in Black Hawk, Polk, Woodbury, Scott, Lee, Hamilton, Clinton, Buchanan, and Lee counties)

Iowa Child Care and Early Education Network
Iowa Child Care and Early Education Network provides child care and education resources for early childhood professionals, child care providers, parents, advocates, policy makers, and others interested in early childhood.
www.iowachildnetwork.org

Iowa Community Empowerment programs
Community Empowerment was founded on the premise that communities and state government can work together to improve the well being of our youngest children by uniting agencies, organizations and community partners to speak with a shared voice to support, strengthen and meet the needs of all young children and families. Individuals in local communities work together can identify and implement the best means for attaining desired results
www.empowerment.state.ia.us

Parents as Teachers (PAT)
Parent education and family support program serving families throughout pregnancy until their child enters kindergarten, usually age 5. Parents are supported by PAT-certified parent educators trained to translate scientific information on early brain development into specific when, what, how and why advice for families. By understanding what to expect during each stage of development, parents can easily capture the teachable moments in everyday life to enhance their child's language development, intellectual growth, social development and motor skills.
www.parentsasteachers.org

Iowa Resources

211 Information & Referral
Call the phone number 211 to receive information and referrals to human services for a number of health related topics. Some of the topics include, after school programs, Head Start, family resource centers, family support & parent education programs, summer camps and recreation programs, mentoring, tutoring, protective services, and child health insurance.
Tel: 211
Arc of Iowa (Urbandale IA)
State-wide advocacy organization of parents and others representing people with intellectual and developmental disabilities.
www.thearcofiowa.org  Tel: (515)331-4426 or (800)362-2927

ASK Family Resource Center (Des Moines IA)
ASK stands for "Access for Special Kids." The ASK Family Resource Center of Iowa is a "one-stop-shop" for children and adults with disabilities and their families. The member organizations provide a broad range of information, advocacy, support, training, and direct services.

Member organizations of ASK Resources:
Parent Training and Information Center (PTI)
Learning Disabilities Association of Iowa
Self-Advocacy and Leadership for Youth with Disabilities. (SALYD)
Family Voices of Iowa (FVI)
Families of Iowa Network for Disabilities (F.I.N.D.)
Brain Injury Association of Iowa
The Health Information Center
www.askresource.org  Email: info@askresource.org
Tel: (515)243-1713 or (800)450-8667  TDD: 1(800)735-294

Brain Injury Association of Iowa (Urbandale IA)
Advocacy organization representing people with brain or head injuries
www.biaia.org  Tel: (515)331-8960 or (800)444-6443

Center for Disabilities and Development (CDD) (Iowa City)
The CDD works to improve the health and independence of people with disabilities and advance the community systems on which they rely. CDD can help find the information you want.
www.healthcare.uiowa.edu/cdd/index  Tel: (319)356-1118

Child Health Specialty Clinics-Parent Consultants
Parent Consultants are themselves parents of children with special health care needs. Under Iowa's Title V program, Parent Consultants provide free peer support to other parents of children with special health care needs. They are located in Child Health Specialty Clinics Regional Centers. These clinics serve children and youth ages birth-21 years who have a chronic condition (physical, developmental, behavioral, or emotional), who have increased risk for a chronic condition, and who have a need for special services.

Clinic locations:
Carroll: (712)792-5530  Council Bluffs: (712)328-6798
Creston: (641)782-9500  Davenport: (319)421-2141 or 2143
Des Moines: (515)727-4121  Dubuque: (319)588-0981
Fort Dodge: (515)955-8326  Iowa City (central office): (319)356-1118
Mason City: (641)422-7388  Ottumwa: (641)682-8145
Sioux City: (712)279-3411  Spencer: (712)264-6362 or 6363
Waterloo: (319)272-2315  West Burlington: (319)752-6313

Iowa Resources continued…
Children-At-Home (CAH) (Source: www.dhs.state.ia.us/docs)
CAH serves children with serious emotional disturbance, mental retardation, developmental disabilities, or brain injuries and their families, based on their income level. By providing an array of in-home and out-of-home support services, families are able to prevent temporary or long-term residential placements. The Children-at-Home program provides similar assistance to that provided by the Family Support Subsidy (FSS) program, except that the assistance is provided on an “as needed” basis and is generally time-limited, in many cases one-time-only.
www.dhs.state.ia.us

Citizens’ Aide/Ombudsman
Independent and impartial agency to which citizens can air their grievances about government.
www.legis.state.ia.us/ombudsman Tel: (515)281-3592

Des Moines Child Guidance Center
Information on outreach services provided to more than 50 central Iowa schools to help children achieve healthy emotional and social development so they can succeed academically.
www.orchardplace.org/content/services/guidance

Easter Seals Iowa (Des Moines IA)
Provides exceptional services to ensure that all people with disabilities or special needs and their families have equal opportunities to live, learn, work and play in their communities.
ia.easterseals.com Tel: (515)289-1933 TTY(515)289-4069

Foundation 2
Offers crisis intervention programs
www.foundation2.org Tel: (319)362-2174

HCBS Habilitation Services Program
Iowa Home and Community Based Waiver program for mental illness.
www.ime.state.ia.us/HCBS/HabilitationServices

ID Action (Iowans with Disabilities in Action)
Presents the tools to do everything from registering to vote to running for office.
www.idaction.org Tel: (866)432-2846

International Dyslexia Association-Iowa Branch (Gowrie IA)
Parent organization advocating for early identification and multi-sensory approach to teaching and learning for those affected by dyslexia. Tel: (515)352-3548

Iowa Advocates for Mental Health Recovery www.iarecovery.org

Infonet (publication of the Governor’s DD Council)
Information for Iowans with disabilities, including legislative updates.
www.infonetiowa.com

Iowa Resources continued…
Iowa Area Education Agencies (AEA)
The AEA website has information about the regional service agencies which provide school improvement services for students, families, teachers, and their communities. Your local Parent & Educator Coordinator (PEC) can also be reached through the AEA.
www.iowaaea.org

Iowa Association of Community Providers
Information to locate a provider of mental health, residential and vocational services in Iowa
www.iowaproviders.org  Tel: (515)270-9495

Iowa COMPASS (Iowa City IA)
Iowa’s free, statewide information and referral for people with disabilities, their families, and service providers. www.iowacompass.org  Email: iowa-compass@uiowa.edu
Tel: (800)779-2001  TTY:(877)689-0032

Iowa Consortium for Mental Health
Conducts and supports mental health services research focusing on the occurrence, recognition, and treatment of serious mental illness in community-base setting
www.ICMentalHealth.org  Tel: (319)353-5436

Iowa Department of Human Service (DHS)
Information about the Division of Mental Health and Developmental Disabilities and county plans/policies and procedures; staff contact; and links to other disability resources or the Iowa Dept. of Human Services. Resource to all parties involved in the delivery of psychological services for people eligible for Medicaid in Iowa.
www.dhs.state.ia.us  Tel: (800)972-2017
Division of Mental Health  Tel: (515)281-5874

Iowa Department of Inspections and Appeal
Contact information and procedural information for regarding agency inspections.
www.state.ia.us/government/dia  Tel: (515)281-7102

Iowa Dual Recovery Anonymous
Provides information about meeting sites and the advantages of simultaneous treatment of co-occurring disorders (mental health and substance abuse).
www.iowadra.org

Iowa Early Care and Education Professional Development
Provides information for individuals caring for children in Iowa.
www.iaeceprofdev.org

Iowa Federation of Families for Children’s Mental Health
Provides education, resources, and information and referrals to families who have children with emotional or behavioral difficulties.
www.iffcmh.org  Email: iowaffcmh@aol.com Tel: (319)462-2187  Families: (888)462-2187

Iowa Resources continued…
Iowa Governor’s DD Council (Developmental Disabilities)
www.state.ia.us/ddcouncil Tel:(515)281-9082

Iowa Legal Aid
Along with attorneys from Volunteer Lawyer Projects, helps those facing basic issues of health, safety, and survival.
www.iowalegalaid.org Tel:(800)532-1275

Iowa Legislative
Information on the Iowa Legislature including bills, legislators, history, and current law.
www.legis.state.ia.us Senate Tel: (515)281-3371 House Tel: (515)281-3221

Iowa Medicaid Enterprise
Site for people who receive or want to know more about Medicaid.
www.ime.state.ia.us

Iowa Office of Consumer Affairs
Represent the interests of consumers (adults and children) in the planning and evaluation of mental health policy among other mission statements.
www.iowaofficeofconsumeraffairs.com Tel: (515)281-7274

Iowa Protection and Advocacy Services, Inc.
Information on human and legal rights related to public education, employment opportunities, and residence or treatment in the least restrictive environment. www.ipna.org

Iowa Respite & Crisis Care Coalition (IRCCC) (Urbandale IA)
Parent-driven organization provides referral, advocacy, information and limited funding for respite and crisis care services.
www.irccc.com Tel: (515)309-0858 or (877)255-3140)

Iowa Statewide Independent Living Council
Statewide network for centers of independent living.
www.iowasilc.org Tel: (515)282-0275 or (877)466-7442 TTY: 1(800)469-0623

Iowa Training Consortium
Advertises, and encourages training and education to build supportive communities for Iowans with disabilities. www.disabilitytraining.org Tel: (319)353-6448

Iowa Vocational Rehabilitation Services
Work with individuals with disabilities to achieve their employment and economic goals.
www.dvrs.state.ia.us Tel: (515)281-4311 or (800)532-1486 TTY: 1(800)288-7185

Learning Disabilities Association of Iowa (Indianola IA)
An advocacy, support and training organization of parents of children who learn differently and believe they should be taught differently. www.ida-ia.org Tel: (888)690-5324

Iowa Resources Continued...
Magellan Behavioral Care of Iowa (Magellan)
Magellan works with the Iowa Department of Human Services and the Iowa Department of Public Health to administer the Iowa Plan. The Iowa Plan makes sure mental health and substance abuse services are available for eligible Medicaid recipients. Substance abuse treatment is also available through the Department of Public Health funding for people with limited incomes who are not enrolled through Medicaid.
www.magellanoiowa.com   Tel:(800)317-3738

NAMI IOWA   (Des Moines IA)
Sponsors Basics classes for parents of children with serious emotional disorders and other caregivers, Parents & Teachers as Allies in-services, Family-to-Family classes, Peer-to-Peer classes, In Our Own Voice and Provider Training. NAMI IOWA works to improve the lives of children and adults living with serious mental illnesses and their families through advocacy, support and education. Local NAMI affiliates and support groups are located in various communities across Iowa. Contact the NAMI IOWA office for information about a local group near you.
www.namiioawa.org   Email: info@namiioawa.com
Tel:   Email: (515)254-0417 or (800)417-0417

National Association of Social Workers, Iowa Chapter
www.iowanasw.org   Tel: (515)277-1117

Parenting Monthly
List of support groups and classes offered primarily in central Iowa.
www.parentingmonthly.org

Prevent Child Abuse
parent training/support
Contact: www.pcaiowa.org

Federal Agencies

Center for Mental Health Services (CMHS)
Children, Adolescents and Family Resources
www.mentalhealth.samhsa.gov
Federal Agencies continued…

**Centers for Disease Control and Prevention (CDC)**
Data and statistics on suicide and information available on mental illnesses.  [www.cdc.gov](http://www.cdc.gov)

**Centers for Medicare & Medicaid Services (CMS)**
CMS administers the Medicare, Medicaid and SCHIP (State Children’s Health Insurance Program) programs.  [www.cms.hhs.gov](http://www.cms.hhs.gov)

**Department of Education (DOE)**
**Office of Special Education and Rehabilitative Services (OSERS)** information for families, school districts and states in: special education, vocational rehabilitation and research.  [www.ed.gov/about/offices/list/osers/index.html](http://www.ed.gov/about/offices/list/osers/index.html)

**Insure Kids Now**
The U.S. Department of Health and Human Services’ national campaign to link the nation’s 10 million uninsured children 1 from birth to 18 years to free and low-cost health insurance.  [www.insurekidsnow.gov](http://www.insurekidsnow.gov)

**National Institute of Mental Health (NIMH)**
The mission of NIMH is to diminish the burden of mental illness through research.  [www.nimh.nih.gov](http://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 and implement effective and coordinated prevention and intervention programs. The agency also works to improve the juvenile justice system.  [www.ojjdp.ncjrs.org](http://www.ojjdp.ncjrs.org)

**Office of the U.S. Surgeon General**

**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.  [www.mentalhealthcommission.gov](http://www.mentalhealthcommission.gov)

**Social Security Administration (SSA)**  [www.ssa.gov](http://www.ssa.gov)  Tel: (800)772-1213


**U.S. Department of Health and Human Services**
**Substance Abuse and Mental Health Services Administration (SAMHSA)**  [www.samhsa.gov](http://www.samhsa.gov)
Children’s Mental Health and Advocacy Organizations

About Our Children
Scientifically-based, parent-friendly website of the NYU Child Study Center that includes a wide range of information on child mental health disorders and associated parenting issues. It has over 200 faculty reviewed articles, resources for children and parents, and a publications section that includes newsletters and manuals developed by the faculty of the Child Study Center.
www.aboutourkids.org

Autism Society of America
Information and resources on autism.
www.autism-society.org

Bazelon Center for Mental Health Law
Works on a broad array of children's mental health issues.
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.
www.bpkids.org

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, and their families, and protecting every child from harm.
www.cwla.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.
www.chadd.org

Children Now
www.childrennow.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.
www.childrensdefense.org
Children’s Mental Health and Advocacy Organizations continued…

Children’s Health Council
www.childrenshealthcouncil.org

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.
www.ccbd.net/index.cfm

Covering Kids & Families
www.Coveringkidsandfamilies.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.
www.ffcmh.org

National Alliance on Mental Illness (NAMI)
NAMI is the nation’s largest grassroots mental health organization dedicated to improving the lives of children and adults living with mental illness and their families. Founded in 1979, NAMI has become the nation’s voice on mental illness, a national organization including NAMI organizations in every state and in over 1100 local communities across the country who join together to meet the NAMI mission through advocacy, research, support, and education.
www.nami.org

National Center for Mental Health and Juvenile Justice (NCMHJJ)
NCMHJJ promotes awareness of the mental health needs of youth in the juvenile justice system and assists the field in developing improved policies and programs based on the best available research and practice. Their web site includes many excellent resources on addressing the mental health needs of youth involved in the juvenile justice system.
www.ncmhjj.com

National Child Traumatic Stress Network Center
The National Child Traumatic Stress Network Center works toward raising the standard of care and improve access of services to traumatized children, their families and communities throughout the United States. They provide valuable resources for parents, caregivers, educators and professionals on child traumatic stress.
www.nctsn.org

National Disability Rights Network (NDRN)
NDRN is a national organization of protection and advocacy and client assistance programs for children and adults with disabilities. These programs provide legally based advocacy services for people with disabilities, including mental illnesses, in the United States.
www.napas.org
Children’s Mental Health and Advocacy Organizations continued…

**National Health Law Program (NHeLP)**
The National Health Law Program has a number of excellent publications, resources and information on Medicaid and other important health-related topics.

*www.healthlaw.org*

**National Mental Health Association (NMHA)**
NMHA is an advocacy, education and support organization working to address the needs of people with mental health related needs and mental illnesses.

*www.nmha.org*

**National Parent Network on Disabilities**
*www.npnd.org*

**National Parent Information Network (NPIN)**
*www.npin.org*

**New Freedom Initiative: State Coalitions to Promote Community-Based Care (Olmstead)**
Support for states and territories in their efforts to respond to the goals outlined in the President's New Freedom Commission on Mental Health Report. The initiative provides financial assistance, technical assistance and training to promote community-based care.

*www.olmsteadcommunity.org*

**OCD Resource Center**
Information and resources available on obsessive compulsive disorder.

*www.ocdresource.com*

**Parent to Parent - USA**
A national non-profit organization committed to assuring access and quality in Parent to Parent support across the country. Parent to Parent programs provide emotional and informational support to families of children who have special needs most notable by matching parents seeking support with an experiences, trained "Supporting Parent."

*www.p2pusa.org*

**Youth Law Center**
Staff attorneys investigate reports of abuse of children in adult jails, juvenile detention facilities, state institutions, and child welfare systems, and uses training, technical assistance and negotiation to bring about needed change. If abusive conditions or practices continue, the Center uses litigation as a last resort to protect children and ensure humane treatment.

*www.ylc.org*
Special Education and School-Based Mental Health

Centers for School Mental Health -- Technical Assistance Centers
In 1995, two national training and technical assistance centers focused on mental health in schools were established with partial support from the U.S. Department of Health and Human Services and the Center for Mental Health Services. One center is at UCLA and the other is at the University of Maryland at Baltimore. The web sites include information and resources on school-based mental health programs.

www.smhp.psych.ucla.edu (UCLA)  www.csmha.umaryland.edu (U of MD at Baltimore)

Council for Exceptional Children  www.cec.sped.org

IDEA Partnership
The IDEA Partnership is dedicated to improving outcomes for students and youth with disabilities by joining state agencies and stakeholders through shared work and learning. The web site includes many helpful resources for schools, families and advocates.

www.ideapartnership.org

Intervention Central
This website offers free tools and resources to help school staff and parents to promote positive classroom behaviors and foster effective learning for all children and youth.

www.interventioncentral.org

National Disability Rights Network (NDRN)
Provide legally based advocacy services for people with disabilities, including mental illness. Provides protection and advocacy and client assistance programs for children with disabilities.

www.napas.org

National Information Center for Children and Youth with Disabilities (NICHCY)
NICHCY is an information and referral center that provides information on disabilities and disability-related issues (including mental illnesses) for families, educators, and other professionals, with a special focus on children and youth from birth to age 22.

www.nichcy.org

National Technical Assistance Center on Positive Behavioral Interventions and Supports (PBIS)
Addresses the behavioral and discipline systems needed for successful learning and social development of students. The Center provides capacity-building information and technical support about behavioral systems to assist states and districts in the design of effective schools.

www.pbis.org

SchoolMentalHealth.org
Offers school mental health resources for clinicians, educators, administrators, parents/caregivers, families, and students. The resources included in the site emphasize practical information and skills based on current research, including prominent evidence based practices, as well as lessons learned from local, state, and national initiatives.

www.schoolmentalhealth.org
School Psychiatry Program and the Mood & Anxiety Disorders Institute (MADI) Resource Center  The School Psychiatry Program and the Mood & Anxiety Disorders Institute (MADI) Resource Center, both part of the Department of Psychiatry at Massachusetts General Hospital (MGH), jointly created Schoolpsychiatry.org. This website is committed to enhancing the education and mental health of every student in every school. The website has resources for parents, educators and clinicians to ensure that each group is working together to support children and teens with mental health conditions.

www.schoolpsychiatry.org

Technical Assistance Alliance for Parent Centers  The Technical Assistance Alliance for Parent Centers is an innovative project that supports a unified technical assistance system for the purpose of developing, assisting and coordinating Parent Training and Information Projects and Community Parent Resource Centers under the Individuals with Disabilities Education Act (IDEA).

www.taalliance.org

Wrightslaw: Special Education Law  The Wrightslaw web site is designed for families, advocates, educators, and attorneys looking for accurate, up-to-date information about special education law and advocacy for children with disabilities, including those with mental illnesses.

www.wrightslaw.com

Professional Organizations

American Academy of Child & Adolescent Psychiatry (AACAP)  www.aacap.org

American Academy of Pediatrics  www.aap.org

American Psychiatric Association (APA)  www.psych.org

American Psychological Association (APA)  www.apa.org

American School Counselors Association (ASCA)  www.schoolcounselor.org

American School Health Association (ASHA)  www.ashaweb.org

National Association of Social Workers  www.naswdc.org
Professional Organizations continued…

National Association of State Mental Health Program Directors (NASMHPD)  
www.nasmhpd.org

National Association of School Psychologists (NASP)  www.nasponline.org

Academic Centers Focused 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.  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.  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.  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.  www.georgetown.edu/research/gucdc/cassp.html

New York University Child Study Center  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.  www.rtc.pdx.edu

Yale Child Study Center  
The mission of the Center is to understand child development, social, behavioral, and emotional adjustment, and psychiatric disorders and to help children and families in need of care.  info.med.yale.edu
Suicide Prevention

American Foundation for Suicide Prevention (AFSP)
www.afsp.org

Columbia University Teen Screen Program
A national mental health and suicide risk screening program dedicated to helping parents find teens with the known risk factors for suicide by making voluntary mental health check-ups available to all American families.
www.teenscreen.org  Tel: (212)265-4453

JED Foundation
The work of the JED Foundation is focused on college students.
www.jedfoundation.org

National Strategy for Suicide Prevention
www.mentalhealth.org/suicideprevention

SOS – Signs of Suicide Program
www.mentalhealthscreening.org/highschool

Suicide Prevention Action Network (SPAN)
www.spanusa.org

Suicide Prevention Resource Center (SPRC)
www.sprc.org

Yellow Ribbon Suicide Prevention Program
www.yellowribbon.org

Youth Suicide Prevention School-Based Guide
www.theguide.fmhi.usf.edu

Websites for Children & Teens

KidsHealth
KidsHealth has separate areas for children, teens and parents. Each of these sections includes its own design, age-appropriate content, and tone. There are many in-depth features, articles, animations, games, and resources developed by experts in the health of children and teens. For information for teen mental health, click on "teens" and then click on "Your Mind" to access a broad array of resources for teens.
www.kidshealth.org
Websites for Children & Teens continued…

Mindzone – Cope. Care. Deal.
A mental health web site for teens that includes plenty of extremely helpful information. The funding for Mindzone comes from the Annenberg Foundation Trust at Sunnylands with support from the Annenberg Public Policy Center of the University of Pennsylvania. www.copecaredeal.org

Reach Out!
This Australian-based website contains valuable information for any teenager to help improve their mental health and wellbeing during the transition-age years. The interactive site includes coping tips, forums, fact sheets, personal stories and resources regarding mental illness, school, employment and relationships. www.reachout.com.au

Step Out of the Silence
A virtual community where youth can share their experiences with mental illnesses through artwork, prose, poetry, photography, and graphic art. The website also offers information on how youth can participate in anti-stigma campaigns and advocacy efforts regarding mental health. www.stepoutofthesilence.org

Miscellaneous Mental Health Related Resources

Health Central Network
Provides timely, in-depth, trusted medical information, personalized tools and resources, and connections to a vast community of leading experts and patients for people seeking to manage and improve their health. www.ncadi.samhsa.gov Tel: (703)302-1040

Learning Disabilities Association of America
Provides support to people with learning disabilities, their parents, teachers and other professionals. www.ldaamerica.org Tel: (888)690-5324

Mental Health Recovery & WRAP
Recovery and wellness information. www.mentalhealthrecovery.com Tel: (802)254-2092

Minds and K9s, Inc.
A mental health educational organization that provides resources and programs on mental health www.MindsandK9s.org Tel: (913)250-5433

National Rehabilitation Information Center (NARIC)
Access resources for employment, advocacy, benefits and education. www.naric.com Tel: (800)346-2742
Miscellaneous Mental Health Related Resources continued…

The National Research and Training Center on Psychiatric Disability
Research, training, technical assistance and dissemination activities designed to promote self-
determination among people with psychiatric disabilities.
www.psych.uic.edu/uicnrtc  Tel: (312)422-8180

National Alliance for Research on Schizophrenia & Depression (NARSAD)
Patient advocacy group provides information about depression, schizophrenia, autism, mental
illnesses, medications, and research. www.narsad.org  Tel: (515)829-0091

National Council on Alcoholism
Works to promote prevention, intervention, research and treatment of drug and alcohol.
www.ncadd.org  Tel: (800)622-2255

National Dissemination Center for Children with Disabilities
Information on disabilities, special education and related services, IEPs, transition and more.
www.nichcy.org  Tel: (800)695-0285

National Empowerment Center
Provides information consumers might need in order to regain control over their lives and the
resources that affect their lives. www.power2u.org  Tel: (800)769-3728

National Mental Health Consumers Self-Help Clearinghouse
Consumer run technical assistance center with connections to peer run groups.
www.mhselfhelp.org  Tel: (800)553-4539

Partnership for Prescription Assistance
Patient assistance program clearinghouse. www.pparx.org  Tel: (888)477-2669

Recovery International
www.lowselfhelpsystems.org  Tel: (312)337-5661

ULifeline
An online resource center for college student mental health and emotional well-being.
www.ulifeline.org

______________________________________________________________________________

Information for Foster and Adoptive Parents

The Passage from Youth to Adulthood
This guide to services and information is written to help young people with disabilities who have
gone through the foster care system make a successful transition. It includes where, why, when
and how to make the most of the years after foster care. While the guide is geared toward youth
in Florida, much of the planning and information (especially about Federal Laws) is applicable to
youth in other states. www.floridaschildrenfirst.org
IFAPA – Adoption Information Specialist
Iowa Foster & Adoptive Parents Association provides information specialists to strengthen and support adoptive families through training opportunities, educational materials, and information on services, connections with adoptive families, support groups, and follow-up information.

IFAPA – Adoption Respite Program
Families who receive subsidized adoptions are eligible for a limited number of days of respite per year (July 1-June 30). Iowa Foster & Adoptive Parents Association (IFAPA) administers the Subsidized Adoption Respite Program.

IFAPA – Foster Care Respite Program
Each child or teen in foster care is eligible for 24 days of respite care per calendar year. Iowa Foster & Adoptive Parents Association (IFAPA) administers the Foster Care Respite Program.

Iowa Foster & Adoptive Parents Association (IFAPA) (Ankeny IA)
Serves foster and adoptive families, by providing education, resources, and information to children with mental health needs and their families.

Contact IFAPA for information regarding the programs listed above:
www.ifapa.org  Email: ifapa@ifapa.com  Tel: (515)289-4567 or (800)277-8145

Parent Liaisons
The Iowa Foster and Adoptive Parents Association, using funds provided by the Iowa Department of Human Services, contracts with foster and/or adoptive parents to provide peer support for other foster and adoptive parents. The liaisons contact each new foster parent, provide information and support to families, visit area support groups, and relate concerns to the Department of Human Services. www.ifapa.org/liasons

Resources and Organizations Focused on Specific Mental Health Disorders

Anxiety Disorders
Anxiety Disorders Association of America
www.adaa.org  Tel: (240)485-1001

Attention Deficit/Hyperactivity Disorder
ADD Resources
www.addresources.org

Children & Adults with Attention Deficit Disorders (CHADD)
Iowa chapter contact information is available at the national website. www.chadd.org

Autism

Autism Society of Iowa
www.autismia.org  Tel: (515)327-9075 or (888)722-4799
Resources and Organizations Focused on Specific Mental Health Disorders continued…

**Autism Society of America**  [www.autism-society.org](http://www.autism-society.org)

**National Alliance for Autism Research**  [www.naar.org](http://www.naar.org)

**Borderline Personality Disorder**

BPD Central  [www.bpdcentral.com](http://www.bpdcentral.com)

**Co-Occurring Disorders**

**Dual Diagnosis**
Treatment and education options concerning co-occurring addiction and mental illness.  [www.dualdiagnosis.org](http://www.dualdiagnosis.org)

**Depression & Bipolar Disorder**

Child and Adolescent Bipolar Foundation (CABF)  [www.cabf.org](http://www.cabf.org)

Depression & Bipolar Support Alliance (DBSA)  
[www.dbsalliance.org](http://www.dbsalliance.org)  Tel: (312)642-0049 or (800)826-3632

**Fetal Alcohol Syndrome**

National Organization on Fetal Alcohol Syndrome  [www.nofas.org](http://www.nofas.org)

**Obsessive Compulsive Disorder OCD**

Obsessive Compulsive Disorder  [www.ocdonline.com](http://www.ocdonline.com)

Obsessive Compulsive Disorder  [www.ocdchicago.org](http://www.ocdchicago.org)

**Schizophrenia**

Schizophrenia  [www.schizophrenia.com](http://www.schizophrenia.com)

**Tourette Syndrome**

Tourette Syndrome Association  [www.tsa-usa.org](http://www.tsa-usa.org)
Section VIII.

Appendix
| Appendix 3 | behavior log |
| Appendix 4 | medication log |
| Appendix 5 | contact information-school |
| Appendix 6 | contact information-resources |
# behavior log

**child's/teen's name:**
__________________________________________________________________________________

<table>
<thead>
<tr>
<th>date</th>
<th>description of behavior</th>
<th>intervention</th>
<th>who learned what?</th>
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medication log

child’s/teen's name: ________________________________________________________________

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<th>date</th>
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<th>medication</th>
<th>frequency</th>
<th>change/results</th>
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APPENDIX
## contact information—school

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<th>school staff</th>
<th>name</th>
<th>address</th>
<th>phone</th>
<th>email</th>
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<td>principal</td>
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<td>counselor</td>
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<td>nurse</td>
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## Contact Information — Resources

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<th>Support Groups/Contacts</th>
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<th>Email</th>
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APPENDIX
Contact Information—local resources continued...

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<th>agencies &amp; providers</th>
<th>address</th>
<th>phone</th>
<th>email</th>
<th>note</th>
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APPENDIX
Contact Information—local resources continued...

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<th>address</th>
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APPENDIX
Contact Information—local resources continued...

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