



DISABILITY & HEALTH
INFORMATION CENTER

A PROGRAM OF MISSOURI FAMILY TO FAMILY RESOURCE CENTER | UMKC INSTITUTE FOR HUMAN DEVELOPMENT | UCEDD

A NEW WAY TO SUPPORT FAMILIES

MISSOURI FAMILY TO FAMILY RESOURCE CENTER
DISABILITY & HEALTH INFORMATION CENTER

Missouri Family to Family Disability & 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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Asperger Syndrome

Welcome to the Missouri Family to Family Disability & Health Information Center (also known as the MODDRC). You are receiving this packet of information because a request was made by you (or someone on your behalf) to Missouri Family-to-Family.

We have compiled information from a number of sources and have included them in this packet, which is designed to provide:

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

When contacting Missouri Family to Family, you are connecting to staff with 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. Our goal is to inform individuals with disabilities or special healthcare needs and/or their families about services and supports that will increase their quality of life and connect to them peer support as well as provide opportunities for leadership development and volunteerism. We also seek to provide information and training to community agencies so that they can provide services to individuals with disabilities or special healthcare needs and/or their families.

Thank you for connecting with us. This packet of information is one of the many ways that we can support you in your journey with disability.



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: Asperger Syndrome

What is Asperger Syndrome?

Asperger syndrome (AS) is one of several conditions often referred to as “autism spectrum disorders” (ASD). Other ASD’s include autism, Rett syndrome, childhood disintegrative disorder, and pervasive developmental disorder – not otherwise specified (PDD-NOS).

The condition is named after Hans Asperger, a Viennese pediatrician. He first noticed certain behaviors in boys who were his patients. Although the boys seemed to have normal intelligence and language, they had trouble communicating well with others. They were physically awkward, and had poor social skills. Dr. Asperger wrote about the condition in the 1940’s, but it was not well known until the 1980’s.

Boys are three to four times more likely than girls to have Asperger syndrome. Some studies say that as many as two out of every 10,000 children have AS. Other studies say that the rate is even higher. Children with Asperger syndrome do not tend to lose their speech and language. Often they have average or higher vocabulary and grammar. However, they tend to be very literal and don’t understand slang or expressions that many people use in everyday language. People with AS usually have normal to above normal intelligence.

What do I look for?

A child with Asperger syndrome might:

- not be interested in or not play appropriately with other kids his or her own age
- only be interested in talking about one topic or object of interest, and not notice when another person isn’t interested in talking about it with them anymore
- know lots of facts and statistics about something they are most interested in
- repeat words or phrases over and over again
- have speech patterns that sound robotic or very formal
- have problems with reading comprehension, math or writing skills
- not use facial expressions
- not pick up non-verbal cues such as facial expressions or body language of others
- be physically awkward in activities involving balance or coordination
- seem only concerned with his/her own needs or interests
- react in strange ways to sounds, smells, sights, tastes or touch (for example, they might be bothered by a light or sound that no one else notices)

- only want to wear certain types of clothing or fabric
- be very literal (only understand the direct meaning of words or expressions, not the implied or socially understood meaning)
- have behaviors or habits that seem odd or “quirky”
- not like changes in routine or schedule.

How do I know for sure?

Asperger syndrome is usually discovered later than other autism spectrum disorders. Children can begin to show signs of AS by the age of three. It is often found between the ages of five and nine. Sometimes children with AS are diagnosed with ADHD first. There are a number of different tests or screening tools that can be used to diagnose AS. However, which test or tool is used depends on the doctor or clinic you visit. Parents who think their child may have Asperger syndrome should first talk with their pediatrician about what they have noticed and their concerns. The next step is usually a full team evaluation by professionals who have expert knowledge in diagnosing AS in children.

What can I do?

If you think your child might have Asperger syndrome it is very important to find out as soon as possible. Getting help early can make a big difference in the life of the child. There is

no “cure” for AS. Because each child is different, there is no set treatment plan. However, there are a number of things that can help a child with AS, including:

- Parent education and training
- Educational interventions
- Social skills training
- Language therapy
- Sensory integration training
- Behavioral/cognitive therapy
- Medication

It can help to make sure that all the people in your child’s life (teachers, caregivers, doctors, therapists) know what is going on and work together. It is usually up to the parent(s) to make sure that this happens.

What can I expect for the future?

Asperger syndrome is a lifelong condition. Children who have it will grow up to be adults with AS. They might still have issues with social situations. As children with AS reach puberty and adulthood they may develop new symptoms. Some people do not find out that they have Asperger syndrome until they are adults.

The good news is that with support and encouragement, children can learn to cope and adapt to living with AS. They can do well in school and go to college. They can have jobs, families, and lead a fulfilling life in the community.



BEST 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, including:

- Information on therapies
- Medical treatment
- Accommodations
- Interventions

On the following pages, you will find more information on autism from sources MOF2F 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.

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



Treating Asperger Syndrome

Because Asperger Syndrome can present a pattern of behaviors and problems that differ widely from child to child, there isn't a "typical" or prescribed treatment regimen. However, your child may benefit from the following forms of treatment:

- Parent education and training
- Specialized educational interventions for the child
- Social skills training
- Language therapy
- Sensory integration training for younger kids
- Psychotherapy or behavioral/cognitive therapy for older children
- Medications

It will help if you involve all of your child's caregivers in the treatment. The health professionals who are caring for your child should know what the others are doing, and you will often find yourself acting as the "case manager" in this scenario. Teachers, babysitters, other family members, close friends, and anyone else who cares for your child also should be involved.

It's important to know that many people can provide assistance. Finding the right program for your child is key and getting

help early is

important. Kids with AS can and do experience great gains with the appropriate treatment and education.

Helping Your Child

Although AS presents challenges for affected kids and their parents, you can help your child adjust and offer support in many ways:

- Look into educational or training programs for parents. You're your child's first teacher and you'll continue to be the cornerstone in supporting his or her development.
- Teach your child self-help skills. Learning these skills helps kids achieve maximum independence.
- Because it's not always obvious that a child has AS, alert others to the fact that your child has special needs. As a parent, you may have to take on the role of educator when dealing with teachers, medical personnel, and other caregivers.
- Find a program that addresses your child's specific needs or areas of "deficiency." The Autism Society of America (ASA) encourages family members to talk to the program director to determine if the curriculum or program addresses



their child's particular issues.

- Choose special programs or treatments that focus on long-term outcomes and that take the developmental level of your child into consideration.
- Remember that your child is part of a family unit and that his or her needs should be balanced with those of other family members.
- Get support for yourself and other family members. You can't help your child if you are not meeting your own emotional and physical needs. Your community may offer support groups at a local hospital or mental health center. There is considerable state-to-state variation in the types of government-sponsored services and other programs available to children with autism spectrum disorders and their families.

Your Child's Future

Currently, few facilities are specifically dedicated to providing for the needs of kids with AS. Some children are in mainstream schools where their progress depends on the support and encouragement of parents, caregivers, teachers, and classmates. However, some go to special schools for kids with autism or learning disabilities.

Many people with AS can function well in most aspects of life, so the condition does not have to prevent your child from succeeding academically and socially.

You may feel overwhelmed and discouraged if your child is diagnosed with AS. Remember that your child's treatment team can provide enormous support and encouragement for your child — and your family.

This article is an excerpt from KidsHealth.org. For the full article, go to <http://kidshealth.org/parent/medical/brain/asperger.html>

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PERSONAL STORIES



This section will provide you with the perspective of parents, family members and those living with the disability or special health care needs. Written personal stories are one way of connecting to others who have similar experiences. Through these stories you can gain insight as you share the joys and challenges experienced by others and learn from their suggestions.

Another way of connecting with others is through the Sharing Our Strengths (SOS) peer support network. SOS provides you with an individualized match specific to your needs. This may include being matched to mentors with a similar disability experience, a mentor located in a similar part of the state or concerning a specific issue. If you are interested in being matched with or becoming a mentor, please contact us.



Parenting Children with Asperger's Syndrome

By Kelly Knosby

I am a wife and mother to two sons that have autism. Matthew is 18 and has Pervasive Developmental Disorder, and Blaine is 15 and has Asperger's syndrome. We live in central Missouri.

When I think about raising a child with Asperger's, I have come to realize the experience is a journey, if you will. Being parents to Blaine has brought many good times and joy to our lives, really too many blessings to count. One of the best times was when Blaine was confirmed in our Church. The entire congregation came to celebrate with us. It was standing room only. Blaine did a beautiful job in the service, and we were so proud of him.

One of our biggest challenges has been with the education system. The public schools said he didn't "qualify" for the help that we believed he needed, so we made the decision to home school so that he could get the one-on-one attention that he needs. Home schooling isn't easy, but I do the best I can, given that I am not a school teacher.

You think you know what is going to happen for your child, but sometimes it turns out to be something quite the opposite. Other times, things seem to work out perfectly!

For parents just starting out with the Asperger's diagnosis, my best tip to them would be to do TONS of research about your child's condition. There are many resources out there at your fingertips. Also remember to have lots of patience with your child, and with yourself! Parents, remember you are not alone. Don't be afraid to ask for help, whether it is respite care, your church's support, your family, or talking to another parent. People are eager to help you, if you just ask!



Living with Asperger's Syndrome

by Jim Davis


As a 65-year-old man who just retired after a successful career, I'd like to share my experiences. As a child I always did well in school, but I was never very popular. I am tall, kind of skinny and a bit awkward. I worked hard at baseball and basketball, but I was never better than an average player. My best subjects in school were math and science, and I earned a Bachelor of Science in Physics from the University of Rolla in 1967. My wife Claudia and I married in the spring of 1966. We now have two adult sons and a grandchild on the way!

With the Vietnam War at full strength in the late 1960s, I chose to join the Air Force rather than be drafted. I went to Officer's Training School and graduated as a Second Lieutenant. My first assignment was at a laboratory in Albuquerque, New Mexico, and my responsibilities involved editing a series of technical manuals on nuclear weapon effects.

After two years, I was reassigned to Whiteman Air Force Base as a missile launch officer. When I went for training, I was overwhelmed. The control capsule was like an airplane cockpit. It was full of switches, dials and lights. There was no way I could do this! Fortunately, there was a large technical manual that gave step-by-step instructions for everything that needed to be done, so I really didn't have to "learn" much. I had always learned by figuring things out rather than by memorization.

After I got out of the Air Force, I returned to Kansas City with my family of four. After working for an insurance company for about a year, I was hired as a technical writer for a major employer in KC. I spent a good part of my career writing technical manuals for operating manufacturing equipment. I spent part of the time in Human Resources, where I developed training materials for classes. HR was hard for me, because it was so people-oriented. I made it clear that I was not capable of leading training classes. My managers had always respected me, and they were diligent in trying to leverage my strengths and avoid my weaknesses.

It was in the mid 2000's that I began to wonder if I had some mild form of autism. As the world became more about learning systems and less about figuring out how to do things, work got more difficult for me. Fortunately, my performance was good enough through the years that my managers looked for ways to use my talents.



As Information Technology and the internet took over more and more of the way work was done, it became more difficult for me. It wasn't about computers. I was very good at using Microsoft Word to develop the technical manuals. It was the explosion of information and its lack of organization that was devastating for me. I just couldn't learn things, and meetings became more difficult to "stay tuned into." Work didn't fit the way I thought anymore, and I didn't have the flexibility to adapt to the changes. Fortunately, I was able to retire before my performance dropped to the level that I could no longer be productive.

When the TV show, *Boston Legal*, added a character with Asperger's syndrome, I thought, "That's me." I read a couple of books about AS: *Diagnosing Jefferson*, by Norm Ledgin, and *Solutions for Adults with Asperger's Syndrome*, by Juanita Lovett. These books convinced me that I do have AS (although I haven't been officially diagnosed). What I learned is that people with AS think differently. We are very good at compensating for our deficiencies but we're pretty rigid in the way we think. We also have difficulty with interpersonal communication and relationships. This has made things difficult for Claudia and me through the years.

These two books helped me understand why Thomas Jefferson was so good at so many things, including keeping meticulous records of his expenses, but he went bankrupt because he couldn't manage his estate. And I understand why Einstein was a genius at theoretical physics but struggled with basic arithmetic – and couldn't remember his phone number. Both these high achievers couldn't develop the necessary skills to do things that didn't fit their way of thinking. They couldn't successfully adapt. Yet they were able to be very successful by using their strengths.

I think one of the most important things for young people with AS is to figure out what they are good at and look for a way to pursue their strengths to achieve success. I was lucky. I pretty much fell into the right things at the right time. However, I had to stick to it through some rough moments, or I never would have gotten there.

Here is my advice to young people: Don't give up! Find your strengths and find a way to use them to be successful in life. Okay, so maybe you are a little "different." But this can be an advantage just as much as it can be a disadvantage. Your differences can make you better at doing certain things than other people can do them.



FAMILY SUPPORT ADVOCACY & SERVICES

This section will provide 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

Missouri Family-to-Family Resource Center

Housed at the UMKC-Institute for Human Development, UCEDD

Missouri Family-to-Family is a statewide network of parents, family members, and individuals with disabilities and/or special health care needs providing information and peer support through the MOF2F Disability & Health Information Center and Sharing Our Strengths (SOS). SOS is a statewide support network of parents, family members, individuals with developmental disabilities and/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.

Toll Free: 800-444-0821

Web: www.mofamilytofamily.org



The Family Partnership members include individuals with special health care needs as well as parents, family members or legal guardians. The Partnership has three professional Family Partners who share responsibility for each of SHCN's service areas. The Family Partners are parents of individuals with special healthcare needs served by the bureau of SHCN. In addition to providing information and resources to local members, they serve as the Partnership's contact person for their designated areas.

Family Partners can be reached through the following agencies:

Special Health Care Needs (SHCN)

Missouri Department of Health and Senior Services

Toll Free: 800-451-0669

Miller County Health Center

Toll-Free: 1-866-809-2400, ext. 308

Missouri Autism Centers

Missouri funds four autism centers that are resources for diagnosis, treatment, and training and are dedicated to decreasing the wait list for obtaining a diagnosis of autism funded by the Department of Mental Health, Division of Developmental Disabilities.

Thompson Center – Columbia

1-888-720-0015

<http://thompsoncenter.missouri.edu>

Cardinal Glennon – St. Louis

314-577-5609

<http://www.cardinalglennon.com/>

Children's Mercy – Kansas City

816-234-3674

<http://www.childrensmercy.org/>

SMSU Autism Center – Cape Girardeau

573-986-4985

<http://www.semo.edu/autismcenter/>

Training & Information

MPACT (Missouri Parents Act)

MPACT is a statewide parent training and information center that serves parents of children with all disabilities. Their main focus is helping parents in their effort to effectively advocate for their children's educational rights and services.

Toll Free: 800-743-7634

Web: www.ptimpact.org

MO-FEAT (Missouri Families for Effective Autism Treatment)

MO-FEAT's mission is to provide advocacy, education, and support for families and the autism community, and to support early diagnosis and effective treatment. MO-FEAT provides monthly parent support and informational meetings on issues concerning home- and school-based intervention and identification of autism spectrum disorders. MO-FEAT offers quarterly community outings for family support and networking. MO-FEAT publishes an extensive statewide resource directory as well as literature on autism and effective treatment. MO-FEAT participates in advocacy efforts at the state level in order to help guide autism policy in our state.

Toll Free: 877-275-8988

Web: <http://www.mo-feat.org>



Organization for Autism Research (OAR)

OAR set out to use applied science to answer questions that parents, families, individuals with autism, teachers and caregivers confront daily. OAR provides information for families, professionals, and more on their website.

Web: <http://www.researchautism.org/family/index.asp>

Association for Science in Autism Treatment (ASAT)

ASAT's mission is to share accurate, scientifically sound information about autism and treatments for autism.

Web: <http://www.asatonline.org>

First Signs

First Signs is dedicated to educating parents and professionals about autism and related disorders.

Web: <http://www.firstsigns.org/>

The Roadmap to the Future: Transitioning into Adulthood with ASD

The purpose of this website is to give families, self-advocates, teachers, health care providers and other professionals an introduction to the process of planning for the transition from adolescence to adulthood. It is also meant to provide resources and options to consider for the future.

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

Support Groups

If you need help finding a support group near you, contact us! We would love to connect you.

The **Missouri Autism Report** is a monthly newsletter that publishes news and local support group meetings and events related to Asperger syndrome and autism across the state of Missouri.

Web: www.moautismreport.com



Missouri Service System Contacts

First Steps

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.

Toll free: 866-583-2392

<http://dese.mo.gov/divspeced/FirstSteps/>

Missouri Department of Mental Health > Division of Developmental Disabilities > Missouri Office of Autism Services

Throughout the State of Missouri, treatment services are available to children with a diagnosis of autism. The funding for these services are distributed through the Department of Mental Health. To access these services, a child must be determined eligible for regional office services and your service coordinator can assist in obtaining autism treatment services. To find the regional office for your area, call the number listed above or visit:

<http://www.dmh.mo.gov/dd> and click on “Regional Offices.”

Toll free: 800-207-9329

<http://dmh.mo.gov/dd/autism/>

