

no one model fits all

which
treatment
and how
much

Parents' Guide
to



my child's progress

how
can I evaluate
treatment

what should I look out for



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AS THE PARENT OF A YOUNG CHILD recently diagnosed with autism, you probably have many questions about what the diagnosis means for your child and your family. You will, no doubt, receive a great deal of sometimes conflicting information about autism, its causes, and its treatment. This information may be very difficult for you to sort through as you look for answers to questions such as why your child developed autism, what you can do to help your child reach his maximum potential, and what kinds of treatment he should receive. You may also find that there are different theories about what causes autism and how it should be treated, some of which have little or no scientific basis.

This parent's guide was developed to help you understand the information you receive about autism treatments. It was revised in 2006, and its contents reflect the most recent research and best professional opinion available at the time. In the booklet, we look at the treatments that, to date, have shown the most promise in scientific studies. We also provide descriptions of some other treatments that, while being well known, have little scientific support. At the end of the booklet, we tell you where to get more information about autism and its treatment.

Introduction

what causes autism?

AN EARLY REACTION OF SOME PARENTS to having a child with autism is to ask the question: *What did I do to cause this?* While there are many things we do not know about autism, we do know that parents do not cause their children to develop this disorder.

In a majority of cases of autism, the cause is not apparent. Studies have shown, however, that genetics plays a very important role and, in most cases, the condition probably originates before birth.



For about 20% of children with autism, we can point to a specific genetic (inherited) or environmental cause. Known causes include exposure to the drug thalidomide in the womb, and German measles (rubella) contracted in the womb or during early childhood. There is also an increased risk of developing autism for children with specific genetic disorders such as Tuberous Sclerosis, Fragile X Syndrome, Angelman Syndrome, untreated Phenylketonuria (PKU), and certain chromosome abnormal-

ities. A family that has one child with autism has an increased risk of having another child affected with the condition.

Over the years, a number of factors have been cited as causes of autism even though there is no scientific evidence to support the theories about them. Among these factors are allergies to gluten (found in wheat flour) or casein (found in milk), an immune deficiency, a vitamin deficiency, yeast infection, and mercury poisoning. It has also been proposed that childhood immunizations are a causal factor in the development of autism, primarily due to the presence in these products of Thimerosal, a mercury-containing preservative. Although studies of large populations have not supported this theory, Thimerosal has been removed from most childhood vaccines. In 2004, the Institute of Medicine issued a final report on this matter, incorporating new evidence from epidemiological studies from the U.S., Denmark, Sweden, and the United Kingdom. (This report is available at <http://www.fda.gov/cber/vaccine/thimerosal.htm>.) The report rejected the theory of a causal relationship between Thimerosal-containing vaccines and autism. Furthermore, as public health professionals point out, there are potentially very serious health consequences for children who do not receive these immunizations.

HOW SHOULD I BEGIN GATHERING INFORMATION ABOUT TREATMENTS?

Before we talk about treatments for autism, we offer three suggestions to guide you as you begin to look for services for your child.

Match the treatment to your child's individual needs. One of the first rules of designing a treatment plan for any developmental problem is to individualize the treatment. The same applies when developing a plan for treating a child with autism. A child with autism is – above all – an individual first. For this reason, finding an appropriate treatment requires you to answer the question: *Which treatment and how much of it is right for my child at this time?* The answer to this question begins with a complete assessment of your child's strengths, challenges, and needs by a multi-disciplinary team including professionals such as a physician, a psychologist, and an occupational, physical, or speech therapist. It should also include an assessment of your family's ability to participate in treatment. When treating a young child for autism, the family plays a critical role in supporting the treatment provided by professionals outside the family and helping to implement the treatment plan in the home.

Be open-minded but skeptical. Most of the treatments that may be presented as effective for autism have not been shown to be effective

in scientific studies. Some may even be harmful, especially when used with young children. At the same time, some of these treatments have strong parent advocates who believe their children have been helped by them. In addition, the professionals who

propose these services may be overly optimistic about what their services can achieve for a given child. Be open-minded about a new treatment, but do not hesitate to ask critical questions of the person who is proposing it for your child. Read as much as you can about the treatment and discuss it with an independent professional you trust. Your child's pediatrician or a psychologist or child psychiatrist may be able to help you evaluate different treatment approaches.



Insist on ongoing evaluation of your child's progress.

When planning for services, you and the planning team need to agree on who will evaluate your child's progress in treatment and how often it will be done. You also need to think carefully about how progress will be evaluated, keeping in mind that behaviors sometimes get worse before they get better. An honest evaluation will help you decide whether or not to continue with the treatment. Many treatments for autism require a great deal of time and effort from the child and the family. Treatment programs can create stress for the child and for the family, and they may be costly in dollar terms. To continue with a treatment that is not helping your child is a waste of resources. More importantly, it takes away from the time that may be devoted to other, possibly more helpful, services or to activities that may improve the quality of life for the family.

WHAT DO WE KNOW ABOUT THE TREATMENT OF AUTISM?

Let's look at what we know about treating autism.

We know that most children with autism can improve with early diagnosis, a comprehensive treatment program, and good support at home. They can live with their families and go to school in their home communities. Many will become fully functioning members of society. How far a child progresses depends on many things, including whether or not he or she has mental retardation in addition to autism.

We 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 aimed at improving the quality of life for the person with autism. **Treatment goals should emphasize development of social skills and functional communication.** Functional communication does not necessarily mean talking. Some children may not learn to talk, but will be able to communicate effectively using another method.

We know that there is no "one model fits all" treatment for autism. Children with autism display a wide range of developmental differences, and often a wide range of functioning with respect to these differences. For example, some children may be hyperactive while others show a very low level of activity. Some children will have no speech while others may have good language skills. A treatment approach that is successful with one child may not be helpful to another. Indeed, this is one reason why evaluating the effectiveness of treatments is so difficult. We do know, however, that intensive early intervention in highly structured educational settings results in improved outcomes in most young children with autism.

HOW CAN I EVALUATE A TREATMENT PROGRAM?

The accepted treatment for autism is a comprehensive, highly-structured educational program that uses principles of child development and positive behavior modification. The actual interventions may look like teaching or like play. Comprehensive means that the programs focus on a range of skills and behaviors including social and communication skills. Such programs are the most thoroughly studied and have the most scientific support. If you are seeking a program for your child, there are a number of things you should look for, questions you should ask of the people who are offering the services, and certain things to look out for.

What Should You Look For In A Program?

Controlled studies of comprehensive autism treatment programs, while not showing any clear superiority of one over another, do point to certain characteristics that appear to contribute to program effectiveness. The following characteristics appear to lead to better outcomes:

1. The intervention is started as early as possible after a confirmed diagnosis, although the model programs that have been studied focus on children age 3 to 5 years.
2. There is a comprehensive assessment that helps determine whether the treatment is appropriate for the child and what should be included in the treatment plan.
3. Services are individualized – tailored to the child's needs and the family's ability to support them.
4. There is a written treatment plan that tells what behaviors and skills are targeted for change and how the child's progress will be measured.
5. The programs focus on the child's ability to: 1) attend to elements of the environment that are essential for learning, especially social stimuli; 2) imitate others; 3) comprehend and use language; 4) play appropriately with toys; and 5) interact socially with others.
6. The treatment uses systematic and structured teaching and emphasizes generalization of skills to more complex, natural environments.
7. The teaching environment is supportive and is characterized by predictability and routine.
8. The services are intensive.
7. Families are involved in developing and carrying out the treatment plan.
8. The planning team considers changing the services when the child has achieved the target objectives, when the child fails to progress after a certain period of time, or when there is an unexpected change in the child's behavior or health condition.
9. All individuals working with the child and the family in all environments cooperate with one another.

What Is “Enough” Treatment?

We know that effective programs are intensive. This means that services take up a significant number of hours a week and they occur in all settings where the child spends a significant amount of time. Across the treatment programs reviewed for this document, the amount of time devoted to active treatment was typically 20-30 hours per week. This number of hours was usually the **total** of all interventions in all settings including, for example, school or preschool hours, therapy (speech, physical, occupational) hours, time spent in socialization programs, and time devoted to in-home intervention by both professionals and parents.

The number of hours that a child is in treatment should be based on his or her age, health considerations, severity of autistic symptoms, severity of maladaptive behaviors that interfere with learning, how well the child is progressing in treatment, how well he tolerates the treatment, and the family’s ability to participate in and support the treatment. The involvement of parents is crucial to ensure that the behavioral and educational outcomes and strategies most important to the family are targeted by the interventions. Parents also play a critical role by providing additional hours of instruction to their child.



What About Medication For Autism?

There is no medication for autism itself, but drugs are sometimes used to treat certain symptoms associated with autism. These drugs are called *psychoactive* or *psychotropic* medications. They affect the brain and are usually used to treat mental illness or emotional problems. In people with autism, psychoactive drugs have been used to treat behaviors such as aggression, self-injury, anxiety, attention-deficit, social withdrawal, and obsessive rituals that often accompany this disorder. Let's look at some examples.

Some of the newer types of medications for depression are used to treat obsessive rituals in people with autism. Drugs usually used to treat a psychotic disorder are sometimes used to treat severe aggression or other challenging behaviors associated with autism. Stimulant drugs, such as those used for attention deficit disorder, are sometimes used to decrease activity level and increase attention in children with autism, but these drugs may also increase aggressiveness and stereotypical behaviors in some children.

Sometimes a person with autism may have a mental or emotional disorder such as depression or anxiety, just like people without autism. When this occurs, psychoactive medication may be used to treat the disorder. In such a case, the person's psychiatric diagnosis would guide the selection of the drug.

When using psychoactive medications it is important to select a drug that has the least likelihood of harmful side effects. Finally, because psychoactive drugs can cause very dangerous side effects when used with young children, they should be used with extreme caution with this population.

What Questions Should I Ask Professionals Who Want To Treat My Child?

You may find it useful to ask the following questions of service providers who are proposing a specific treatment for your child.

- What does the treatment consist of and how does it work?
- What scientific evidence is there that the treatment is effective?
- Is the treatment developmentally appropriate for my child?
- Could it possibly harm my child?
- What will the treatment require from my family in terms of time and money?

- Will I as a parent be trained to help develop and carry out the treatment?
- How will I be kept informed about my child's progress?
- How will we decide whether the treatment should be continued or stopped?
- How will this treatment be coordinated with other services my child may receive?

What Should I Look Out For When Evaluating Treatments?

Even though you may not be an expert in child development or the treatment of developmental disorders, you can still make judgments about treatments that are presented to you. You only need to rely on your common sense and logic. For example, the following are some warning signs that should cause you to question a treatment:

- The claim is made that the treatment is effective or desirable for every person with autism.
- The claim is made that children will respond dramatically to the treatment and some will be cured, particularly if treated early.
- The evidence for effectiveness consists only of reports of individual cases or anecdotes rather than carefully designed studies using groups of children.



- Treatment does not involve identification of specific objectives, target skills, or behaviors.
- Treatment is not based on a thorough assessment of the child and family, and development of an individualized treatment plan.

Remember. Any treatment type other than education represents only one of several possible options for a person with autism. Treatment should always depend on individual assessment information that points to it as an appropriate choice for a particular child and his or her family.

What Does The Research Say About Alternative Treatments For Autism?

In the absence of specific proven treatments for autism, a number of “alternative” treatments have been proposed. In general, these alternatives are not supported by scientific evidence. In this section, we look briefly at some of these alternative therapies. Each one



has its supporters among the professionals who provide it, as well as among families who have used the service, despite the lack of evidence for effectiveness in treating autism.

Nutritional supplements. High doses of certain vitamins and minerals have been proposed as treatments for autism. The most frequently reported treatment combines vitamin B6 (pyridoxine) and magnesium. It has been shown that a deficiency of these two elements can lead to nerve problems, but there is no evidence to support the theory that high doses of these or other supplements are effective treatments for autism.

Special diets. Special diets have been proposed as treatments for autism by those who believe that autism in some children is related to food allergies. They believe that removing these foods from the diet will result in improvement in symptoms. The most widely-publicized diets remove cows' milk products (containing casein) and wheat products (containing gluten). No controlled studies have demonstrated a relationship between food allergies and autism.

Immune globulin injections. There is some evidence that small numbers of children with autism have abnormal immune systems. As a result, some people suggest using immune globulin injections to make the immune system stronger, and thereby improve autistic symptoms. There is no specific theory to explain why this therapy might be effective in the treatment of autism. In addition, there is no scientific evidence that treatment with these injections has a significant effect on autistic symptoms.

Hormone therapy. Two hormones – secretin and adrenocorticotropin hormone (ACTH) – have been proposed as treatments for autism. Secretin is a hormone that aids digestion and ACTH helps regulate growth and other processes in a normally growing child. The use of these substances to treat autism came about after the publication of case reports that claimed improvements in symptoms of autism among children receiving these hormones for other reasons. (For example, secretin is used in the diagnosis of stomach and intestinal problems.) The theory linking either of these two hormones and autism has not been clearly defined, and no controlled studies have demonstrated that they are safe and effective treatments for autism.

Chelation therapy. Some people believe that autism is the result of childhood exposure to toxins (chemicals that can be poisonous to people) in the environment. Mercury, a component of the preservative Thimerosal discussed above, is the element most often blamed for this effect. People who believe this theory of autism recommend “chelation” therapy – putting another chemical in the body to remove the harmful one. Several substances have been shown to speed the

removal of mercury from the body, but there is no evidence that this therapy affects functioning in autistic children. Moreover, the substances used for chelation can themselves be harmful to humans. Since this treatment is both unproven and possibly harmful, it is not recommended for the treatment of autism.

Auditory integration training (AIT). This approach to treating autism is based on the theory that certain symptoms of autism are a result of hearing or listening problems. AIT begins with a test of the child's hearing. Based on the results of the test, the child listens to specially-modified music that is supposed to have a corrective effect. There are two main approaches to AIT – Bérard and Tomatis – neither of which is supported by research. In fact, the Tomatis method as used in schools has been shown to be ineffective, and there is evidence that it may actually have a negative effect on children with learning disabilities.

Facilitated communication. In facilitated communication, a person called a “facilitator” supports the autistic child's hand on a keyboard or letter board while the child spells out messages. People who believe in this method claim that the messages spelled out are communications from the child. Studies of this method, however, suggest that the communication actually originates with the facilitator. While popular several years ago, facilitated communication is no longer seen as a credible approach to treating autism.

WHERE CAN I GET MORE INFORMATION ABOUT TREATMENT FOR AUTISM?

There are many sources of information on autism and its treatment. The sources include print media, videos, and information on the Internet. If you would like more information, a good place to start is HRC's Resource Center where you will find more than 200 references on autism. Staff members can guide you in your search.

Parents looking for information on the Internet are especially cautioned to maintain their open-minded skepticism. Most information provided through this medium does not get the same type of critical review given to books and articles published in the mainstream press. Therefore, the claims that are made there may have little basis in fact.

We would also like to bring your attention to an HRC publication intended to help parents of all newly-diagnosed children evaluate information and participate effectively in the development of a service plan for their child. This booklet, entitled *Putting the Pieces Together*, is available from your Counselor or you may pick one up in the Resource Center.

Finally, parents coping with a child's diagnosis of autism may experience some or all of a wide range of emotions including anger, frustration, depression, fear, helplessness, resentment, grief, guilt, and self-blame. Many parents have found that one of the most helpful things they can do is speak to other parents of children with autism who can share their experiences and understand the emotional reactions that often accompany this diagnosis. Ask your HRC Counselor for information about the many support groups for parents of children with autistic disorders that meet regularly in the greater Los Angeles and Orange County areas.





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