Office of Autism Services

Navigating Autism Services: A Community Guide for Missouri

Division of Developmental Disabilities

Department of Mental Health

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Navigating Autism Services: A Community Guide

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 disorders" unless otherwise stated.

The Missouri Autism Resource Guide was published in 1998 by the Missouri Departments of Mental Health (DMH), Elementary and Secondary Education (DESE), and the University of Missouri-Columbia. In 2008, a workgroup of autism-related agencies and organizations gathered to discuss updates to the existing resource 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. Many families find services later in their journey that they wish they had known about right away. 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. We hope this Guide will give you a place to start your journey.

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

Autism Alliance of Greater Kansas City, 816-842-2452, www.autismalliancekc.org

Autism Society of America, www.autismsource.org

Autism Speaks, 1-888-AUTISM2, www.autismspeaks.org

Missouri Division of Developmental Disabilities, Office of Autism Services, 573-526-3848, www.dmh.missouri.gov/mrdd/progs/autism/autism.htm

Missouri Families for Effective Autism Treatment (MO-FEAT), 1-877-275-8988, www.mofeat.org

Autism in Missouri

Missouri has a strong history of advocacy on behalf of persons with autism. Our state is home to some of the top universities and researchers in our country, who are also seeking to solve the puzzle of what causes autism and how to best treat it. In addition, our state government has worked diligently to improve autism services.

How many people in Missouri have autism?

We don't have complete information on the total number of people who are diagnosed with autism spectrum disorders in Missouri. The Center for Disease Control's (CDC) Autism and Developmental Disabilities Monitoring (ADDM) Project estimated that 1 in 137 children in the St. Louis area had a diagnosis of autism spectrum disorder (ASD) in 2002. Nationally, the CDC estimates that 1 in 150 children have an ASD based on counts from key cities.

How many people with autism are served by the Division of Developmental Disabilities?

Missouri's Department of Mental Health - Division of Developmental Disabilities (DD) is a key provider of services for people who have autism. The Division of DD served 5,500 children and adults with autism in 2007, and 6,400 persons with autism in 2008, a growth of 16% percent. These numbers only show how many people with autism diagnoses were eligible for services from this one agency in 2007 and 2008. Many other state agencies provide autism-related services, and each of those has its own eligibility criteria.

How can I find more information about autism in Missouri?

Project IAN (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. Information from families is analyzed by state, so Missouri data can be compared to data supplied by IAN participants in other states.

The Missouri Blue Ribbon Panel on Autism was organized in 2007 to report on the state of autism in Missouri and make recommendations to Missouri lawmakers for improvements. Family members, experts, physicians, state agencies, and others testified before the panel. A report was produced in December 2007. The **Missouri Commission on Autism Spectrum Disorders** was then created in 2008 within legislation that also created 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 plan will deal with an integrated system of training, treatment, and services for individuals of all ages with autism spectrum disorders. Read more at the Department of Mental Health Website.

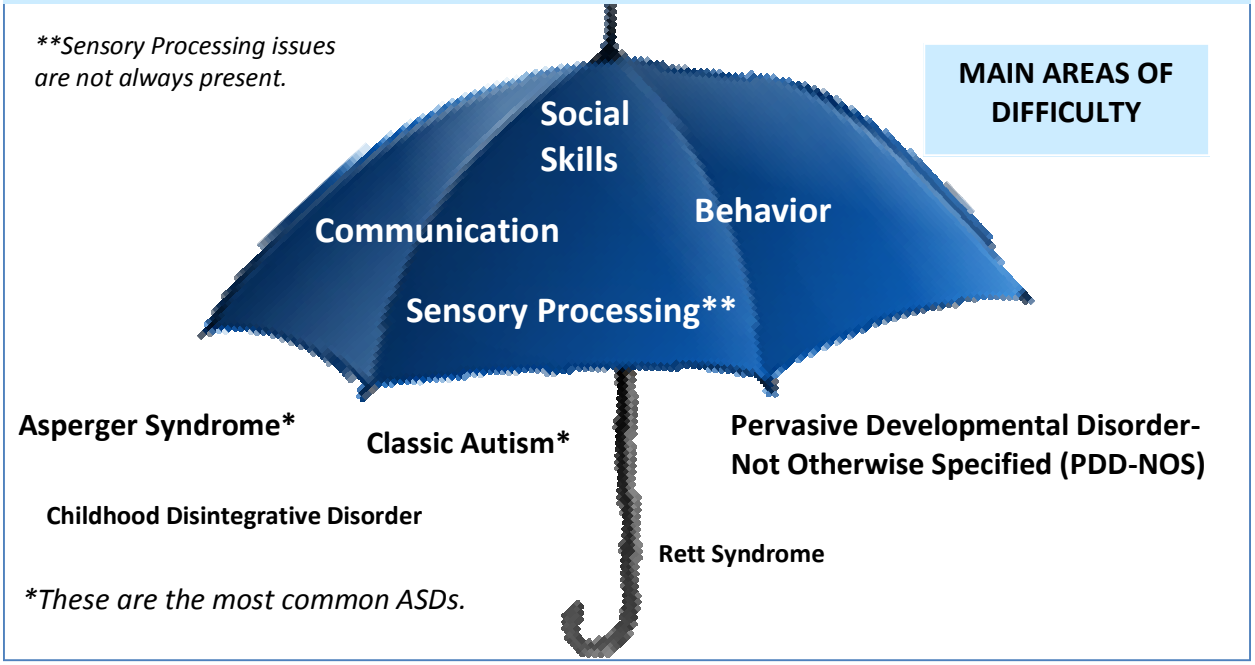
Go Online	Missouri Blue Ribbon Panel on Autism Report (2007) at www.senate.mo.gov/autism/autism2007.pdf
Indepth	Project IAN—Missouri-specific data is available from State Stats http://dashboard.ianexchange.org/statestats.aspx

What are Autism Spectrum Disorders?

Autism spectrum disorders (ASDs), also called Pervasive Developmental Disorders, are a cluster of **neurobiological** disorders that develop during childhood before the age of three. Autism is 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.

Neurobiological *means that there are differences in the brain that affect how people think and act.*

The Umbrella of Autism Spectrum Disorders



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.

Go Online	Autism Information Center (Center for Disease Control and Prevention) at www.cdc.gov/ncbddd/autism/index.htm or call 1-800-CDC-INFO.
Read More	*The Official Autism 101 Manual* by Karen Simmons (2006)
Go Online	Read *Next Steps: A Guide for Families New to Autism*, Autism Society of America at www.autism-society.org or call 1-800-3-AUTISM.

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.

Who Should I Tell?

It is your decision about 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. 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.

Where Do I Start?

1. **Call your Regional Office** to talk with someone about eligibility for services (Pg. 11).
2. **Begin intervention services**:

   Under age 3: Missouri First Steps Program (Pg. 9).

   Age 3 and up: Schedule an evaluation through your public school district's special services department.
3. **Find a support group**. (See the list at www.dmh.mo.gov/mrdd/autismsupport.htm).
4. **Educate yourself about autism** (Pg. 22).
5. **Learn more about special education**. Contact Missouri Parents Act (MPACT), the publicly funded parent training and information center (Pg. 10).
6. **Start a system for organizing reports and notes**.
7. **If you need resources** call Missouri Families for Effective Autism Treatment (MO-FEAT) at 1-877-275-8988 or email info@mofeat.org, or call the Autism Alliance of Greater Kansas City at 816-842-2452.
8. **To talk with a parent** who has volunteered to be a mentor for other parents, call Sharing Our Strengths at 1-800-444-0821 (Pg. 19).
9. **Work towards a routine schedule** for home and try making a schedule of your daily activities using pictures or words.
10. **Find a behavior therapist** to teach you strategies for increasing the behaviors you want to see.

Go Online	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/family/diagnose.hml and *Using Visual Schedules: A Guide for Parents* at www.iidc.indiana.edu/irca/education/visualSchedules.html.
Call	*Autism Speaks 100 Day Kit*. Call 1-888-AUTISM-2 to order, or go to www.autismspeaks.org/community/family_services/100_day_kit.php.

Roles of Professionals

Who Can Be of Help	How They Can Help
Psychiatrist	A medical doctor who can diagnose autism as well as other illnesses and treat the mental health issues associated with autism. A psychiatrist can prescribe medication or other treatments to treat issues such as depression and anxiety, aggression, ADD/ADHD, obsessive-compulsive behavior, tic disorders, and more.
Neurologist	A medical doctor who can diagnose autism and other neurological disorders. A neurologist also checks the neurological functioning of the body and may order tests such as MRI's or EEG's. A neurologist can prescribe medication or other treatments to treat issues such as depression and anxiety, aggression, ADD/ADHD, obsessive-compulsive behavior, tic disorders, seizure disorders, and more.
Developmental Pediatrician	A medical doctor who is a pediatrician with special training and certification in developmental-behavioral pediatrics. A developmental pediatrician is skilled in diagnosis of autism and developmental disorders. This doctor looks at the whole child and can recommend treatments including medication.
Psychologist	A licensed psychologist with specialized training in developmental disorders, such as a clinical psychologist or neuropsychologist. A psychologist, or neuropsychologist, can diagnose or recommend treatment for autism and other developmental disorders. He or she may address coping skills, behavior management, social skills, and strategies for improving functioning.
Behavior Analyst	A psychologist or therapist who is specially trained to analyze and treat behaviors that interfere with learning and functioning.
Speech-Language Pathologist (SLP)	A therapist who specializes in understanding and use of language, and the pronunciation of speech sounds. A speech-language pathologist may address understanding and use of words, grammar, social skills, reading comprehension, and written language.
Occupational Therapist (OT)	A therapist who specializes in assessing and treating fine motor skills, play and social skills, handwriting, sensory integration, and daily living skills such as dressing and feeding.
Physical Therapist (PT)	A therapist who specializes in assessing and treating gross motor skills (jumping, ball skills, using stairs), strength, and coordination.

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. It is important to ask questions about which might be the most effective for your child.
Here are some examples:

- Early Intensive Behavior Intervention (EIBI) / Applied Behavior Analysis (ABA)
- Relationship Development Intervention (RDI)
- Developmental, Individual-Difference, Relationship-Based (DIR) Model (Floortime)
- Structured Teaching – TEACCH Model (Treatment and Education of Autistic and Related Communication-Handicapped Children)

A group of family members, health care professionals, and educators are meeting to develop recommendations for Missouri standards of practice for screening, diagnosis and ongoing assessment of autism. The project is called the Missouri Autism Guidelines Initiative (MAGI). Read more at the Office of Autism Services website at www.dmh.missouri.gov/mrdd/progs/autism/autism.htm.

☆ *Questions to Ask Providers*

What is this treatment and what does it do?

Is this something I could do with my child and stay with it? Will this cause more stress for our family or reduce stress?

Is there real science to support this treatment?

Can I afford the treatment?

How will I be involved in the therapy?

How will I know whether my child is making progress?

Could I talk with another family about their experience with this therapy and this provider?

☆ *Parent-to-Parent Advice*

Have hope about treatments, but use common sense. Be cautious when you see or hear claims of cures.

Use caution with treatments that require payment before the treatment begins.

Think about the source of the information you read. Is someone trying to sell you something?

Double-check things you read on the Internet.

Pay special attention to studies that are published in high-quality scientific journals with peer-reviewed research. Do other studies show the same findings?

Go Online	*A Parent's Guide to Research* from the Organization for Autism Research at www.researchautism.org/resources/reading/index.asp. Read Online or order by mail.
Read	Read *Autism Spectrum Disorders: Interventions and Treatments for Children and Youth* by Richard Simpson (2004).

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. Children who have a medical diagnosis of an autism spectrum disorder automatically qualify for early intervention services in Missouri. First Steps provides screening, evaluation, and intervention services. For children with autism spectrum disorders, typical services might include speech therapy, occupational therapy, applied behavior analysis (ABA), and/or special instruction (developmental therapy). Sometimes families benefit from counseling, parent education, consultation with a nutritionist, or social work services. No two children or families are alike, and every child and family needs different amounts and types of services.

Early intervention services are documented in an Individualized Family Service Plan (IFSP). Families help to design the plan for services, which are delivered in the place where the child usually spends his or her day.

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.

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.

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 13) and have a need for medical services. Healthy Children and Youth provides funding for screening, referrals to doctors and services, and assistance with planning. Services include case management, home health and nursing, and personal care services.

Go Online	Find out more about the Children with Special Health Care Needs program online at www.dhss.mo.gov/SHCN/CSHCN or call toll-free 1-800-451-0669. Read about Healthy Children and Youth at www.dss.mo.gov/ mhk/hcy.htm.
Call	Call Missouri First Steps 1-866-583-2392 or find First Steps info online at www.dese.mo.gov/divspeced/FirstSteps/.

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 www.dese.mo.gov/divspeced or call 573-751-4212 for information about special education law and school services.

Read *10 Steps of Special Education* and *All About the IEP* at www.nichcy.org

If my child has an autism spectrum diagnosis, will he automatically qualify for special education services? Students with a medical diagnosis of autism spectrum disorder (ASD) often qualify for special education services. However, a medical 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 medical 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 process 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 can request a re-evaluation. A student who qualifies for special education has an Individualized Education Program (IEP) that documents the educational services and supports he or she needs in order to learn at school.

Project ACCESS is a project funded by DESE at Missouri State University that provides autism resource information to public schools across Missouri serving students with autism spectrum disorders. Assistance is provided through phone support, on-site consultations at the school, professional development trainings, and internet support. School districts must request this support for their teachers. On-site child specific consultations can be arranged through the use of **Missouri Autism Consultants**. School staff can also be trained as **In-District Autism Consultants**.

Additional Resources

MPACT: Missouri Parents Act 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. The program receives federal funding in addition to state funding from DESE.

Go Online	Read about Project ACCESS at Missouri State University's website at http://education.missouristate.edu/access/ or call 1-866-481-3841.
Call	Call Missouri Parents Act (MPACT) for assistance with special education at 1-800-743-7634, or visit their website at www.ptimpact.com.

Support Services — Three to 21 Years

Division of Developmental Disabilities

What is a Regional Office?

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

- Determine eligibility for services (Intake);
- Deliver service coordination through developing person-centered plans, monitoring services, and linking families with appropriate resources; and
- Contract for services written in the person-centered plan.

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

It is important to enroll in your local Regional Office of the Division of Developmental Disabilities in order 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.missouri.networkofcare.org and click on Developmental Disabilities.

OR Call Toll-free: 1-800-207-9329

Service Coordination

Every individual who is eligible for Regional Office services may receive targeted case management, also called service coordination. Service coordinators help people with disabilities and their families to identify and obtain needed services and supports, including assistance with completing paperwork. They make referrals to other community agencies and may attend school IEPs. The individual or family will work with the service coordinator to develop a person-centered 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. Service 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 an autism-specific program within the Division of DD. Now there are five Autism Projects in Missouri. The Projects fund various services including classes for parents, respite care, IEP advocacy, 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 above. If you are already enrolled with your Regional Office but are not sure whether you are in your local Autism Project, ask your service coordinator to check.

Go Online	Missouri Department of Mental Health - Division of Developmental Disabilities, www.dmh.missouri.gov/mrdd/mrddindex.htm.
Go Online	For information on the Missouri Autism Projects go directly to www.dmh.missouri.gov/mrdd/progs/autism/AutismProjects.htm.
Call	Missouri's Office of Autism Services (through the Division of Developmental Disabilities) can be reached at 1-800-207-9329.

Support Services — Three to 21 Years

Division of Developmental Disabilities

Service Options

Self-directed services are an option for individuals and families who wish to exercise more control in choosing staff and how their supports are delivered. Persons with disabilities and their families who choose self-directed services hire and supervise their own *Personal Assistants*. A service coordinator will continue to assist the family, visiting the home to be sure the program is successful. The coordinator will also help to explain the program and prepare the spending plan. A *fiscal agent* is available if needed to issue paychecks, collect taxes and other details to relieve the family of this responsibility. If the individual or family needs help hiring or supervising the personal assistant or making decisions, a *support broker* is also available.

Self-directed services have a documented history of success and improved consumer satisfaction. To learn more, interested persons should contact their service coordinator.

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 to 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 SB40 board may have programs and funding to assist with housing, employment supports, or other services. Some SB40 boards also provide service coordination.

Recreation Supports In some areas, the Parks and Recreation Department, the YMCA, or other local organizations may provide recreation supports for people with disabilities .

Go Online	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 www.macdds.org/index.html.
Call	Explore recreation programs near you. Contact the Missouri Park and Recreation Association at www.mopark.org or call 573-636 3828, Missouri YMCA at http://missouriymcas.org/, and Special Olympics Missouri at www.somo.org or call 1-800-846-2682.

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 administers three 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. Two 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.

Other services are covered by these waivers such as adaptive equipment and home modifications that are needed to help individuals live safely with family, in a group home or independently.

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 below.

Private Health Insurance

Some private insurance companies cover evaluation and therapy services related to care of people with autism spectrum disorders. Others do not. Call your insurance company to ask about your family's benefits. When you submit a claim, you may want to appeal the claim if coverage is denied. Missouri autism advocates are currently working towards insurance coverage for autism.

Call	To find a MO HealthNet office, call the Missouri Department of Social Services – Family Support Division at 1-800-735-2966 or visit www.dss.mo.gov/fsd/.
Indepth	Read more from the Missouri Department of Insurance at www.insurance.mo.gov or call the Consumer Hotline at 1-800-726-7390.
Go Online	Read about waivers at www.dmh.mo.gov/mrdd/progs/waiver/hcbw.htm. Your service coordinator can also help you understand the waiver options through the Division of Developmental Disabilities.

Planning for Transition to Adulthood

Planning for Transition through the IEP 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.

Person-Centered Planning is a process that takes place across the lifespan (see page 11) but is especially important in laying out a road map for services and supports needed for adulthood. You will want your son or daughter's person-centered plan to include needs that match their age and interests. Your service coordinator from the Regional or Senate Bill 40 Office can help identify who should be involved in the meetings. Through the person-centered plan, you will explore the interests your young adult has, how they can be pursued, and what supports may be needed for Continued Education, Career Exploration, Residential Living, Recreation and Leisure, and more.

Legal Issues

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.

Estate 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 Missouri 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 Missouri

Go Online	Read *A Guide for Transition to Adulthood* from the Organization for Autism Research at www.researchautism.org/resources/reading/index.asp.
Indepth	*Missouri Association on Higher Education and Disability (MO-AHEAD) Guidebook* at www.moahead.org. See the modules at www.missouritransition.org.
Call	Contact Missouri Developmental Disability Resource Center or Missouri Protection & Advocacy about their joint statewide trainings on guardianship and other alternatives for legal protection. See the back cover of this guide for contact information.

Adult Services and Supports

As your child grows and you continue to develop the Person-Centered Plan, you will want to consider the places that offer 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 who they can serve.

Department of Health and Senior Services

Division of Senior and Disability Services

Home and Community Based Services are available for persons over age 18 who m e e t 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.

Adult Day Care Programs offer support therapy and recreation services to the participant, as well as to the family, by providing care and supervision during the day. Participants attend the program on a scheduled basis and services may include the following: recreation and exercise, counseling, therapy, medical care, transportation, and other services. Contact the Section for Long Term Care at 573-526-8524 for a list of adult day care programs.

Division of Community and Public Health — Special Health Care Needs

Physical Disabilities Waiver

This program is available to people over age 21 years who are eligible for Medicaid (MO Healthnet) and previously received services through Healthy Children and Youth. They must still have a need for in-home medical services. Services include Private Duty Nursing, Personal Care, Advanced Personal Care, and Home Health Nurse Visits.

Non-emergency Medical Transportation

Some transportation is provided by The Special Health Care Needs program and is subject to income guidelines. It can only be used for transportation to and from certain programs. Call for more specific information.

Call	For information and referrals, or to request assessment for eligibility for Senior and Disability Services programs, call 1-800-235-5503.
Go Online	Find out more about the Special Health Care Needs program online at www.dhss.mo.gov/SHCN/CSHCN or call 1-800-451-0669.
Call	If you suspect abuse or neglect of a senior or an adult with disabilities, call 1-800-392-0210.

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 an employment initiative to assist people in career planning and obtaining community employment by providing service coordination and individualized supports for those who receive Division of DD services. For more information call Darla Wilkerson at 816-889-3960.

Division of Vocational Rehabilitation

Vocational Rehabilitation operates three programs under the Department of Elementary and Secondary Education (DESE).

Vocational Rehabilitation (VR) provides supports for people with disabilities to help them find and keep a job. 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.

Disability Determination Services (DDS) determines medical eligibility for Missourians who have filed for disability benefits with the Social Security Administration (SSA). If DDS determines you have a disability, then the Social Security office will decide what 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.

Independent Living aims to increase independent functioning in the community**.** The **Missouri Centers for Independent Living** are located throughout the state. They 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/.

Go Online	Missouri Division of Vocational Rehabilitation at http://dese.mo.gov/vr/ or call 1-877-222-8963.
Call	To apply for Social Security disability benefits, or to find your local office, call the Social Security Administration at 1-800-772-1213.
Go Online	Read *Missouri's Guide to Home and Community Based Services* at www.disabilityinfo.mo.gov/gcd/PIC/GCDServices.pdf.

Assistive Technology

Assistive Technology (AT) can play an important role in helping an individual to communicate or to access a computer. 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.

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.

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:

ETC – 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 while their own equipment is being repaired. **Show-Me Loans** provides families with low-interest financial loans to help buy equipment.

Kids Assistive Technology (KAT). Families of low and moderate income may apply for funding help for devices needed by their children through age 20.

TAP for Internet provides no-cost computer adaptations for persons who aren't 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 AT Conference & Expo with Parent/Advocate scholarships available.

MoAT also has equipment demonstration centers, recycled equipment programs, and more. A full description of all programs and contact info 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.

How Do You Know if a Person Needs Assistive Technology?

Evaluations for assistive technology 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 AT, call Missouri Assistive Technology for a referral.

Go Online	Order a *Family Information Guide to Assistive Technology* from the Family Center on Technology and Disability (FCTD) at www.fctd.info.
Call	Call Missouri Assistive Technology toll-free at 1-800-647-8557 or visit their website at www.at.mo.gov .
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 disorders 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.

Who Can Help Me Find Child Care?

The Missouri Child Care Resource and Referral (CCR&R) Network is part of the National Association of Child Care Resource and Referral Agencies, a national non-profit. Through MOCCRRN, local Child Care Resource and Referral agencies in Missouri help promote inclusive childcare services. Each agency has an Inclusion Specialist on staff to answer questions and provide technical assistance regarding Inclusion. MOCCRRN'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	Call Missouri Child Care Resource and Referral Network at 1-800-200-9017 or visit www.moccrrn.org
Go Online	Find more information from the Center for Inclusive Child Care at www.inclusivechildcare.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." Using respite is an important way for you to take care of yourself and avoid burnout. There are different types of respite programs. Some offer staff who are trained to provide respite care, and some offer funding for respite services. Talk to your service 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 works or doesn't 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 for how to manage your child's behavior at home. Using respite services to take breaks for yourself is also an important tool in managing stress.

Finding Supports

Sharing Our Strengths — Peer mentor program for Missouri
1-800-444-0821, www.sharingourstrengths.com

Missouri Families for Effective Autism Treatment — Mentors
1-877-275-8988, www.mofeat.org

Autism Alliance of Greater Kansas City — New family luncheon
816-842-2452, www.autismalliancekc.org

A-List — Online 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
1-800-558-8652, www.missouripeoplefirst.org

Family Voices of Missouri — Health and disability resources
417-619-2609, www.familyvoices.org/states.php?state=MO

Sibling Support Programs

Contact the Missouri Developmental Disability Resource Center to find a sibling support group in your area. If a *Sibshop* is available in your region, this is an excellent resource. The Judevine Center for Autism (314-432-6200) and the Thompson Center for Autism (1-888-720-0015) also 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 towards that dream.
- Focus on your child's successes and abilities.
- Celebrate the small joys and achievements along the way.

"Never stop learning.
Never stop fighting.
Never stop teaching.
Never stop loving your child.
Do what you can.
Do what you need to.
Do your best. That is all that you can do."

Quote taken from
Making Autism a Gift
by Robert Cimera (2007)

Call	Call the Missouri Developmental Disability Resource Center to find a mentor or a support group at 1-800-444-0821 or visit http://moddrc.org.
Read More	Read the article *Sibling Perspectives: Some Guidelines for Parents* from the Indiana Resource Center for Autism (IRCA) at www.isdd.indiana.edu/irca/family/SibPerspect.html.

Where to Look for More Information

Classes for Families

Autism Alliance of Greater Kansas City
816-842-2452
www.autismalliancekc.org
Hosts "New Parent Luncheons" in Kansas City.

Judevine Center for Autism
314-432-6200
www.judevine.org
Offers classes throughout Missouri for family members on understanding autism, and more.

Missouri Autism Projects
www.dmh.missouri.gov/mrdd/progs/autism/AutismProjects.htm
Several of the regional Projects offer classes and trainings for families.

Missouri Parents Act (MPACT)
1-800-743-7634
www.ptimpact.com
Check out "*Understanding the IEP Process for Children with Autism Spectrum Disorders.*"

Lending Libraries

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

Children's Mercy—Kraemer Family Resource Center
Kansas City
816-234-3900
www.childrensmercy.org

Friends of the Thompson Center
Columbia
1-888-720-0015

MO-FEAT will aim to make the resources referenced in this guide available at the lending libraries above, so that families across the state will have access to these materials.

Becoming informed and seeking quality services for your loved one is one of the best gifts you can give! ***Knowledge is power.***

Missouri Families for Effective Autism Treatment (MO-FEAT)
St. Louis
1-877-275-8988
www.mofeat.org
Library for use in office. Will mail info statewide.

Special School District of St. Louis County Family and Community Resource Center (FCRC)
314-989-8438/989-8431
www.ssd.k12.mo.us/parenteducation/fcrc.html
Lends book and media resources within St. Louis County

St. Louis Children's Hospital Family Resource Center
314-454-2350
www.stlouischildrens.org

Internet Resources

Autism Internet Modules
www.autisminternetmodules.org/user_mod.php
Online modules with information and videos on Evidence-Based Interventions for Social Skills, Classroom Instruction, and General Intervention.

Missouri Department of Mental Health
www.dmh.missouri.gov/mrdd/reourceguide.htm
Links to national and state level resource guides.

Missouri Developmental Disabilities Resource Center
Kansas City
1-800-444-0821
www.moddrc.org
Maintains a lending library that serves the state with resources that can be mailed to you.

Missouri Disability Portal
www.disabilityinfo.mo.gov
The disability portal is a one stop access point for the public to obtain information on disability resources.

Office of Autism Services
www.dmh.mo.gov/mrdd/progs/autism/autism.htm

Emergency Identification

Things you should know about me

I have an autism spectrum disorder.
I may not communicate well during stress.

Name_____

Medical Conditions_____

Age_____ **Blood Type**_____

Contact Person_____

Phone_____

Contact Person_____

Phone_____

I can speak: ☐YES ☐NO

I can understand you: ☐YES ☐NO

Medications_____

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 lack awareness of danger, 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.

Tips for Families

- Contact your local fire and police departments and ask them to keep information about your child on file.
- Have a family plan for emergencies.
- 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. Visit www.aap.org/advocacy/emergprep.htm.

Identification

Basic information should always be available about your loved one. Consider these tools:

- 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 is another tool.

Toolbox: Tear Out and Take Along

✂Cut out this page to create an **Emergency ID Card.** Make several of these cards. Place copies where they could be easily found by emergency responders such as in a pocket, car, backpack, purse or wallet, and at home. You can also provide this card to care providers.

✂Cut out this page to create an **Emergency ID Card.** Make several of these cards. Place copies where they could be easily found by emergency responders such as in a pocket, car, backpack, purse or wallet, and at home. You can also provide this card to care providers.

Doctor_____

Doctor Phone_____

Psychiatrist _____

Psychiatrist Phone_____

Service Coordinator_____

Coordinator Phone_____

After-hours Phone_____

Other Phone_____

Medications_____

_____

Handling Mental Health Crisis

If you experience a mental health crisis with your loved one or yourself, talk with your doctor and seek psychiatric help as soon as possible. Many people make improvement with proper medical treatment. Your service coordinator may have additional resources.

Tips for Caregivers

1. Stay calm. Your mood can help to calm the person down.
2. Take safety precautions to keep yourself safe and the person with autism safe. Remove breakable items from the room.
3. Call someone to assist you if needed.
4. Utilize respite services, so you can take a much-needed break.
5. Discuss with your doctor what to do in case of crisis and when to take the person to an emergency room.
6. Let your local law enforcers know that you have a loved one who may be unpredictable during crisis. Discuss how to best handle the person and any other tips that would help them respond in the safest manner possible.
7. **Call 911 if there is a serious threat of harm.**

Toolbox: Tear Out and Take Along

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DIVISION OF
DEVELOPMENTAL
DISABILITIES

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

Navigating Autism Services: A Community Guide for Missouri is the product of a family-professional partnership.

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We believe that families who have loved ones with autism spectrum disorders need a roadmap to help them navigate services, so they can find answers as quickly and easily as possible.

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State Agency Contact Information

Governor's Council on Disability—Missouri Disability Portal
www.disabilityinfo.mo.gov/directory/search1.shtml

Missouri Department of Elementary and Secondary Education (DESE)
573-751-4212
www.dese.mo.gov

Missouri Department of Health and Senior Services (DHSS)
573-751-6400
www.dhss.mo.gov

Missouri Planning Council for Developmental Disabilities (MPCDD)
1-800-500-7878
www.mpcdd.com

Missouri Assistive Technology (MoAT)
1-800-647-8557
www.at.mo.gov

Missouri Developmental Disability Resource Center (MODDRC)
1-800-444-0821
www.moddrc.org

Missouri Department Social Services (DSS)
1-800-735-2966
www.dss.mo.gov

Missouri Protection and Advocacy (MO P&A)
1-800-392-8667
www.moadvocacy.org