



**Autism**



# A NEW WAY TO SUPPORT FAMILIES

**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.**

*This packet was developed with funding from the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, Division of Services for Children with Special Health Needs, grant number H84MC08005 as well as Federal Funding from the Missouri Planning Council on Developmental Disabilities as established through the - P.L. 106-402*

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 first-hand 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.



# 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.



## Overview: Autism

Autism. It's a word we see more and more of these days - in newspapers, magazines, television and movies, at our doctors' offices, and even in government hearings. Some argue that autism is finally getting the attention it has always deserved, while others believe that the numbers of people with autism are now growing too rapidly to ignore. Researchers say the rate of new cases of autism is truly on the rise in the United States and around the world, with the Centers for Disease Control and Prevention (CDC) reporting 1 in every 110 children being diagnosed with an Autism Spectrum Disorder.<sup>1</sup>

### Why do I hear different words used?

Autism (sometimes called "classical autism" or "autistic disorder") is actually just one of several conditions often referred to as "autism spectrum disorders" (ASD). This group also includes milder forms of autism called "Asperger's syndrome" and "pervasive developmental disorder – not otherwise specified" (PDD-NOS). Two other rarer forms of ASD are called "Rett's syndrome", and "childhood disintegrative disorder."

Sometimes this group of conditions is called "Pervasive Developmental Disorders" in place of autism spectrum disorders. At this point, it's very likely you feel a bit confused.



<sup>1</sup> (Rice, 2006)

### What's really important?

For the most part, people who have ASDs do not look any different than others around them. But autism and related disorders do affect the way people think, learn, behave, and interact with the world around them and others; sometimes in a noticeable way, sometimes invisibly.

ASDs are called "spectrum" disorders because of the wide range of abilities and struggles shown by different persons who have autism. For example, those who have ASDs can have much higher than normal intelligence in certain areas or have a cognitive disability.

Right now, no medical test (like a blood test or genetic testing) can show that a child has autism. Instead, experts find the disorder by using other kinds of tests to look for signs of autism in three major parts of child development: communication, social skills, and behavior. These tests look at things like a child's eye contact, pretend play skills, amount of interest in other kids, and speech skills. They also look for unusual or repetitive behaviors (things a child does over and over again).

### What do I look for?

A child with an autism spectrum disorder might:

- not be interested in playing with other kids his or her own age;
- play in strange ways with toys or ordinary things, like lining up cars or animals in a row, spinning objects, or playing with a piece of string for long amounts of time;
- not look people in the eye unless they are told to do so
- want to be alone or to not be touched;
- not know how to play pretend games, like feeding a doll or playing firefighter;



- “not hear” others when they talk to him or her, but respond to other sounds;
- repeat words or sentences over and over again, called echolalia (ek-o-lay-lee-uh);
- only be interested in thinking and talking about one subject, not noticing when another person isn’t interested in talking about it with them anymore;
- always want things to be done the same way, and have trouble with changes in his or her routine;
- have a hard time understanding their own feelings or guessing how others may feel in different situations;
- react in strange ways to sounds, smells, tastes, sights, or touch;
- lose skills they once were able to do, like forgetting words they already knew

### Other concerns

Children and adults with ASD are at greater risk for other conditions, such as learning disabilities, ADHD, Fragile X syndrome, Tourette syndrome, and tuberous sclerosis (which causes brain tumors). Also, 20 to 30 percent of children with ASD will begin experiencing epileptic seizures by the time they reach adulthood.<sup>2</sup> Adolescents with ASD may be more likely to suffer from depression than others their same age.

### What can I do?

If you think your child or a child you know may have an ASD, it is very important to find out for certain as soon as possible. Acting quickly can make a big difference in the life of a child with autism. If you see warning signs, talk to your doctor and ask for a referral to a developmental specialist.

Autism Spectrum Disorders are diagnosed by teams of health professionals, often including a doctor, psychologist, speech therapist, and occupational therapist. They can also be diagnosed by a special kind of doctor called a “developmental

pediatrician.” These people are trained to see the signs of autism, and can tell a family if their child has any one of the autism spectrum disorders, something else, or nothing at all.

From there, parents of a child who has an ASD can connect with teachers, doctors and therapists to build a treatment plan. This may involve more than one kind of therapy or “intervention”. There are many choices to consider, so it is important for parents to do their homework. Be cautious about claims of ways to “cure” autism that lack a track record proven helpful by science.

Effective programs will focus on teaching the child new tasks in simple steps, building structure into his/her day, and giving positive reinforcement (praise or rewards) when the child shows desired behaviors. Children with ASD make the most progress when parents, school, and therapists work closely together as a “team”. (see Current Practices section)

If the child is under age 3, contact the Missouri First Steps program for help in finding out if a child may be showing signs of ASD. If the child is over the age of 3, you can contact your local public school to begin the same process. (see Missouri Service Systems section)

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

### Works Cited

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<sup>2</sup> (Autism Fact Sheet (Publication No. 09-1877), 2009)







# 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.



*On the following pages, you will find more information on autism 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.*



## Autism Spectrum Disorders (ASD's): Treatment

There is no single best treatment for all children with ASDs. However, well-planned, structured teaching of specific skills is very important. Some children respond well to one type of treatment while others have a negative response or no response at all to the same treatment. Before deciding on a treatment program, it is important to talk with the child's healthcare providers to understand all the risks and benefits.

It is also important to remember that children with ASDs can get sick or injured just like children without ASDs. Regular medical and dental exams should be part of a child's treatment plan. Often it is hard to tell if a child's behavior is related to the ASD or is caused by a separate health condition. For instance, head banging could be a symptom of the ASD, or it could be a sign that the child is having headaches. In those cases, a thorough physical exam is needed. Monitoring healthy development means not only paying attention to symptoms related to ASDs, but also to the child's physical and mental health, as well.



### Early Intervention Services

Research shows that early intervention treatment services can greatly improve a child's development.<sup>1,2</sup> Early intervention services help children from birth to 3 years old (36 months) learn important skills. Services include therapy to help the child talk, walk, and interact with others. Therefore, it is important to talk to your child's doctor as soon as possible if you think your child has an ASD or other developmental problem.

Even if your child has not been diagnosed with an ASD, he or she may be eligible for early intervention treatment services. The Individuals with Disabilities Education Act (IDEA) says that children under the age of 3 years (36 months) who are at risk of having developmental delays may be eligible for services. These services are provided through an early intervention system in your state. Through this system, you can ask for an evaluation.

In addition, treatment for particular symptoms, such as speech therapy for language delays, often does not need to wait for a formal ASD diagnosis. While early intervention is extremely important, intervention at any age can be helpful.

### Types of Treatments

There are many different types of treatments available. For example, auditory training, discrete trial training, vitamin therapy, anti-yeast therapy, facilitated communication, music therapy, occupational therapy, physical therapy, and sensory integration.



The different types of treatments can generally be broken down into the following categories:

- Behavior and Communication Approaches
- Dietary Approaches
- Medication
- Complementary and Alternative Medicine

### **Behavior and Communication Approaches**

According to reports by the American Academy of Pediatrics and the National Research Council, behavior and communication approaches that help children with ASDs are those that provide structure, direction, and organization for the child in addition to family participation.

#### ***Applied Behavior Analysis (ABA)***

A notable treatment approach for people with an ASD is called applied behavior analysis (ABA). ABA has become widely accepted among healthcare professionals and used in many schools and treatment clinics. ABA encourages positive behaviors and discourages negative behaviors in order to improve a variety of skills. The child's progress is tracked and measured. There are different types of ABA. Following are some examples:

- Discrete Trial Training (DTT) - DTT is a style of teaching that uses a series of trials to teach each step of a desired behavior or response. Lessons are broken down into their simplest parts and positive reinforcement is used to reward correct answers and behaviors. Incorrect answers are ignored.
- Early Intensive Behavioral Intervention (EIBI) - This is a type of ABA for very young children with an ASD, usually younger than five, and often younger than three.
- Pivotal Response Training (PRT) - PRT aims to increase a child's motivation to learn, monitor his own behavior, and

initiate communication with others.

Positive changes in these behaviors should have widespread effects on other behaviors.

- Verbal Behavior Intervention (VBI) - VBI is a type of ABA that focuses on teaching verbal skills.

Other therapies that can be part of a complete treatment program for a child with an ASD include:

#### ***Developmental, Individual Differences, Relationship-Based Approach (DIR; also called "Floortime")***

Floortime focuses on emotional and relational development (feelings, relationships with caregivers). It also focuses on how the child deals with sights, sounds, and smells.

#### ***Treatment and Education of Autistic and related Communication-handicapped Children (TEACCH)***

TEACCH uses visual cues to teach skills. For example, picture cards can help teach a child how to get dressed by breaking information down into small steps.

#### ***Occupational Therapy***

Occupational therapy teaches skills that help the person live as independently as possible. Skills might include dressing, eating, bathing, and relating to people.

#### ***Sensory Integration Therapy***

Sensory integration therapy helps the person deal with sensory information, like sights, sounds, and smells. Sensory integration therapy could help a child who is bothered by certain sounds or does not like to be touched.

#### ***Speech Therapy***

Speech therapy helps to improve the person's communication skills. Some people are able to learn verbal communication skills. For others, using gestures or picture boards is more realistic.



## The Picture Exchange Communication System (PECS)

PECS uses picture symbols to teach communication skills. The person is taught to use picture symbols to ask and answer questions and have a conversation.

## Dietary Approaches

Some dietary treatments have been developed by reliable therapists. But many of these treatments do not have the scientific support needed for widespread recommendation. An unproven treatment might help one child, but may not help another.

Many biomedical interventions call for changes in diet. Such changes include removing certain types of foods from a child's diet and using vitamin or mineral supplements. Dietary treatments are based on the idea that food allergies or lack of vitamins and minerals cause symptoms of ASDs. Some parents feel that dietary changes make a difference in how their child acts or feels. If you are thinking about changing your child's diet, talk to the doctor first. Or talk with a nutritionist to be sure your child is getting important vitamins and minerals.

## Medication

There are no medications that can cure ASDs or even treat the main symptoms. But there are medications that can help some people with related symptoms. For example, medication might help manage high energy levels, inability to focus, depression, or seizures. Also, the U.S. Food and Drug Administration approved the use of risperidone (an antipsychotic drug) to treat 5- to

16-year-old children with ASDs who have severe tantrums, aggression, and cause self-injury.

## Complementary and Alternative Treatments

To relieve the symptoms of ASDs, some parents and healthcare professionals use treatments that are outside of what is typically recommended by the pediatrician. These types of treatments are known as complementary and alternative treatments (CAM). They might include special diets, chelation (a treatment to remove heavy metals like lead from the body), biologicals (e.g., secretin), or body-based systems (like deep pressure).<sup>3</sup>

These types of treatments are very controversial. Current research shows that as many as one third of parents of children with an ASD may have tried complementary or alternative medicine treatments, and up to 10% may be using a potentially dangerous treatment.<sup>4</sup> Before starting such a treatment, check it out carefully, and talk to your child's doctor.

To read this article and others like it, visit:  
[www.cdc.gov/ncbddd/autism/](http://www.cdc.gov/ncbddd/autism/)

## References

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4. Levy, S. *Complementary and Alternative Medicine Among Children Recently Diagnosed with Autistic Spectrum Disorder*; *Journal of Developmental and Behavioral Pediatrics*, December 2003; vol 24: pp 418-423. News release, Health Behavior News Service





## National Dissemination Center for Children with Disabilities



### What About School?

Early diagnosis and intervention are very important for children with autism/PDD. Under the Individuals with Disabilities Education Act (IDEA), children with autism/PDD may be eligible for early intervention services (birth to 3) and an educational program appropriate to their individual needs. In addition to academic instruction, special education programs for students with autism/PDD (ages 3 to 22) focus on improving communication, social, academic, behavioral, and daily living skills. Behavior and communication problems that interfere with learning often require the assistance of a professional who is particularly knowledgeable in the autism field to develop and help implement a plan which can be carried out at home and school.

The classroom environment should be structured so that the program is consistent and predictable. Students with autism/PDD learn better and are less confused when information is presented visually as well as verbally. Interaction with nondisabled peers is also important, for these students provide models of appropriate language, social, and behavioral skills. Consistency and continuity are very important for children with autism/PDD, and parents should always be involved in the development of their child's program, so that learning activities, experiences, and approaches will be most effective and can be carried over into the home and community.

With educational programs designed to meet a student's

individual needs and specialized adult support services in employment and living arrangements, many children and adults with autism/PDD grow to live, work, and participate fully in their communities.

#### Tips for Parents

Learn about autism/PDD. The more you know, the more you can help yourself and your child. Your State's PTI (*Parent Training and Information Center*) can be especially helpful. You'll find resources and organizations in NICHCY's online State Resources Sheet. (find the sheet at: [www.nichcy.org/Pages/StateSpecificInfo.aspx](http://www.nichcy.org/Pages/StateSpecificInfo.aspx)) (MODDRC note: Missouri Parents ACT (MPACT) serves Missouri families as the statewide PTI. Find contact information for MPACT in the Family Supports section of this packet.)

Be mindful to interact with and teach your child in ways that are most likely to get a positive response. Learn what is likely to trigger meltdowns for your child, so you can try to minimize them. Remember, the earliest years are the toughest, but it does get better!

Learn from professionals and other parents how to meet your child's special needs, but remember your son or daughter is first and foremost a child; life does not need to become a never ending round of therapies.

If you weren't born loving highly structured, consistent schedules and routines, ask for help from other parents and professionals on how to make it second nature for you. Behavior, communication, and social



skills can all be areas of concern for a child with autism and experience tells us that maintaining a solid, loving, and structured approach in caring for your child, can help greatly.

Learn about assistive technology that can help your child. This may include a simple picture communication board to help your child express needs and desires, or may be as sophisticated as an augmentative communication device. Work with professionals in early intervention or in your school to develop an IFSP (*Individualized*

*Family Service Plan*, a written plan for providing services to families with a child (age 0-3) with an identified developmental delay) or an IEP (Individualized Education Plan) that reflects your child's needs and abilities. Be sure to include related services, supplementary aids and services, AT, and a positive behavioral support plan, if needed (for information on positive behavioral support plans, visit: [www.pbis.org](http://www.pbis.org)),

Be patient, and stay optimistic. Your child, like every child, has a whole lifetime to learn and grow.

To view this article and additional information online, visit the NICHCY website at: <http://www.nichcy.org/>



## Positive Behavior Supports

An excerpt from the Texas Autism Resource Guide for Effective Teaching

Positive behavior supports (PBS) or positive behavior interventions and supports (PBIS) is not a discrete set of interventions but involves assessing student needs, strengths and skills, and planning a series of positive interventions that can help the student meet her potential (Horner, Carr, Strain, Todd, & Reed, 2002).

### Description

According to Odom and colleagues (2003), PBS is a group of procedures designed primarily to address the problem behaviors of children with autism (AU). The procedures include functional assessment, prevention of problem behavior, and differential reinforcement of alternative behaviors that replace the problem behavior.

Dunlap and Fox (1999) described an individualized support model incorporating all of these elements and its effects on children with AU engaging in serious problem behavior. In another study, Lorimer, Simpson, Myles, and Ganz (2002) used functional assessment and the Social Stories™ techniques developed by Gray and Garland (1993) as a prevention technique to reduce the problem behavior of a child with AU. Keen, Sigafoos, and Woodyatt (2001) used functional assessment to determine the functions of children's prelinguistic behavior and taught functional communication behaviors that lead to more frequent communication.

PBS and applied behavior analysis (ABA) share a foundation in the science of behavior. In fact, PBS has its roots in ABA. However, it has many additional features. These include:

- Placing a high value on embracing person-centered planning approaches when addressing problem behaviors
- Examining a broad range of variables affecting behavior

- Making changes in natural life environments and multiple settings to influence behavior
- Adopting non-aversive intervention techniques to help an individual change his/her behavior
- Focusing on producing positive changes in quality of life for the individual with problem behavior and his/her family (Beach Center on Disability, 2008).

The Association for Positive Behavior Supports (APBS; 2008) defines PBS as a set of research-based strategies designed to increase quality of life and decrease problem behavior by teaching new skills and making changes in a person's environment. Positive behavior support combines (a) valued outcomes, (b) behavioral and biomedical science, (c) validated procedures, and (d) systems change to enhance quality of life.

Procedures that fall under the PBS model include (a) functional behavioral assessment, (b) collaborative teaming, (c) proactive support strategies, (d) positive consequence strategies, (e) teaching replacement skills, (f) systems change, (g) addressing competing behaviors, (h) group action planning, and (i) addressing cultural and economic diversity.

Almost all of the interventions in this guide (find at <http://www.txautism.net/manual.html>), used individually or in combination meet the above criteria and thus are considered PBS interventions. Just as there is no one intervention called ABA, there is no one intervention known as PBS.

### Summary

PBS is an individual-centered approach that looks specifically and broadly at student needs and plans interventions that facilitate life success.



## Interventions References

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## Resources and Materials

- Association of Positive Behavior Support: <http://www.apbs.org> APBS promotes the use of positive behavior supports. This website has a member resource center that offers a large number of resources for parents, teachers, administrators, and professionals.
- Beach Center on Disability: <http://www.beachcenter.org/pbs> This link enables users to access information about using PBS in the home and at school, as well as a PBS newsletter and training opportunities.
- Positive Behavior Interventions and Supports: <http://www.pbis.org> This website offers resources for parents and teachers as well as information concerning PBS and the law and the use of PBS in school districts.
- Positive Behavior Supports: <http://www.nasponline.org/resources/factsheets/pbs> This website offers resources for parents and teachers as well as information concerning PBS and the law and the use of PBS in school districts.







# 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.



## From Waiting and Wondering... to Living and Learning

By Danielle, mother of a ten year old boy with autism

I just knew something was different. He was a beautiful blond-haired, blue-eyed, smiling boy – our first child. But something was off.

First, it was his reaction to lights and sounds as an infant. Restaurants became a thing of the past for my husband and me. Any loud, boisterous environment would set him off in crying spells that refused to be soothed. Then it was his failure to meet normal developmental milestones – rolling over, sitting up, crawling (never did), walking, and talking. He spoke no words until age two and a half.

The funny thing was, every time I voiced my concerns to someone who I should've been able to trust – our pediatrician (at that time, but no more), a child psychiatrist in the family, early intervention therapists, teachers, and more, I got blank looks or lousy explanations.

"Boys are slower to mature. Don't worry – he'll talk eventually. He's just going at his own pace – be patient." So, I dutifully followed their advice. Regret #1.

After several years of uncomfortable motherly feelings I couldn't explain, a good friend of mine with no "professional degree" and no stamp of approval from some governing board laid it out.

"Have you ever considered that maybe he has autism?" she asked. Her innocent question hit me like a load of bricks. She pulled out an article from Time or Newsweek or some other popular semi-scientific news source. It talked about the growing concern about autism in the United States and around the world. For the first time, I read a list of symptoms for autism. It fit. I hated it, but it fit.

I was stunned and confused. I was questioning. I was analyzing every action I saw him do. Some things made sense; some things didn't. I wish I

could say I dove headlong into a self-education frenzy about all things autism. But I didn't. Fear held me hostage. Regret #2.

He was bright. We knew it. He could point to every animal in our deck of animal cards as I named them. He would smile and giggle as I cheered for him on every correct answer. He was a delight. I showed him my love, and he accepted it and loved me back. He connected with us, but always on his own terms.

Socially, he paid no attention to other kids around him. He went to an early education developmental preschool four days a week, and never cared about who else was there. We joined a weekly play group with a small group of friends – six kids his own age. Every week, he found a toy to push – mowers, strollers, shopping carts. He would walk around and around the perimeter of the playroom, ignoring the other children. They never bothered him. He just didn't need them to be happy.

Then someone told me about a diagnostic clinic at one of our state universities – a place where we could find out for sure. We made the call, waited for paperwork, mailed back the huge packet, and waited again. Nine months to wait. Can you imagine waiting nine months just to be seen? But that was the deal. In many places it still is the deal even today. Precious time for intervention ticks by while families wait for a diagnosis.

We were getting towards the end of our wait when my husband was transferred for his job. We moved several states away and started a new round of waiting for the diagnostic clinic there. Nine more months. Regret #3.

Finally, we received a provisional diagnosis of PDD-NOS, meaning they thought he had some form of autism, but weren't sure which kind yet. Come back again in a year, they told us. Our son



was already in kindergarten by the next visit. Autistic Disorder, they said this time. Strangely, I actually felt relief. All that waiting and wondering was finally settled. Now I felt free to move on.

Our son is now about to turn ten years old. Over the years, we learned a lot. He has grown and changed so much. He has overcome obstacles and encountered new ones. Most everything we discovered along the way made life with autism just a little better, more peaceful, or more manageable. We found out that other parents are an awesome resource. Every family has a story to share and wisdom to offer. To many of us, it's a

relief to share things we've learned the difficult way with someone else. It becomes even more worthwhile when we make another family's path just a little smoother – the trip to understanding just a little shorter.

There is camaraderie between families where autism resides. We know how special every child with autism is, and how difficult a day can be. We know how to understand behaviors that other people in the world might not accept. Mostly, we share the belief that there is hope for our kids to have meaningful futures. We work together to make that belief a reality.



## A Right to our Own Life, Our Own Way

An excerpt, By Jean-Paul Bovee

At this time, I am a 31-year-old man with autism. I have had many years to really understand what autism is to me. That has been a growing process, of which many things have had to be learned at their own speed. I found out that I was a person with autism at age 9, but the real knowledge about what it all means is a lifelong process. It requires getting the skills to really understand how you work, think, and live.

There are many issues within autism that should be addressed from the person with autism's point of view. The first is the subject of "fixing" or "curing" autism. First, autism is a developmental disability. We do not talk about curing mental retardation, Down syndrome, or cerebral palsy. Why, then, talk about curing autism? If it is a part of that person, then it is not realistic to talk about curing it.

Second, to talk about autism as all bad all of the time, and as something to eradicate, is making a value judgment on myself and other people with autism. It is saying that we have less value because of what we deal with. God made all of us equal and made all of us good. Where we go with what He has given us is up to us!! I don't want anyone's "fix," nor do most people with autism I know. It would take away what makes us who we are, and it would make us little robotic clones who would have none of their humanity left. Cure is a word that does not belong in the autism consciousness.

I do want to stress that people with autism should be helped to the point where they can help themselves. We need the best treatment and education we can get. We need to learn to cope in

a world where we are a minority. I do not embrace or attack blindly any methodology that works with autism. But I do attack aspects of treatments that are harmful as well as any methods that treat persons with autism as if they were all alike. I also attack false promises, false messiahs, and people who would sell their souls for money to get rich off of autism. The focus should be not on "cure" but on helping people with autism to function and to cope in a world where discrimination, prejudice, and hate exist for those who are not in the majority.

Education should be equal for all, and appropriate for all, but it must be chosen individually. If adaptations and supports are needed so that children with autism can learn, make them. If methods or materials need to be provided so that children with autism can succeed, provide them. Education for all in their own way of learning should be the rule, not the exception.

Employment of people with autism is an issue of great concern. I have a good job with all of the benefits that come with it, but I am in a very small minority. Most people with autism are unemployed or working in "sheltered workshops" or in jobs that don't fit their talents and skills. In fact, the statistics show that 95% of people with autism are unemployed. Is it because we do not have the skills to work? I do not think so. What is keeping us unemployed is the lack of neurotypical social skills. It is the getting along with people, and all of the talking. That is 80% of a work day, while the other 20% consists of work. We don't do so well on the 80%, and that is what gets people fired.







## 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.

## 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: <http://www.sharingourstrengths.com>

SOS is a statewide support network of parents, family members, individuals with developmental disabilities or special healthcare needs, 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.

### MO-FEAT (Missouri Families for Effective Autism Treatment)

2388 Schuetz Road Suite A-49  
 St. Louis, MO 63146  
 Phone: 314-993-0806  
 Toll free: 877-275-8988  
 Email: [info@mofeat.org](mailto:info@mofeat.org)  
 Web: <http://www.mo-feat.org>

### Autism Alliance of Greater Kansas City

PO Box 45664  
 Kansas City, MO 64171  
 Phone: 816-842-2452  
 Web: <http://www.autismalliancekc.org>

### Farmington Autism Support Group

Angel Wright - Phone: 314-335-9657  
 Email: [abaangelw@yahoo.com](mailto:abaangelw@yahoo.com)

### Fresh Perspective (Southeast MO)

Kay Anderson - Phone: 573-568-3184 or  
 Nora Saddler - Phone: 573-568-2635

### Gateway Autism Organization (GAO)

P.O. Box 29485  
 St. Louis, MO 63126  
 Marla Taggart - Phone: 314-640-5227 or  
 314-845-2711  
 Email: [Mktaggart@aol.com](mailto:Mktaggart@aol.com)

### Mothers of Children with Autism (MCA)

Columbia, MO  
 Lora Hinkel - Email: [lorahinkel@hotmail.com](mailto:lorahinkel@hotmail.com)

### Support Group for Autism

1409 Kent Rd.  
 Mexico, MO 65265  
 Karen Hoover - Phone: 573-253-1429  
 Email: [MomDadLoveYou@aol.com](mailto:MomDadLoveYou@aol.com)

### Southwest Missouri Autism Project (Springfield)

1740 S. Glenstone, Suite S  
 Springfield, MO 65804  
 Phone: 417-890-1399  
 Toll free: 800-420-7410

### Southeast Missouri Autism Project

909 Broadway  
 Cape Girardeau, MO 63701  
 Phone: 573-339-9300 or  
 Betty Hearnese at 573-683-6187

### MPACT (Missouri Parents Act)

8301 State Line Road, Suite 204  
 Kansas City, MO 64114  
 Phone: 816-531-7070  
 TDD: 816-931-2992  
[msavage@ptimpact.org](mailto:msavage@ptimpact.org)  
[www.ptimpact.com](http://www.ptimpact.com)



## Support for Families, continued

### Association for Science in Autism Treatment

P.O. Box 188  
Crosswicks, NJ 08515-0188  
Email: [info@asatonline.org](mailto:info@asatonline.org)  
Web: <http://www.asatonline.org>

### Autism Society of America

4340 East-West Hwy, Suite 350  
Bethesda, Maryland 20814  
Phone: 301-657-0881  
Toll free: 800-3AUTISM (328-8476)  
Web: <http://www.autism-society.org>

### Autism Speaks, Inc.

2 Park Avenue  
11th Floor  
New York, NY 10016  
Phone: 212-252-8584  
Email: [contactus@autismspeaks.org](mailto:contactus@autismspeaks.org)  
Web: <http://www.autismspeaks.org>

### MAAP Services for Autism, Asperger Syndrome, and PDD

P.O. Box 524  
Crown Point, IN 46307  
Phone: 219-662-1311  
Email: [info@maapservices.org](mailto:info@maapservices.org)  
Web: <http://www.maapservices.org>

### National Dissemination Center for Children with Disabilities

U.S. Dept. of Education  
Office of Special Education Programs  
P.O. Box 1492  
Washington, DC 20013-1492  
Toll free: 800-695-0285  
Email: [nichcy@aed.org](mailto:nichcy@aed.org)  
Web: <http://www.nichcy.org>

### National Institute of Child Health and Human Development (NICHD)

National Institutes of Health, DHHS  
31 Center Drive, Rm. 2A32 MSC 2425  
Bethesda, MD 20892-2425  
Phone: 301-496-5133  
Web: <http://www.nichd.nih.gov>

### National Institute on Deafness and Other Communication Disorders Inform. Clearinghouse

1 Communication Avenue  
Bethesda, MD 20892-3456  
Toll free: 800-241-1044  
TTD/TTY: 800-241-1055

### National Institute of Mental Health (NIMH)

National Institutes of Health, DHHS  
6001 Executive Blvd. Rm. 8184, MSC 9663  
Bethesda, MD 20892-9663  
Phone: 301-443-4513  
Toll free: 866-415-8051  
TTY: 301-443-8431  
Web: <http://www.nimh.nih.gov>





# 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.





## Missouri Service System Contacts

### First Steps

Phone: 573-522-8762

Toll free: 866-583-2392

Email: [webrepliespefs@dese.mo.gov](mailto:webrepliespefs@dese.mo.gov)

First Steps is the Missouri program for children, ages 0-3, who show signs of possible developmental delay or disability. The program provides "early intervention" to help at-risk infants and toddlers gain important developmental skills. First Steps brings families together with early intervention specialists to learn new ways to encourage and support their child's development within their daily activities.

### Missouri Office of Autism Services

Phone: 573-526-3848

Email: [Julia.Kaufmann@dmh.mo.gov](mailto:Julia.Kaufmann@dmh.mo.gov)

Created in 2008, the Office of Autism Services is under the direction of the Missouri Department of Mental Health, Division of Developmental Disabilities. It works to provide leadership in the state of Missouri for the development of a statewide plan regarding service, support, and treatment issues related to Autism Spectrum Disorders. View Missouri's 2007 Report on Autism at: <http://www.dmh.mo.gov/mrdd/progs/autism/autism.htm>.

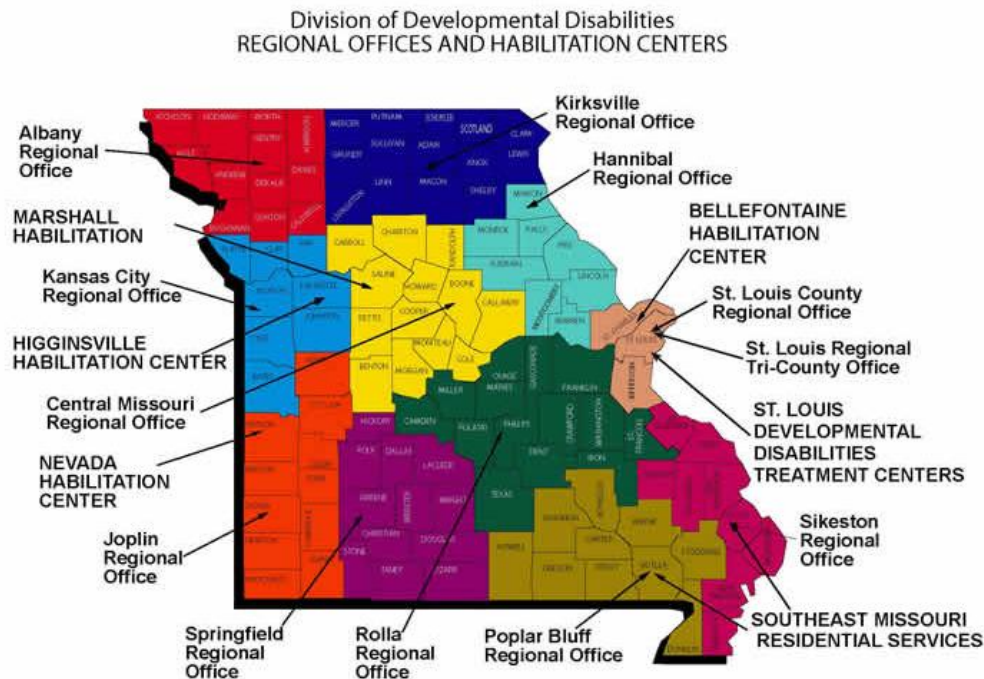
### Regional Offices, Division of Developmental Disabilities, Missouri Department of Mental Health

Toll free: 800-207-9329

Email: [ddmail@dmh.mo.gov](mailto:ddmail@dmh.mo.gov)

Web: <http://www.dmh.mo.gov/dd>

Apply through one of 11 regional offices to access many state services, including funding through HCBS (Home and Community-Based) waiver programs. To find the regional office for your area, call the number listed above or visit: <http://www.missouri.networkofcare.org> and click on Developmental Disabilities.



## Missouri Service System Contacts, continued

### Autism Diagnostic, Assessment and Treatment centers:

#### Thompson Center for Autism and Neurodevelopmental Disorders

University of Missouri

205 Portland Street

Columbia, MO 65211

Phone: 573-882-6081

Web: <http://thompsoncenter.missouri.edu/>

E-mail: [thompsoncenter@missouri.edu](mailto:thompsoncenter@missouri.edu)

#### Children's Mercy Hospital

2401 Gillham Road

Kansas City, MO 64108

Phone: 816-234-3000

Web: [www.childrens-mercy.org](http://www.childrens-mercy.org)

#### Southeast Missouri State University Autism Center for Diagnosis & Treatment

One University Plaza, Mailstop 9450

611 North Fountain Street

Cape Girardeau, MO 63701

Phone: 573-986-4985

Web: [www.semo.edu/autismcenter](http://www.semo.edu/autismcenter)

Email: Rona Mallard, [rmallard@semo.edu](mailto:rmallard@semo.edu)

#### The Knights of Columbus Developmental Center at Cardinal Glennon

##### SSM Cardinal Glennon

Children's Medical Center

1465 S. Grand Blvd.

St. Louis, MO 63104

Phone: 314-577-5609

Web: [www.cardinalglennon.com](http://www.cardinalglennon.com)

#### Center for Child Health & Development

##### KU Medical Center

3901 Rainbow Blvd.

Kansas City, KS 66160

Phone: 913-588-5741

Web: [www.kumc.edu/cchd/](http://www.kumc.edu/cchd/)

Email: Phyllis Young, [pyoung@kumc.edu](mailto:pyoung@kumc.edu)

