

# SUPPORT FAMILIES

Welcome to the Missouri Developmental Disability Resource Center (MODDRC). You are receiving this letter with an enclosed packet of information because a request was made by you (or someone on your behalf) to the MODDRC.

We have compiled information from a number of sources and have included them in this packet, which is divided into the following sections:

- Overview of a specific disability, special health care need, or other major topic
- Current practices
- Personal Stories
- Family support, advocacy and services
- Missouri Service Systems

The MODDRC, which has now expanded to include Missouri's Family-to-Family Health Information Center, seeks to inform and connect individuals with disabilities or special health care needs and/or their families to peer support. We also provide opportunities for leadership development and volunteerism. When contacting the MODDRC, you are connecting to staff that have firsthand knowledge about disability related issues because they have the experience of living with the disability, either as an individual, parent or family member.

Thank you for using the MODDRC. This packet of information is one of the many ways that the MODDRC can support you in your journey with disability. We hope you will connect with us again.

Missouri Developmental Disability Resource Center/Family-to-Family Health Information Center is housed within Missouri's University Center for Excellence in Developmental Disabilities Education, Research and Services (UCEDD) at the University of Missouri-Kansas City, Institute for Human Development.

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#### Section 1



# Overview

The purpose of this section is to help you gain a better understanding of a specific disability or special health care need. It is intended to provide a basic explanation of the disability and possible causes and characteristics.

If you would like more in-depth information on this topic, other topics of information or if it is not the topic you requested, please feel free to contact us again.

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# **Overview: Bipolar Disorder**

We all go through times when we feel "down" or sad and when we feel "up" or happy. But some of us go through deeper lows and higher highs than others. When mood changes become extreme and come in waves, or "episodes", a person may be showing signs of bipolar disorder (also known as manic-depressive illness).

These changes in mood are different than the kind most people feel. The feelings are usually very strong and last for most of the day, almost every day, for at least one week. The person will show signs, called symptoms, of mania (mae-neeuh) during "manic" episodes and sadness during "depressive" (dee-press-iv) episodes.

Here are some signs to watch for:

Symptoms of mania:

- acts more silly, excited, or joyful than normal for the person, even when there is no real reason for it
- gets mad easily, has a short temper, or is very cranky
- sleeps less than usual, but doesn't act tired
- takes more risks than normal
- stays very busy, and looks for constant fun or excitement
- has trouble staying with a task, jumps from one thing to another
- talks fast and has racing thoughts
- thinks and/or talks about sex often, even at a very young age

Symptoms of depression:

- has deep sadness that lasts a long time
- feels hopeless or like he or she is worth nothing
- no longer wants to do things that used to be fun for him or her
- talks about having pain more often, like stomach or head aches
- eats a lot more or less than usual
- sleeps a lot, but still acts tired

• may think about death or taking his or her own life through suicide

Bipolar disorder runs in families. Most times, a child with a family member who has bipolar disorder will not get it themselves. But children who have a mom, dad, brother, or sister with the illness are four to six times more likely to show signs of bipolar disorder than those with no family history. (National Institute of Mental Health, 2010)

The brain is the part of our bodies that is in charge of both our thoughts and feelings. For a person with bipolar disorder, the brain has a harder time keeping control of these things. This



means that mood swings happen more often and are more powerful. When something causes the person stress, a mood swing may be triggered.

Bipolar disorder can be confused with other conditions, like ADHD or regular depression, so it is important to see a doctor to find out for sure and begin a plan to treat it.

Learning about Bipolar Disorder can be confusing. Don't be afraid to ask questions of your doctors, others who have gone through it, and our staff here at the Missouri Developmental Disability Resource Center/ Family-to-Family Health Information Center. We're here to help.

National Insitute of Mental Health. (2010). *Bipolar Disorder in Children and Teens: A Parent's Guide.* Rockville, MD

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# **Current Practices**

The purpose of this section is to provide you with the most current techniques and procedures for supporting people with developmental disabilities or special health care needs. These could include such things as:

- Information on therapies
- Medical treatment
- Accommodations
- Interventions

If you would like more information on current practices, please feel free to contact us again.

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On the following pages, you will find more information on Bipolar Disorder from sources the MODDRC regards as respected and trustworthy. All information has been reprinted with permission and is for educational purposes only. For more information regarding your personal situation, please consult your team of medical professionals.



#### **Bipolar Disorder: Diagnosis and Treatment**

It's much easier to tell if someone has a broken bone or an ear infection than it is to determine that someone has bipolar disorder. But specially trained doctors can often figure it out by looking at the way the person acts or talks and by listening to the person's symptoms or past experiences. If a doctor says someone has bipolar disorder, it can usually be treated so that the person lives a full, creative, productive life.

A combination of medicines can help prevent the symptoms and treat them if they occur. Sometimes it takes the doctor a while to find the right medicines or the right amounts for a particular person. Treatment also involves talking with a doctor on a regular basis to learn how to manage intense moods. Sometimes talking with other people who also have bipolar disorder helps, too. Over time, someone with bipolar disorder can learn what to do to feel more in control during mood shifts. Having bipolar disorder can be hard. The intense moods can cause someone to act in extreme ways. Mood problems can cause trouble in relationships and in the everyday things a person wants to do. Someone with bipolar illness doesn't mean to be so intense or unpredictable. People with bipolar illness often don't realize how their extreme moods affect others. Having a parent or a brother or sister with bipolar disorder can be hard on kids.

Although there's no cure for bipolar disorder, it's important to know that the condition can be treated and managed, especially if it's diagnosed early. And scientists are doing a lot of research, especially on how it affects kids. This research is helping doctors understand more about how to help people with bipolar disorder.

Reviewed by: D'Arcy Lyness, PhD Date reviewed: February 2007

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Depression and Bipolar Support Alliance

### Finding Peace of Mind: Treatment Strategies for Depression and Bipolar Disorder

#### How are mood disorders treated?

A good treatment plan often includes medication to stabilize mood, talk therapy to help with coping skills, and support from a peer-run group like DBSA (Depression and Bipolar Support Alliance) to help you manage your illness. Seeking treatment does not mean you are weak or a failure, it means you have the strength and courage to look for a way to feel better. Getting treatment for depression or bipolar disorder is no different than getting treatment for diabetes, asthma, high blood pressure or arthritis. Don't let feelings of shame or embarrassment keep you from getting help.

#### What is psychotherapy (talk therapy)?

Psychotherapy can be an important part of treatment. A good therapist can help you cope with the feelings you are having and change the patterns that contribute to your illness. Behavioral therapy concentrates on your actions; cognitive therapy focuses on your thoughts; and interpersonal therapy looks at your relationships with others. Your loved ones may join you in sessions of family or couples therapy. Group therapy involves several, usually unrelated people working with the same therapist and each other. Many therapists use a combination of approaches. One approach is not necessarily better than another the best choice is the one that works best for you.

# How is medication used to treat depression and bipolar disorder?

There are many safe, effective medications that may be prescribed to relieve symptoms of depression or bipolar disorder. You and your doctor will work together to find the right medication or combination of medications for you. This process may take some time, so don't lose hope.

No two people will respond the same way to a medication, and many people need to try several before they find the best one(s). Different treatments may be needed at different times in a person's life.

Keep your own records of treatment how you feel each day, what medications (and dosages) you take and how they affect you to help your doctor develop a treatment plan for you. DBSA's Personal Calendar can be very helpful with this.

Your doctor may start your treatment with a medication approved to treat mood disorders. He or she might also add other medications which have been approved by the Food and Drug Administration (FDA) as safe and effective treatments for other illnesses of the brain, but have not yet been specifically approved to treat depression or bipolar disorder. This is called "offlabel" use, and can be helpful for people whose symptoms don't respond to traditional treatments.

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#### Is it safe to take medication if I am pregnant or nursing?

Try to discuss pregnancy ahead of time with your doctor if you are planning it. If you become pregnant, inform your doctor immediately. You and your doctor should discuss your health in detail and make medication decisions based on vour need for the medication compared to the risk the medication may pose to your baby's health. The greatest period of risk for most medications is during the first three months of pregnancy, but some medications may also be harmful to a baby during later stages of pregnancy. Medications may also be present in breast milk, so your doctor may advise you to stop breastfeeding if you take medication.

#### How do mood disorders and treatments affect children?

Children with mood disorders often have a different set of symptoms than adults do. For example, children with bipolar disorder may switch more quickly between mania and depression, or experience more mixed states. Mania often appears as irritability or rage in children, and may be misdiagnosed as Attention Deficit Hyperactivity Disorder (ADHD).

Many mood disorder medications used for adults are prescribed for children. If your child has a mood disorder, make sure he or she is being treated by a doctor who has experience treating mood disorders in children. A child with bipolar disorder may have a manic episode if treated with antidepressants alone, so talk to your child's doctor to see if mood stabilizers should be tried first.

Much has been written about the use of certain types of depression medication in children and adolescents and the possibility of increased risk of suicide. Families and physicians must make informed decisions that compare benefits and risks of all treatment options. Treatment involves more than taking a medication. Parents must monitor their children's moods and behaviors and develop a close working relationship with

their child's health care provider that includes regular follow-up appointments.

#### How do mood disorders and treatments affect older adults?

With older adults, depression or bipolar disorder can sometimes be mistaken for normal signs of aging. These symptoms are not a normal part of growing older. Treatment can be very helpful for older adults, and they should be given a thorough physical examination if they have symptoms of a mood disorder. It's also important for older adults to be aware of possible medication interactions or medication side effects if they are taking several medications for different conditions.

#### What should I do if I experience side effects?

Many of the medications that affect the brain may also affect other systems of the body, and cause side effects such as dry mouth, constipation, sleepiness, blurred vision, weight gain, weight loss, dizziness or sexual problems. Some side effects become less or go away within days or weeks, while others can be long-term.

Don't be discouraged by side effects; there are ways to reduce or get rid of them. It may help to change the time you take your medication to help with sleepiness or sleeplessness, or take it with food to help with nausea. Sometimes another medication can be prescribed to block an unwanted side effect, or your dosage can be adjusted to reduce the side effect to a tolerable level. Other times your medication must be changed. Tell your doctor about any side effects you are having. The decision to change or add medication must be made by you and your doctor together, you should *never stop taking your* medication or change your dosage without talking to your doctor first.

Contact your doctor or a hospital emergency room right away if side effects cause you to become very ill with symptoms such as fever, rash, jaundice (yellow skin or eyes) breathing problems, heart problems (skipped beats,



#### racing), or other severe changes that concern you. This includes any changes in your thoughts, such as hearing voices, seeing things or having thoughts of death or suicide.

Be sure your doctor knows about all the medications you are taking for your mood disorder and any other physical illnesses you have. This includes over-the-counter or "natural/herbal" treatments. Even natural treatments may interact with your medications and change the way they work.

#### What if I don't feel better?

If you don't feel better right away, remember that it isn't your fault, and you haven't failed. Never be afraid to get a second opinion if you don't feel your treatment is working as well as it should. Here are some reasons your treatment may not be giving you the results you need.

**Not enough time:** Often a medication may not appear to work, when the reality is that it may not have had enough time to take effect. Most medications for mood disorders must be taken for two to four weeks before you begin to see results. Some can take as long as six to eight weeks before you feel their full effect. So, though it may not be easy, give your medication time to start working.

**Dosage too low:** With most medications used to treat mood disorders, the actual amount reaching the brain can be very different from one person to the next. A medication must reach the brain to be effective, so if your dose is too low and not enough reaches your brain, you might incorrectly assume the medication doesn't work, when you actually just need your doctor to adjust your dosage.

Different type (class) of medication needed:

Your doctor may need to prescribe a different type of medication, or add one or more different types of medication to what you are currently taking.

#### Not taking medications as prescribed:

A medication can have poor results if it is not taken as prescribed. Even if you start to feel better, keep taking your medication so you can keep feeling better. If you often forget to take your medications, consider using an alarm or pager to remind you, or keeping track of what you have taken using a pillbox with one or more compartments for each day. It may also be helpful for you to keep a written checklist of medications and times taken, or to take your medication at the same time as a specific event: a meal, a television show, bedtime or the start or end of a work day.

**Side effects:** Some people stop taking their medication or skip doses because the side effects bother them. Even if your medication is working, side effects may keep you from feeling better. In some cases, side effects can be similar to symptoms of depression or mania, making it difficult to tell the difference between the illness and the effects of the medication. If you have trouble with side effects, they don't go away within a few weeks, and the suggestions on page 6 don't help, talk to your doctor about changing the medication, but don't stop taking it on your own.

**Medication interactions:** Medications used to treat other illnesses may interfere with the medication you are taking for your depression or bipolar disorder. For example, some medications may keep others from reaching high enough levels in the blood, or cause your body to get rid of them before they have a chance to work. Ask your doctor or pharmacist about the possible interactions of each newly-prescribed medication with other medications you are taking.

**Other medical conditions:** Sometimes a medication may not work for reasons not related to your mood disorder. Medical conditions such as hypothyroidism, chronic fatigue syndrome, and brain injury can limit the effectiveness of your medication. Sometimes normal aging or menopause can change your brain chemistry and make it necessary to change your dosage or your medication. It's a good idea to have a complete



physical examination and discuss your complete medical history with your doctor.

Substance abuse: Alcohol or illegal drug abuse may interfere with the treatment of depression or bipolar disorder. For example, alcohol reduces the effectiveness 8 of some antidepressants. The combination of alcohol or drugs with your medication(s) may lead to serious or dangerous side effects. It can also be difficult to benefit from talk therapy if you are under the influence. If you are having trouble stopping drinking or using, you may want to consider a seeking help from a 12-step recovery program or a treatment center.

Non-response: Response to any medication, especially those for depression and bipolar disorder, can be very different for each individual. A certain percentage of people won't respond to a particular medication at all. If you are one of these people, don't give up hope. There are many treatment strategies available for you and your doctor to try.

#### What are some other treatments for depression and bipolar disorder?

#### **Electroconvulsive therapy (ECT)**

In the 1930s, researchers discovered that applying a small amount of electrical current to the brain caused small mild seizures that changed brain chemistry. Over the years, much has been done to make this form of treatment milder and easier for people to tolerate. ECT can be effective in treating severe depression. However, there can be side effects such as confusion and memory loss. The procedure must be performed in a hospital with general anesthesia.

#### **Transcranial Magnetic Stimulation (TMS)**

In TMS therapy, a small hand-held device with a special electromagnet is placed against the scalp and delivers short magnetic pulses that affect the brain. This is believed to help correct the chemical imbalance that causes depression. TMS therapy does not require surgery, hospitalization, or anesthesia. The side effects associated with TMS, such as a mild headache or lightheadedness, are relatively infrequent and usually go away

soon after the treatment session. The FDA has not yet approved TMS for treatment of depression. Clinical trials are ongoing.

#### Vagus Nerve Stimulation (VNS)

VNS involves implanting a small battery-powered device, similar to a pacemaker, under the skin on the left side of the chest. The device is programmed to deliver a mild electrical stimulation to the brain, which may work to correct the chemical imbalance. Studies have shown that VNS can benefit individuals who have not found relief with other treatments. The most common side effects of VNS are hoarseness, sore throat and shortness of breath. The FDA has approved VNS as a therapy for preventing epileptic seizures, but VNS is not yet approved for the treatment of depression. Clinical trials are ongoing.

#### Magnetic Stimulation Therapy (MST)

MST uses powerful magnetic fields to induce a small, mild seizure, similar to one produced through ECT. Clinical trials have recently begun. Researchers believe MST will be able to treat specific areas of the brain. It is hoped that this treatment will not affect memory or concentration. If these treatments interest you, discuss them with your doctor. Work with your doctor in a collaborative partnership to find the treatments that work best for you.

#### What are some things to find out from the doctor?

- What dosage(s) of medication should be taken, at what time(s) of day, and what to do if you forget to take your medication.
- How to change your dosage, if this needs to be done before your next visit.
- The possible side effects of your medication(s) and what you should do if you experience a side effect that bothers vou.
- How you can reach your doctor in an • emergency.
- How long it will take to feel better and what type of improvement you should expect.



- The risks associated with your treatment and how you can recognize problems when they happen.
- If your medication needs to be stopped for any reason, how you should go about it. (Never stop taking your medication without first talking to your doctor.)
- If psychotherapy is recommended as part of your treatment, and what type.
- If there are things you can do to improve your response to treatment such as changing your diet, physical activity or sleep patterns.
- What you can do if your current medication isn't helpful what your next step will be.
- The risks involved if you are pregnant, plan to become pregnant or are nursing.

• The risks involved if you have another illness, such as heart disease, cancer or HIV.

#### **Never Give Up Hope**

Right now you might be dealing with symptoms that seem unbearable, and it can be difficult to have patience as you search for effective treatment. The most important thing you can do is believe that there is hope. Treatment does work, and most people can return to stable, productive lives. Even if you don't feel 100% better right away, it's important to stick with treatment and remember that you are not alone.

This information was provided by the Depression and Bipolar Support Alliance, the nation's leading patient-directed educational organization focusing on depression and bipolar disorder. For more information like this, visit the DBSA website at <u>www.dbsalliance.org</u>





Depression and Bipolar Support Alliance

### **Psychotherapy: How it Works and How it Can Help**

Psychotherapy (also known as talk therapy) can be an important part of treatment for depression or bipolar disorder (manic depression). A good therapist can help you cope with feelings and symptoms, and change behavior patterns that may contribute to your illness.

Talk therapy is not just "talking about your problems"; it is also working toward solutions. Some therapy may involve homework, such as tracking your moods, writing about your thoughts, or participating in social activities that have caused anxiety in the past. You might be encouraged to look at things in a different way or learn new ways to react to events or people.

Most of today's psychotherapy is brief and focused on your current thoughts, feelings and life issues. Focusing on the past can help explain things in your life, but focusing on the present can help you cope with the present and prepare for the future. You might see your therapist more often at the beginning of treatment, and later, as you learn to manage problems and avoid triggers, you might go to psychotherapy appointments less often.

#### Psychotherapy can help you:

- Understand your illness
- Define and reach wellness goals
- Overcome fears or insecurities
- Cope with stress
- Make sense of past traumatic experiences
- Separate your true personality from the mood swings caused by your illness

- Identify triggers that may worsen your symptoms
- Improve relationships with family and friends
- Establish a stable, dependable routine
- Develop a plan for coping with crises
- Understand why things bother you and what you can do about them
- End destructive habits such as drinking, using drugs, overspending or unhealthy sex.

#### Who provides talk therapy?

Your therapist may be a psychiatrist (MD), psychologist (PhD, PsyD, EdD, MS), social worker (DSW, MSW, LCSW, LICSW, CCSW), counselor (MA, MS, LMFT, LCPC), or psychiatric nurse (APRN, PMHN). Your ability to talk honestly and openly with your therapist, set clear goals and make real progress is important. Think of your relationship with your therapist as a partnership. The two of you will work together to help you feel better. You do not need to feel ashamed or embarrassed about talking openly and honestly about your feelings and concerns.

#### How do I get started?

Make a list of the things that are bothering you and the issues you would like help with. Bring it with you to your first appointment. You might include:

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• Issues in your family or other relationships



- Symptoms like changes in eating or sleeping habits
- Anger, anxiety, irritability or troubling feelings
- Thoughts of hurting yourself

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In your first few sessions, you will probably do most of the talking. You should tell the therapist why you are there and what you would like to get from therapy. Make a list of short- and long-term goals with your therapist at the beginning of treatment. After a few sessions, your therapist may be able to give you an idea of how long therapy will take and when you can expect to see changes in your moods.

#### How will I know if I'm making progress?

After some time has passed, check the list and see if you're closer to reaching your goals. It may be helpful to track how you feel each day and how you cope with difficult situations. Review your progress with your therapist. Improvement won't happen overnight, but you should see some change, even if it's just a better understanding of your own thoughts and feelings. It is also helpful to learn everything you can about depression and bipolar disorder and their treatments. Check your local library for other books and reference materials.

#### What if I'm not making progress?

If, after some time, you don't begin to feel some relief, you have a right to seek a second opinion (as you would with any illness) from another therapist or mental health professional. You have a right to have the best treatment possible, and you *can* feel better.

#### What type of therapy is best for me?

There are many types of talk therapy and most therapists use a combination of approaches. Behavioral therapy concentrates on your actions; cognitive therapy focuses on your thoughts; and interpersonal therapy looks at your relationships with others. Your loved ones may join you in sessions of family or couples therapy. Group therapy involves several, usually unrelated people working with the same therapist and each other. One approach is not necessarily better than another the best choice is the one that works best for you.

# What are some therapies commonly used for depression or bipolar disorder?

**Interpersonal therapy (IPT)** was originally developed to treat depression. It has since been adapted for bipolar and other disorders. It is time-limited and goal-oriented, and addresses a person's symptoms, social relationships and roles. IPT focuses on what is happening "here and now" and attempts to help a person change, rather than just understand his or her actions and reactions. The patient and therapist examine current and past relationships. IPT does not focus on unconscious or subconscious motivations, wishes or dreams. It looks at conscious, outward action and social adjustment. It does not try to change the personality, but rather to teach new skills that can lessen symptoms.

An IPT therapist is an active supporter of the patient on the wellness journey. The therapist does not assign homework, but may encourage a patient to engage in social activities. The therapist helps the patient review his or her symptoms and relate these symptoms to one of four things: grief over a loss, conflicts with others, changes in life status such as moving or changing jobs or isolation/ lack of social skills. The therapist and patient then work through specific situations, one by one, to relieve symptoms and stress.

**Cognitive-behavioral therapy (CBT)** combines cognitive therapy, which involves examining how thoughts affect emotions, and behavioral therapy, which involves changing a person's reactions to challenging situations. CBT is goal-oriented and works best when the patient takes an active role. One aspect of CBT helps a person recognize the automatic thoughts or core beliefs that contribute to negative emotions. The therapist helps the person see that some of these thoughts and beliefs are false or don't make sense and helps



the person change them. Types of automatic thoughts may include focusing on one negative idea (an unkind person) and applying the negative quality to everything (the human race in general); viewing things as "all good" or "all bad"; or applying labels such as "loser," "no good," or "worthless." Types of core beliefs may include, "I have to succeed at everything"; "Everyone has to love me"; "It's a disaster if things don't go the way I plan or expect"; or "I can't change the miserable way I am."

The behavioral aspect of CBT takes place after a person has a more calm state of mind. The person can then take actions that help him or her move closer to planned goals. For example, if depression has caused someone to withdraw from life, that person may be encouraged to participate in hobbies or spend time with friends. Or a person may be gently coached, under supervision, to confront situations, things or people that cause fear or panic. Through practice, a person learns new, healthier behaviors.

With CBT, the therapist assigns homework. It may include journaling, reviewing notes or tapes of the therapy session, or trying a new approach to an old problem. There may also be exercises to make a person more aware of his or her own thoughts and actions without judging them.

The most important parts of any type of therapy are partnership, communication, goals, collaboration, trust, understanding and action. Successful therapy can help a person change thoughts, beliefs, perceptions, actions and moods for the better.

This information was provided by the Depression and Bipolar Support Alliance, the nation's leading patient-directed educational organization focusing on depression and bipolar disorder. For more information like this, visit the DBSA website at <u>www.dbsalliance.org</u>

#### Section 3



# Personal Stories

The purpose of this section is to provide you with the perspective of parents, family members and those living with the disability or special health care need. These stories give you insight of what life was like growing up and what life looks like now, as well as some of the joys and challenges that were experienced.

Written personal stories are one way of connecting to others who have similar experiences. Another way of connecting with others is through the Sharing Our Strengths peer support network. This service of the MODDRC provides you with an individualized match specific to what you want. This may include being matched to mentors with a similar disability experience, a mentor located in a similar part of the state or around a specific issue. If you are interested in being matched or in becoming a mentor for someone else, please contact us.

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# Help Yourself First to Help the One You Love

By Jean, personally affected by bipolar disorder and mother of a child with bipolar disorder

Hi, my name is Jean. I have three sons, 23, 20, and 19. My 20 year old has Asperger's Syndrome and my 19 year old has bipolar disorder, with psychotic features. I also have been diagnosed as having bipolar disorder. I am going to write specifically about my 19 year old who has bipolar disorder.

My son was diagnosed with bipolar disorder at the age of 10. It was a very frightening diagnosis to hear, even though I knew my father-in-law was bipolar, too. (At the time, I hadn't been diagnosed.) Being a "good" mom, I read all the books I could find on child/adolescent bipolar disorder. They helped a lot, as did talking to other parents whose children were bipolar. I definitely recommend doing both if you can.

My son was hospitalized multiple times for his condition. The first time was the worst; they took him to the psych ward and told me I couldn't see him for 24 hours. They took away his clothes and made him wear scrubs. He had to "earn" his clothes back with good behavior. He was only 10 years old.

The best advice I can give to anyone is take care of yourself first. Find a support group. Take a bubble bath or get out of the house and away from the chaos at least weekly.

The second thing I can recommend is to educate yourself about the disorder. Read, read, read! Do some internet research; contact the MODDRC for information and get connected with another parent who has a child like yours. Support from family members is crucial.

It's rough during the adolescent years, but we've had several good years with my son since. He's grown into a mature, somewhat responsible young man. While I love him deeply, there were times I hated his behavior. If you feel the same way, it's natural – don't do the "guilts" over it.

### Jordan's Story

A Story of System of Care Success

When Jordan first came to a system of care at age 10, he and his mother were having serious problems getting help for his mental health needs. Having been diagnosed with bipolar disorder at age 6, Jordan's needs were complex and compounded by his mother's own issues related to substance abuse, homelessness, and a chronic, life-threatening illness.

Jordan's mother first realized that he had special needs when he experienced speech delays at a very young age. As Jordan grew older, his "cycling" between periods of extreme highs and lows became more apparent, as did his suicidal thoughts and hallucinations. Jordan and his mother received assistance from agencies representing child welfare, education, public health, mental health, and public housing, but these services were not intensive enough. When Jordan reached a critical moment where he was hospitalized, his mother considered giving up custody so he could receive residential care for his symptoms.

Having been involved with the system of care for several years, the hospital knew that a system of care was ready to help children, youth, and families with complex mental health needs.





Working closely with Jordan's school social worker and special education coordinator, the hospital's discharge planner helped enroll Jordan in the system of care.

Once enrolled in the system of care, Jordan began to see substantial improvements in his life. The first was that Jordan, his mother, and other people in their lives worked in partnership with service providers to create Jordan's care plan. Jordan's service providers included the hospital, his school, and the mental health department's children's intensive services system, which provided mobile mental health case management. Initially Jordan's plan involved therapeutic respite care and a specialized camp for children with serious mental health needs, but additional supports and services were available because the entire county operated under the system of care's framework.

While at the camp, Jordan received highly structured services tailored to his unique needs. This camp presented an opportunity for service providers to try different approaches to see which ones were most effective. When camp concluded, the system of care facilitated communication between camp representatives and Jordan's school to ensure that the lessons learned were transferred from Jordan's camp counselors to his teacher. Because of this communication, Jordan's teacher learned strategies she could use in the classroom to effectively manage his behaviors, which in turn led to fewer disruptions and an improved learning environment for Jordan and his classmates. For instance, Jordan's teacher learned that his classroom behavior would improve dramatically if she gave him positive feedback three times an hour.

The collaboration among all the service providers has led to more than just improvements at school. The symptoms associated with Jordan's bipolar disorder have been substantially reduced. Jordan has far fewer hallucinations and periods of suicidal thoughts or behaviors than before. The personal situation of Jordan's mother improved because of the system of care's services. She now has adequate childcare for Jordan, which allows her to go to work. She also no longer blames herself for her son's situation. The relationships she developed through the system of care have helped her to be more trusting of others who genuinely want to help. The system of care worked because of collaboration, shared resources, and the close connection between the system of care and the family.

Jordan's Story provided by SAMHSA (Substance Abuse and Mental Health Services Administration, a division of the U.S. Department of Health and Human Services)



# Family Support, Advocacy and Services

The purpose of this section is to provide you with a listing of organizations specifically designed to meet the support needs of individuals with developmental disabilities or special health care needs and their families. This listing includes parent organizations, support groups or other advocacy organizations.

MODDRC/F2F | 1-800-444-0821 | MODDRC@UMKC.EDU

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WWW.MODDRC.ORG



## **Support for Families**

#### Sharing Our Strengths (SOS) Peer Support Network

215 W. Pershing Road, 6<sup>th</sup> floor Kansas City, MO 64108 Toll free: 800-444-0821 Web: <u>http://www.sharingourstrengths.com</u>

SOS is a statewide support network of parents, family members, individuals with developmental disabilities, and professionals who are matched with peer mentors to share experiences, offer emotional support and to network with others. You can request an individual parent to parent or peer support match with another parent or individual who has experienced similar circumstances.

#### Missouri Depression and Bipolar Support Alliance (DBSA) Chapters/Support Groups

Please note: DBSA chapters are volunteer-run and many of the numbers listed are personal phone numbers. Due to this, please be considerate of the time of day you are calling. Also, please remember these are not crisis lines. If you are in need of emergency assistance, please call 911 or 800/273-TALK. When contacting chapters via email, please put 'DBSA' in the subject line.

Affton DBSA St. Louis Self Help Center Nancy Bollinger or Jamie Stange Phone: (314) 781-0199 Email 1: <u>nancy.bollinger@selfhelpcenter.org</u> Email 2: <u>jamie.stange@selfhelpcenter.org</u> Web: <u>www.selfhelpcenter.org</u>	St. Louis DBSA Greater St. Louis Helen Minth - Phone: (314) 652-6100 Email: <u>hminth@sbcglobal.net</u> Sarah Earll - Phone: (314) 652-6100 Email: <u>ssearll@sbcglobal.net</u> Web: <u>www.stlempowerment.org</u>
Cape Girardeau DBSA Southeast Missouri Jill Schmidt - Phone: (573) 824-5246 or (573) 225-9175 Bill Marietta - Phone: (573) 334-8619 Email 1: <u>dbsa.semo@yahoo.co</u> Email 2: <u>wgmarietta@yahoo.com</u> Web: <u>www.communitycaringcouncil.org/DBSA</u>	Town and Country DBSA St. Louis Christian Community John Trevaskis – Phone: (314)222-0753 Email: johntrevaskis@westhillsstl.org Tom Vrooman - Email: tomvrooman@westhillsstl.org Web: www.westhillsstl.org/dbsa
Cape Girardeau DBSA Southeast MO Parents of Children with Mental Illness Laura Brown - Phone: (573) 334-4418 or (573) 579-0095 Jill Schmidt - Phone: (573) 824-5246 or (573) 225-9175 Email: <u>dbsa.semo@yahoo.com</u> Web: <u>www.communitycaringcounsel.org/DBSA</u>	West Plains DBSA West Plains Carol Eck - Phone: (417) 257-6762 Email: <u>carol.eck@ozarksmedicalcenter.org</u>
Columbia DBSA Central Missouri Jessica Thompson or Tom Hall Phone: (573) 999-6494 Email: <u>dbsa_columbia@yahoo.com</u>	



#### National Alliance on Mental Illness - Missouri

3405 West Truman Blvd., Suite 102 Jefferson City, MO 65109-2501 Phone: (573) 634-7727 Toll free: (800) 374-2138 Web: <u>www.nami.org</u> Email: <u>namimofamilies@yahoo.com</u>

NAMI-Missouri has affiliated local groups throughout the state. For information about a group close to you, please call the phone numbers listed above or visit the NAMI website and click on "Find your local NAMI" on the home page.

#### **Missouri Parents of Bipolar Children**

Web: www.health.groups.yahoo.com/Missouri Parents with Bipolar Children/MO

Online parent support group for Missouri families experiencing Bipolar Disorder

#### **Depression and Bipolar Support Alliance**

730 N. Franklin Street, Suite 501 Chicago, Illinois 60654-7225 Toll free: (800) 826-3632 Web: www.dbsalliance.org

#### **Child and Adolescent Bipolar Foundation (CABF)**

820 Davis St., Suite 250 Evanston, IL 60201 Phone: (847) 492-8519 Web: <u>www.bpkids.org</u> Email: <u>responseteam@bpkids.org</u>

#### National Federation of Families for Children's Mental Health

9605 Medical Center Dr. Rockville, MD 20850 Phone: (240) 403-1901 Web: <u>www.ffcmh.org</u> Email: <u>ffcmh@ffcmh.org</u>



# Missouri Service Systems

The purpose of this section is to provide you with a listing of agencies focused on areas such as educational, medical care or social services to individuals with developmental disabilities or special health care needs. This includes listings such as state or local agencies, hospitals, clinics or education systems.

MODDRC/F2F | 1-800-444-0821 | MODDRC@UMKC.EDU

WWW.MODDRC.ORG



### **Missouri Service System Contacts**

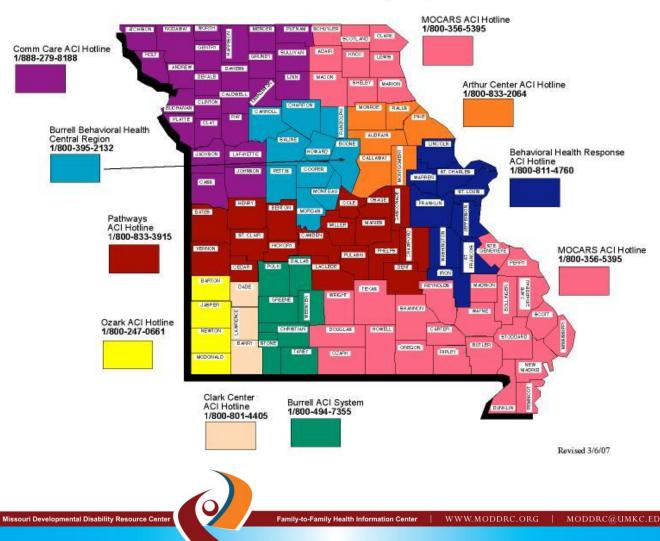
#### **Missouri Department of Mental Health**

1706 E. Elm St. P.O. Box 687 Jefferson City, MO 65102 Phone: 573-751-4122 Toll free: 800-364-9687 TT phone: 573-526-1201 Web: <u>http://www.dmh.missouri.gov</u>

Call the toll free number listed above to find the community mental health center for your area, or visit: <u>http://www.dmh.mo.gov/cps/org/adminagents.htm</u>

#### **Access Crisis Intervention (ACI)**

The Access Crisis Intervention line is able to help you 24 hours a day, 7 days a week. They will talk with you about your crisis and help you decide what help is needed. Contact numbers for support vary by county or region.



# Access Crisis Intervention (ACI) Hotlines