

AUTISM

Parent Handbook

Answers to common questions



Artwork: "I love You, Mom," by Melissa Dahl, a girl with autism, drawn at age 3.

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California
CADDRE

Dear parents:

We made this parent handbook to give you basic information on autism and where to find help. This booklet will be available in English, Spanish, Chinese, and Vietnamese. Please show the booklet to your family, friends, and teachers, so they can better understand autism and how they can help. We know that there may be a hard journey ahead for you and your family. We hope this booklet is useful and that it directs you to the help that you need.

Sincerely,

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California CADDRE
Director

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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 only be affected by autism a little bit. Other children may have behaviors that are more difficult and serious. There are also different kinds of autism (see page 4).

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. Many children will improve as they get older. Some children will get worse around age 13. The earlier children get help with learning and speaking, the better they will do.

About 5 out of every 1,000 children have 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 some common signs of autism in 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 those who love them
- does not react when you call their 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 actions may affect others
- shows little interest in playing with other children by age 3

Has a hard time talking and communicating, such as

- 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

Does the same thing over and over

- repeats actions, such as spins a toy in a circle or rocks back and forth for hours
- hurts oneself, such as bites or bangs head

Has an odd response to sounds or touch

- does not feel pain like others
- does not like to be held or cuddled



Artwork created by Peter Villeger for the Disability Mural
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What are the different kinds of autism?

Autistic Disorder

Children with this kind of autism have all the behaviors of autism. This kind of autism is also called "classic autism."

Asperger Syndrome

Children with this kind of autism often have good language skills and high intelligence, but they may have problems relating to others and may have only very specific interests.

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

Children with this kind of autism have some behaviors of autism but not all. Many children with PDD-NOS have fewer difficulties than those with classic autism.

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 test (also called a “developmental evaluation”) for your child. You can also call your local Regional Center for a test (see page 12 for information). Some schools also give tests for autism.

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

Many doctors use a book to diagnose autism called the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV-R). We have included the information about autism from this manual on page 14.



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 12). 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 residents.

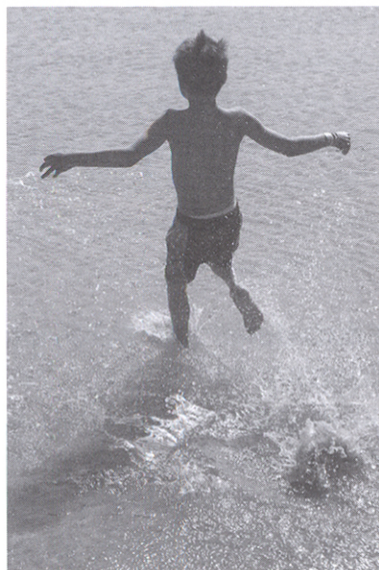
Talk to other parents: Talking to other parents who have children with autism can be very helpful. You can contact parent groups in your area to meet other parents and to get support and legal help (see page 12).



Does autism change over time?

Some children with autism improve as they get older. Classes and programs 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 teenagers with autism to help them live independently. 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, autism may get worse when they become teenagers. One out of three teenagers with autism develops a seizure disorder called "epilepsy." Some research suggests that children with autism who also have mental retardation and poor language skills are more likely to have epilepsy as teenagers.



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 “treatments” and “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 do not cure autism, but they can help children improve.

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 very young, this type of therapy should begin as early as possible. Ask for more information from your school or Regional Center (see page 12).

Medication: Certain kinds of medications can reduce difficult behaviors in some children with autism. If your child has other medical conditions, such as epilepsy or attention disorder, your doctor may offer medications that help these conditions too. Please contact your doctor to find out more.

Other Treatments: 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 in people with autism are different than those without autism. These differences in the brain may develop before a baby is born. We know that autism sometimes runs in families. Many studies are trying to find out which genes may lead to autism. Studies are also looking at how events and the environment during pregnancy, infancy, and early childhood might play a role in autism.

The California Center for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) is working to identify children with autism and find out what is causing autism. CADDRE is based in the California Department of Health Services. We are working with families, doctors, specialists, and scientists all over California.



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 13 there is a list of books you can read to learn about autism. It will be easier for you to help if you know more about autism.
2. **Teach your children about autism.** Help them to be understanding and kind. Plan a play date for your child and the child with autism.
3. **Use your skills to help.** Many kids with autism are on special diets or in special classes. If you are a good cook, offer to help with meals. You can also drive the child to and from special classes. Or, if you have good computer skills, you can help by finding information about autism on the Internet.
4. **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.
5. **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.

6. **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.
7. **Offer to watch the child so the parents can go out and take a break.** Parents can relax while they are out, knowing their child is in good hands.
8. **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.
9. **Give gifts that are useful.** Great gift ideas include supplies for their special classes. Checking with your loved one is a way to make sure you'll give a helpful gift.
10. **Join an autism group to show support for people with autism.**



Where can I get more help?

Local Organizations

To find help close by, contact:

Family Resource Centers Network of California

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

916-962-0832

www.frcnca.org/directory.html

info@frcnca.org

Regional Centers

Children and adults with autism can get help from their local "Regional Center." 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. Children with autism may be able to attend special classes and therapies. You need to ask for an "intake evaluation" to see if you are eligible to get help at your local regional center. To find a Regional Center near you, contact:

916-654-1897

www.dds.cahwnet.gov/rc/rcsvs_home.cfm

Regional Centers are part of the California Department of Developmental Services.

National Autism Organizations

Autism Society of America (ASA)

800-3AUTISM (800-328-8476)

www.autism-society.org

Cure Autism Now (CAN)

888-8AUTISM (888-828-8476)

www.canfoundation.org

Families for Early Autism Treatment (FEAT)

916-843-1536

www.feat.org

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

800-370-2943

www.nichd.nih.gov/autism/

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

www.cdc.gov/ncbddd/dd/ddautism.htm

The Schafer Autism Report

www.sarnet.org

News and information service on autism.

Books on Autism

www.autism-resources.com/childrengenres/autism.html

www.specialneeds.com

www.good-books-bad-books.com/d-books/autism.html



DSM IV 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.