

Autism and Related Disorders

INFORMATION FOR PATIENTS AND FAMILIES



INSIDE:

What are the symptoms of autism?.....	2
What about Asperger's syndrome?.....	3
How is autism diagnosed?.....	3
What causes autism?.....	3
Diagnosis: The earlier, the better.....	3
How is autism treated?.....	4
How to help your child.....	6
Where to learn more and get help.....	7
Autism myths and truths.....	8

AUTISM IS...

...not rare.

As many as 1 out of every 80 males in Utah are diagnosed with an autism spectrum disorder (autism affects boys 6 times more often than girls). In America and worldwide, it's the fastest growing developmental disability. The increase may be caused in part by growing awareness and broader criteria for diagnosis.

...often misunderstood.

Sometimes people don't know what to make of autism symptoms. To some, a person with autism may appear odd, difficult, or rude. People might not know that this behavior is caused by a brain disorder.

...manageable.

Autism behaviors are a challenge — both for people with autism and for their caregivers, teachers, or employers. Yet people with autism can learn skills to help them live fulfilling, happy lives. Caregivers can manage the stress of autism with the right support.



Has a loved one recently been diagnosed with autism or Asperger's Disorder? If so, you may be feeling uncertain and overwhelmed. This handout can help by giving you some basic information about autistic disorders — including symptoms, causes, treatment, and what lies ahead.

What is autism?

Autism is a brain disorder that makes it hard for a person to communicate and interact with others. A child is born with autism, or with the tendency to develop it. And unfortunately, right now it's not something you can prevent.

Autism is the most common of a group of related disorders called **autistic spectrum disorders (ASDs)**. The next most common autistic spectrum disorder is **Asperger's syndrome**, which is also briefly described in this handout. While an ASD is sometimes first diagnosed in an adult, these disorders are most often identified and diagnosed in childhood. (This handout primarily refers to autism in childhood, but the general principles are similar for adults with autism — and the resources on page 7 are helpful for adult patients.)

The reason ASDs are called "spectrum" disorders is that they affect people differently and to different degrees. Symptoms and behaviors can vary, ranging from mild to severe. For this reason, treatment plans are highly individualized.

Remember that autism symptoms happen along a spectrum. They may be present in different combinations, and with different degrees of severity. And although children don't outgrow autism, symptoms may lessen as child receives treatment.

WHAT ABOUT ASPERGER'S DISORDER?

Asperger's syndrome was first described in the 1940s, but wasn't recognized as a separate disorder until 1994. People with Asperger's syndrome tend to have good vocabularies and grammar skills, but communication problems include speaking very formally, being very literal, and having trouble with non-verbal communication (body language, eye gaze, and so forth).

A classic symptom of Asperger's syndrome is an intense focus on a single subject — being obsessed with details and becoming an expert on that subject.

Other symptoms of Asperger's syndrome may include:

- Repetitive rituals or routines
- Motor skill problems, such as clumsy movements or being late in developing certain skills
- Problems with social skills
- Being highly sensitive to sensory information, such as light, sound, texture, and taste

What are the symptoms of autism?

People with autism have one or more symptoms in each of the areas listed below. While many of these symptoms show up in childhood, autism warning signs can be seen in babies. See “Diagnosis: the earlier, the better” on the next page for a resource to help you watch for autism signs in your infant or toddler.

<p>PROBLEMS WITH SOCIAL INTERACTIONS</p>	<p>People with autism:</p> <ul style="list-style-type: none"> • Don't use or respond to social cues like eye-to-eye contact, facial expressions, or body postures. • Have trouble making friends and mixing with others. • Appear aloof, and seem to prefer to spend time alone. • Lack interest in sharing ideas, fun activities, or achievements with others. • May not want to cuddle or be cuddled. • Don't engage in imaginative or symbolic play.
<p>TROUBLE COMMUNICATING</p>	<p>People with autism:</p> <ul style="list-style-type: none"> • Have delayed language development. • Have trouble starting or maintaining conversation. Talk AT — not WITH — others in one-sided conversations. • May repeat words or phrases. • Have difficulty expressing needs — may gesture or point instead of using words. • Are not responsive to verbal cues — may appear deaf.
<p>REPEATING PATTERNS OF BEHAVIOR, INTERESTS, AND ACTIVITIES</p>	<p>People with autism:</p> <ul style="list-style-type: none"> • Have intense preoccupations with certain topics. • May have unusual attachments to particular objects. • Insist on schedules, routines, and rituals. • Display sustained odd play or gestures (for example, spinning objects, hand or finger flapping, or rocking). • May hurt themselves (for example, bite their own arms) or physically attack others. • Are noticeably over-active or under-active. • May have uneven development of motor skills (for example, can stack blocks, but not kick a ball).
<p>OTHER</p>	<p>People with autism:</p> <ul style="list-style-type: none"> • May be overly sensitive to sounds, sights, sensations, and smells. For example, particular smells might cause a child to gag. Bright lights or even a hug may cause the child to draw back. • May be overly sensitive to pain — or may be noticeably under sensitive to pain. • Show little or no fear of danger.

How is autism diagnosed?

There's no single test to diagnose autism. Instead, doctors rely on the following:

- **Checklists and questionnaires** from parents, school professionals, and medical specialists who have observed the person in various situations. The questionnaires ask about the person's behaviors, relationships with others, body use, verbal communication, and play habits.
- **Standard medical criteria.** A doctor diagnoses autism only if the information gathered meets standard criteria for the disorder. Along with using the checklists and questionnaires above, your doctor gathers this information by interviewing and observing your child.
- **Medical tests.** Additional tests might be used to get more information. These tests don't "diagnose" autism. But they can help rule out or discover other conditions that may be causing symptoms (or making them worse).
- **Hearing evaluations** to rule out hearing problems and **speech and language evaluations** to assess speech, language, and overall communication abilities. These evaluations are very important because autism has a significant effect on overall communication skills.
- **Evaluation by specialists.** Consulting with one or more specialists can often be helpful in the complex process of diagnosing autism.

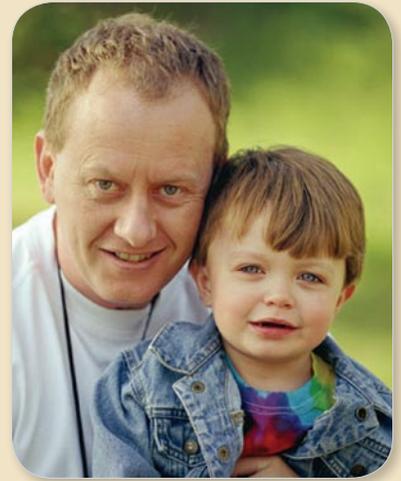
What causes autism?

Autism was first identified in 1943, but we still don't know what causes it. Since people are either born with autism or the potential to develop it, scientists are studying both genetic and environmental factors.

- **Genetic factors.** Scans show differences in brain shape and structure in people with autism. Scientists think these changes are genetic.
- **Environmental factors.** If a person has a genetic tendency towards autism, certain environmental factors may "trigger" it. Factors being studied include viral infections, metabolic imbalances, and exposure to certain chemicals.
- **NOT vaccines.** There are NO proven links between vaccines and autism. Research studies have repeatedly shown identical autism rates for patients who have received vaccines (such as the polio vaccine or MMR) or vaccine preservatives (such as thimerosal) and patients who have not received them.

DIAGNOSIS: THE EARLIER, THE BETTER

Autism can be diagnosed as early as 12 to 18 months, and early treatment is one key to successful management of the disorder. Your pediatrician should do developmental screening at the 18-month well-baby checkup, but a parent's observations are important for diagnosis. **The First Signs website** (www.firstsigns.org) contains valuable screening tools, or ask your doctor about the **Modified Checklist for Autism in Toddlers (M-CHAT)**.



LOVE AND AFFECTION?

Contrary to popular belief, children with autism can and do give affection. But because their brains process things differently, they have different ways of giving and accepting love. Families need to be patient in learning how to be affectionate on the child's terms.

IS IT AUTISM?

Diagnosing autism requires a careful look at other conditions that may be causing symptoms or making them worse, for example:

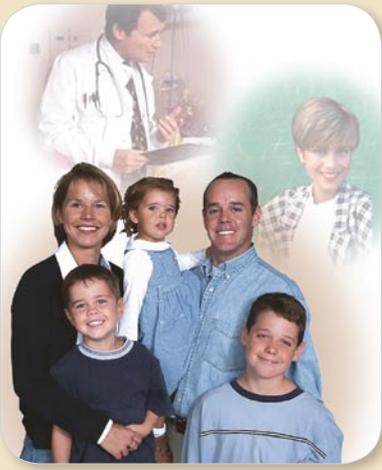
- Other behavior disorders like ADHD, oppositional defiant disorder, or conduct disorder
- Other developmental disorders, learning disabilities, or mental retardation
- Hearing loss
- Anxiety or depression
- Epilepsy

These conditions sometimes co-exist with autism, or are mistaken for it.

How are autism spectrum disorders treated?

Studies show that **early, individualized, and intensive** treatment has the most positive impact on the abilities of a person with autism. Therapy for specific functional problems might even begin before a formal diagnosis is complete.

Since no single strategy works with every person, **individualized** treatment chooses and combines strategies to meet a person's unique needs. An **intensive** approach means a patient is engaged actively and productively in meaningful activities for a minimum of 25 hours per week — with a treatment provider, family members, caregivers, or teachers. Each strategy below aims at the same overall goal: reducing symptoms and helping the person with autism succeed in various settings and relationships.



WHO'S INVOLVED?

Treatment for autism is a **team effort**. Here's who might participate:

- **Doctor** (primary care doctor, psychiatrist, neurologist, or other)
- **Mental health specialist** (counselor, therapist, school psychologist, or other)
- **Occupational therapist** (helps a person with play/social skills, daily living skills, feeding skills, and sensory integration)
- **Speech-language pathologist** (helps improve language, communication social skills, and learning skills — and in some cases, can also address feeding difficulties)
- **Care manager** (person who can connect you to resources and help coordinate and reinforce treatment)
- **Family members** (parents or spouses)
- **Teachers, school staff, coaches,** and other key people in the life of a person with autism

As you put together a team for yourself or your child, keep in mind that **YOU are the most important person on the team**. You're in the best position to help make sure that treatments are working well together. Stay in touch with your care team. Let them know what's working and what isn't. Speak up if you feel you or your child aren't getting the help needed.

Behavioral and communication training

A variety of approaches can help people with ASDs change behavior and improve communication skills:

- **SCERTS Model.** This model addresses key areas of weakness for ASDs, such as social communication (SC) and emotional regulation (ER), along with helping caregivers provide transaction supports (TS) that build on a child's strengths. The SCERTS model helps families incorporate skills learned in treatment into the family's everyday routines (such as getting dressed, meals, or playtime).
- **Applied Behavioral Analysis (ABA) or Early and Intensive Behavioral Intervention (EIBI).** Traditional ABA uses highly structured teaching activities that focus on specific educational concepts. Contemporary ABA is more flexible. It uses positive behavioral support and incidental teaching (teaching that occurs within ongoing activities and is based on the student's interest and motivation). Treatment involves up to 40 hours a week for two years.
- **Project TEACCH (Treatment and Education of Autistic and Related Communication-Handicapped Children).** This classroom-based model focuses on accommodating the learning styles of children with ASDs. It keeps distractions to a minimum, uses pictures and visual prompts to reinforce learning, and uses a highly structured schedule.
- **Parent-led treatment: RDI (Relationship Development Intervention) and DIR (Developmental, Individual-Difference, Relationship-Based Model).** These programs are based on a parent coaching model — a consultant teaches parents and family members, who then work with the child. Play-centered therapy emphasizes the child's interests and interactions between child and parent. "Floor time" exercises aim to help children improve skills in attention, communication, and logical thought.
- **Sensory Integration Therapy.** This occupational therapy model helps people with autism integrate and use sensory information to better function in daily life. Occupational therapy with this approach helps people improve emotional regulation and motor skills for daily living and play.
- **The Listening Program.** This music-based program, when combined with other approaches, can help people improve their skills in processing sounds.
- **PECS (Picture Exchange Communication System) and other visual strategies.** For children who struggle with spoken language, these strategies help them communicate by exchanging pictures.
- **Video modeling.** With this teaching method, target behaviors are videotaped, and the child watches the videotapes to memorize and imitate the behaviors.

Treatment of other problems

Many children with autism face other **developmental problems**. The most common are attention deficit/hyperactivity disorder (ADHD), anxiety, learning disabilities, depression, and bipolar disorder. These can lead to symptoms that are often treated with medication:

- **Medication to reduce tantrums, self-injury, or aggression.** Your doctor may prescribe risperidone (Risperdal) or a similar medication if your child has trouble with severe tantrums or aggression.
- **Medication to reduce hyperactivity or lack of attention.** Children with autism sometimes have problems focusing on tasks, and feel a need to be moving all the time. Your doctor may prescribe medication to help your child focus.
- **Medication to reduce anxiety, repetitive behaviors or routines.** To address these symptoms, your doctor may prescribe an appropriate medication. There are several alternatives, so if the first medication prescribed doesn't help, your doctor can prescribe a different one.

People with autism often face other specific **medical problems** as well, and treating them can reduce ASD symptoms. Talk to your care team if you notice any of these:

- **Difficulties with eating.** Children with ASDs can take "picky eating" to the extreme — refusing foods based on texture or type, or eating only specific foods.
- **Gastrointestinal problems.** People with ASDs can have cramps, diarrhea, and bloating.
- **Sleep disturbances.** People with ASDs often have trouble falling asleep, or wake early in the morning.

After trying therapy or medication, if your child continues to struggle with the problems listed above — and if they disrupt relationships or routines at home, school, work, or with friends — talk with your doctor about consulting a mental health provider who specializes in autism spectrum disorders.

Alternative approaches

"What else can we do? We'll try anything." As a parent you may feel this way, and you'll probably hear or read about many therapies in addition to those described in this booklet. These are often referred to as "alternative therapies," and include vitamin therapy, special diets, and others.

Be careful with alternative therapies. Most alternative therapies have NOT been tested in scientific studies. Some therapies are dangerous, such as chelation (the use of chemicals to remove metals from the body). Other therapies are expensive and ineffective, such as treatment with the hormone secretin.

A common sense approach? Don't go it alone. For your child's sake, discuss any alternative therapy you are considering with your child's treatment team. For other tips, see the panel at right.



APPROACH TREATMENTS WISELY

It's tempting to look for a "magic bullet" that will cure your child's condition quickly and permanently. But if a treatment approach sounds too good to be true, it probably is. Here are some tips for evaluating and using any therapy:

- **Keep in touch with your doctor.** Make sure your doctor knows about any new approach you try. For any therapy that includes medication or that affects your child's body, make sure a doctor supervises it closely.
- **Try one approach at a time.** Wait at least 3 months to decide whether an approach is working. This way you can tell what's helpful, and what isn't.
- **Take careful notes.** If this is a new treatment, take detailed notes on its outcomes and side effects. It can be helpful to record your child's behavior on video — before, during, and after the therapy.

How to help your child with an autism spectrum disorder

Use this page to help you guide your child's treatment — at home, at school, and with your child's doctor.

✓ Home plan

- **Commit to participating in treatment.** Once you find a treatment plan that works for your child and your family, commit to supporting it. Treatment may be challenging at times — remind each other of your commitment.
- **Learn as much as you can, and educate your loved ones.** Use the autism resources on the next page.
- **Find a support group.** The F.E.A.T. and Utah Parent Center websites list local support groups. See the facing page.
- **Help your child communicate and manage sensory input.** Use pictures or demonstrations to communicate. Speak directly and simply, avoiding slang or figures of speech. Carefully expose your child to new sensations.
- **Help your other children understand — and remember their needs as well.** Siblings often struggle with the time and attention a child with autism needs. Use the books listed on the facing page to help your other children express their feelings.
- **Consider family counseling.** You and other family members may want counseling (psychotherapy) to help heal the feelings that autism can bring up. Ask your doctor for advice or a referral.
- **Communicate acceptance.** Autism or Asperger's is a challenge, but it is only one aspect of your child's total character. Focus on what your child CAN do — there is more than one right way to do most things. Look for strengths, and you will find them.

✓ School plan

- **Consider a specialized school.** Depending on your child's situation and the treatment plan, you may want to consider a school that specializes in this disorder. This strategy may be especially helpful in the early years — age 7 and under. See the Utah Parent Center website for links to specialized schools.
- **Meet with teachers and other school staff.** Make sure your child's teachers understand autism or Asperger's. Work with them to develop a school plan with behavior goals (much like your home plan). Make sure they participate in follow-up evaluations. Involve the school counselor and principal as needed.
- **Get involved.** Attend school events and meetings. Volunteer in your child's classroom. You'll gain insight into your child and build valuable relationships with school staff.
- **Know your rights.** Your child may need special services at school. Two federal laws outline your child's right to a free and appropriate public education (FAPE) regardless of disability:
 - Individuals with Disabilities Education Act (IDEA), part B
 - Section 504 of the Rehabilitation Act of 1973

✓ Medical plan

- **Build a good care team.** Ask your child's doctor to help you connect with others who can help your family manage autism. For example, a speech-language pathologist can help determine and deliver treatment. A child psychiatrist may help diagnose and treat your child. A case manager or social worker can point you to services and coordinate care.
- **Develop a treatment plan.** Treatment for autism isn't "one size fits all." With your care team and loved ones, decide on a treatment plan that meets your child's needs AND your family's abilities. Since treatment may involve the whole family, you need to make sure everyone's on board.
- **If treatment includes medication, make sure your child takes it as prescribed.** Don't let your child skip doses. And make sure your child's doctor tells you what to do if a dose is missed.
- **Tell your doctor about other medications your child takes.** These include herbs, vitamins, and over-the-counter remedies. These may interfere with prescribed medication.
- **Ask questions and give feedback.** Follow through with all aspects of treatment, and give it time to work. But talk to the care team if you don't see good results. You may need to adjust your child's plan.

Where to learn more and get help

The resources listed here offer information, support, and advice for managing autism spectrum disorders.

Books for parents/caregivers, teachers, or adult patients

- ***A Parent's Guide to Asperger Syndrome and High-Functioning Autism: How to Meet the Challenges and Help Your Child Thrive.*** Sally Ozonoff, Geraldine Dawson, and James McPartland. Guilford Press 2002.
- ***Asperger's and Girls.*** Tony Attwood, Temple Grandin, Teresa Bolick, Catherine Faherty, et al. Future Horizons 2006.
- ***Autism Spectrum Disorders: The Complete Guide to Understanding Autism, Asperger's Syndrome, Pervasive Developmental Disorder, and other ASDs.*** Chantal Sicile-Kira and Temple Grandin. Perigee 2004.
- ***Building Bridges Through Sensory Integration: Therapy for Children with Autism and Other Pervasive Developmental Disorders.*** Paula Aquilla, Shirley Sutton, and Ellen Yack. Future Horizons 2003.
- ***Ten Things Every Child with Autism Wishes You Knew.*** Ellen Notbohm. Future Horizons 2005.
- ***Playing, Laughing and Learning with Children on the Autism Spectrum: A Practical Resource of Play Ideas for Parents and Carers.*** Julie Moor. Jessica Kingsley Publishers 2008.
- ***The Complete Guide to Asperger's Syndrome.*** Tony Attwood. Jessica Kingsley Publishers 2008.
- ***The First Year: Autism Spectrum Disorders: An Essential Guide for the Newly Diagnosed Child.*** Nancy D Wiseman. Da Capo Press 2009.
- ***The Way I See It: A Personal Look at Autism and Asperger's.*** Temple Grandin. Future Horizons 2008.
- ***What You Can Do Right Now to Help Your Child With Autism.*** Jonathan Levy. Sourcebooks 2007.

Books for siblings and classmates

- ***All About My Brother.*** Sarah Peralta. Autism Asperger Publishing Company 2002. (ages 5 to 9)
- ***Andy and His Yellow Frisbee.*** Mary Thompson. Woodbine House 1996. (ages 9 to 12)
- ***The Autism Acceptance Book: Being a Friend to Someone with Autism.*** Ellen Sabin. Watering Can Press 2006. (ages 9 to 12)
- ***Everybody is Different: A Book for Young People Who Have Brothers or Sisters with Autism.*** Fiona Bleach. Autism Asperger Publishing Company 2002. (ages 4 to 8)
- ***Ian's Walk: A Story about Autism.*** Laurie Lears and Karen Ritz. Albert Whitman & Company 2003. (ages 4 to 8)
- ***I am Utterly Unique: Celebrating the Strengths of Children with Asperger Syndrome and High-Functioning Autism.*** Elaine Marie Larson. Autism Asperger Publishing Company 2006. (ages 4 to 8)
- ***My Friend with Autism: A Coloring Book for Peers and Siblings.*** Beverly Bishop and Craig Bishop. Future Horizons 2003. (ages 9 to 12)

Websites and organizations

www.intermountainhealthcare.org/pedsrehab Learn about Intermountain's pediatric rehab services.

www.aap.org/healthtopics/autism.cfm The autism center at the American Academy of Pediatrics includes helpful resources.

autismcouncilofutah.org The Autism Council of Utah lists a variety of resources.

www.autism-society.org The Autism Society of America provides information about autism, links to research, and information on local chapters.

www.autismspeaks.org Autism Speaks provides resources to parents and patients.

www.medhomeportal.org/link/946 The Baby Watch Early Intervention Program is a collection of free services provided by public and private agencies to support families of eligible children from birth to age three in enhancing potential growth and development.

www.cdc.gov/ncbddd/autism/actearly The Center for Disease Control's "Act Early" site has tools to help you watch for developmental milestones from 3 months to 5 years, plus other resources.

www.familyvoices.org Family Voices aims to achieve family-centered care for children and youth with disabilities or special health care needs.

www.autismspeaks.org/docs/family_services_docs/100_day_kit.pdf The First 100 Days Kit is helpful for families after an initial diagnosis — it maps out steps for the first 100 days.

www.firstsigns.org First Signs is dedicated to identifying children with developmental disorders, so treatment can start early. Find screening tools such as the Modified Checklist for Autism in Toddlers (M-CHAT).

www.medhomeportal.org The Utah Collaborative Medical Home provides links to local treatment. Under "Diagnoses and Conditions," choose Autism Spectrum Disorder, then click the Services link.

www.utahfeat.org Utah Families for Effective Autism Treatment (F.E.A.T.) was founded by parents of children diagnosed with ASDs.

utahparentcenter.org/resources_autism.htm The Utah Parent Center provides links to local resources for autism. You can also call 1.800.468.1160.

Myths and truths about autism

Have you heard any of these myths about autism? Get the truth.

MYTH

“People with autism can’t express love.”

“Autism only happens to people of low intelligence.”
OR, *“All people with autism have special abilities.”*

“Autism is caused by bad home environment.”

“Autism is caused by mercury, or by early childhood vaccines.”

“Autism can’t be diagnosed until well into childhood.”

“Autism and Asperger’s can be outgrown.”

TRUTH

Children with autism can and do give affection — on their own terms. With treatment and support they can learn to express themselves more richly, but it’s also important to be patient and watch for your child’s unique way of showing his or her love.

People with autism have a wide range of IQ scores and skills. Only 10% of people with autism have special skills in one narrow area.

Autism is a biological disorder. Environmental factors can affect autism behaviors, but they don’t cause autism itself.

Multiple research studies have shown NO connection between vaccines and autism. Also, studies have shown NO connection between mercury and autism. Be sure to get the necessary vaccines for your child, and avoid dangerous “chelation therapies” designed to remove metals from the body.

Actually, the signs of autism show up as early as 18 months of age, or even sooner — and the sooner treatment begins, the better. Make sure your doctor evaluates your baby or toddler for autism, especially if you think something may be wrong.

These disorders are not like a “childhood phase” — they don’t disappear with time. However, they can be effectively treated. With appropriate treatment, love, and support, children and adults with autism can lead productive and happy lives.