

# Understanding Autism: A Parent's Guide

## **Introduction**

As a parent, you may have many questions regarding your child's autism diagnosis. As you look for answers, you may encounter information about autism, its causes, and possible treatments. All of these different opinions can make it challenging for a family to organize options and begin to choose a treatment plan that best fits the family.

We hope that this packet will help better prepare you to understand the information you receive about treatments for autism, as well as give you the chance to look over the most recent professional opinions about autism.

Westside Regional Center anticipates supporting your family as you proceed from your child's initial diagnosis to ongoing support throughout his or her lifetime.

## **What is Autism?**

Many parents may initially ask, "How and why did my child develop autism?" Unfortunately, no apparent cause exists for most cases, but most experts believe that autism is primarily a genetic condition. For about 10% of cases, experts believe that autism has either a specific genetic (from parent to child) or environmental cause. For example, there is an increased risk for autism from specific genetic disorders such as Fragile X Syndrome, Angelman Syndrome, Tuberous Sclerosis, Rhetts Disorder, untreated Phenylketonuria, and some chromosome abnormalities. Known environmental causes include taking thalidomide during pregnancy (a type of sedative now not routinely available in the United States) or having German measles (rubella) during pregnancy.

There are three main behaviors that are found in all children with autism:

1. Difficulty with social interaction: Children with autism may not be able to relate easily to people, have a hard time playing with other children, or have certain behaviors, such as avoiding eye contact or making socially inappropriate gestures in conversation.
2. Problems with communication: Children with autism may have a delay in, or sometimes total lack of, language development. Children may also repeat words or phrases, have a general difficulty with speech, or have an inability to start or carry on conversation with others.
3. Repetitive movements or behaviors: Children with autism may consistently repeat activities. This can also consist of a child's inflexible need for routines or rituals. Some common examples are hand-flapping, rocking their bodies back-and-forth, or spinning.

## **How did my child receive this diagnosis?**

Your child's diagnosis depends on a careful examination of his/her 1) social behavior, 2) communication, and 3) activities and interests – as well as researching his/her relationships with family and medical and health history. Therefore, the complete evaluation usually has six specific parts:

- **Review of relevant background information.** This is an essential first step – it allows the doctor or psychologist to understand your own parental concerns, as well as review the results of your child’s previous tests, school evaluations, and medical history. It also helps to avoid repetitious testing, which can be very stressful to your child.
- **Parent/caregiver interview.** Your interview is extremely important to the diagnosis because there is no one who knows your child better. In fact, parents are usually the first to notice signs of autism because they are able to watch their child more carefully and regularly. Therefore, the doctor or psychologist will probably ask you for a detailed history of your pregnancy, in addition to your child’s birth, health, development history, and current behaviors.
- **Medical evaluation by a multi-disciplinary team (which might include a pediatrician, child psychologist, child psychiatrist, occupational therapist and/or speech pathologist,).** This usually includes a physical examination and developmental/ neurological examination by qualified health professionals. The exams focus on checking your child for any medical conditions that are associated with autism, as well as testing for any problems with hearing, vision, movement or body coordination.
- **Direct behavioral observation.** Direct observation is very important for several reasons. It allows the doctor or psychologist to watch your child’s behavior – both in situations that he/she is familiar with (such as playing with his/her toys or interacting with family), as well as how he/she reacts to new places or meeting new people.
- **Cognitive assessment.** Our cognitive skills determine how we learn and this assessment focuses on better understanding your child’s thought processes. This step is important because the results help you to choose autism treatments that better fit your child’s situation. It is important to know that about 70% of children with autism also have some degree of mental retardation. However, since it is very difficult to test intelligence, especially for younger children, it is best to re-test your child as he/she gets older.
- **Adaptive functioning.** This test focuses on your child’s ability to function independently in real-life situations. For example, this might include a focus on your child’s living skills, such as eating dressing, or going to the bathroom. However, it also assesses how your child is able to talk or relate to other people. Most of the time, this involves your doctor or psychologist asking you questions about how your child is functioning.
- **Medical testing.** The evaluation might also include neurological testing (for example, an MRI or image of the brain), genetic testing (for example, blood tests for chromosomes, fragile X syndrome or Rett’s disorder), or metabolic testing (errors of metabolism, thyroid, etc) to make sure that there are no other health concerns. These evaluations should be discussed with your physician.

Also certain less common conditions and complications associated with autism may be screened for:

- growth impairment, birth defects and brain development (neurodevelopmental) disorders resulting from Fetal Alcohol Syndrome;

- Tuberos Sclerosis (a genetic disease that causes benign tumors to grow in the brain and on other vital organs such as the skin, kidneys, heart, eyes, lungs); and
- birth defects and hearing loss associated with Congenital Infections (these infections are generally caused by viruses that may be picked up by the baby at any time during the pregnancy up to the time of delivery).

Not every child requires all of the above tests and your doctor or psychologist should address which tests are right for your child.

### **Evaluating Treatments**

Although there is no cure for autism, many treatments have been offered and tried. Westside Regional Center has a great deal of information on treatments that have been shown to work and treatments that have not been shown to be effective. Before you explore the various treatments for autism, here are some suggestions to help you evaluate your options for your child's therapy.

**Find a team of trusted professionals.** You'll need to make important decisions about your child's education and treatment. Find a team of doctors, teachers and therapists that you trust. These professionals can help evaluate the resources in your area and help explain the federal regulations regarding children with disabilities. WRC physicians can help you with local resources if desired.

**Approach any treatment with hopeful skepticism.** The number of treatments for autism has increased greatly over the years and many show promise of improving behavioral symptoms. However, it is important to remember that sometimes what people say is effective for autism may *not have been shown to work* by scientific studies. Some treatments may even have harmful side effects, especially for younger children. Therefore, it is important to ask questions, research as much as possible about a specific treatment, and discuss opinions with a trusted health care provider.

**Determine whether this treatment is right for your child.** No child with autism is the same—children with autism often display a wide range of functioning and developmental differences. For example, some children are unable to speak while others will easily be able to verbally communicate. Some children will also have more severe behavioral and social difficulties than others with the same diagnosis. For these reasons, one of the most important things to remember when designing a treatment plan is to individualize it specifically for your child. You must ask yourself, “Is the treatment right for my child? Which issues do I specifically want to address?” The best place to start is to have a complete assessment of your child's strengths, challenges, and needs by a team of medical professionals, including a physician, psychologist, occupational therapist, and a speech therapist (this could be done by the medical professionals working within WRC). The exam would allow you to research treatments that specifically focus on the issues that are most important for your child.

**Understand how much time and commitment the treatment will require.** It is important to know that your family will play an important role in supporting and helping to carry out treatments. Some treatments may be stressful, not only for your child, but for

your entire family –in the amount of time and effort required from the family, as well as the price in dollar terms. When considering possible treatments, you should consider both the financial and emotional costs. *Does the benefit outweigh the costs of the treatment?* Also, if you decide to pursue a specific treatment, it is important that you know how to evaluate the treatment and see if it is working. This allows you to monitor the progression of your child, so that you can decide whether or not you should continue or stop the treatment after a period of time.

**Be aware that not every treatment can or should be done at the same time.** Many families feel pressure that they must do “everything” for their child with autism immediately. This is not the case! In fact, some treatments for autism have been shown to be effective for older children but not for younger children and vice versa. Children may suffer from over-scheduling treatments. In addition, as research is being conducted, some treatments that you may start now may be shown to be ineffective later.

### **Management and Treatment of Autism**

While an individual treatment’s success depends both on the quality of the provider as well as the response of the child, here are some basic guidelines about management strategies.

We do know that children with autism can improve with early diagnosis, strong support at home, and a comprehensive treatment plan. Frequently, they can live at home and attend schools in their own communities. We also know that a child’s progress in treatment does not mean that he or she will “outgrow” the diagnosis of autism or become indistinguishable from other children in all situations. Therefore, services should be focused on improving the quality of life for the person with autism.

Although treatments may differ between children, management strategies include the following:

- Early intervention (children younger than 3 years). Appropriate interventions in this age group usually take place in homes or child care centers and are individualized. They include speech therapy, occupational or physical therapy, behavioral methods, early developmental education, or highly structured social play interventions.
- School-based interventions (children older than 3 years). Educational interventions and programs vary somewhat in philosophy, what is taught, and how they’re taught, but should always provide the child with structure and methods that will help develop social skills, functional communication, and learning. Speech and occupational therapy and use of peers without autism as role models and playmates are usually included in these programs. For children age three and older, many therapies are considered an educational support, provided through the public school system. For children over three, your service coordinator can assist you in advocating for certain therapy services through the IEP process.
- Behavior management. Behavioral therapy, including communication development, has been shown to be effective in reducing problem behaviors and improving how the child responds to change. The overall goal of the approach is to reinforce desirable behaviors and reduce undesirable ones. Examples of behavioral therapy approaches include Applied Behavior Analysis (ABA), DIR/Floortime,

Relationship Development Intervention (RDI), and TEACCH. Westside Regional Center can provide more information on these therapies.

### **Medications**

Medications are sometimes used to treat certain symptoms or behaviors associated with autism. For people with autism, these drugs have been used to treat behaviors that often accompany the disorder (such as aggression, anxiety, attention-deficit, or self-injury). These drugs are called *psychotropic* medications.

There is one type of psychotropic medication that has been approved by the U.S. Food and Drug Administration (FDA) for treating the symptoms of autism, specifically the symptom of aggression. This medication is called Risperdal, or the generic, risperidone. You should ask your physician if your child would benefit from this medication and your child should be under the care of a specialist, such as a child psychiatrist, while on the medication. The side effects include irritability, weight gain and some children on this medication develop diabetes. Therefore, testing for weight gain and diabetes must occur regularly and throughout the time the medication is used.

Other medications (that have been tried, but are not U.S. FDA approved for autism symptoms) include sedatives, stimulant medications, antidepressant medications, medications for Alzheimer's disease, anti-anxiety medications, and anti-psychotic medications. All of these medications affect the functioning of the brain and have serious potential side effects so should be discussed with medical specialists. None of them have been studied in the long-term (over 2 years) for effects on brain development. However, some doctors have found that in some children there is a positive effect. Therefore, when using medications, it is important to have a specific plan for showing a positive effect, to be aware of harmful side effects, especially for younger children and those who may not be able to communicate side effects, and to take extreme care.

### **Alternative Therapies**

Because autism is a lifelong condition for which presently there is no medical cure, it has become the focus of several non-medical treatments. However, since these alternative interventions have not been proven to be effective through scientific studies, they are not funded by regional center or school districts. Nevertheless, WRC has included a brief look at some of these therapies due to the rise in the number of available alternative treatments.

**Vitamins and Supplements.** Some people believe that vitamin deficiencies cause symptoms of autism. Nutritional supplements to treat autism follows the belief that high doses of certain vitamins can affect brain development, nerve problems, or depression. Frequently reported nutritional supplement plans include high doses of omega-3 fatty acids, vitamin A, vitamin C, or the combination of high amounts of magnesium and vitamin B6. However, there is no scientific evidence that such treatments are effective for autism. Caution should be used if they are taken because, in some cases, they can have physically harmful side effects.

**Special Diets.** Special diets to treat autism are supported by those who believe that autism in children is related to food allergies and that, if you remove certain foods from a child's

diet, symptoms will improve. No studies have shown that food allergies cause autism. The most widely known diet is the gluten and/or casein free diet. This diet has not been shown in scientific studies to be an effective treatment for autism, but some doctors and parents do report positive effects. These diets are not endorsed by the American Academy of Pediatrics. Some diets are extremely difficult to follow, can worsen behaviors around foods, can cause nutritional deficiencies (such as bone density loss from lack of calcium), and are costly to maintain.

**Chelation therapy.** Some people believe that autism is a result of childhood exposure to toxins. Mercury is the element most often blamed for this effect. People who believe this theory recommend chelation therapy – putting another chemical in the body to remove the harmful one. However, there is no scientific evidence that this therapy helps children with autism. The substance chemicals used for chelation can themselves be extremely harmful. Several children have died due to administration of these chemicals. Since the treatment is both unproven and potentially harmful, it is generally not recommended as treatment for autism.

### **Medical Professionals**

The health care system can be very confusing, especially when your child has special needs and your doctor is unfamiliar with autism. Generally, if your doctor is willing to learn about autism and help you find specialists as the need arises, you should be able to get complete health care for your child. To make the process easier, below is a description of several medical specialties:

- General Pediatrician – medical doctor who specializes in the primary health care of children and adolescents (0-21yrs). Should be able to communicate with specialists, coordinate care and provide your child with a medical home.
- Developmental Pediatrician – pediatrician who has training in child development with an emphasis on conditions where development, learning, or behaviors are not typical.
- Child neurologist – medical doctor who specializes in conditions of the brain and nervous system. Child neurology focuses on the neurological conditions of children.
- Family Practice Doctor – medical doctor whose practice includes the primary health care of children, pregnant women, and adults.
- Child Psychiatrist – medical doctor who specializes in the prevention, diagnosis, and treatment of mental illness. Child psychiatrists specialize in the mental health of children.

### **What to expect medically**

Your primary care physician should continue to provide regularly-scheduled medical care and preventive screenings. Additionally, children who are diagnosed early for autism (<2-3 years old) should be re-tested by 5-6 years of age to check if the diagnosis is still the same, to check current levels of intellectual functioning, and to track if treatments are working. Some children who are diagnosed with autistic symptoms early on lose the diagnosis as they get older.

Also, people with autism are at higher risk for certain medical conditions. Your child may have some of these or may develop them over time, but not every person with autism has these problems. They include:

- ***Seizures/epilepsy.*** Generally up to 30% of those with autism have epilepsy, but an even higher number may eventually have one or more seizures. A pediatric neurologist should be consulted for this problem.
- ***Mental Retardation.*** Approximately 50-70% people with autism have mental retardation as well. However, since testing for intelligence can be extremely difficult, especially for younger children, it is important to have your child retested as he or she gets older.
- ***Mental Health problems.*** These problems may include issues with depression or anxiety. However, attention-deficit hyperactivity disorder (ADHD) is one of the most commonly diagnosed neuropsychiatric disorders.

Many of these conditions can be avoided or minimized with good medical care and therapies. Your doctors should assess your child for these conditions and they should be treated promptly.

### **Resources – WRC**

- Early Start (for ages 0-3)
- Family Resource Center (310-258-4063)
- Health and Medical Department (310-258-4254)
- Service Coordination
- Support Groups – Birth to Five Parent, Teen Social Group, Networking and Social Group
- Trainings & Events – self advocacy, consumer discussion, and behavior management

While WRC offers the above services and resources, we understand that you may look for information and other opinions on your own. Please be careful because a lot of information available on the internet is not accurate information, especially about the causes of autism and miracle cures.

### **References**

California Department of Developmental Services. Autistic Spectrum Disorders: Best Practice Guidelines for Screening, Diagnosis and Assessment. 2002.

Committee on Children with Disabilities. American Academy of Pediatrics: The Pediatrician's Role in the Diagnosis and Management of Autistic Spectrum Disorder in Children. PEDIATRICS Vol. 107 No. 5 May 2001, pp. 1221-1226.

Rubin, Leslie and Crocker, Allen. Medical Care for Children & Adults with Developmental Disabilities. 2006

Similar guides:

Foothill Autism Alliance. [Autism Power Pak](#).

South Central Los Angeles Regional Center. “Autism: A Guide for Parents and Other Caregivers.”

Harbor Regional Center. “Guía para Padres sobre Autismo”/ “Parents’ Guide to Autism”