

AUTISM

PARENT HANDBOOK

Answers to common questions



Artwork: "Hey Diddle Diddle," by Eytan Nisinzweig, an artist with autism.

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The path to prevention starts with research.

Dear Parents:

We are very pleased to publish the 2nd edition of the Autism Parent Handbook. This popular handbook was developed with input from the first Community Advisory Board of California CADDRE who believed parents were looking for basic, accurate information about autism spectrum disorders in multiple languages. It explains what to do if you think your child has autism and where to find help. Please share the handbook with your family and friends and your child's teachers. The information will help them better understand autism and ways they can help. We appreciate the support of Kaiser Permanente and the California Department of Public Health for publication of this updated edition of the handbook. We are grateful to Eytan Nisinzweig, a young man with autism, for allowing us to use his artwork. His drawing on the cover depicts the popular nursery rhyme:

*Hey diddle, diddle,
The cat and the fiddle,
The cow jumped over the moon.
The little dog laughed
To see such sport,
And the dish ran away with the spoon.*

Sincerely,



Lisa Croen, PhD
Director, Autism Research Program
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What is autism?

Autism is a disorder of the brain that happens while a child is still growing. Autism changes how a child's brain grows. Autism is called a "developmental disorder" because it affects how a child develops. Children with autism think and act differently than other people. Children with autism may:

- Have a hard time relating to other people
- Have a hard time talking and communicating
- Do the same things over and over

Some children may have less obvious symptoms. Other children may have behaviors that are more severe. The different kinds of autism, sometimes called "autism spectrum disorders", are explained on page 6. In this book, "autism" is used to refer to autism spectrum disorders (ASD).

Autism is not a disease. You cannot get autism by being near or touching a person who has autism. There is no cure for autism yet, and autism does not go away. With good education, intervention, and support, children may improve as they get older. Behavior may get more challenging around puberty. The earlier children get help with learning and speaking, the better they will do.

About 1 out of every 110 children has some kind of autism. Boys have autism more often than girls. Children from all over the world in all kinds of families have autism.

What are the common signs of autism in young children?

Below are signs of autism that you may see as your child grows. A child with autism may only have some of these signs. If your child has some of these signs and you are worried that your child can't do things other children the same age can do, please tell your doctor.

Has a hard time relating to other people

- does not show an interest in people, even family members or other caregivers
- does not react when you call his/her name or does not look people in the eye
- does not understand tone of voice or facial expressions
- is not aware of others' feelings or how his/her actions may affect others
- shows little interest in playing with other children by age 3

Has a hard time talking and communicating

- does not babble by first birthday
- does not speak one word by 16 months
- loses words and language skills at any age
- does not use common gestures, such as waving bye-bye or pointing to show you things

Does the same thing over and over

- repeats actions, such as spinning a toy in a circle or lining things up or rocking back and forth for hours
- hurts oneself, such as biting self or banging head

Has an odd response to sounds or touch

- does not seem to feel pain like others
- does not like to be held or cuddled
- is bothered by loud noises



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What are the different kinds of autism?

Autistic Disorder

Children have symptoms in all 3 areas of development affected by autism – relating to others, communicating, and repeating actions. Children may have high, average, or low intelligence.

Asperger's Disorder

Children do not have a speech delay and may have high intelligence, but they have problems relating to others and may have only very specific or unusual interests.

Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)

Children have some behaviors of autism, but not all. They have problems relating to others and may have only very specific or unusual interests. Many children with PDD-NOS have fewer difficulties than those with autistic disorder.

These kinds of autism are sometimes called 'autism spectrum disorders.'

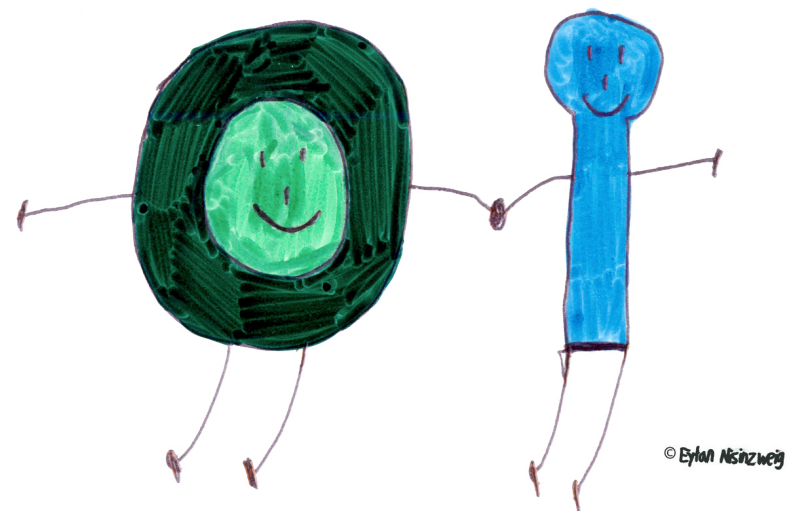
What can I do if I think my child has autism?

If you think that your child may have autism, please talk to a doctor. Ask for a "developmental evaluation" or "developmental assessment" for your child. Some schools also give evaluations for autism. If you live in California, you can also call your local Regional Center for an evaluation (see page 14 for information).

Most evaluations can diagnose autism in children who are three years old or older. Some children can be diagnosed earlier. If your child does have autism, it is important to find out as early as possible. It is never too early to ask for an evaluation.

The symptoms of autism are listed in a book called the Diagnostic and Statistical Manual of Mental Disorders Text Revision (DSM IV-TR). We have included the information about autism from that manual on page 16.

Even without a formal diagnosis, if you are concerned about your child's development, language, or behavior, you may want to get professional advice on how to best assist your child.



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My child has autism. What do I do next?

Get help: There are places you can go for help. Some of this help is free and some of it is not. Call your school district to find out what kinds of classes or programs they have for children with autism. You may also be able to get help through your local Regional Center (see page 14). You may need to make many calls and talk to many people before you find the help you need. Do not give up.

Get informed: It is important to find out what your rights are. Children with autism who live in California have the legal right to certain kinds of help. Your child can get help even if you and your child are not U.S. citizens or legal residents.

Talk to other parents: Talking to other parents who have children with autism can be very helpful. You can contact parent groups in your area to meet other parents and to get support and legal help (see page 14). Asking for help is sometimes hard to do, but reaching out and connecting with other parents and community resources will help your whole family as well as your child.

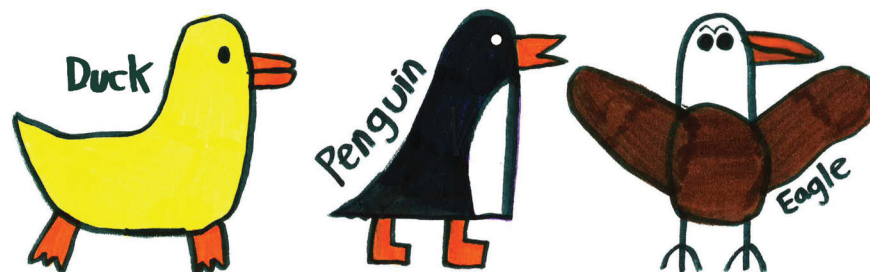
Does autism change over time?

With good education and support, some children with autism can improve as they get older. Classes and programs (sometimes called interventions) can help children to speak, play with others, and gain other important skills. It is good to start these programs as early as possible.

Parents and professionals can work together to teach life-skills to children and teenagers with autism. Some people with autism are able to work and live on their own. Other people with autism need help throughout their lives.

For some children, the symptoms of autism may not improve. They may also develop other symptoms as they get older. Some children may develop a seizure disorder in their teenage years.

We're all different
but we're still just birds



© Eytan Nisinzweig

How can autism be treated?

There is no cure for autism yet, but there are many different classes and programs for children with autism. These programs are also called “therapies” (or “interventions”). It is important to find the programs that work best for your child and family. Some may work well for one child, but not for another. These programs do not cure autism, but they can help children improve. The earlier the therapies begin, the better the outcomes may be.

Educational and Behavioral Programs: Teachers in these programs can help children learn new behaviors and gain social and language skills. Because children learn quickly when they are very young, this type of therapy should begin as early as possible. Ask for more information from your school or Regional Center (see page 14). Parents play an important part in teaching their children. They can teach skills and chores around the home and reinforce the things their child is learning in these programs.

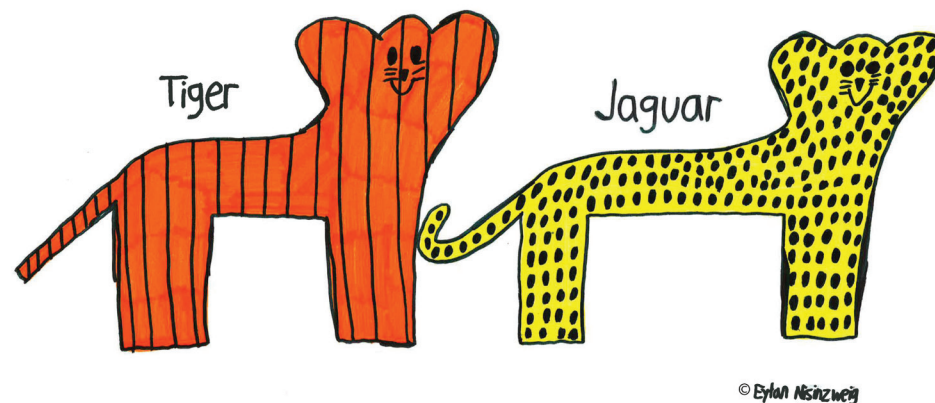
Medication: Medications do not cure autism, but certain kinds of medications can reduce difficult behaviors in some children. If your child has other conditions, such as epilepsy, attention or other behavioral problems, your doctor may offer medications that help these conditions too. Please contact your doctor to find out more.

Other Interventions: You may hear about other therapies, sometimes called “alternative treatments.” Most of these have not been tested to make sure they are helpful and safe. These treatments may or may not help your child. Please get information about any treatment before using it to make sure that it will not harm your child.

What causes autism?

We do not know what causes autism. We know that parts of the brain develop differently in people with autism. These differences may begin before a baby is born. We know that autism sometimes runs in families. Many studies are trying to look for genes that contribute to autism. Studies are also looking at how events and the environment during pregnancy, infancy, and early childhood might play a role in autism.

Researchers across the country are working to discover the causes of autism. Parents and children are needed to participate in research studies to help scientists understand why some children develop autism. By participating in research, parents learn more about their child and make a major contribution to science.



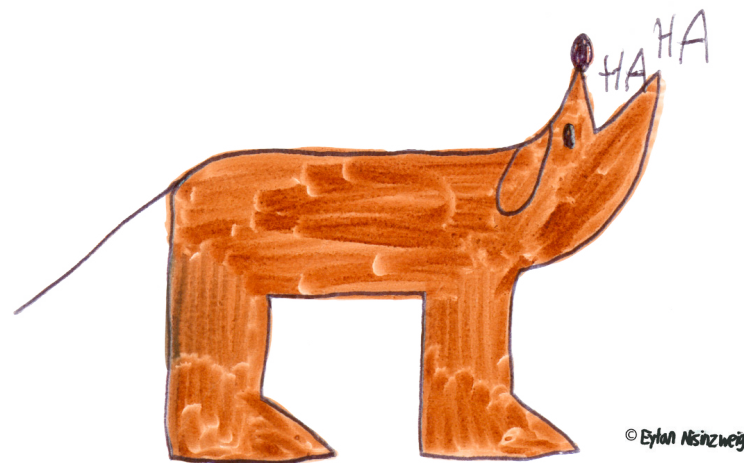
What can family and friends do to help?

It may be hard to tell your family and friends that your child has autism. When you are ready to tell them, give them this booklet so they can learn more about autism and how they can help.

If you are a friend or family member who wants to help the parent of a child who has autism, you can:

1. **Learn about autism.** On page 15 there is a list of websites and books to help you learn about autism. It will be easier for you to help if you know more about autism.
2. **Use your skills to help.** Many kids with autism are in special classes. You can help by driving the child to and from special classes. If you have good computer skills, you can help by finding information about autism on the internet.
3. **Visit the child in his or her home if it is better for the child.** It can be hard for some children with autism to visit other people's houses. Shorter visits may be better than longer visits.
4. **Try not to ask why the child does not do things other kids do, or why they act the way they do.** This is part of autism. It can be hard for parents when other people expect their child to act a certain way.
5. **Give a child with autism a small task to do instead of a big one.** Children with autism usually learn better by breaking big tasks down into smaller tasks. This is the most common way to teach children with autism. This will help the child to learn and feel good about what he or she can do.

6. **Offer to watch the child so parents can go out and take a break.** Parents can relax while they are out, knowing their child is in good hands. You can help by being consistent with rules and behavioral expectations set by the child's parents.
7. **Plan activities that the child with autism will like.** If she is a good swimmer, go to a pool or beach. If he likes animals, plan a trip to the zoo. Try to find an activity where everyone in the family can be comfortable.
8. **Give gifts that are useful.** Great gift ideas include supplies for a child's special classes or interests. Check with the parents to find out what will be helpful.
9. **Join an autism group to show support for people with autism.**
10. **Participate in research studies.** Children with and without autism and their families are needed to help learn what is causing autism.



Where can I get more help?

California Organizations

To find help close by, contact:

Family Resource Centers Network

Family resource centers offer parent-to-parent support and help parents, families, and children find and use needed services.

www.frcnca.org
(916) 962-0832

Regional Centers

Children and adults with autism can get help from their local "Regional Center." Children with autism may be able to attend special classes and therapies. Parents may be able to have someone come to their home to help watch their child so that they can take a break (also called "respite") or go to parent trainings. You need to ask for an "intake evaluation" to see if you are eligible to get help at your local Regional Center. Regional Centers are part of the California Department of Developmental Services. To find a Regional Center near you, contact:

www.dds.ca.gov/RC/Home.cfm
(916) 654-1897

Public school districts

If your child is age 3 or older, contact your local school district in writing and request a psycho-educational evaluation. See the California Public School Directory at: www.cde.ca.gov/re/sd

National Organizations

American Academy of Pediatrics

www.aap.org/healthtopics/autism.cfm

Autism Society of America (ASA)

www.autism-society.org
(800) 3AUTISM (800-328-8476)

Autism Speaks

www.autismspeaks.org
(888) AUTISM2 (888-288-4762)

First Signs

www.firstsigns.org
(978) 346-4380

National Center for Birth Defects and Developmental Disabilities, Autism Information Center

www.cdc.gov/ncbddd/autism
(800) 232-4636

National Institute of Child Health & Human Development (NICHD) Information Resource Center

www.nichd.nih.gov/autism
(800) 370-2943

Books about Autism

www.autism-resources.com/childrengenres
www.specialneeds.com
www.good-books-bad-books.com/d-books/autism.html

DSM IV-TR criteria for autism

Many doctors use the criteria below to tell if a child has autism:

- A. A total of 6 (or more) items from (1), (2), and (3), with at least 2 from (1), and 1 each from (2) & (3):
- (1) Qualitative impairment in social interaction, as manifested by at least two of the following:
 - a. Marked impairment in the use of multiple nonverbal behaviors, such as eye-eye gaze, facial expression, body postures, and gestures to regulate social interactions.
 - b. Failure to develop peer relationships appropriate to developmental level.
 - c. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest).
 - d. Lack of social or emotional reciprocity.
 - (2) Qualitative impairments in communication, as manifested by at least one of the following:
 - a. Delay in or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime).
 - b. In individuals with adequate speech, marked impairments in the ability to initiate or sustain a conversation with others.
 - c. Stereotyped and repetitive use of language or idiosyncratic language.
 - d. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level.
 - (3) Restrictive, repetitive, and stereotyped patterns of behavior, interests, and activities as manifested by at least one of the following:
 - a. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.
 - b. Apparently inflexible adherence to specific, nonfunctional routines or rituals.
 - c. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting or complex whole-body movements).
 - d. Persistent preoccupation with parts of objects.
- B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used to social communication, or (3) symbolic or imaginative play.
- C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.