# Developmental Screening FACT SHEET

## What is child development?

A child's growth is more than just physical. Children grow, develop, and learn throughout their lives, starting at birth. A child's development can be followed by how they play, learn, speak, and behave.

# What is a developmental delay? Will my child just grow out of it?

Skills such as taking a first step, smiling for the first time, and waving "bye bye" are called developmental milestones. Children reach milestones in playing, learning, speaking, behaving, and moving (crawling, walking, etc.). A developmental delay is when your child does not reach these milestones at the same time as other children the same age. If your child is not developing properly, there are things you can do that may help. Most of the time, a developmental problem is not something your child will "grow out of" on his or her own. But with help, your child could reach his or her full potential!

## What is developmental screening?

Doctors and nurses use developmental screening to tell if children are learning basic skills when they should, or if they might have problems. Your child's doctor may ask you questions or talk and play with your child during an exam to see how he or she learns, speaks, behaves, and moves. Since there is no lab or blood test to tell if your child may have a delay, the developmental screening will help tell if your child needs to see a specialist.

# Why is developmental screening important?

When a developmental delay is not recognized early, children must wait to get the help they need. This can make it hard for them to learn when they start school. In the United States, 17 percent of children have a developmental or behavioral disability such as autism, intellectual disability (also known as mental retardation), or Attention-Deficit/Hyperactivity Disorder (ADHD).

In addition, many children have delays in language or other areas. But, less than half of children with problems are identified before starting school. During this time, the child could have received help for these problems and may even have entered school more ready to learn.

## I have concerns that my child could have a developmental delay. Whom can I contact in my state to get a developmental assessment for my child?

Talk to your child's doctor or nurse if you have concerns about how your child is developing. If you or your doctor think there could be a problem, you can take your child to see a developmental pediatrician or other specialist, and you can contact your local early intervention agency (for children under 3) or public school (for children 3 and older) for help. To find out whom to call in your area about these services, contact the National Information Center for Children and Youth with Disabilities at www.nichcy.org/states.htm or call the Centers for Disease Control and Prevention (CDC) at 1-800-232-4636. In addition, CDC has links to information for families at www.cdc.gov/actearly. If there is a problem, it is very important to get your child help as soon as possible.

## How can I help my child's development?

Proper nutrition, exercise, and rest are very important for children's health and development. Providing a safe and loving home and spending time with your child – playing, singing, reading, and even just talking – can also make a big difference in his or her development.

For other ideas of activities to do with your child, and for child safety information, go to www.cdc.gov/ncbddd/child/ and look in the "developmental milestones" section.





# Autism Spectrum Disorders FACT SHEET

## What are autism spectrum disorders?

Autism spectrum disorders (ASDs) are a group of developmental disabilities caused by a problem with the brain. Scientists do not know yet exactly what causes this problem. ASDs can impact a person's functioning at different levels, from very mildly to severely. There is usually nothing about how a person with an ASD looks that sets them apart from other people, but they may communicate, interact, behave, and learn in ways that are different from most people. The thinking and learning abilities of people with ASDs can vary – from gifted to severely challenged. Autistic disorder is the most commonly known type of ASD, but there are others, including "pervasive developmental disorder-not otherwise specified" (PDD-NOS) and Asperger Syndrome.

## What are some of the signs of ASDs?

People with ASDs may have problems with social, emotional, and communication skills. They might repeat certain behaviors and might not want change in their daily activities. Many people with ASDs also have different ways of learning, paying attention, or reacting to things. ASDs begin during early childhood and last throughout a person's life.

#### A child or adult with an ASD might:

- not play "pretend" games (pretend to "feed" a doll)
- not point at objects to show interest (point at an airplane flying over)
- not look at objects when another person points at them
- have trouble relating to others or not have an interest in other people at all
- avoid eye contact and want to be alone
- have trouble understanding other people's feelings or talking about their own feelings
- prefer not to be held or cuddled or might cuddle only when they want to
- appear to be unaware when other people talk to them but respond to other sounds

- be very interested in people, but not know how to talk, play, or relate to them
- repeat or echo words or phrases said to them, or repeat words or phrases in place of normal language (echolalia)
- have trouble expressing their needs using typical words or motions
- repeat actions over and over again (hand flapping, finger movements, rocking, etc.)
- have trouble adapting when a routine changes
- have unusual reactions to the way things smell, taste, look, feel, or sound
- lose skills they once had (for instance, stop saying words they were using)
- \* Note: Contact your child's doctor or nurse if your child experiences a dramatic loss of skills at any age.

## What can I do if I think my child has an ASD?

Talk with your child's doctor or nurse. If you or your doctor think there could be a problem, ask for a referral to see a developmental pediatrician or other specialist, and you can contact your local early intervention agency (for children under 3) or public school (for children 3 and older). To find out whom to call in your area about these services, contact the National Information Center for Children and Youth with Disabilities at www.nichcy.org/states.htm or call the Centers for Disease Control and Prevention (CDC) at 1-800-232-4636. In addition, CDC has links to information for families at www.cdc.gov/autism.

Right now, the main research-based treatment for ASDs is intensive structured teaching of skills, often called behavioral intervention. It is **very** important to begin this intervention as early as possible in order to help your child reach his or her full potential. Acting early can make a real difference!





# Asperger Syndrome FACT SHEET

## What is Asperger syndrome?

Asperger syndrome is one of the autism spectrum disorders (ASDs). Although symptoms are present early in life, Asperger syndrome is usually diagnosed when a child is school aged. As with other ASDs, scientists do not know exactly what causes Asperger syndrome, but it is known that the brain of someone with this condition functions differently than that of someone without Asperger syndrome.

# What are the signs of Asperger syndrome?

People with Asperger syndrome have problems with social, emotional, and communication skills, as well as unusual behaviors and interests.

## Children and adults with Asperger syndrome might:

- Have trouble understanding other people's feelings or talking about their own feelings.
- Have a hard time understanding body language.
- Avoid eye contact.
- Want to be alone; or want to interact, but not know how.
- Have narrow, sometimes obsessive, interests.
- Talk only about themselves and their interests.
- Speak in unusual ways or with an odd tone of voice.
- Have a hard time making friends.
- Seem nervous in large social groups.
- Be clumsy or awkward.
- Have rituals that they refuse to change, such as a very rigid bedtime routine.
- Develop odd or repetitive movements.
- Have unusual sensory reactions.

With appropriate services and support, people with Asperger syndrome can make progress in managing or overcoming these challenges and can learn to emphasize their strengths.

# How is Asperger syndrome different from other autism spectrum disorders?

Children with Asperger syndrome do not have a language delay and, by definition, must have an average or above average IQ (measure of intelligence). Children with other autism spectrum disorders may have a language delay and can have an IQ at any level.

# What can I do if I think my child has Asperger syndrome?

Talk with your child's doctor or nurse. If you or your doctor thinks there could be a problem, ask for a referral to see a specialist such as a developmental pediatrician or psychologist. Talk with your child's teacher or school counselor, too.

Your child might benefit from intensive social skills training at school or in the community. Your child also might need speech therapy to learn how to talk with other people, or medicine to help with anxiety and attention problems. Other therapies including physical and occupational therapy also might be helpful depending on your child's needs. To find out whom to call in your area about these services, contact the National Information Center for Children and Youth with Disabilities at www.nichcy.org/states.htm or call the Centers for Disease Control and Prevention (CDC) at 1-800-232-4636. CDC also has links to resources for families at www.cdc.gov/autism.

It is <u>very</u> important to begin this intervention as early as possible in order to help your child reach his or her full potential. Acting early can make a real difference!





# ADHD FACT SHEET

#### What is ADHD?

Attention-deficit/hyperactivity disorder (ADHD) is one of the most common neurobehavioral disorders of childhood. It is sometimes referred to as Attention Deficit Disorder (ADD). It is usually first diagnosed in childhood and often lasts into adulthood. Children with ADHD have trouble paying attention, controlling impulsive behaviors (may act without thinking about what the result will be), and, in some cases, are overly active.

## What are some of the signs of ADHD?

It is normal for children, at one time or another, to have trouble focusing and behaving. However, in children with ADHD, the symptoms continue instead of getting better, and they can make learning very difficult.

#### A child with ADHD might:

- have a hard time paying attention and daydream a lot
- not seem to listen
- be easily distracted from schoolwork or play
- forget things
- be in constant motion or unable to stay seated
- squirm or fidget
- talk too much
- not be able to play quietly
- act and speak without thinking
- have trouble taking turns
- interrupt others

Deciding if a child has ADHD is a several step process. There is no single test to diagnose ADHD, and many other problems, like anxiety, depression, and certain types of learning disabilities, can have similar symptoms. One step of the process involves having a medical exam, including hearing and vision tests, to rule out other

problems with symptoms like ADHD. Another part of the process may include a checklist for rating ADHD symptoms and taking a history of the child from parents, teachers, and sometimes, the child.

## What can I do if I think my child may have ADHD?

Talk with your child's doctor or nurse. If you or your doctor have concerns about ADHD, you can take your child to a specialist such as a child psychologist or developmental pediatrician, or you can contact your local early intervention agency (for children under 3) or public school (for children 3 and older). To find out whom to call in your area about these services, contact the National Information Center for Children and Youth with Disabilities at www.nichcy.org/states.htm or call the Centers for Disease Control and Prevention (CDC) at 1-800-232-4636.

CDC sponsors the National Resource Center, a program of CHADD – Children and Adults with Attention-Deficit/ Hyperactivity Disorder. Their Web site has links to information for people with ADHD and their families (www.help4adhd.org). The National Resources Center operates a call center with trained staff to answer questions about ADHD. The number is 1-800-233-4050.

In order to make sure your child reaches his or her full potential, it is very important to get help for ADHD as early as possible.





# Cerebral Palsy FACT SHEET

## What is cerebral palsy?

Cerebral means having to do with the brain. Palsy means weakness or problems with using the muscles. Cerebral palsy is a group of disorders that affect a person's ability to move and keep their balance and posture as a result of an injury to parts of the brain, or as a result of a problem with development. Often the problem happens before birth or soon after being born. Cerebral palsy causes different types of disabilities in each child. A child may simply be a little clumsy or awkward, or unable to walk at all.

# What are some of the signs of cerebral palsy?

The signs of cerebral palsy vary greatly because there are many different types and levels of disability. The main sign that your child might have cerebral palsy is a delay reaching the motor or movement milestones. If you see any of these signs, call your child's doctor or nurse.

#### A child over 2 months with cerebral palsy might:

- have difficulty controlling head when picked up
- have stiff legs that cross or "scissor" when picked up

#### A child over 6 months with cerebral palsy might:

- continue to have a hard time controlling head when picked up
- reach with only one hand while keeping the other in a fist

#### A child over 10 months with cerebral palsy might:

- crawl by pushing off with one hand and leg while dragging the opposite hand and leg
- not sit by himself or herself

#### A child over 12 months with cerebral palsy might:

- not crawl
- not be able to stand with support

#### A child over 24 months with cerebral palsy might:

- not be able to walk
- not be able to push a toy with wheels

## What causes cerebral palsy?

Cerebral palsy is caused by a problem in the brain that affects a child's ability to control his or her muscles. Problems in different parts of the brain cause problems in different parts of the body. There are many possible causes of problems, such as genetic conditions, problems with the blood supply to the brain before birth, infections, bleeding in the brain, lack of oxygen, severe jaundice, and head injury.

# What can I do if I think my child might have cerebral palsy?

Talk with your child's doctor or nurse. If you or your doctor have concerns about cerebral palsy, you can seek the help of a specialist such as a developmental pediatrician or child neurologist, and you can contact your local early intervention agency (for children under 3) or public school (for children 3 and older). To find out whom to call in your area about these services, contact the National Information Center for Children and Youth with Disabilities at www.nichcy.org/states.htm or call the Centers for Disease Control and Prevention (CDC) at 1-800-232-4636.

To help your child reach his or her full potential, it is very important to get help for him or her as early as possible!





# Intellectual Disability (also known as Mental Retardation) FACT SHEET

## What is intellectual disability?

Intellectual disability, also known as mental retardation, is a term used when there are limits to a person's ability to learn at an expected level and function in daily life. Levels of intellectual disability vary greatly in children – from a very slight problem to a very severe problem. Children with intellectual disability might have a hard time letting others know their wants and needs, and taking care of themselves. Intellectual disability could cause a child to learn and develop more slowly than other children of the same age. It could take longer for a child with intellectual disability to learn to speak, walk, dress, or eat without help, and they could have trouble learning in school.

Intellectual disability can be caused by a problem that starts any time before a child turns 18 years old – even before birth. It can be caused by injury, disease, or a problem in the brain. For many children, the cause of their intellectual disability is not known. Some of the most common known causes of intellectual disability – like Down syndrome, fetal alcohol syndrome, fragile X syndrome, genetic conditions, birth defects, and infections – happen before birth. Others happen while a baby is being born or soon after birth. Still other causes of intellectual disability do not occur until a child is older; these might include serious head injury, stroke, or certain infections.

# What are some of the signs of intellectual disability?

Usually, the more severe the degree of intellectual disability, the earlier the signs can be noticed. However, it might still be hard to tell how young children will be affected later in life.

There are many signs of intellectual disability.

For example, children with intellectual disability may:

- sit up, crawl, or walk later than other children
- learn to talk later, or have trouble speaking
- find it hard to remember things
- have trouble understanding social rules
- have trouble seeing the results of their actions
- have trouble solving problems

# What can I do if I think my child may have intellectual disability?

Talk with your child's doctor or nurse. If you or your doctor think there could be a problem, you can take your child to see a developmental pediatrician or other specialist, and you can contact your local early intervention agency (for children under 3) or public school (for children 3 and older). To find out whom to call in your area about these services, contact the National Information Center for Children and Youth with Disabilities at www.nichcy.org/states.htm or call the Centers for Disease Control and Prevention (CDC) at 1-800-232-4636.

To help your child reach his or her full potential, it is very important to get help for him or her as early as possible!





# Vision Loss FACT SHEET

#### What is vision loss?

Vision loss means that a person's eyesight cannot be corrected to a "normal" level. Vision loss can vary greatly among children and can be caused by many things.

#### What causes loss of vision?

Vision loss can be caused by damage to the eye itself, by the eye being shaped incorrectly, or even by a problem in the brain. Babies can be born unable to see, and vision loss can occur anytime during a person's life.

## When should my child be checked?

Your child should be checked for vision problems by an eye doctor (an ophthalmologist), pediatrician, or other trained specialist at:

- newborn to 3 months
- 6 months to 1 year
- about 3 years
- about 5 years

Having your child's vision checked is especially important if someone in your family has had vision problems.

# What are some of the signs of vision loss?

#### A child with vision loss might:

- close or cover one eye
- squint the eyes or frown
- complain that things are blurry or hard to see
- have trouble reading or doing other close-up work, or hold objects close to eyes in order to see
- blink more than usual or seem cranky when doing close-up work (such as looking at books)

One eye of a child with vision loss could look out or cross. One or both eyes could be watery, and one or both of the child's eyelids could also look red-rimmed, crusted, or swollen.

## What can I do if I think my child may have vision loss?

Talk with your child's doctor or nurse. If you or your doctor think there could be a problem, you can take your child to see a pediatric eye doctor (ophthalmologist) or other specialist, and you can contact your local early intervention agency (for children under 3) or public school (for children 3 and older). To find out whom to call in your area about these services, contact the National Information Center for Children and Youth with Disabilities at www.nichcy.org/states.htm or call the Centers for Disease Control and Prevention (CDC) at 1-800-232-4636. In addition, CDC has information about vision loss at www.cdc.gov/ncbddd.

Treating vision problems early may protect your child's sight, and teaching children with severe vision loss how to function as early as possible can help them reach their full potential.

A CONTRACTOR OF THE STATE OF TH



# Hearing Loss FACT SHEET

## What is hearing loss in children?

Hearing loss can vary greatly among children and can be caused by many things. In the United States, 1 to 3 children per 1,000 are born with hearing loss each year. Most children also experience mild, temporary hearing loss when fluid gets in the middle ear from allergies or colds. Sometimes as a result of an ear infection, fluid stays in the middle ears, which can sometimes cause hearing loss and delays in your child's speech. Some children have permanent hearing loss. This can be from mild (they don't hear as well as you do) to complete (where they can't hear anything at all).

# What are some of the signs of hearing loss?

The signs and symptoms of hearing loss are different for different children. If you see any of these signs call your child's doctor or nurse:

- does not turn to the source of a sound from birth to 3 or 4 months of age
- does not say single words, such as "dada" or "mama" by 1 year of age
- turns head when he or she sees you but not if you only call out his or her name: this usually is mistaken for not paying attention or just ignoring, but could be the result of a partial or complete hearing loss
- hears some sounds but not others

# What causes hearing loss? Can it be prevented?

Hearing loss can happen any time during life – from before birth to adulthood. Babies who are born early, who have low birth weight, or who are exposed to infections in the womb might have hearing loss, but this can happen to full-term, normal weight babies as well. Genetic factors are the cause of hearing loss in about 50% of babies – some of these babies might have family members who are deaf. Illnesses, injuries, certain medicines, and loud noise levels can cause children and adults to lose hearing.

Some causes of hearing loss can be prevented. For example, vaccines can prevent certain infections, such as measles or meningitis (an infection of the fluid around the brain and spinal cord), which can cause hearing loss. Another cause that can be prevented is a kind of brain damage called kernicterus, which is caused by bad jaundice. This can be prevented by using special lights (phototherapy) or other therapies to treat babies with jaundice before they go home from the hospital.

# What can I do if I think my child might have hearing loss?

Talk with your child's doctor or nurse. If you, your doctor, or anyone else who knows your child well, think your child might have hearing loss, ask that a hearing test be given as soon as possible. To have your child's exact levels of hearing measured, see an audiologist or an ear, nose, and throat doctor (ENT, otolaryngologist) who works with infants and children. If your child is under age 2 or does not cooperate for the hearing exam, a test (called brain-stem evoked-response audiometry) could be given. This test allows the doctor to check your child's hearing without having to rely on your child's cooperation. Your child will not be hurt; most babies even sleep through the test. This test is done routinely with newborn babies in all states.

Hearing loss can affect a child's ability to develop speech, language, and social skills. The earlier a child who is deaf or hard-of-hearing starts getting services, the more likely the child's speech, language, and social skills will reach their full potential. Services can be received through your local early intervention agency or public school. To find out whom to call in your area about these services, contact the National Information Center for Children and Youth with Disabilities at www.nichcy.org/states.htm or call the Centers for Disease Control and Prevention (CDC) at 1-800-232-4636. In addition, CDC has links to information for families at www.cdc.gov/ncbddd/ehdi.



# Fetal Alcohol Spectrum Disorders

## What are fetal alcohol spectrum disorders?

Fetal alcohol spectrum disorders (FASDs) is the name given to a group of conditions that a person can have if that person's mother drank alcohol while she was pregnant. These conditions include physical and intellectual disabilities, as well as problems with behavior and learning. Often, a person has a mix of these problems. FASDs are a leading known cause of intellectual disability and birth defects.

# What causes FASDs and how can they be prevented?

FASDs are caused by a woman's drinking alcohol while she is pregnant. There is no known amount of alcohol that is safe to drink while pregnant. All drinks that contain alcohol can harm an unborn baby. There is no safe time to drink during pregnancy. Alcohol can harm a baby at any time during pregnancy. So, to prevent FASDs, a woman should not drink alcohol while she is pregnant, or even when she might get pregnant. FASDs are 100% preventable. If a woman doesn't drink alcohol while she is pregnant, her child will not have an FASD.

## What are some signs of FASDs?

Signs of FASDs can be physical or intellectual. That means they can affect the mind or the body, or both. Because FASDs make up a group of disorders, people with FASDs can show a wide range and mix of signs.

Physical signs of FASDs can include abnormal facial features such as narrow eye openings and a smooth philtrum (the ridge between the upper lip and nose), small head size, short stature, and low body weight. Rarely, problems with the heart, kidneys, bones, or hearing might be present.

Intellectual and behavioral signs of FASDs might include problems with memory, judgment or impulse control, motor skills, academics (especially in math), paying attention, and low IQ. Specific learning disabilities are also possible.

# What can I do if I think my child has an FASD?

Talk to your child's doctor or nurse. If you or the doctor thinks there could be a problem, ask to see a specialist (someone who knows about FASDs) such as a developmental pediatrician, child psychologist, or clinical geneticist. In some cities, there are clinics whose staffs have special training in recognizing and dealing with children with FASDs. Also contact your local early intervention agency (for children younger than 3 years of age) or local public school (for children 3 years of age or older). To find out whom to call in your area about these services, contact the National Information Center for Children and Youth with Disabilities at www.nichcy.org/states.htm or call the Centers for Disease Control and Prevention (CDC) at 1-800-232-4636.

To learn more about FASDs, go to the Centers for Disease Control and Prevention (CDC) website at **www.cdc.gov/fasd**, or the National Organization on Fetal Alcohol Syndrome at **www.nofas.org**.

To help your child reach his or her full potential, it is very important to get help for FASDs as early as possible!



# Fragile X Syndrome

### What is fragile X syndrome?

Fragile X syndrome (FXS) is the most common known cause of intellectual disability (formerly referred to as mental retardation) that can be inherited, that is passed from parent to child. It is estimated that FXS affects about 1 in 4,000 boys and 1 in 6,000 to 8,000 girls. Both boys and girls can have FXS, but girls usually are more mildly affected.

#### What causes FXS?

The cause of FXS is genetic. FXS occurs when there is a change in a gene on the X chromosome called FMR1. The FMR1 gene makes a protein needed for normal brain development. In FXS, the FMR1 gene does not work properly. The protein is not made, and the brain does not develop as it should. The lack of this protein causes FXS.

## What are some signs of FXS?

#### Children with FXS might:

- Sit up, crawl, or walk later than other children
- Have trouble with learning and solving problems
- Learn to talk later, or have trouble speaking
- Become very anxious in crowds and new situations
- Be sensitive about someone touching them
- Bite or flap their hands
- Have trouble making eye contact
- Have a short attention span
- Be in constant motion and unable to sit still
- Have seizures

## Some children with FXS have certain physical features such as:

- A large head
- A long face
- Prominent ears, chin, and forehead
- Flexible joints
- Flat feet
- Macroorchidism (enlarged testicles in males; more obvious after puberty)

These physical features tend to become more noticeable as the child gets older.

www.cdc.gov/actearly

# What conditions are common among children with FXS?

Children with FXS might have learning disabilities, speech and language delays, and behavioral problems such as attention-deficit/hyperactivity disorder (ADHD) and anxiety. Some older males can develop aggressive behavior. Depression can also occur. Boys with FXS usually have a mild to severe intellectual disability. Many girls with FXS have normal intelligence. Others have some degree of intellectual disability, with or without learning disabilities. Autism spectrum disorders (ASDs) occur more often among children with FXS.

### What can I do if I think my child has FXS?

Talk with your child's doctor or nurse. If you or your doctor think there could be a problem, the doctor can order a blood test for FXS or refer you to a developmental specialist or geneticist, or both. Also, contact your local early intervention agency (for children younger than 3 years of age) or public school (for children 3 years of age or older) to find out if your child qualifies for intervention services. To find out whom to call in your area, contact the National Information Center for Children and Youth with Disabilities at www.nichcy.org/states.htm or call the Centers for Disease Control and Prevention (CDC) at 1-800-232-4636.

In addition, CDC has links to information for families at www.cdc.gov/ncbddd/single\_gene/fragilex.htm.

Additional resources include the National Fragile X Foundation (www.fragilex.org) and the Fragile X Research Foundation (www.fraxa.org). CDC also supports the efforts of the Fragile X Clinical & Research Consortium (www.fragilex.org/html/clinics.htm) which can be reached through the National Fragile X Foundation.

While there is no cure for fragile X syndrome, therapies and interventions can improve the lives of those affected and of their families. It is <u>very</u> important to begin these therapies and interventions as early as possible to help your child reach his or her full potential. Acting early can make a real difference!





# Duchenne Muscular Dystrophy FACT SHEET

## What is Duchenne muscular dystrophy?

Duchenne muscular dystrophy (DMD) is a genetic disorder that causes muscles to gradually weaken over time. A person with DMD will eventually lose the ability to walk and will have problems with breathing and his or her heart. It most often affects boys and occurs among all races and cultures. Sometimes this disorder affects other members of a person's family, but in many cases it is new to a family.

## What are the signs of DMD?

A child who has DMD does not reach certain developmental milestones at the same time as other children of the same age, particularly motor or movement milestones. Most boys with DMD start walking later than other children and are thought to be clumsy and fall a lot. In some cases a child might have learning and speech delays.

#### Children with DMD might:

- Not be able to walk by 15 months of age
- Walk with the legs apart, on the toes, or walk with the belly pointed out (also called lordosis), or both
- Fall frequently
- Need help getting up from the floor or "walk" up their legs with their hands in order to stand (also called Gowers maneuver)
- Have difficulty with motor skills such as running, hopping, jumping, or climbing stairs
- Have larger calves than other children of the same size or age (also called pseudohypertophy)
- Frequently complain of having tired legs
- Have behavior and learning difficulties
- Have delayed speech

Most children with motor or movement concerns do not have DMD, but should still be seen by a health care professional.

#### What causes DMD?

Children who have DMD make no or low amounts of a protein called dystrophin. Dystrophin acts like glue,

holding muscles together by keeping the structure of muscle cells. Without it, muscles weaken over time and become unable to work properly.

## How and when is DMD diagnosed?

A simple and inexpensive blood test called creatine kinase (CK) can help make the diagnosis. If the test results are positive, the doctor might order additional tests. DMD is usually not identified until a child is 3 to 6 years of age, but can be diagnosed earlier.

# What can I do if I think my child might have DMD?

Talk with your child's doctor or nurse. If you or your doctor think there could be a problem, ask for a referral to see a developmental pediatrician, neurologist, or other specialist and contact your local early intervention agency (for children younger than 3 years of age) or public school (for children 3 years of age or older) to find out if your child qualifies for intervention services. To find out whom to speak to in your area, you can contact the National Information Center for Children and Youth with Disabilities at <a href="https://www.nichcy.org/states.htm">www.nichcy.org/states.htm</a> or call the Centers for Disease Control and Prevention (CDC) at 1-800-232-4636. In addition, CDC has links to additional information for families on their Duchenne muscular dystrophy webpage at <a href="https://www.cdc.gov/ncbddd/duchenne">www.cdc.gov/ncbddd/duchenne</a>.

If your child is diagnosed with DMD, there are many groups that can help you, including the Parent Project Muscular Dystrophy: http://www.parentprojectmd.org and the Muscular Dystrophy Association: http://www.mda.org/.

To help a child with DMD reach his full potential, it is very important to get help for him as early as possible. Acting early can make a real difference!



# Important Milestones By The End Of 3 Months

Babies develop at their own pace, so it's impossible to tell exactly when your child will learn a given skill. The developmental milestones listed below will give you a general idea of the changes you can expect, but don't be alarmed if your own baby's development takes a slightly different course.

#### Social and Emotional

- Begins to develop a social smile
- Enjoys playing with other people and may cry when playing stops
- Becomes more expressive and communicates more with face and body
- Imitates some movements and facial expressions

#### Movement

- Raises head and chest when lying on stomach
- Supports upper body with arms when lying on stomach
- Stretches legs out and kicks when lying on stomach or back
- Opens and shuts hands
- Pushes down on legs when feet are placed on a firm surface
- Brings hand to mouth
- Takes swipes at dangling objects with hands
- Grasps and shakes hand toys

#### Vision

- Watches faces intently
- Follows moving objects
- Recognizes familiar objects and people at a distance
- Starts using hands and eyes in coordination

#### Hearing and Speech

- Smiles at the sound of your voice
- Begins to babble
- Begins to imitate some sounds
- Turns head toward direction of sound

#### **Developmental Health Watch**

Alert your child's doctor or nurse if your child displays any of the following signs of possible developmental delay for this age range.

- Does not seem to respond to loud noises
- Does not notice hands by 2 months
- Does not follow moving objects with eyes by 2 to 3 months
- Does not grasp and hold objects by 3 months
- Does not smile at people by 3 months
- Cannot support head well by 3 months
- Does not reach for and grasp toys by 3 to 4 months
- Does not babble by 3 to 4 months
- Does not bring objects to mouth by 4 months
- Begins babbling, but does not try to imitate any of your sounds by 4 months
- Does not push down with legs when feet are placed on a firm surface by 4 months
- Has trouble moving one or both eyes in all directions
- Crosses eyes most of the time (occasional crossing of the eyes is normal in these first months)
- Does not pay attention to new faces, or seems very frightened by new faces or surroundings
- Experiences a dramatic loss of skills he or she once had

From CARING FOR YOUR BABY AND YOUNG CHILD: BIRTH TO AGE 5 by Steven Shelov, Robert E. Hannermann, © 1991, 1993, 1998, 2004 by the American Academy of Pediatrics. Used by permission of Bantam Books, a division of Random House, Inc.





# Important Milestones By The End Of 7 Months

Babies develop at their own pace, so it's impossible to tell exactly when your child will learn a given skill. The developmental milestones listed below will give you a general idea of the changes you can expect, but don't be alarmed if your own baby's development takes a slightly different course.

#### Social and Emotional

- Enjoys social play
- Interested in mirror images
- Responds to other people's expressions of emotion and appears joyful often

#### Cognitive

- Finds partially hidden object
- Explores with hands and mouth
- Struggles to get objects that are out of reach

#### Language

- Responds to own name
- Begins to respond to "no"
- Can tell emotions by tone of voice
- Responds to sound by making sounds
- Uses voice to express joy and displeasure
- Babbles chains of sounds

#### Movement

- Rolls both ways (front to back, back to front)
- Sits with, and then without, support on hands
- Supports whole weight on legs
- Reaches with one hand
- Transfers object from hand to hand
- Uses hand to rake objects

#### Vision

- Develops full color vision
- Distance vision matures
- Ability to track moving objects improves

### **Developmental Health Watch**

Alert your child's doctor or nurse if your child displays any of the following signs of possible developmental delay for this age range.

- Seems very stiff, with tight muscles
- Seems very floppy, like a rag doll
- Head still flops back when body is pulled to a sitting position
- Reaches with one hand only
- Refuses to cuddle
- Shows no affection for the person who cares for him or her
- Doesn't seem to enjoy being around people
- One or both eyes consistently turn in or out
- Persistent tearing, eye drainage, or sensitivity to light
- Does not respond to sounds around him or her
- Has difficulty getting objects to mouth
- Does not turn head to locate sounds by 4 months
- Does not roll over in either direction (front to back or back to front) by 5 months
- Seems impossible to comfort at night after 5 months
- Does not smile on his or her own by 5 months
- Cannot sit with help by 6 months
- Does not laugh or make squealing sounds by 6 months
- Does not actively reach for objects by 6 to 7 months
- Does not follow objects with both eyes at near (1 foot) and far (6 feet) ranges by 7 months
- Does not bear weight on legs by 7 months
- Does not try to attract attention through actions by 7 months
- Does not babble by 8 months
- Shows no interest in games of peek-a-boo by 8 months
- Experiences a dramatic loss of skills he or she once had

From CARING FOR YOUR BABY AND YOUNG CHILD: BIRTH TO AGE 5 by Steven Shelov, Robert E. Hannermann, © 1991, 1993, 1998, 2004 by the American Academy of Pediatrics. Used by permission of Bantam Books, a division of Random House, Inc.





# Important Milestones By The End Of 1 Year (12 Months)

Babies develop at their own pace, so it's impossible to tell exactly when your child will learn a given skill. The developmental milestones listed below will give you a general idea of the changes you can expect, but don't be alarmed if your own baby's development takes a slightly different course.

#### Social and Emotional

- Shy or anxious with strangers
- Cries when mother or father leaves
- Enjoys imitating people in his play
- Shows specific preferences for certain people and toys
- Tests parental responses to his actions during feedings
- Tests parental responses to his behavior
- May be fearful in some situations
- Prefers mother and/or regular caregiver over all others
- Repeats sounds or gestures for attention
- Finger-feeds himself
- Extends arm or leg to help when being dressed

### Cognitive

- Explores objects in many different ways (shaking, banging, throwing, dropping)
- Finds hidden objects easily
- Looks at correct picture when the image is named
- Imitates gestures
- Begins to use objects correctly (drinking from cup, brushing hair, dialing phone, listening to receiver)

### Language

- Pays increasing attention to speech
- Responds to simple verbal requests
- Responds to "no"
- Uses simple gestures, such as shaking head for "no"
- Babbles with inflection (changes in tone)
- Says "dada" and "mama"
- Uses exclamations, such as "Oh-oh!"
- Tries to imitate words

#### Movement

- Reaches sitting position without assistance
- Crawls forward on belly
- Assumes hands-and-knees position
- Creeps on hands and knees
- Gets from sitting to crawling or prone (lying on stomach) position
- Pulls self up to stand
- Walks holding on to furniture
- Stands momentarily without support
- May walk two or three steps without support

### Hand and Finger Skills

- Uses pincer grasp
- Bangs two objects together
- Puts objects into container
- Takes objects out of container
- Lets objects go voluntarily
- Pokes with index finger
- Tries to imitate scribbling

### **Developmental Health Watch**

Alert your child's doctor or nurse if your child displays any of the following signs of possible developmental delay for this age range.

- Does not crawl
- Drags one side of body while crawling (for over one month)
- Cannot stand when supported
- Does not search for objects that are hidden while he or she watches
- Says no single words ("mama" or "dada")
- Does not learn to use gestures, such as waving or shaking head
- Does not point to objects or pictures
- Experiences a dramatic loss of skills he or she once had

From CARING FOR YOUR BABY AND YOUNG CHILD: BIRTH TO AGE 5 by Steven Shelov, Robert E. Hannermann, © 1991, 1993, 1998, 2004 by the American Academy of Pediatrics. Used by permission of Bantam Books, a division of Random House, Inc.





# Important Milestones By The End Of 2 Years (24 Months)

Children develop at their own pace, so it's impossible to tell exactly when yours will learn a given skill. The developmental milestones below will give you a general idea of the changes you can expect as your child gets older, but don't be alarmed if your child takes a slightly different course.

#### Social

- Imitates behavior of others, especially adults and older children
- More aware of herself as separate from others
- More excited about company of other children

#### **Emotional**

- Demonstrates increasing independence
- Begins to show defiant behavior
- Separation anxiety increases toward midyear then fades

### Cognitive

- Finds objects even when hidden under two or three covers
- Begins to sort by shapes and colors
- Begins make-believe play

#### Language

- Points to object or picture when it's named for him
- Recognizes names of familiar people, objects, and body parts
- Says several single words (by 15 to 18 months)
- Uses simple phrases (by 18 to 24 months)
- Uses 2- to 4-word sentences
- Follows simple instructions
- Repeats words overheard in conversation

#### Movement

- Walks alone
- Pulls toys behind her while walking
- Carries large toy or several toys while walking
- Begins to run
- Stands on tiptoe
- Kicks a ball
- Climbs onto and down from furniture unassisted
- Walks up and down stairs holding on to support

### Hand and Finger Skills

- Scribbles on his or her own
- Turns over container to pour out contents
- Builds tower of four blocks or more
- Might use one hand more often than the other

### **Developmental Health Watch**

Alert your child's doctor or nurse if your child displays any of the following signs of possible developmental delay for this age range.

- Cannot walk by 18 months
- Fails to develop a mature heel-toe walking pattern after several months of walking, or walks only on his toes
- Does not speak at least 15 words
- Does not use two-word sentences by age 2
- By 15 months, does not seem to know the function of common household objects (brush, telephone, bell, fork, spoon)
- Does not imitate actions or words by the end of this period
- Does not follow simple instructions by age 2
- Cannot push a wheeled toy by age 2
- Experiences a dramatic loss of skills he or she once had

From CARING FOR YOUR BABY AND YOUNG CHILD: BIRTH TO AGE 5 by Steven Shelov, Robert E. Hannermann, © 1991, 1993, 1998, 2004 by the American Academy of Pediatrics. Used by permission of Bantam Books, a division of Random House, Inc.





# Important Milestones By The End Of 3 Years (36 Months)

Children develop at their own pace, so it's impossible to tell exactly when yours will learn a given skill. The developmental milestones below will give you a general idea of the changes you can expect as your child gets older, but don't be alarmed if your child takes a slightly different course.

#### Social

- Imitates adults and playmates
- Spontaneously shows affection for familiar playmates
- Can take turns in games
- Understands concept of "mine" and "his/hers"

#### **Emotional**

- Expresses affection openly
- Expresses a wide range of emotions
- By 3, separates easily from parents
- Objects to major changes in routine

### Cognitive

- Makes mechanical toys work
- Matches an object in her hand or room to a picture in a book
- Plays make-believe with dolls, animals, and people
- Sorts objects by shape and color
- Completes puzzles with three or four pieces
- Understands concept of "two"

#### Language

- Follows a two- or three-part command
- Recognizes and identifies almost all common objects and pictures
- Understands most sentences
- Understands placement in space ("on," "in," "under")
- Uses 4- to 5-word sentences
- Can say name, age, and sex
- Uses pronouns (I, you, me, we, they) and some plurals (cars, dogs, cats)
- Strangers can understand most of her words

#### Movement

- Climbs well
- Walks up and down stairs, alternating feet (one foot per stair step)
- Kicks ball
- Runs easily
- Pedals tricycle
- Bends over easily without falling

### Hand and Finger Skills

- Makes up-and-down, side-to-side, and circular lines with pencil or crayon
- Turns book pages one at a time
- Builds a tower of more than six blocks
- Holds a pencil in writing position
- Screws and unscrews jar lids, nuts, and bolts
- Turns rotating handles

### **Developmental Health Watch**

Alert your child's doctor or nurse if your child displays any of the following signs of possible developmental delay for this age range.

- Frequent falling and difficulty with stairs
- Persistent drooling or very unclear speech
- Cannot build a tower of more than four blocks
- Difficulty manipulating small objects
- Cannot copy a circle by age 3
- Cannot communicate in short phrases
- No involvement in "pretend" play
- Does not understand simple instructions
- Little interest in other children
- Extreme difficulty separating from mother or primary caregiver
- Poor eye contact
- Limited interest in toys
- Experiences a dramatic loss of skills he or she once had

From CARING FOR YOUR BABY AND YOUNG CHILD: BIRTH TO AGE 5 by Steven Shelov, Robert E. Hannermann, © 1991, 1993, 1998, 2004 by the American Academy of Pediatrics. Used by permission of Bantam Books, a division of Random House, Inc.





# Important Milestones By The End Of 4 Years (48 Months)

Children develop at their own pace, so it's impossible to tell exactly when yours will learn a given skill. The developmental milestones below will give you a general idea of the changes you can expect as your child gets older, but don't be alarmed if your child takes a slightly different course.

#### Social

- Interested in new experiences
- Cooperates with other children
- Plays "Mom" or "Dad"
- Increasingly inventive in fantasy play
- Dresses and undresses
- Negotiates solutions to conflicts
- More independent

#### **Emotional**

- Imagines that many unfamiliar images may be "monsters"
- Views self as a whole person involving body, mind, and feelings
- Often cannot tell the difference between fantasy and reality

#### Cognitive

- Correctly names some colors
- Understands the concept of counting and may know a few numbers
- Tries to solve problems from a single point of view
- Begins to have a clearer sense of time
- Follows three-part commands
- Recalls parts of a story
- Understands the concepts of "same" and "different"
- Engages in fantasy play

#### Language

- Has mastered some basic rules of grammar
- Speaks in sentences of five to six words
- Speaks clearly enough for strangers to understand
- Tells stories

#### Movement

- Hops and stands on one foot up to five seconds
- Goes upstairs and downstairs without support
- Kicks ball forward
- Throws ball overhand
- Catches bounced ball most of the time
- Moves forward and backward with agility

#### Hand and Finger Skills

- Copies square shapes
- Draws a person with two to four body parts
- Uses scissors
- Draws circles and squares
- Begins to copy some capital letters

### **Developmental Health Watch**

Alert your child's doctor or nurse if your child displays any of the following signs of possible developmental delay for this age range.

- Cannot throw a ball overhand
- Cannot jump in place
- Cannot ride a tricycle
- Cannot grasp a crayon between thumb and fingers
- Has difficulty scribbling
- Cannot stack four blocks
- Still clings or cries whenever parents leave
- Shows no interest in interactive games
- Ignores other children
- Doesn't respond to people outside the family
- Doesn't engage in fantasy play
- Resists dressing, sleeping, using the toilet
- Lashes out without any self-control when angry or upset
- Cannot copy a circle
- Doesn't use sentences of more than three words
- Doesn't use "me" and "you" correctly
- Experiences a dramatic loss of skills he or she once had

From CARING FOR YOUR BABY AND YOUNG CHILD: BIRTH TO AGE 5 by Steven Shelov, Robert E. Hannermann, © 1991, 1993, 1998, 2004 by the American Academy of Pediatrics. Used by permission of Bantam Books, a division of Random House, Inc.





# Important Milestones By The End Of 5 Years (60 Months)

Children develop at their own pace, so it's impossible to tell exactly when yours will learn a given skill. The developmental milestones below will give you a general idea of the changes you can expect as your child gets older, but don't be alarmed if your child takes a slightly different course.

#### Social

- Wants to please friends
- Wants to be like her friends
- More likely to agree to rules
- Likes to sing, dance, and act
- Shows more independence and may even visit a next-door neighbor by herself

#### **Emotional**

- Aware of gender
- Able to distinguish fantasy from reality
- Sometimes demanding, sometimes eagerly cooperative

#### Cognitive

- Can count 10 or more objects
- Correctly names at least four colors
- Better understands the concept of time
- Knows about things used every day in the home (money, food, appliances)

#### Language

- Recalls part of a story
- Speaks sentences of more than five words
- Uses future tense
- Tells longer stories
- Says name and address

#### Movement

- Stands on one foot for 10 seconds or longer
- Hops, somersaults
- Swings, climbs
- May be able to skip

#### Hand and Finger Skills

- Copies triangle and other shapes
- Draws person with body

- Prints some letters
- Dresses and undresses without help
- Uses fork, spoon, and (sometimes) a table knife
- Usually cares for own toilet needs

### **Developmental Health Watch**

Alert your child's doctor or nurse if your child displays any of the following signs of possible developmental delay for this age range.

- Acts extremely fearful or timid
- Acts extremely aggressively
- Is unable to separate from parents without major protest
- Is easily distracted and unable to concentrate on any single activity for more than five minutes
- Shows little interest in playing with other children
- Refuses to respond to people in general, or responds only superficially
- Rarely uses fantasy or imitation in play
- Seems unhappy or sad much of the time
- Doesn't engage in a variety of activities
- Avoids or seems aloof with other children and adults
- Doesn't express a wide range of emotions
- Has trouble eating, sleeping or using the toilet
- Can't tell the difference between fantasy and reality
- Seems unusually passive
- Cannot understand two-part commands using prepositions ("Put the doll on the bed, and get the ball under the couch.")
- Can't correctly give her first and last name
- Doesn't use plurals or past tense properly when speaking
- Doesn't talk about her daily activities and experiences
- Cannot build a tower of six to eight blocks
- Seems uncomfortable holding a crayon
- Has trouble taking off clothing
- Cannot brush her teeth efficiently
- Cannot wash and dry her hands
- Experiences a dramatic loss of skills he or she once had

From CARING FOR YOUR BABY AND YOUNG CHILD: BIRTH TO AGE 5 by Steven Shelov, Robert E. Hannermann, © 1991, 1993, 1998, 2004 by the American Academy of Pediatrics. Used by permission of Bantam Books, a division of Random House, Inc.





## Resources

# "Learn the Signs. Act Early." Web: www.cdc.gov/actearly

#### **GOVERNMENT RESOURCES**

 Centers for Disease Control and Prevention (CDC),
 National Center on Birth Defects and Developmental Disabilities (NCBDDD)

Phone: 1-800-232-4636 Web: www.cdc.gov/ncbddd

 National Dissemination Center for Children with Disabilities

Web: www.nichcy.org/states.htm

■ Department of Education Web: www.ed.gov/index.html

■ National Institute of Mental Health

Phone: 1-866-615-6464 Web: www.nimh.nih.gov

■ State Health Insurance Program (SCHIP)

Phone: 1-877-543-7669 Web: www.insurekidsnow.gov

#### SPECIAL RESOURCES

American Academy of Pediatrics (AAP)

Phone: 1-847-434-4000 Web: www.aap.org

Parent to Parent-USA Web: www.p2pusa.org

#### **AUTISM SPECTRUM DISORDERS (ASD)**

Autism Society of America (ASA)

Phone: 1-800-328-8476 Web: www.autism-society.org

Autism Speaks

Phone: 1-888-288-4762 Web: www.autismspeaks.org

■ First Signs

Phone: 1-978-346-4380 Web: www.firstsigns.org

Organization for Autism Research (OAR)

Phone: 1-703-243-9710 Web: www.researchautism.org

Asperger Syndrome Education Network (ASPEN)
 Phone: 1-732-321-0880 Web: www.aspennj.org

MAAP Services for Autism, Asperger Syndrome, and PDD
 Phone: 1-219-662-1311
 Web: www.maapservices.org

CDC's Resources on Vaccines and Autism
 Web: www.cdc.gov/ncbddd/autism/vaccines.htm

## ATTENTION-DEFICIT/HYPERACTIVITY DISORDER (ADHD)

 Children and Adults with Attention Deficit/Hyperactivity Disorder (CHADD)

Phone: 1-800-233-4050 Web: www.chadd.org

Attention Deficit Disorder Association (ADDA)
 Phone: 1-800-939-1019 Web: www.add.org

#### **CEREBRAL PALSY**

United Cerebral Palsy (UCP)

Phone: 1-800-872-5827 Web: www.ucp.org

National Institute of Neurological Disorders and Stroke (NINDS)
 Phone: 1-800-352-9424 Web: www.ninds.nih.gov

Reaching for the Stars Phone: 1-877-561-7387

Web: www.reachingforthestars.org

#### INTELLECTUAL DISABILITY (also known as Mental Retardation)

 American Association of Intellectual and Developmental Disabilities (formerly American Association on Mental Retardation)

Phone: 1-800-424-3688 Web: www.aaidd.org

■ The Arc of the United States

Phone: 1-800-433-5255 Web: www.thearc.org

#### **HEARING LOSS**

Centers for Disease Control and Prevention (CDC),
 Early Hearing Detection and Intervention Program (EHDI)

Phone: 1-800-232-4636 Web: www.cdc.gov/ncbddd/ehdi

American Academy of Audiology (AAA)

Phone: 1-800-222-2336 Web: www.audiology.org

American Academy of Pediatrics Bright Futures

Phone: 1-847-434-4000 Web: brightfutures.aap.org/web

American Speech-Language-Hearing Association (ASHA)
 Phone: 1-800-638-8255 Web: www.asha.org

#### **VISION LOSS**

National Federation of the Blind (NFB)

Phone: 1-410-659-9314 Web: www.nfb.org

American Council of the Blind (ACB)

Phone: 1-800-424-8666 Web: www.acb.org

American Foundation for the Blind (AFB)

Phone: 1-800-232-5463 Web: www.afb.org

#### FETAL ALCOHOL SYNDROME DISORDER (FASD)

Centers for Disease Control and Prevention (CDC),
 Fetal Alcohol Syndrome Program

Phone: 1-800-232-4636 Web: www.cdc.gov/ncbddd/fas

National Organization on Fetal Alcohol Syndrome (NOFAS)
 Phone: 1-800-666-6327 Web: www.nofas.org



