



# Office of Autism Services

## Navigating Autism Services: A Community Guide for Missouri

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Division of  
Developmental  
Disabilities

Department of Mental  
Health





# Navigating Autism Services: A Community Guide for Missouri

A Publication of the Missouri Office of Autism Services

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*Please note that the word “autism” in this guide  
refers to “Autism Spectrum Disorder.”*

## About this Guide

In 1998, the Division of Developmental Disabilities convened a meeting with the Missouri Department of Elementary and Secondary Education and the University of Missouri – Columbia to develop an autism-specific resource guide. In 2008, the Office of Autism Services within the Division of Developmental Disabilities convened a second meeting of stakeholders to make recommendations for an updated guide. The workgroup noted that several autism resource directories were now available in Missouri but expressed the need for a navigation guide to help people understand the services available for people with autism in Missouri, how to access these services, and where to start.

Families often say that they are not given enough direction after a family member is diagnosed with autism. Families report confusion and frustration when faced with navigating the seemingly endless maze of services from the medical, educational, and community provider fields. The purpose of this navigation guide is to help ease the journey by providing basic information about autism, resources, and services for people of all ages with autism in Missouri.

Originally published in 2009, this guide represents its second comprehensive revision, reflecting the many advances in law, policy, and supports for individuals with autism spectrum disorder (ASD) since then.

### *Where can I go to find additional autism resources for Missouri?*

- Missouri Division of Developmental Disabilities, Office of Autism Services, 800-207-9329, [www.dmh.mo.gov/dd/autism](http://www.dmh.mo.gov/dd/autism)
- Missouri Families for Effective Autism Treatment (MO-FEAT), 877-275-8988, [www.mofeat.org](http://www.mofeat.org)
- Autism Resource Guidebook, <http://dmh.mo.gov/docs/dd/autresourceguide.pdf>
- Autism Speaks, 888-AUTISM2, [www.autismspeaks.org](http://www.autismspeaks.org)
- Autism Society of America, [www.autismsource.org](http://www.autismsource.org)
- Autism Society – The Heartland, 913-7016-0042, [www.asaheartland.org](http://www.asaheartland.org)



information that not only represents the latest research into causes but also treatments that have no scientific backing and may, in fact, be harmful. What is particularly troubling is that the scientific community says there is no cure for autism, but there are people who claim they can cure the disorder, and some of them can be found in Missouri.

It is important to find accurate information from credible sources/websites. If you want information about getting a good evaluation for ASD in Missouri, you should read ***Autism Spectrum Disorders: Missouri Best Practice Guidelines for Screening, Diagnosis, and Assessment***. There is a companion publication called ***Families Overview and Summary of Best Practice*** that is targeted for families, and it provides basic information about what families should look for when they take their child to a professional who can diagnose autism spectrum disorder. If you would like to read about evidence-based interventions for individuals with ASD, you should read ***Autism Spectrum Disorders: Guide to Evidence-based Interventions***.

If you would like information about financial resources, employment, and transition, a good place to start is the [Office of Autism Services'](#) website. There you will find links to sources that are believed to be trustworthy.

If you would like to learn about the history of autism in Missouri along with the plan that has been published by the Missouri Commission on Autism Spectrum Disorders to help improve services to anyone at any age with autism in Missouri, you should read the ***Show-Me State Plan for Autism Spectrum Disorders*** which was released in June of 2011.

**IAN Project (Interactive Autism Network)** is an online resource, as well as a volunteer registry where parents can enter information about the diagnosis and treatment of their child with autism for use by researchers, participate in surveys, and keep up with the most recent news in the field of ASD. Information from families is analyzed by state, so Missouri data can be compared to data supplied to IAN by participants in other states.

**The Missouri Blue Ribbon Panel on Autism** was created in 2007 to report on the state of autism in Missouri and make recommendations to Missouri lawmakers to address existing needs. Family members, experts, physicians, officials from state agencies, and others testified before the panel. A report was produced in December 2007. Enacted through legislation, the **Missouri Commission on Autism Spectrum Disorders** was created in 2008 as was the Missouri Office of Autism Services within the Department of Mental Health. The members of the commission were appointed by the governor and charged with making recommendations for a comprehensive state plan. The state plan addresses the need for an integrated system of training, treatment, and services for individuals of all ages with autism spectrum disorder. Read more at the Department of Mental Health's website.

## Go Online

Centers for Disease Control and Prevention, Autism Spectrum Disorder, Data and Statistics

<http://www.cdc.gov/ncbddd/autism/data.html>

*Autism Spectrum Disorders: Missouri Best Practice Guidelines for Screening, Diagnosis, and Assessment*

<http://autismguidelines.dmh.mo.gov/pdf/Guidelines.pdf>

*Families' Overview and Summary of Best Practice*

<http://autismguidelines.dmh.mo.gov/pdf/Families.pdf>

*Autism Spectrum Disorders: Guide to Evidence-based Interventions*

<http://autismguidelines.dmh.mo.gov/documents/InterventionSummary.pdf>

Project IAN—<http://iancommunity.org/ian-project>

Missouri Office of Autism Services

[www.dmh.mo.gov/dd/autism/](http://www.dmh.mo.gov/dd/autism/)

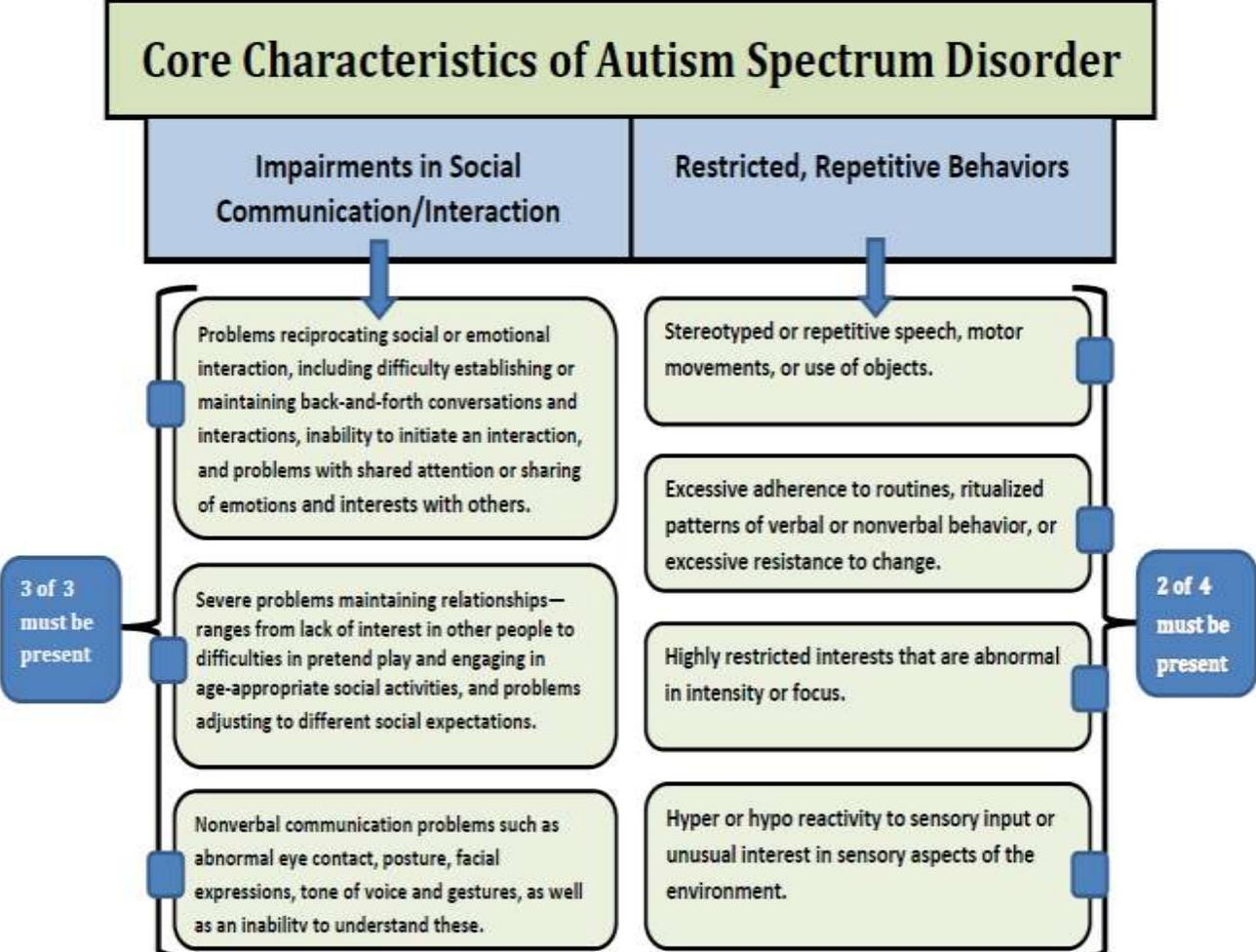
*Show-Me State Plan for Autism Spectrum Disorders*

<http://dmh.mo.gov/docs/dd/showmestateplan.pdf>

*A Parent's Guide to Research* from the Organization for Autism Research (OAR) at [www.researchautism.org/resources/reading/index.asp](http://www.researchautism.org/resources/reading/index.asp). Read Online or order by mail.

# What is Autism Spectrum Disorder?

Autism Spectrum Disorder (ASD) refers to a cluster of **neurobiological** disorders that develops during childhood before the age of three. Individuals with autism have a different way of thinking and approaching the world. We know that autism is not caused by an emotional disturbance, and it is definitely *not* caused by bad parenting. One key to your child’s progress is getting help as soon as possible. Autism affects people in different ways. Each person with autism has his or her own unique level of intelligence, creativity, social skills, behaviors, and ways of communicating. This is why autism is called a “spectrum” disorder. There are many factors that help us to predict how a person with autism will be able to function and learn. All people with autism can make progress and continue to learn skills well into adulthood. Yet, some characteristics of autism are likely to remain throughout a person’s life. Social differences can persist and may affect employment and relationships.



The diagnosis of ASD is based on symptoms, currently or by history, in the two areas highlighted above in blue. Although symptoms may begin in early childhood, they may not be recognized fully until social demands exceed capacity. Symptoms must cause functional impairment.

Source: American Academy of Pediatrics

# After a Diagnosis of Autism

## How Should I Feel?

There is no right or wrong way to react to a diagnosis. You may have feelings of sadness, fear, guilt, denial, confusion, anxiety, or even relief about having an answer. These feelings will come and go in no particular order throughout your journey. Some people are ready to jump into treatment right away, and others need more time. Talking with another parent may be a source of support and a reminder that you are not alone. Housed in the Institute for Human Development at the University of Missouri – Kansas City, Sharing Our Strengths is a program that helps individuals across Missouri connect with others going through (or having gone through) similar experiences. Read more about Sharing our Strengths at <http://www.sharingourstrengths.com/>.

## Who Should I Tell?

It is your decision when to tell other people that your child has been diagnosed with autism. The people who work with your child will likely find it helpful to have this information as soon as possible. This is particularly true when safety is a concern. It is not uncommon for individuals with autism to be attracted to water or for them to wander. When you share the news with family members, you may find a range of reactions and feelings. Keep in mind that everyone copes differently with the news of a diagnosis. Find other parents who have had a similar experience and can support you.

### Go Online

Autism Information Center (Centers for Disease Control and Prevention) at [www.cdc.gov/ncbddd/autism/index.html](http://www.cdc.gov/ncbddd/autism/index.html) or call 800-CDC-INFO

#### Autism Speaks

- A Parent's Guide to Autism <http://www.autismspeaks.org/family-services/tool-kits/family-support-tool-kits>
- Order Autism Speaks 100 Day Kit at: <http://www.autismspeaks.org/family-services/tool-kits/100-day-kit>

Interactive Autism Network (IAN) Community [http://www.iancommunity.org/cs/about\\_ian](http://www.iancommunity.org/cs/about_ian)

- Newly Diagnosed [http://www.iancommunity.org/cs/newly\\_diagnosed](http://www.iancommunity.org/cs/newly_diagnosed)
  - It's not Your Fault
  - You're Not Alone
  - Getting a Handle on It: Educating Yourself
  - ASD and Advocacy Groups
  - Becoming Your Child's Advocate
  - Caring for Yourself
  - Participating in Research: Being Part of the Long-Term Solution

Missouri Office of Autism Services (Brochures, Resources, Publications, Manuals, and more) [www.dmh.mo.gov/dd/autism/](http://www.dmh.mo.gov/dd/autism/)

Visit the Indiana Resource Center for Autism website and read *When Your Child is Diagnosed with an Autism Spectrum Disorder* at [www.iidc.indiana.edu/irca](http://www.iidc.indiana.edu/irca) and *Using Visual Schedules: A Guide for Parents* at [www.iidc.indiana.edu](http://www.iidc.indiana.edu)

### Read More

*Next Steps: A Guide for Families New to Autism*, Autism Society of America at [www.autism-society.org](http://www.autism-society.org) or call 800-3-AUTISM

*The Official Autism 101 Manual* by Karen Simmons (2006)

## Where Do I Start?

1. **Call your Regional Office** to talk with someone about eligibility for services.
2. **Begin intervention services:**
  - Under age 3: Missouri First Steps Program
  - Age 3 and up: Schedule an evaluation through your public school district's special services department.
3. **Find a support group.**
  - See Resources, Supports at <http://dmh.mo.gov/dd/autism/>
  - Autism Speaks, Support Groups <http://www.autismspeaks.org/community-and-support-network/support-groups?page=6>
4. **Educate yourself about autism.**
5. **Learn more about special education.**
  - Contact Missouri Parents Act (MPACT), the publicly funded parent training and information center.
  - The Missouri Autism Guidelines Initiative has created a [video](#) that outlines simple steps for building an effective Individualized Education Program (IEP) team and writing goals.
  - Individualized Education Program (IEP): Summary, Process, and Practical Tips. <http://www.autismspeaks.org/family-services/tool-kits/iep-guide>
  - Parent's Guide to Special Education in Missouri <http://dese.mo.gov/se/compliance/documents/ParentGuide.pdf>
  - The Department of Elementary and Secondary Education's (DESE) Parent Involvement webpage <http://dese.mo.gov/se/se-ep-parentinvolvementforparents.htm>

**6. Start a system for organizing reports and notes.**

- Children’s Mercy Hospital and Clinics’ Section of Developmental and Behavioral Science offers training (Taking Care of Business) to help with this. Call 913-696-5711.
- In [this issue](#) of the [Special Ed Advocate Newsletter](#), we explain the importance of keeping and organizing records.

**7. If you need resources, call Missouri Families for Effective Autism Treatment (MO-FEAT) at 877-275-8988 or email [info@mofeat.org](mailto:info@mofeat.org) or look in the Office of Autism Services *Autism Resource Guide* at <http://dmh.mo.gov/docs/dd/autresourceguide.pdf>.**

**8. To talk with a parent who has volunteered to be a mentor for other parents, call *Sharing Our Strengths* at 800-444-0821.**

**9. Work toward a routine schedule for home** and try making a schedule of your daily activities using pictures or words.

- From Autism Speaks Challenging Behaviors Tool Kit, page 41  
[http://www.autismspeaks.org/sites/default/files/section\\_5.pdf](http://www.autismspeaks.org/sites/default/files/section_5.pdf)

**10. Find a behavior therapist** to teach you strategies for increasing the behaviors you want to see.

# Roles of Professionals

Who Can Help	What They Do and How They Can Help
Behavior Analyst	A highly-trained practitioner who must be both board certified and licensed in Missouri, a behavior analyst uses the methods of Applied Behavior Analysis to teach new and developmentally-appropriate skills and to assist families and caregivers in replacing dangerous or undesirable behaviors with more appropriate ones.
Developmental Pediatrician	<p>A developmental pediatrician is a medical doctor with special training and certification in developmental-behavioral pediatrics.</p> <p>A developmental pediatrician can provide diagnoses and assessment for intervention planning. This doctor looks at the whole child and can recommend treatments including medication.</p>
Neurologist	<p>A neurologist is a medical doctor who can provide diagnoses and assessment for intervention planning. A neurologist also checks the neurological functioning of the body and can order tests such as MRIs or EEGs.</p> <p>A neurologist can prescribe medication or other interventions to address issues such as depression and anxiety, aggression, ADD/ADHD, obsessive-compulsive behavior, tic disorders, seizure disorders, and more.</p>
Occupational Therapist (OT)	An occupational therapist specializes in assessing and addressing fine motor skills, play and social skills, handwriting, sensory integration, and daily living skills such as dressing and feeding.
Physical Therapist (PT)	A physical therapist specializes in assessing and addressing gross motor skills (jumping, developing ball skills, and using stairs), strength, and coordination.
Psychiatrist	<p>A psychiatrist is a medical doctor who can provide diagnoses and assessments for intervention planning and can also address the mental health issues associated with autism.</p> <p>A psychiatrist can prescribe medication or other interventions to address issues such as depression and anxiety, aggression, ADD/ADHD, obsessive-compulsive behavior, tic disorders, and more.</p>
Psychologist	<p>A licensed psychologist has specialized training in developmental disorders. A licensed psychologist can be a clinical psychologist or neuropsychologist.</p> <p>A psychologist or neuropsychologist can provide diagnoses and assessment for intervention planning and can address the mental health issues associated with autism. He or she may address coping skills, behavior management, social skills, and strategies for improving functioning.</p>
Speech-Language Pathologist (SLP)	A speech-language pathologist specializes in the understanding and use of language and the pronunciation of speech sounds. A speech-language pathologist may address use of words, grammar, social skills, reading comprehension, and written language.

## Making Decisions about Intervention

We know more about what works in treating autism than we did 10 or 20 years ago, but there are still many questions to be answered. Today, there are hundreds of treatment options available.

Historically across the country, families often did not receive an assessment for intervention planning when their loved one was diagnosed with autism. Sometimes without a roadmap, families will become frantic to help their loved ones with ASD. At times, they have fallen prey to promotions of products and treatments that promise a cure for autism. Several recent publications have helped families and professionals understand which treatments have scientific evidence to help with some of the symptoms of autism but, as was mentioned earlier, there is no “cure” for autism. Missouri has addressed the rising prevalence of ASD and has been a leader in developing a service system to help individuals with ASD access credible services. Additionally, in Missouri, a panel of experts and family members were assembled to develop two publications: *Autism Spectrum Disorders: Missouri Best Practice Guidelines for Screening, Diagnosis, and Assessment* (published in 2010) and *Autism Spectrum Disorders: Guide to Evidence-based Interventions* (published in 2012). Perhaps the most talked-about therapy for individuals with autism is applied behavior analysis, which is the science devoted to teaching individuals age- and developmentally-appropriate skills, including social, self-care, communication, and other skills of daily living.

In addition, families may want to view a free online training module called *Autism Spectrum Disorders: Evidence Based Practice and Interventions* that was produced by the Central Missouri Rapid Response Initiative and is available on the University of Missouri’s Extension website at <https://thompsoncenter.missouri.edu/training/online-training-modules/>

Questions to Ask Professionals	Parent-to-Parent Advice
<p>When a diagnosis is made, was an assessment for intervention planning developed? What are the recommendations?</p> <p>What is this treatment and what does it do?</p> <p>Is there real science to support this treatment?</p> <ul style="list-style-type: none"> <li>• Is this an evidence-based practice?</li> <li>• If not, will it aid in the health of my loved one? Could this do harm to my loved one?</li> </ul> <p>How much will the treatment cost? What are the payment options?</p> <p>How will I be involved in the therapy? What do I need to do to help support my child (loved-one) with this therapy?</p> <p>How will I know whether my child is making progress?</p> <p>Could I talk with another family about their experience with this therapy and this provider?</p>	<p>Have hope about treatments, but use common sense. Be cautious when you see or hear claims of cures.</p> <p>Use caution with treatments that require payment before the treatment begins.</p> <p>Don't believe everything you read on the internet. Make sure the information is from a credible source. Is someone trying to sell you something?</p> <p>Pay special attention to studies that are published in high-quality scientific journals with peer-reviewed research. Do other studies show the same findings?</p> <p>Be wary of research that is not reputable and claims of research that have commercial or monetary ties.</p>

Go Online
<p><i>A Parent's Guide to Research</i> from the Organization for Autism Research at <a href="http://www.researchautism.org/resources/reading/index.asp">www.researchautism.org/resources/reading/index.asp</a>. Read Online or order by mail.</p> <p>IAN has topics commonly explored by families including alternative treatments. <a href="http://www.iancommunity.org/cs/therapies_treatments/">http://www.iancommunity.org/cs/therapies_treatments/</a></p>
Read More
<p><i>Autism Spectrum Disorders: Interventions and Treatments for Children and Youth</i> by Richard Simpson (2004)</p>

# Early Intervention and Health Care Services

## Department of Elementary and Secondary Education

### [Early Intervention through the First Steps Program](#)

First Steps is an early intervention program designed to serve children from birth to age three who have developmental delays or diagnosed conditions associated with developmental delays. Children who have a medical diagnosis of an autism spectrum disorder automatically qualify for early intervention services in Missouri. After a child is referred to First Steps, a team of professionals is available to provide screening, evaluation, and assessment services. After a child is determined eligible, an Individualized Family Service Plan (IFSP) will be developed by the child's team, which includes the parents. The IFSP team determines which services will benefit the child and family. First Steps services are designed to help the family or caregivers in their daily activities, which is why services take place where children typically learn and play, such as a child's home, a relative's home, or child care center. Services may include speech therapy, occupational therapy, applied behavior analysis (ABA), physical therapy, special instruction, nutrition and/or social work. No two children or families are the same, and every child and family needs different amounts or types of services.

When children reach three years of age, they may qualify for services through the school district's early childhood special education program. The IFSP team will begin discussing the transition to school district services when a child is around 2 1/2 years of age. Call Missouri First Steps 866-583-2392 or find First Steps info online at <https://dese.mo.gov/special-education/first-steps>.

## Department of Insurance, Financial Institutions, and Professional Registration

### [Private Health Insurance Coverage](#)

In 2010, a law was passed in Missouri that requires private health insurance companies who do business in Missouri to provide coverage for individuals with autism. Among important covered services are applied behavior analysis, psychiatric care, psychological care, therapeutic care, habilitative or rehabilitative care, and pharmacy care. Missouri's Department of Insurance, Financial Institutions, and Professional Registration regulates private insurance companies that do business in Missouri, and available on its website is a guide for parents to determine if their child's autism treatment is reimbursed by insurance, answers to frequently asked questions, and other information about autism and resources related to insurance. The law also requires that professionals practicing applied behavior analysis in Missouri be licensed. Find out more about Missouri's autism insurance law at [www.insurance.mo.gov/consumers/autismFAQ/](http://www.insurance.mo.gov/consumers/autismFAQ/)

## Department of Health and Senior Services

### [Children with Special Health Care Needs](#)

This program provides assistance for individuals up to age 21 years who meet financial and medical eligibility guidelines. The program focuses on early identification of children with special needs; funding for preventive, diagnostic and treatment services; and provision of service coordination activities for families. Find out more about the Children with Special Health Care Needs program online at <http://health.mo.gov/living/families/shcn/> or call toll-free 800-451-0669.

## Department of Social Services

### [Healthy Children and Youth](#)

This program is available to individuals up to age 21 years who are eligible for Medicaid (MO HealthNet – see page 17) and have a need for medical services. Healthy Children and Youth (HCY) provides funding for screening, referrals to doctors and services, and assistance with planning. HCY services are many and include both medical and behavioral health care services. Read about Healthy Children and Youth at [www.dss.mo.gov/mhk/hcy.htm](http://www.dss.mo.gov/mhk/hcy.htm).

## School Services — Three to 21 Years

## Department of Elementary and Secondary Education

Your public school can play an important role in intervention for autism. The Department of Elementary and Secondary Education (DESE) oversees the administration of special education services in Missouri according to the federal law, the Individuals with Disabilities Education Act (IDEA 2004) and state regulations for special education. Visit DESE at <http://dese.mo.gov/se/index.html> or call 573-751-4212 for information about special education law and school services.

### Go Online

The Department of Elementary and Secondary Education (DESE) <https://dese.mo.gov/>

### [If my child has a diagnosis of Autism Spectrum Disorder, will he/she automatically qualify for special education services?](#)

Students with a clinical diagnosis of Autism Spectrum Disorder (ASD) often qualify for special education services. However, a clinical diagnosis of an ASD given by a doctor or a licensed psychologist does not necessarily qualify a student for special education services through the school. The school is required by law to *consider* the clinical diagnosis and any reports, but the school does not *have to* agree with the recommendations. The school is also required by law to

conduct an evaluation and determine if there is a need for special education. This evaluation process may include additional testing. Occasionally, the team may feel that the child's disability is not having an effect on his education. If a student does not qualify for special education services but begins to have difficulty later, the parent may request a re-evaluation. A student who qualifies for special education has an Individualized Education Program (IEP) that documents the educational services and supports that he or she needs in order to learn at school.

### **Project ACCESS**

Project ACCESS is a contracted project funded by the Missouri Department of Elementary and Secondary Education, Office of Special Education. Project ACCESS is located at Missouri State University in Springfield. Project ACCESS provides autism support and resource information to public schools in the form of on-site, telephone, and internet consultations. In addition, Project ACCESS designs autism-specific professional development opportunities (both online as well as face-to-face) and trains professionally credentialed individuals to present these trainings. These trainings are offered to Missouri school district staff and educators who work with young people ages 0-21 years, who experience autism spectrum disorder and/or related disabilities. On-site, child-specific consultations can be arranged through the use of Missouri Autism Consultants (MACs), and district staff can be trained to become In-district Autism Consultants (IDACs). Read about Project ACCESS at Missouri State University's website at <http://education.missouristate.edu/access/> or call 866-481-3841.

## **Additional Resources**

### **MPACT: Missouri Parents Act**

MPACT is a statewide parent training and information center that offers information on special education and assistance to help parents effectively advocate for their children's educational rights. MPACT offers training on the IEP process and provides parent mentors. All services are free, and most MPACT staff and volunteers are also parents of children with disabilities. MPACT offers specialized training for families of children with an ASD. This training takes a thorough look at the IEP process with an emphasis on autism spectrum disorders. Specific information includes how children are evaluated for autism, what types of evaluation might be used, medical diagnosis versus educational category, and the definition and eligibility criteria for the educational category of autism. Call Missouri Parents Act (MPACT) for assistance with special education at 800-743-7634, or visit their website at [www.ptimpact.org](http://www.ptimpact.org).

# Support Services

## Division of Developmental Disabilities

### [What is a Regional Office?](#)

The Division of Developmental Disabilities provides services through 11 Regional Offices across the state. The Regional Offices perform these duties:

- Determine eligibility for services (Intake);
- Deliver support coordination through developing Individual Support Plans, monitoring services, and linking families with appropriate resources; and
- Contract for services written in the Individual Support Plan.

The Division's services and supports are available in families' homes, the community, and in licensed residential centers.

*It is important to contact your local Regional Office of the Division of Developmental Disabilities to see if your loved one qualifies to access services through the Department of Mental Health. The Regional Office is a door that you must go through in order to receive services from many other agencies in the state.*

To find your Regional Office, go to [www.dmh.mo.gov/dd/facilities](http://www.dmh.mo.gov/dd/facilities)

Or call toll-free: 800-207-9329

### [Support Coordination](#)

Every individual who is eligible for Regional Office services may receive targeted case management, also called support coordination. Support coordinators help people with disabilities and their families identify and obtain needed services and supports, including assistance with completing paperwork. They make referrals to other community agencies and may attend school IEP meetings. The individual or family will work with the support coordinator to develop an Individual Service Plan. *Person-centered planning* is a process used to determine goals, outcomes, and supports needed for a person with the developmental disability. The planning team develops action plans, explores natural supports, and discusses additional services if needed. Support coordinators also advocate for, monitor, and evaluate services along with the individuals and their families or guardians.

## [What are the Missouri Autism Projects?](#)

In the early 1990s, families advocated for autism-specific programming within the Division of DD. The Division responded by establishing five Autism Projects in Missouri that are funded by General Revenue. The Projects fund various services including parent training, respite care, social skills classes, and more. You must be enrolled with your local Regional Office to receive assistance from your region's Project. The contact information for enrollment can be found below. If you are already enrolled with your Regional Office but are not sure whether you are in your local Autism Project, ask your support coordinator to check. For information on the Missouri Autism Projects go directly to <http://dmh.mo.gov/dd/autism/autismprojects.html> or call Missouri's Office of Autism Services at 800-207-9329.

## [Service Options](#)

Self-directed services are an option for individuals and families who wish to exercise more control in choosing staff and deciding how their supports are delivered. Persons with disabilities and their families who choose self-directed services hire service personnel and supervise their own services. A support coordinator will continue to assist the family by visiting the home to be sure the program is successful. The support coordinator will also help to explain the program and prepare the spending plan or budget. A fiscal management service is used to issue paychecks, pay employer taxes, perform background screening for employees, and manage the budget to support families as they take on the responsibility of being an employer. The individual or family may also hire a support broker to provide information and assistance in order to self-direct supports.

Self-directed services have a documented history of success and improved consumer satisfaction. To learn more, interested persons should contact their support coordinator or visit the DMH-DD website at <http://dmh.mo.gov/dd/progs/selfdirect.html>.

## [In-home Services](#)

The Division funds many services including in-home services, speech therapy, physical therapy, occupational therapy, behavior therapy, crisis intervention services, and respite care. Both medical and behavioral assistance can be provided in a person's home or during other activities in the community.

## [Out-of-home Services](#)

The Division also funds out-of-home services for people in residential or community settings. Some people live in smaller supported living arrangements, and others live in larger residential centers.

## Local Supports

### [Senate Bill 40 Boards](#)

Find out whether your county has a Senate Bill 40 (SB 40) Board. The SB 40 Boards use special county tax dollars to provide for people with developmental disabilities in the community. Your SB 40 Board may have programs and funding to assist with housing, employment supports, or other services. Many SB 40 Boards also provide support coordination. To learn more about Senate Bill 40 Boards and find out whether there is one in your county, visit the Missouri Association of County Developmental Disabilities Services at <http://macdds.org/>

### [Recreation Supports](#)

In some areas, the Parks and Recreation Department, the YMCA, or other local organizations may provide recreation supports for people with disabilities. Explore recreation programs near you. Contact the Missouri Park and Recreation Association at [www.mopark.org](http://www.mopark.org) or call 573-636-3828, Missouri YMCA at <http://missouriyucas.org/> and Special Olympics Missouri at [www.somo.org](http://www.somo.org) or call 800-846-2682.

## Funding for Services and Supports

## Division of Developmental Disabilities

### [Home and Community-Based Services Waivers](#)

The Missouri Department of Mental Health's Division of Developmental Disabilities operates five Home and Community-Based (HCBS) waiver programs for individuals who have developmental disabilities, including autism. These waivers are the main source of funding for people who live in the community in group homes, supported living, or with their families. Eligibility for each waiver is determined by the Regional Office. Four of the waivers require the individual to be eligible for Medicaid. Eligibility for Medicaid is determined by the Missouri Department of Social Services — Family Support Division. The most recently approved Home and Community-Based Waiver is called the Partnership for Hope Waiver. It is called county-based because counties must choose to be a part of it. In addition, the Partnership for Hope Waiver has added four new services - personal electronic safety devices, professional assessment and monitoring, dental services, temporary residential services, and career preparation services. More information about the Partnership for Hope Waiver can be found at <http://dmh.mo.gov/dd/progs/waiver/partnership.html>. Read about Financial Resources for Missouri Children and Youth with Developmental Disabilities at <http://dmh.mo.gov/dd/autism/docs/autfinancial.pdf>.

## Department of Social Services — Family Support Division

### [Medicaid Eligibility — MO HealthNet](#)

There are four ways that a person might be considered eligible for Medicaid in Missouri: MO HealthNet for Kids; MO HealthNet for Families; MO HealthNet for the Aged, Blind and Disabled; and MO HealthNet for Disabled Children. Eligibility is mostly based on income and resources, but there are several other eligibility categories and programs that have different criteria and services. To enroll in MO HealthNet, you can complete an application online or contact the Family Support Division Office in the county where you live for further assistance. To find your county office, see the contact information that follows. MO HealthNet eligibility can be confusing, but a brochure called *A Guide to MO HealthNet (Medicaid) Benefits & Services* can help explain basic information and services. You can view that brochure at <http://dmh.mo.gov/docs/dd/guidemohealthnet.pdf> . To find a MO HealthNet office, call the Missouri Department of Social Services – Family Support Division at 800-735-2966 or visit [www.dss.mo.gov/fsd/](http://www.dss.mo.gov/fsd/).

### [Private Health Insurance](#)

Legislation was signed into law in June of 2010, requiring private insurance companies operating in Missouri to provide coverage under group health insurance policies for psychiatric care, psychological care, habilitative or rehabilitative care including applied behavior analysis (ABA) therapy, and therapeutic and pharmacy care to children who have been diagnosed with Autism Spectrum Disorder (ASD). The benefit for ABA therapy is capped at \$40,000 per year for children until their 19th birthday. There are no annual limits on the number of visits. The treatment must be prescribed by the child’s physician or psychologist and detailed in a treatment plan that is subject to review at least every six months. This cap will be adjusted periodically for inflation. If you have an individual health plan (rather than coverage through your employer), you may add this coverage; however, there may be an additional cost. The law also establishes licensure requirements for therapists who provide the ABA therapy to children with ASD. More information can be found at <http://insurance.mo.gov/consumers/autismFAQ/> or by calling the Consumer Hotline at 800-726-7390.

## Assistive Technology

### [Show-Me Loans](#)

Show-Me Loans are low-interest loans to Missourians with a disability. The general loan enables Missourians an option to purchase assistive technology equipment and devices, home access improvements, or vehicle access modifications for persons with disabilities in Missouri. Read about low-cost loans from Assistive Technology at [www.at.mo.gov/loans.html](http://www.at.mo.gov/loans.html).

### [Show-Me Loans, WorkAbility Loans](#)

The WorkAbility loan program available to Missourians is for the purchase of equipment needed by someone with a disability to work from home or a remote site away from an office. Computers,

equipment used on a farm or ranch, tools, office machines, hearing aids, and software are examples of eligible equipment.

### [Show-Me Loans, Accessible Vehicle Loans](#)

Missouri Assistive Technology also offers a low interest financing option for accessible vehicles. The Accessible Vehicle loan range is up to \$30,000. Interest rates are 2% to 4%, based on household income. Terms of the loan will vary. To obtain an application, learn more about the parameters of this loan, or to review interest rates and loan terms, call 800-647-8557.

## Planning for Transition to Adulthood

Transition means movement – in this case, from one stage of life to another. Adolescents with autism have their own unique strengths and challenges as they move toward adulthood. Parents and caregivers want their children to be happy and healthy and to lead fulfilling lives with dignity. To accomplish this, it is important to encourage your youth to have as much independence and involvement in the community as possible for his/her level of ability and to build as many life skills as possible. For individuals with ASD, the transition planning process should ideally begin in childhood so that opportunities may be capitalized upon and careful preparations can be made to ensure critical aspects of adult life are not left to last-minute decisions. An excellent resource about transition is the *Autism Speaks Transition Toolkit* at <http://www.autismspeaks.org/family-services/tool-kits/transition-tool-kit>.

As families plan for the future, they need a roadmap of resources about:

- Planning for Transition through the IEP
- Post-Secondary Education
- Health, safety, and emergency preparedness
- Legal Protections and Financial Planning

A training module called *Autism Spectrum Disorders: Transition to Adulthood* is available through MU Thompson Center for Autism and Neurodevelopmental Disorders website at <http://thompsoncenter.missouri.edu/training/online-training-modules/> and provides an overview of the transition process for families and community professionals.

### [Person-Centered Planning](#)

Person-Centered Planning (PCP) is a process that takes place across the lifespan but is especially important in laying out a roadmap for services and supports needed for adulthood. Person-centered planning is an ongoing problem-solving process used to help people with disabilities plan for their future. In PCP, groups of people focus on an individual and that person's vision of what he/she would like to do in the future. This team meets to identify opportunities for the focus individual to develop personal relationships, participate in the community, increase control over his/her own life, and develop the skills needed to achieve these goals. Your support coordinator or

a special teacher can help identify who should be involved in the meetings. You will discover the interests your young adult has and what supports may be needed for continued education, career exploration, residential living, and recreation.

### [Planning for Transition through the IEP](#)

If your child receives special education services in the public school, an important part of the transition planning process is the development of a transition plan as part of the Individualized Education Program (IEP) by the age of 16. Based on transition assessments and input from the parents and the student, the IEP team sets goals for the youth's life after school in the areas of education and training, employment, and independent living. These goals form the basis for the services that the student will receive while he or she is still in school. It is important to note that both families and experts agree that this kind of transition should begin much earlier than 16.

Important IEP goals for the transition years involve preparation for the future. Skills addressed through the IEP can pave the road to future employment and continued education. Consider needs in these areas:

- **Self-Determination** — having freedom and control over your life through making choices
- **Independent Living** — activities of daily living such as self-care, home-care, cooking, shopping
- **Health Care** — taking care of one's own medication; knowing what to do in an emergency
- **Money Management** — making purchases, banking, personal budgeting

The road to adulthood includes encouraging your child's independence and involvement in the community. Remember to consider the need to teach social skills and use of public transportation. If your student is considering college, start exploring resources as soon as you can. Talk with your school guidance counselor to make sure your student has the right credits. Look into the type of testing and documents needed by colleges in order to provide accommodations. Read *A Guide for Transition to Adulthood* from the Organization for Autism Research at [www.researchautism.org/resources/reading/index.asp](http://www.researchautism.org/resources/reading/index.asp).

### [Planning for Post-Secondary Education](#)

Individuals with intellectual disabilities may be able to get certain types of federal student aid. They may receive funding from the Federal Pell Grant, Federal Supplemental Educational Opportunity Grant, and Federal Work Study programs if they are enrolled or accepted for enrollment in a Comprehensive Transition and Postsecondary (CTP) program for students with intellectual disabilities at an institution of higher education (a college or career school) that participates in the federal student aid programs. Enrollees must be maintaining satisfactory academic progress and meet the basic federal student aid eligibility requirements, except individuals are not required to have a high school diploma or GED and are not required to be pursuing a degree or certificate.

A CTP program is a degree, certificate, or non-degree program that is offered by a college or career school approved by the U.S. Department of Education.

In Missouri, there are two CTP programs:

- **THRIVE** is located at the University of Central Missouri in Warrensburg, Missouri. For more information about the THRIVE Program, email [thrive@ucmo.edu](mailto:thrive@ucmo.edu) or call 660-543-4204.
- **SUCCEED** is located at the University of Missouri in St. Louis (UMSL). For more information about the SUCCEED Program, visit their website at <http://www.umsl.edu/~pcs/succeed/> or call 314-516-5911.

Other state universities and colleges in Missouri are not CTP programs but they have services for students with disabilities.

- **The University of Missouri—Kansas City (UMKC) offers Adult Continuing Education for Persons with Developmental Disabilities (ACED)** which gives adults the opportunity to attend non-credit classes in an educational and social environment. The ACED program is designed to teach independent living skills and provide life-enhancing experiences. ACED is offered by the UMKC Institute for Human Development, a University Center for Excellence in Developmental Disabilities, Metropolitan Community College-Longview and Metropolitan Community College-Blue River, with funding from the Developmental Disability Services of Jackson County - EITAS. Students, age 16 or older, can attend this program if they have graduated or exited from high school or if they are still enrolled in high school. For more information, visit the UMKC webpage at <http://www.ihd.umkc.edu/aced/>.

For more information about how institutions of higher learning in Missouri are working to strengthen supports for individuals with disabilities entering post-secondary education settings, see *Missouri Association on Higher Education and Disability (MO-AHEAD) Guidebook* at [www.moahead.org](http://www.moahead.org).

### **Autistic Self Advocacy Network (ASAN)**

*Empowering Leadership*, co-published by ASAN and the Daniel Jordan Fiddle Foundation, is a book that is available as a free [PDF](#). This book is an introduction to campus activism written to and by students with disabilities who want to organize on their campus. *Empowering Leadership* includes guides on navigating a disability service program, handling discrimination on campus, networking, accommodations, and more. For more information about ASAN, email [info@autisticadvocacy.org](mailto:info@autisticadvocacy.org)

### **Health, Safety, and Emergency Preparation**

Medical transition happens when an individual moves from pediatric to adult health care. Medical transition is important because it helps youth take control of a vital part of their life and health care, and it helps youth become more self-determined. Read about medical transition at Got Transition <http://gottransition.org>. Medical transition planning involves helping youth understand the adult health care system before they get there. In addition, the careful transition planning from pediatric health care into adult health care helps youth determine what must be in place for health insurance when adulthood is reached. It is important to note that in Missouri, legal adulthood begins at age 18. Actions to take during key time periods in for medical transition planning are:

- Before age 18, begin checking into Supplemental Security Income (SSI) eligibility
- Between ages 12 and 18, look for adult health care plan, depending on the individual's status as a dependent
- Between 18 and 25, finalize adult health care plan

Youth should receive safety instruction for using tools, equipment, and other items that can lead to danger. Because individuals who have autism often have difficulty with abstract thinking and problem solving, they must be taught safety in order to minimize risk of danger to themselves or others.

Developing an emergency care plan is also important. Having a plan available will help ensure that family members, caregivers, and emergency medical services (EMS) personnel will have the important information they need to effectively respond to an emergency. It will also be a resource for other medical personnel. The Missouri Family to Family Disability and Health Information Center, UMKC Institute for Human Development has developed *Partnering with Your EMS*, a resource for partnering with your emergency medical services (EMS) providers in your community. To view *Partnering with your EMS* from the Missouri Developmental Disability Resource Center (MODDRC) Family-to-Family Resource Center, visit <https://vimeo.com/24924219>.

### [Legal Protections](#)

As your child nears age 18, it is important to explore protections within and outside of the legal system for managing his or her affairs. You will want to consider the areas in which your young adult can manage responsibility and areas where assistance may be needed. Learn about options of conservatorship, power of attorney, guardianship, and other alternatives. Contact the Missouri Developmental Disability Resource Center (MODDRC) or [Missouri Protection & Advocacy Services](#) about their joint statewide trainings on guardianship and other alternatives for legal protection. Read about Guardianship and Financial Planning from MODDRC and Family-to-Family Resource Center at [http://www.moddrc.org/fast\\_fact.php?disID=184](http://www.moddrc.org/fast_fact.php?disID=184).

### [Financial Planning](#)

Special needs trusts are designed for individuals with disabilities. If properly structured and administered, special needs trusts do not affect an individual's eligibility for benefits such as SSI or Medicaid. The Midwest Special Needs Trust is an example of a trust. It also has a charitable trust to provide additional assistance to those who meet criteria. Call the Midwest Special Needs Trust at 888-671-1069 or visit them online at [www.midwestspecialneedstrust.org](http://www.midwestspecialneedstrust.org). Special needs trusts can also be established through a personal attorney.

# Adult Services and Supports

As your child grows and you continue to develop the Individual Service Plan, you will want to consider where to obtain the services he or she will need. There are many doors that you can enter for services. Your youth's unique strengths, abilities, and needs will help determine which doors you choose. Each agency also has its own criteria for determining who is eligible for services.

## Department of Health and Senior Services

- **Division of Senior and Disability Services**

### [Home and Community Based Services](#)

Home and Community Based Services are available for persons over age 18 who meet specific guidelines concerning economic, social, and care needs. Services such as personal care, in-home assistance, nursing, respite, adult day health care, and counseling are made available for persons with disabilities and the elderly in their homes. For information and referrals or to request assessment for eligibility for Senior and Disability Services programs, call 573-751-6400. If you suspect abuse or neglect of a senior or an adult with disabilities, call 800-392-0210.

### [Adult Day Health Care Programs](#)

Adult Day Health Care Programs are organized programs consisting of therapeutic, rehabilitative and social activities provided outside the home for a period of less than 24 hours to persons with functional impairments of at least a nursing facility level of care. Contact the Section for Long Term Care at 573-526-8557 for a list of adult day care programs.

- **Division of Community and Public Health— Special Health Care Needs**

### [Physical Disabilities Waiver](#)

This program offers services to individuals who have serious and complex medical needs and are no longer eligible for services under the Healthy Children and Youth program. To be eligible, an individual must be age 21 or older and assessed as requiring placement in an Intermediate Care Facility for the Developmentally Disabled (ICF/DD) absent these services. The services and supports available include attendant care, private duty nursing, and specialized medical equipment/supplies. The Department of Health and Senior Services, Bureau of Special Health Care Needs administers this program. Find out more about the Special Health Care Needs program online at [www.dhss.mo.gov/SHCN/](http://www.dhss.mo.gov/SHCN/) or call 800-451-0669.

## [Non-emergency Medical Transportation](#)

NEMT stands for Non-Emergency Medical Transportation. Most people who have MO HealthNet or MO HealthNet managed care can get a ride to their health care appointments from the NEMT program. The NEMT program can be used without charge when you do not have a way to get to your health care appointment. The NEMT program may use offers public transportation or bus tokens, vans, taxi, ambulance, or even an airplane if necessary to get you to your health care appointment. You may also be able to get help with gas costs if you have a car or have a friend or a neighbor who can take you, although the NEMT program must approve these costs before your appointment.

## Employment and Independent Living

Adults with autism are capable of holding a wide variety of jobs. Many people can work in competitive employment with few or no supports while others might need more supports through Supported Employment. Jobs and careers are designed by the individuals and their support teams.

### **Division of Developmental Disabilities**

The Division of DD has identified employment as a cornerstone of its commitment to inclusion. In 2008, the Division joined the State Employment Leadership Network as a critical first step in strategic planning to increase the ability of individuals with developmental disabilities to gain competitive employment. In 2011, the Division established an employment policy which establishes community integrated employment services and supports as the first service option and primary outcome for individuals (both youth and adults). It also established employment planning (Career Planning) and supports as priorities to explore with all working adults who receive services in order to ensure that supports, services, and outcomes are consistent with what the person is seeking.

To support those goals, the Division has created enhanced employment services for individuals participating in some of Medicaid Waivers operated by DD. For more information, call 573-751-4054.

### **Office of Adult Learning and Rehabilitation Services**

Rehabilitation Services within the Office of Adult Learning and Rehabilitation Services in the Department of Elementary and Secondary Education operates three core programs that support individuals with developmental disabilities – Vocational Rehabilitation, Disability Determinations Services, and Independent Living.

## [Vocational Rehabilitation \(VR\)](#)

VR provides individual counseling, training, and other services to help individuals with disabilities obtain and maintain employment. VR helps students transition from school to the work force and provides adults with job training and on-the-job supports to those who qualify. Learn more about VR services at <http://dese.mo.gov/vr/vocrehab.htm> or call 877-222-8963.

## [Disability Determination Services \(DDS\)](#)

Operating under Social Security regulations, DDS determines medical eligibility for individuals seeking federal disability benefits. If DDS determines that an individual has a disability, then the Social Security office will decide which benefit to award:

- **[Social Security Disability Insurance \(SSDI\)](#)** provides benefits for individuals who are disabled and are "insured" based on the Social Security tax they paid on their earnings or the earnings of their spouse or parents.
- **[Supplemental Security Income \(SSI\)](#)** provides payments to individuals who are disabled, including children under age 18 who have limited income and resources. DDS determines whether the person meets medical eligibility.

To apply for Social Security disability benefits, or to find your local office, call the Social Security Administration at 800-772-1213.

## [Independent Living \(IL\)](#)

The Independent Living (IL) program provides services to people with disabilities to increase their independence and their opportunity to participate in day-to-day life within their communities. There are 22 Centers for Independent Living (CILs) statewide that offer independent living services. The CILs are funded through Vocational Rehabilitation grants and are managed by persons with disabilities who have been successful in establishing their own independent lifestyles. The CILs offer four core services: peer counseling, advocacy, information and referral, and independent living skills training. Some also provide legal, housing, transportation, and educational services. For more information visit the **Missouri Statewide Independent Living Council** at [www.mosilc.org/](http://www.mosilc.org/).

# Assistive Technology

*Having a way to communicate can reduce a person's frustration and improve his or her behavior. Communication devices can give people a dignified way to communicate.*

Assistive Technology (AT) can play an important role in helping an individual communicate or gain greater independence. Use of AT can also help a student access the general education curriculum. The federal special education law, IDEA 2004, requires IEP teams to assess whether a student needs

assistive technology in order to receive a free and appropriate public education. Assistive Technology includes a wide range of equipment including switches and mounts, computer access devices, environmental controls, hearing devices, home modifications, visual aids and augmentative communication devices. Order *A Family Information Guide to Assistive Technology* from the Family Center on Technology and Disability (FCTD) at [www.fctd.info](http://www.fctd.info).

### [Who Helps with Assistive Technology in Missouri?](#)

**Missouri Assistive Technology (MoAT)** helps people in Missouri who have disabilities to learn about and access assistive technology. Programs include:

- **Equipment Technology Consortium (ETC)**—ETC is an equipment loan program. School districts and agencies can borrow equipment such as augmentative communication devices, for people with disabilities to try out or use for up to six weeks. **Show-Me Loans** and **WorkAbility Loans** provide families with low-interest financial loans to help buy equipment.
- **Kids Assistive Technology (KAT)**—Families of low and moderate income may apply for funding to help pay for devices needed by their children through age 20. The purpose of the KAT Program is to provide help when no other funding source is available, or when other funding sources are not adequate to cover the costs of the needed assistive technology or access modifications. Applications for children in families of lower income receive priority.
- **Telecommunications Access Program (TAP) for the Internet**—The TAP for the Internet provides no-cost computer adaptations for persons who are not able to use the Internet or e-mail because of a disability. **TAP for Telephone** provides no-cost adaptive telephone equipment for persons who are unable to use a traditional phone because of a disability.
- **Annual Assistive Technology Conference & Expo** with Parent/Advocate; scholarships are available.

MoAT also has equipment demonstration centers, recycled equipment programs, and more. A full description of all programs and contact information is on the MoAT website. Families may find help with funding for AT devices from Medicaid (MO HealthNet), Medicare, developmental disabilities agencies, private insurance, vocational agencies, or charitable organizations. Call Missouri Assistive Technology toll-free at 800-647-8557, or visit their website at [www.at.mo.gov](http://www.at.mo.gov).

### [How Do You Know if a Person Needs Assistive Technology?](#)

Evaluations to determine whether assistive technology is needed may be available through a nearby university clinic, a hospital, or your public school district. If you need assistance with finding a provider who can assess the need for assistive technology, call Missouri Assistive Technology for a referral.

#### **Read More**

Meaningful Exchanges for People with Autism: An Introduction to Augmentative & Alternative Communication by Joanne Cafiero (2005)

# Child Care and Respite Services

Families of both children and adults with Autism Spectrum Disorder can face challenges when trying to locate care providers for their loved one. It takes special planning to find a care provider who is open to learning about autism and the individual needs of your family member. Find more information at the website of the Center for Inclusive Child Care at [www.inclusivechildcare.org](http://www.inclusivechildcare.org)

## [Who Can Help Me Find Child Care?](#)

Missouri Child Care Aware is part of the National Association of Child Care Resource and Referral Agencies, a national non-profit organization. Through Child Care Aware, local child care resource and referral agencies in Missouri help promote inclusive child care services. Each agency has an Inclusion Specialist on staff to answer questions and provide technical assistance regarding inclusion. Missouri Child Care Aware's inclusion-related services include:

- Child care referrals for families seeking care for children with special needs
- Technical assistance for child care providers and families
- Training for child care providers
- Community public awareness activities

Call Child Care Aware of Missouri at 800-200-9017 or visit [www.mo.childcareaware.org](http://www.mo.childcareaware.org)

## [What is Respite?](#)

Respite is care that is provided for the person with autism so that caregivers can take a break. Respite means "relief." This service may be available to individuals who are enrolled with the Division of Developmental Disabilities. Using respite services is an important way for you to take care of yourself and avoid burnout. There are different types of respite programs. Some offer staff members who are trained to provide respite care, and some offer funding for respite services. Talk to your support coordinator and other families for more information or to find a respite care provider.

## [How Do I Talk with Care Providers about My Family Member's Needs?](#)

- Tell the care provider about your family member—his or her routine, likes, dislikes, what makes him or her happy or sad.
- Talk clearly about your loved one's strengths and unique qualities.
- Be honest about what he or she needs, including any special assistance or equipment. Share openly about what you think does or does not work.
- Be willing to help your care provider solve problems that might arise.
- Remember that you know your loved one with autism better than anyone else. Stand up for his or her rights and trust what you know.
- If you will be away from your loved one for several days, make sure to sign an emergency consent form to authorize care with notes about allergies or other special health care needs.

# Family Supports

Autism affects the whole family and can be stressful to cope with. Talk to your doctor or a professional counselor if you are having difficulty coping. You will find it easier to help your child if you are well. A psychologist or a behavior analyst can help you to develop ideas on how to manage your child's behavior at home. Using respite services to take breaks is also important in managing stress.

## Finding Supports

- **Sharing Our Strengths** — Peer mentor program for Missouri  
800-444-0821, [www.sharingourstrengths.com](http://www.sharingourstrengths.com)
- **Missouri Families for Effective Autism Treatment** — Mentors  
877-275-8988, [www.mofeat.org](http://www.mofeat.org)
- **A-List** — On line support group for families in Missouri who have children with autism.  
Contact MO-FEAT for a referral to this list.
- **People First of Missouri** — Support for adults with disabilities  
800-558-6562, [www.missouripeoplefirst.org](http://www.missouripeoplefirst.org)
- **Family Voices of Missouri** — Health and disability resources  
800-444-0821, [www.familyvoices.org/states](http://www.familyvoices.org/states)

## Sibling Support Programs

Contact the Missouri Developmental Disability Resource Center to find a sibling support group in your area. Easter Seals Midwest (314-432-6200), the Thompson Center for Autism (573-882-6081), and Burrell Autism Center (417-761-5330) have sibling groups that are focused on understanding autism.



### Tips for New Families



- Take small steps. Don't start too many new things at one time.
- Develop a vision for your child's life and work toward that dream.
- Focus on your child's successes and abilities.
- Celebrate the small joys and achievements along the way.

#### Go Online

Call the Missouri Family-to-Family to find a mentor or a support group at 800-444-0821 or visit [www.mofamilytofamily.org](http://www.mofamilytofamily.org).

#### Read More

Read the article *Sibling Perspectives: Some Guidelines for Parents* from the Indiana Resource Center for Autism (IRCA) at <http://www.iidc.indiana.edu/index.php?pageId=377>.

# Where to Look for More Information

## [Classes for Families](#)

Easter Seals Midwest (formerly Life Skills)  
314-432-6200  
<http://www.eastersealsmidwest.org/>

Missouri Autism Projects  
[www.dmh.mo.gov/dd/autism/AutismProjects.htm](http://www.dmh.mo.gov/dd/autism/AutismProjects.htm)

Missouri Parents Act (MPACT)  
800-743-7634  
[www.ptimpact.org](http://www.ptimpact.org)

Burrell Autism Center  
417-761-5330  
[Autisminfo@BurrellCenter.com](mailto:Autisminfo@BurrellCenter.com)

Judevine Center for Autism  
800-780-6545  
<http://judevine.org/contact-us/>

## [Lending Libraries](#)

Children's Mercy—Kraemer Resource Center for Families  
Kansas City  
816-234-3900  
[www.childrensmercy.org](http://www.childrensmercy.org)

Friends of the Thompson Center  
Columbia  
888-720-0015  
E-mail: [FriendTCenter@aol.com](mailto:FriendTCenter@aol.com)

Southeast Missouri State University Autism Center for Diagnosis and Treatment  
Cape Girardeau  
573-986-4985  
<http://semo.edu/autismcenter/>

## [Lending Libraries continued](#)

Missouri Families for Effective Autism Treatment (MO-FEAT)  
St. Louis  
877-275-8988  
[www.mofeat.org](http://www.mofeat.org)

Special School District of St. Louis County Family and Community Resource Center (FCRC)  
314-989-8438/314-989-8431  
[https://www.ssdmo.org/cool\\_tools/fcrc.html](https://www.ssdmo.org/cool_tools/fcrc.html)  
Lends book and media resources within St. Louis County

St. Louis Children's Hospital Family Resource Center  
314-454-2350  
<http://www.stlouischildrens.org/content/familyresourcecenter.htm>

## [Internet Resources](#)

Autism Internet Modules  
[www.autisminternetmodules.org/user\\_mod.php](http://www.autisminternetmodules.org/user_mod.php)  
Online modules with information and videos on evidence-based interventions

Autism Safety Project  
[www.autismsafetyproject.org](http://www.autismsafetyproject.org)  
Information to promote safety in emergency situations

University of Missouri Extension  
<https://extweb.missouri.edu/courses/default.aspx>  
Online modules developed by Missouri Rapid Response

Missouri Family-to-Family  
Kansas City  
800-444-0821  
[www.mofamilytofamily.org](http://www.mofamilytofamily.org)

Missouri Disability Portal  
[www.disabilityinfo.mo.gov](http://www.disabilityinfo.mo.gov)

Office of Autism Services  
[www.dmh.mo.gov/dd/autism](http://www.dmh.mo.gov/dd/autism)

## Safety and Emergency Planning

Special planning may be needed to keep a person with autism safe in the home and in the community. People with autism may be attracted to unsafe things or be less aware of danger in their environment. Visit the Autism Society of America's Safe and Sound Campaign for more information at [www.autism-society.org](http://www.autism-society.org) and Autism Speaks' Autism Safety Project at <http://www.autismspeaks.org/family-services/autism-safety-project>

### Tips for Families

- Develop a family safety plan for emergencies. For information about what to include on the Safety Plan, visit <http://www.autismspeaks.org/family-services/autism-safety-project/community/creating-safety-plans>
- Contact your local fire and police departments and ask them to keep information about your loved one on file. Discuss how to best handle your loved one and any other tips that would help them respond in the most effective manner possible.
- If the individual with autism tends to wander or leave home, educate your neighbors about your loved one. Let them know what to do if they see your child without an adult.
- Have several people identified that you can call in an emergency who are familiar with your loved one's needs.
- Keep medical records in a safe place where you can easily find them.
- Call 911 if there is a serious threat of harm.

### Identification

Basic information should always be available about your loved one with ASD. Consider using the following items:

- An Emergency Contact Form.  
To obtain a downloadable **Autism Emergency Contact Form**, go to <http://www.autismriskmanagement.com/>  
Make a few copies of the completed Autism Emergency Contact Form; keep a copy on your refrigerator, near your phone, in your wallet, or anywhere where you will have easy access to the form while you are either at home or in public.
- An identification bracelet

- A decal in the window of your home and car that lets emergency responders know that a person with autism may be inside
- An autism magnet on your car

#### Go Online

Dennis Debbaudt's *Autism Risk and Safety Management* website at <http://www.autismriskmanagement.com/>

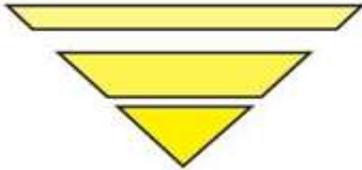
Autism Speaks' website at <http://www.autismspeaks.org/family-services/autism-safety-project>

Autism Society's Safe and Sound Campaign at <http://www.autism-society.org/living-with-autism/how-we-can-help/safe-and-sound/>

#### Read More

Safety Guidebook compiled by the National Center for Missing and Exploited Children <http://www.safeassured-id.com/media/doc/Safety%20Guidebook.pdf>

# DIVISION OF DEVELOPMENTAL DISABILITIES



## Office of Autism Services

Division of Developmental Disabilities  
Missouri Department of Mental Health  
P. O. Box 687  
Jefferson City, MO 65102  
Toll-free: 800-207-9329  
573-751-4054 • 573-526-1201 (TT)

*Navigating Autism Services: A Community Guide for Missouri*  
is a product of the Office of Autism Services, Division of  
Developmental Disabilities, Department of Mental Health.

***We believe that families who have loved ones with Autism Spectrum Disorder need a roadmap to help them navigate services so that they can find answers as quickly and easily as possible.***

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## State Agency Contact Information

**Governor's Council on  
Disability -Missouri Portal**

[www.mo.gov/disability/](http://www.mo.gov/disability/)

**Missouri Department of  
Elementary and Secondary  
Education (DESE)**

573-751-4212

[www.dese.mo.gov](http://www.dese.mo.gov)

**Missouri Department of  
Health and Senior  
Services (DHSS)**

573-751-6400

[www.dhss.mo.gov](http://www.dhss.mo.gov)

**Missouri Planning  
Council for  
Developmental  
Disabilities (MPCDD)**

800-500-7878

[www.mpcdd.com](http://www.mpcdd.com)

**Missouri Assistive  
Technology (MoAT)**

800-647-8557

[www.at.mo.gov](http://www.at.mo.gov)

**Missouri Family-to-Family**

800-444-0821

[www.mofamilytofamily.org](http://www.mofamilytofamily.org)

**Missouri Department of  
Social Services (DSS)**

800-735-2966

[www.dss.mo.gov](http://www.dss.mo.gov)

**Missouri Protection  
and Advocacy (MO  
P&A)**

800-392-8667

[www.moadvocacy.org](http://www.moadvocacy.org)

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