

AUTISM

PARENT HANDBOOK

Answers to common questions



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

2nd Edition

This handbook is brought to you by a collaborative effort between:



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Dear Parents:

We are very pleased to publish the 3rd edition of the Autism Parent Handbook. This popular handbook was originally developed with input from the first Community Advisory Board of the California Center for Autism and Developmental Disabilities Research and Epidemiology (CA 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 the ways they can help. This update of the handbook was made possible through the support of the California Department of Public Health, Kaiser Permanente, and the Bay Area Autism Consortium. The artwork was provided courtesy of Eytan Nisinzweig, a young man with autism. 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.*

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What is autism spectrum disorder?

Autism spectrum disorder (ASD), which is also called autism in this booklet, is a disorder of the brain that happens while a child is very young. Autism changes how a child's brain matures and is called a "developmental disorder" because it also affects how a child develops. Some children with autism may have less obvious symptoms. Other children may have behaviors that are more severe. 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

About 1 out of every 68 children has some kind of autism, according to national figures in 8-year olds. Boys have autism more often than girls. Children from all over the world in all kinds of families have autism.

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 it 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.

What are the common signs of autism spectrum disorder in young children?

Below are signs of autism spectrum disorder that you may notice as your child grows. A child with autism may only have some of these signs. If your child has some of these signs or 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

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
- hurts him or herself, 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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Are there different kinds of Autism?

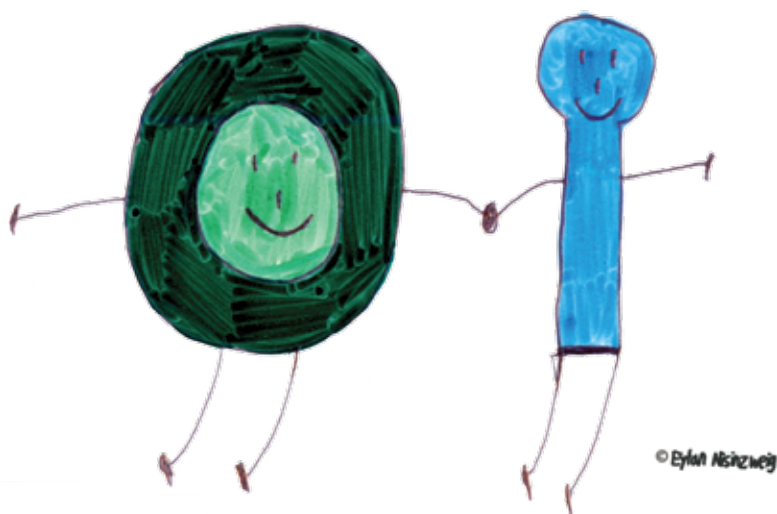
In May 2013, new criteria were established for evaluators to diagnose autism spectrum disorders. Previously, they were recognized as distinct different kinds of autism with different names (autistic disorder, childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS) and Asperger's Disorder). All autism disorders are now combined into one umbrella diagnosis of Autism Spectrum Disorder or ASD.

Doctors use the criteria described on Page 16 to tell if a child has autism spectrum disorder. They ask the parents, caregivers, and sometimes teachers certain questions to determine if the child shows the following symptoms. They will also perform ASD-specific tests to determine the diagnosis. The severity of the ASD will be determined by how much additional support a child needs to function.

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

If you think that your child may have autism or seems delayed in development, please talk to your child's doctor. Ask for a "developmental evaluation" or "developmental assessment" for your child. Some schools also perform 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 evaluators can diagnose autism in children who are two 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.

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.



My child has autism spectrum disorder. 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. You can ask your child's doctor for recommendations. If your child is 3 years or older, 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) and health insurance. 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 child needs and what his/her 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. It can help you understand the best way to access services for your child and show you that you are not alone. You can contact parent groups in your area to meet other parents and to get support and help (see page 14). Asking for help is sometimes hard to do, but reaching out and connecting with community resources will help your whole family as well as your child.

Does autism spectrum disorder change as my child gets older?

With good education and support, most children with autism can improve as they get older. Classes, therapies 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.

For some children, the symptoms of autism may not improve. They may also develop other symptoms as they get older, for example some children may develop seizures in their teens. Behavior may get more challenging as adolescents go through puberty.

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

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



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 their skills. The earlier the therapies begin, the better the outcomes may be. You should talk to the health care provider who evaluated your child for the specific interventions or therapies that would be the most helpful.

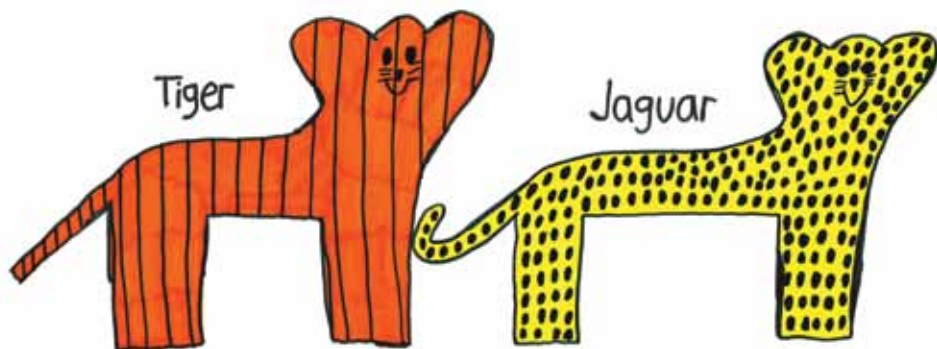
Educational and Behavioral Programs: Teachers and therapists in these programs can help children learn new behaviors and gain social and language skills. Because children learn quickly when they are very young, this type of therapy should begin as early as possible. Ask for more information from your doctor, school or Regional Center (see page 14). Parents play an important part in teaching their children. You can teach skills for daily living at home and reinforce the things your child is learning in their other 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 or complementary 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 from your doctor about any treatment before using it to make sure that it will not harm your child.

What causes autism spectrum disorder?

We do not know what causes autism in most cases, but you should ask your doctor whether any specific tests would be helpful for your child. 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, and some genetic tests may be useful in your child. 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 and society.



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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, you can 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 or therapies. You can help by driving the child to and from these special programs. If you have good computer skills, you can help by finding information about autism on the internet.
3. **Visit the child and their family 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) 993-7781

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

<https://www.aap.org/en-us/about-the-aap/Committees-Councils-Sections/Council-on-Children-with-Disabilities/Pages/Autism.aspx>

Autism Society of America (ASA)

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

Autism Speaks

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

Center for Disease Control and Prevention (CDC) National Center for Birth Defects and Developmental Disabilities, Autism Information Center

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

First Signs

www.firstsigns.org
Email: FirstSigns1@gmail.com

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

www.nichd.nih.gov/health/topics/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-5 Criteria for Autism

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

- (1) Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive):
 - a. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
 - b. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
 - c. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.
- (2) Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive):
 - a. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
 - b. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).
 - c. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).
 - d. Hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).