



National Down Syndrome Society

# a promising future together

*A guide for new and expectant parents*

national down syndrome society  
**ndss**  
Education. Research. Advocacy.

The National Down Syndrome Society envisions a world in which all people with Down syndrome have the opportunity to realize their life aspirations. We are committed to being the national leader in supporting and enhancing the quality of life, and realizing the potential of all people with Down syndrome.

Dear Friend:

If you have recently given birth to, or are expecting, a baby with Down syndrome, you probably have many questions and concerns right now. You might be wondering, as I did when I was a new parent:

- How will Down syndrome affect my baby's development?
- What does the diagnosis mean for me as a parent?
- How will this newcomer affect the rest of my family?
- What is the best course to follow to help my baby reach his or her potential?
- What will he or she be like as an adult?

My daughter was born in 1978. I remember that as a new mother, the thing I wanted most was reassurance that my baby and family would be all right, but there was very little accurate information available to me at that time. As a direct result of my experience, I founded the National Down Syndrome Society to provide assistance to other families of individuals with Down syndrome. One of our first publications was a special booklet for new parents. It was filled with pictures of children with Down syndrome and featured quotes from parents about their experiences and hopes for the future.

Twenty-six years later, we are still providing up-to-date information about Down syndrome and sharing the message that your baby will develop in ways beyond your expectations. This guide for new and expectant parents includes information and tips to help you and your baby get off to the best start possible. It addresses topics related to health care, early intervention, and caring for yourself and your family. It also includes lists of resources that other parents have found helpful. We hope that this packet will provide you with the reassurance you might be searching for at this time.

Congratulations on the recent or upcoming birth of your baby, and may your new family member bring you the joy, love and laughter that my daughter has brought to our family. Keep in mind that you are not alone. Although there will be challenges, an exciting journey lies ahead, and NDSS is here to provide information and support along the way.

Sincerely,



Elizabeth Goodwin  
Founder, NDSS



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# about down syndrome

Down syndrome occurs in one out of every 733 live births, and more than 350,000 people in the United States have this genetic condition. One of the most frequently occurring chromosomal abnormalities, Down syndrome affects people of all ages, races and economic levels. Today, individuals with Down syndrome are active participants in the educational, vocational, social and recreational aspects of our communities. In fact, there are more opportunities than ever before for individuals with Down syndrome to develop their abilities, discover their talents, and realize their dreams. For example, more teens and adults with Down syndrome each year are graduating from high school, going to college, finding employment and living independently. But what exactly is Down syndrome, and how is it diagnosed? This section provides an overview of the genetics of Down syndrome and explains the various tests used for screening and diagnosis. It also discusses how Down syndrome can affect your baby's development.

## What is Down syndrome?

The human body is made of cells. All cells contain a center, called a nucleus, in which genes are stored. Genes, which carry the codes responsible for all our inherited characteristics, are grouped along rod-like structures called chromosomes. Normally, the nucleus of each cell contains 23 pairs of chromosomes, half of which are inherited from each parent. Down syndrome occurs when some or all of a person's cells have an extra full or partial copy of chromosome 21.

The most common form of Down syndrome is known as **Trisomy 21**. Individuals with Trisomy 21 have 47 chromosomes instead of the usual 46 in each of their cells. The condition results from an error in cell division called **nondisjunction**. Prior to or at conception, a pair of 21st chromosomes in either the sperm or the egg fails to separate. As the embryo develops, the extra chromosome is replicated in every cell of the body. This error in cell division is responsible for 95 percent of all cases of Down syndrome.



Down syndrome also encompasses two other genetic conditions: mosaicism and translocation. **Mosaicism** occurs when nondisjunction of chromosome 21 takes place in one of the initial cell divisions after fertilization causing a person to have 46 chromosomes in some of their cells and 47 in others. The least common form of Down syndrome, mosaicism accounts for only 1 to 2 percent of all cases.

**Translocation**, which accounts for 3 to 4 percent of cases of Down syndrome, occurs when part of chromosome 21 breaks off during cell division and attaches to another chromosome, usually chromosome 14. While the total number of chromosomes in the cells remains 46, the presence of an extra part of chromosome 21 causes the characteristics of Down syndrome.

The cause of the extra full or partial chromosome is still unknown. We do know that it is not caused by environmental factors or anything the mother does before or during her pregnancy. Maternal age is the only factor that has been linked to an increased chance of having a baby with Down syndrome resulting from nondisjunction. A 35-year-old woman has a one in 350 chance of conceiving a child with Down syndrome. By age 45, the incidence has increased to one in 30. However, because younger women have higher fertility rates, 80 percent of babies with Down syndrome are born to women under the age of 35. Once a woman has given birth to a baby with Down syndrome, the chance of having a second child with Down syndrome is about 1 in 100, although age may also be a factor.

Maternal age, however, is not linked to the chance of having a baby with translocation. Most cases are sporadic, chance events, but in about one third of translocation cases, one parent is a carrier of a translocated chromosome. For this reason, the chance of translocation in a second pregnancy is higher than that seen in nondisjunction.

### What types of prenatal tests are available to detect Down syndrome?

There are two types of tests for Down syndrome that can be performed before your baby is born: screening and diagnostic tests. **Prenatal screenings** estimate the chance of the fetus having Down syndrome. These tests do not tell you for sure whether your baby has Down syndrome; they only provide a risk assessment. **Diagnostic tests**, on the other hand, can provide a definitive diagnosis with almost 100 percent accuracy.

Many women are now offered screening tests for Down syndrome in the first trimester. The First Trimester Screen includes blood tests between 9 and 13 weeks and a detailed ultrasound of the baby's neck, called a nuchal translucency test, between 11 and 13 weeks. There are also screening tests available in the second trimester that include the Triple Screen test, a combination of three tests that measure quantities of various substances in the mother's blood (alpha-fetoprotein, human chorionic gonadotropin and unconjugated estriol), or the Quad Screen, that measures the substances above in addition to inhibin-A. These screening tests are typically offered between 15 and 20 weeks of gestation. Many women who undergo these tests will be given false-positive readings, and some will be given false-negative readings.

Because maternal serum screening tests are of limited value, they are often performed in conjunction with a detailed sonogram to check for "markers" (characteristics that some researchers feel may have a significant association with Down syndrome). Recently, researchers have developed a maternal

serum/ultrasound/age combination that can yield a much higher accuracy rate at an earlier stage in the pregnancy.

Prenatal screening tests are routinely offered to women over the age of 35, due to their increased chances of giving birth to a child with a disability; however, pregnant women of any age can request a test or choose not to have it done. If the estimate determined by prenatal screening is high, doctors will often advise a mother to undergo diagnostic testing.

The diagnostic procedures available for prenatal diagnosis of Down syndrome are **chorionic villus sampling (CVS)** and **amniocentesis**. These procedures, which carry a small risk of miscarriage, are about 98 to 99 percent accurate in the detection of Down syndrome. Amniocentesis is usually performed between 15 and 22 weeks of gestation and CVS between 9 and 14 weeks.

If you have any questions about these procedures, do not hesitate to ask your doctor. It is important that you receive accurate information and understand all your options. Whether or not to undergo a prenatal screening or diagnostic test is a personal decision, and expectant parents must make the choice that is best for them.

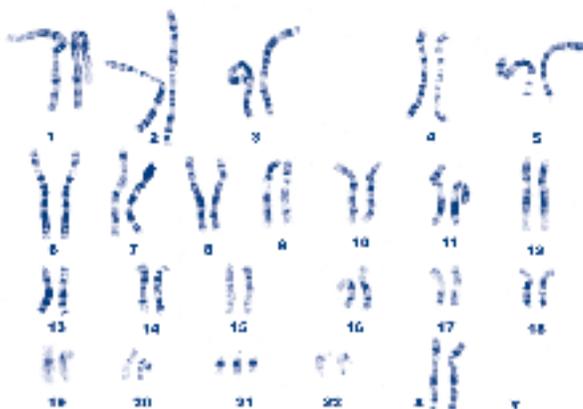


### How is Down syndrome diagnosed in a newborn?

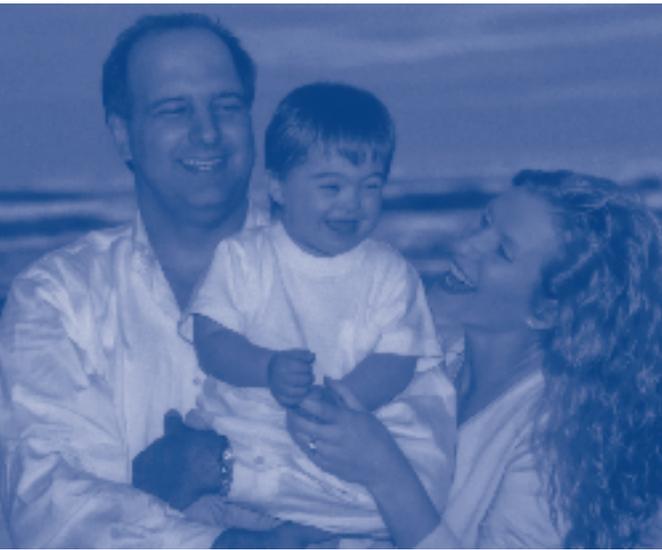
Even though there are many prenatal tests available for Down syndrome, most cases of Down syndrome are diagnosed after the baby is born. Doctors will usually suspect Down syndrome if certain physical characteristics are present. Some of the traits common to babies with Down syndrome include low muscle tone, a flat facial profile, a small nose, an upward slant to the eyes, and a single deep crease across the center of the palm.

Not all babies with Down syndrome have all these characteristics, and many of these features can be found to some extent in individuals who do not have the condition. Therefore, doctors must perform a special test called a **karyotype** before making a definitive diagnosis.

To obtain a karyotype, doctors draw a blood sample to examine your baby's cells. They use special tools to photograph the chromosomes and then group them by size, number and shape. By examining the karyotype, doctors can tell definitively whether or not your baby has Down syndrome.



*Karyotype of a person with Down syndrome, showing three copies of chromosome 21.*



### How will Down syndrome affect my baby's development?

An additional chromosome means that there is excess genetic material in your baby's cells. While this will affect your child's development, it is important to realize that it is not a blueprint that determines his or her potential. Down syndrome is a condition your child has – it's not who your child is. As is true for all people, the skills and knowledge he or she acquires will be a unique combination of innate abilities and life experiences.

In most ways, your baby will be just like other infants. Every baby needs to be fed, held and most of all, loved. But, there are certain health and developmental concerns commonly associated with Down syndrome that you should be aware of.

Individuals with Down syndrome are at an increased risk for certain health complications. Babies, in particular, are more likely to have heart problems, hearing loss and respiratory infections; however, advances in medicine have rendered the majority of these health problems treatable.

In addition, all people with Down syndrome experience delays in their cognitive and physical development. Cognitive delays are usually mild to moderate, and they are not indicative of the many strengths and talents that each individual possesses. Low muscle tone and other physical characteristics associated with Down syndrome can affect how soon your baby will be able to sit up, walk and speak. Rest assured, though, that your child will learn how to do these and many other activities, only possibly somewhat later than his or her peers without Down syndrome.

Good medical care and early intervention can provide a strong foundation for your child's optimal development. The next two sections, "A Healthy Start" and "Early Intervention," will help you begin learning about what you can do to help your baby get off to the best start possible!

## Additional Resources

### BOOKS

***Babies with Down Syndrome: A New Parents' Guide*** (2nd edition). Stray-Gundersen, K. (Ed.) (1995). Rockville, MD: Woodbine House.

Especially for new parents, this book addresses the medical, emotional, educational and social issues related to Down syndrome.

Available from Woodbine House at [www.woodbinehouse.com](http://www.woodbinehouse.com) or (800) 843-7323.

***Understanding Down Syndrome: An Introduction for Parents***. Cunningham, C. (1996). Cambridge, MA: Brookline Books.

The book offers insight on the care of young children, adolescents, and older people with Down syndrome, emphasizing the importance of professional guidance and advice on how to obtain it.

Available from Brookline Books at [www.brooklinebooks.com](http://www.brooklinebooks.com) or (800) 666-2665 or (617) 868-0360.

***A Parent's Guide to Down Syndrome: Toward a Brighter Future***. Pueschel, S.M. (2000). Baltimore MD: Paul H. Brookes Publishing Co.

Geared towards parents and professionals, this book focuses on the physical, mental, social, and emotional aspects of Down syndrome. It places a special emphasis on early intervention.

Available from Brookes Publishing at [www.brookespublishing.com](http://www.brookespublishing.com) or (800) 638-3775.

### VIDEOS

***A Promising Future Together: A Guide for New Parents of Children with Down Syndrome***.

New York, NY: National Down Syndrome Society.

This video provides encouragement and hope for a bright future by sharing the personal experiences of several new parents. Topics include early intervention, local and national resources, and health care screenings.

Contact us at (800) 221-4602 or [info@ndss.org](mailto:info@ndss.org).

### OTHER RESOURCES

[www.ds-health.com/prenatal.htm](http://www.ds-health.com/prenatal.htm)

Article entitled "Prenatal Screening for Down Syndrome" provides an in-depth discussion of prenatal testing and maternal age factors. Written by Len Leshin, MD, FAAP, a member of the NDSS clinical advisory board.

[www.nlm.nih.gov/medlineplus/downsyndrome.html](http://www.nlm.nih.gov/medlineplus/downsyndrome.html)

List of resources on Down syndrome and prenatal testing from Medline Plus.

<http://www.marchofdimes.com/pnhec/159.asp>

This page of the March of Dimes' Pregnancy & Newborn section lists several articles, each of which provides an in-depth discussion of a particular prenatal test.



# a healthy start

One of the main questions on the minds of many new parents is, “Will my baby be healthy?” Many babies with Down syndrome are born without any health problems. However, it is true that newborns with Down syndrome are at a higher risk for certain complications. While your baby may not have any of these potential complications, it is important to be aware of them so you can catch them early if they do occur. This section discusses possible health concerns and useful tools for monitoring your child’s health care and growth patterns. It also provides information on how to select a pediatrician, questions to think about when making decisions about potential treatments, and a discussion of feeding options.

## **What health conditions are associated with Down syndrome?**

Newborns with Down syndrome are at a higher risk for congenital heart defects, hearing and vision loss, respiratory problems, obstructed digestive tracts, childhood leukemia, and other health conditions. They also have an increased susceptibility to infection. Doctors routinely screen for these conditions because some, such as a heart defect, may be present even if no symptoms are readily apparent. While the list of possible health problems can be frightening, keep in mind that your baby will not necessarily have all, or possibly any, of them. If he or she does happen to have one or more of these complications, advances in medicine have rendered most conditions treatable. For instance, the majority of heart conditions can be corrected through surgery.

You can ensure your newborn’s optimal development through informed health care. There is a tremendous amount of information available, so it is important not to let yourself get overwhelmed. Learn at your own pace, and try to focus on those things you can do in the present to get your baby off to a good start. Two good tools to use are the Health Care Guidelines for Individuals with Down Syndrome and the Down Syndrome Growth Charts. Copies of these documents are included in the back of this booklet.



## Specialized Health Information

NDSS has a collection of brochures that provide an overview of the health and developmental concerns in individuals with Down syndrome.

To request more information, contact us at (800) 221-4602 or [info@ndss.org](mailto:info@ndss.org)

## What are the Down Syndrome Health Care Guidelines?

The Down Syndrome Health Care Guidelines follow an individual's development from birth through adulthood and provide information about potential health concerns at each stage. They are compiled by the Down Syndrome Medical Interest Group, a national affiliation of health care providers who specialize in caring for individuals with Down syndrome.

The guidelines help define the standards of quality care for individuals with Down syndrome. In addition to specific recommendations for screening tests, they include information about the kinds of medical conditions that individuals with Down syndrome are at risk for and suggestions for early intervention, diet and exercise, and other issues across the lifespan.

You can use the Health Care Guidelines to ensure that your baby is up to date on required and recommended screenings. While your pediatrician may be knowledgeable about the current recommendations, it is a good idea to provide him or her with a copy to place in your child's file. Also, because you are ultimately the most concerned with your child's development, it is important for you to become familiar with the guidelines and communicate on a regular basis with your physician to make sure your baby is getting the best care possible.

## How do Down Syndrome Growth Charts differ from typical growth charts?

Children with Down syndrome are generally smaller than their typically-developing peers, so Down Syndrome Growth Charts have been created by physicians and researchers to help track your child's development. The percentile curves on these charts were derived from a longitudinal study examining the growth patterns of individuals with Down syndrome.

You can use the Growth Charts to plot points that indicate your baby's weight, length and head circumference at various ages, and examine whether or not these numbers follow typical growth patterns. If you have any questions about your child's development, consult your pediatrician. He or she can help you fill out the charts, explain how your baby's development compares with other infants with Down syndrome of the same age, and let you know if any deviations from the growth curves are cause for concern.

## What should I look for in a pediatrician?

For optimal health care, it makes sense to locate a developmental pediatrician or a specialist knowledgeable about Down syndrome, if any are available in your area. You can also contact NDSS to learn the location of the nearest Down syndrome specialty clinic. However, keep in mind that it is not always necessary to find an expert on Down syndrome. The most important thing when you have a baby with special health care needs is to find a doctor who is willing to learn about the condition and collaborate with you to ensure the best possible care for your child.

One of the best ways to find a pediatrician is to ask families of other children with Down syndrome in your area for recommendations. Your local parent support groups can be a good source of referrals. As a parent, you have a right to interview potential physicians to find the best one for you. Find someone you feel comfortable with and with whom you can communicate freely. Also, do not be intimidated when speaking to physicians. A good doctor recognizes that parents are experts when it comes to their children. He or she respects their concerns and sees them as partners.

## What about alternative therapies?

As a parent, you no doubt want to offer your child every opportunity to achieve his or her full potential. As you research Down syndrome, you will likely come across lots of information about various alternative therapies. Parents often get excited about claims that particular treatments can improve motor and cognitive functions or other areas of development, and many invest a lot of hope and money in these treatments. While this is understandable, you should be aware that although there have been many popular therapies through the years, none have been scientifically proven. In fact, some have been proven ineffective or even harmful.

When considering any potential therapy, be sure to discuss it with your pediatrician. Ask for copies of current research studies that support the therapy's claims and consider the following questions:

- Is the therapy documented to be safe and effective?
- Are the claims realistic?
- What are the credentials and background of the person promoting the therapy? (For example, is he or she certified by a professional organization?)
- Does the person have financial interests in the sale of the therapy?
- Is the therapy expensive or overly demanding of your family's time?
- What are the risks and side effects, and do they outweigh the potential benefits?

You can contact NDSS for further information about alternative therapies and our position statements on specific treatments.



## Hidden Gems: Down Syndrome Clinics

Down Syndrome Clinics provide specialized medical care and other services for individuals with Down syndrome and their families.

To learn if there is a Down syndrome clinic near you, contact the NDSS Goodwin Family Information and Referral Center at (800) 221-4602 or [info@ndss.org](mailto:info@ndss.org). You can also see a list of Down syndrome clinics across the country at: [www.dshealth.com/clinics.htm](http://www.dshealth.com/clinics.htm)



### Should I breastfeed or bottlefeed my baby with Down syndrome?

You may be aware of the tremendous benefits that breastfeeding provides to newborns. Breastmilk contains natural antibodies that fortify babies' immune systems. This is especially important to infants with Down syndrome, who have higher rates of respiratory and other infections. Breastmilk can also reduce bowel problems, which are more common in babies with Down syndrome, and contains an ingredient known to promote brain growth and development.

In addition, the physical process of breastfeeding strengthens babies' jaw and facial muscles, which helps lay a good foundation for speech and language development, and provides skin-to-skin contact, a form of sensory stimulation that creates neural connections that can facilitate future learning.

There are many great reasons to breastfeed, but whether or not to do so is a personal choice. Some mothers breastfeed exclusively while others bottlefeed. Still others combine the two. There are many factors that play into this decision, including whether or not you feel your body is producing enough milk, whether or not your baby has health complications, and whether or not you plan to return to work soon after delivery.

If you do plan to breastfeed, be aware of certain factors that might make it challenging. Babies with Down syndrome have low muscle tone, so it may be difficult for your baby to "latch on" to your breast at first. As these babies also tend to be sleepier than other infants, you will likely have to make an extra effort to raise your baby's alertness and keep him or her awake throughout the entire feeding. Also, if your baby needs surgery, he or she may require a feeding tube for a short time.

Don't worry, though. There are many organizations and individuals that can help you get started and provide tips for overcoming these and any other challenges you may encounter. These same specialists can help you learn how to pump, store and transport your breastmilk or how to select the right baby formula to meet your infant's needs if you choose to bottlefeed.

When it comes to feeding, the important thing is to make the choice that is best for you. Feedings should provide quality time for a mother and her child to bond, so they should always be as comfortable and stress-free as possible for both individuals. A meeting with your hospital's lactation specialist is a great place to start learning about what feeding option may be right for you. Other resources are listed at the end of this section.

## Additional Resources

### BROCHURES

#### **The Heart and Down Syndrome.**

New York, NY: National Down Syndrome Society.

Discusses heart conditions common in babies with Down syndrome and recommended treatments.

Contact us at (800) 221-4602 or [info@ndss.org](mailto:info@ndss.org)

#### **The Neurology of Down Syndrome.**

New York, NY: National Down Syndrome Society.

Discusses neurological conditions associated with Down syndrome, preventative measures, and recommended treatments.

Contact us at (800) 221-4602 or [info@ndss.org](mailto:info@ndss.org) .

#### **Endocrine Conditions in Down Syndrome.**

New York, NY: National Down Syndrome Society.

Discusses potential endocrine conditions associated with Down syndrome and recommended treatments.

Contact us at (800) 221-4602 or [info@ndss.org](mailto:info@ndss.org) .

### BOOKS

***The Down Syndrome Nutrition Handbook: A Guide to Promoting Healthy Lifestyles.*** Guthrie Medlen, J.E. (2002) Bethesda, MD: Woodbine House.

This comprehensive guide for educating children and adults with Down syndrome about nutrition and healthy lifestyles covers nutrition issues from birth through adulthood. It includes a chapter on breast and bottle feeding infants.

Available from Woodbine House at [www.woodbinehouse.com](http://www.woodbinehouse.com) or (800) 843-7323.

#### ***Medical & Surgical Care for Children with Down Syndrome: A Guide for Parents.***

Van Dyke, D.C., Mattheis, P., Eberly, S.S., & Williams, J. (Eds.) (1995). Bethesda, MD: Woodbine House.

This guide gives general information on medical conditions experienced by children with Down syndrome. Some topics covered include preventive care, medical decision -making, and surgical concerns.

Available from Woodbine House at [www.woodbinehouse.com](http://www.woodbinehouse.com) or (800) 843-7323.

### ORGANIZATIONS

#### **Australian Breastfeeding Association**

<http://www.breastfeeding.asn.au/>  
P.O. Box 4000, Glen Iris VIC 3146, Australia  
+61 3 98850855  
[info@breastfeeding.asn.au](mailto:info@breastfeeding.asn.au)

The ABA works to provide accurate and helpful information to women who are interested in learning more about breastfeeding, as well as assistance to women who are currently breastfeeding. ABA has a section of their Web site dedicated to breastfeeding children with Down syndrome at [www.breastfeeding.asn.au/bfinfo/down.html](http://www.breastfeeding.asn.au/bfinfo/down.html).

In addition to the Web site, ABA also provides the following publications: *Nursing your Baby with Down Syndrome*, *Breastfeeding your Down Syndrome Baby*, and *You can Breastfeed your Baby, Even in Special Situations*. You can contact ABA's Lactation Resource Centre at the address and phone number above or by e-mailing [lrc@breastfeeding.asn.au](mailto:lrc@breastfeeding.asn.au).

#### **La Leche League**

[www.lalecheleague.org](http://www.lalecheleague.org)  
1400 N. Meacham Road, Schaumburg, IL  
60173-4808 USA  
(847) 519-7730

La Leche League was founded to give information and encouragement, mainly through personal help, to all mothers who want to breastfeed their babies. While complementing the care of the physician and other health care professionals, it recognizes the unique importance of one mother helping another to perceive the needs of her child and to learn the best means of fulfilling those needs. La Leche League has information specific to breastfeeding children with Down syndrome at [www.lalecheleague.org/FAQ/down.html](http://www.lalecheleague.org/FAQ/down.html).

### OTHER RESOURCES

#### **Down Syndrome Health Issues: News and Information for Parents and Professionals**

[www.ds-health.com](http://www.ds-health.com)

This Web site was created by Len Leshin, M.D., F.A.A.P., a pediatrician and member of the NDSS science advisory board. Dr. Leshin is also the father of a child with Down syndrome. He has written extensively for parents on health issues related to Down syndrome and shares a wealth of information and resources on his site.



# early intervention

The first three years of life will be a critical time in your baby's development. All young children go through the most rapid and developmentally significant changes during this time. During these early years, they achieve the basic physical, cognitive, language, social and self-help skills that lay the foundation for future progress, and these abilities are attained according to predictable developmental patterns. Children with Down syndrome typically face delays in certain areas of development, so early intervention is critical. It can begin anytime after birth, but the sooner it starts, the better. This section provides details on the various kinds of early intervention available, and how to access services.

## What is early intervention?

Early intervention is a systematic program of therapy, exercises and activities designed to address developmental delays that may be experienced by children with Down syndrome or other disabilities. These services are mandated by a federal law called the **Individuals with Disabilities Education Act (IDEA)**. The law requires that states provide early intervention services for all children who qualify, with the goal of enhancing the development of infants and toddlers and helping families understand and meet the special needs of their children. The most common early intervention services for babies with Down syndrome are physical therapy, speech and language therapy, and occupational therapy.



“Early intervention was definitely helpful to her development and to mine. It motivated us to do all we could to help her reach her potential. It was a learning time for both of us.”

## How can early intervention benefit my baby?

Development is a continuous process that begins at conception and proceeds stage by stage in an orderly sequence. There are specific milestones in each of the four areas of development (gross and fine motor abilities, language skills, social development, and self-help skills) that serve as prerequisites for the stages that follow. Most children are expected to achieve each milestone at a designated time, also referred to as a “key age,” which can be calculated in terms of weeks, months or years. Because of specific challenges associated with Down syndrome, your baby will likely experience delays in certain areas of development. However, you can expect your baby to achieve each of the same milestones as other children, just on his or her own timetable. (See the developmental milestones chart on page 18.)

Each type of early intervention addresses specific aspects of your baby’s development. **Physical therapy** focuses on motor development. For example, during the first three to four months of life, infants can be expected to gain head control and the ability to pull to a sitting position (with help) with no head lags and enough strength in the upper torso to maintain an erect posture. Babies with Down syndrome may have low muscle tone, and a physical therapist can illustrate exercises that you can do with your baby to help him or her achieve this milestone.

Before birth and in the first months of life, physical development remains the underlying foundation for all future progress. Babies learn through interaction with their environment. In order to do so, an infant must have the ability to move freely and purposefully. The ability to explore his or her surroundings, to reach and grasp toys, to turn the head in order to follow a moving object with the eyes, to roll over and to crawl in pursuit of a desired object – all of these behaviors are dependent upon gross as well as fine motor development. These physical, interactive activities foster understanding and mastery of the environment, stimulating cognitive, language and social development.

Another long-term benefit of physical therapy is that it helps prevent compensatory movement patterns that individuals with Down syndrome are prone to developing. There can lead to orthopedic and functional problems if not corrected.

**Speech and language therapy** is a critical component of early intervention. Even though your baby may not say his or her first words until 2 or 3 years of age, there are many pre-speech and pre-language skills that must be acquired first. These include the ability to imitate and echo sounds; turn-taking skills (learned through games such as “peek-a-boo”); visual skills (looking at the speaker and objects); auditory skills (listening to music and speech for lengthening periods of time, or listening to speech sounds); tactile skills (learning about touch, exploring objects in the mouth); oral motor skills (using the tongue, moving lips); and cognitive skills (understanding object permanence, and cause and effect relationships).

A speech and language therapist can help with these and other skills, including breastfeeding. Because breastfeeding employs the same anatomical structures used for speech, it can help strengthen your baby’s jaw and facial muscles and lay the foundation for future communication skills.

**Occupational therapy** helps children develop and master skills for independence. When your child is an infant, the therapist can assist with oral-motor feeding problems or, in conjunction with a physical therapist, focus on developing your baby's fine motor skills.

Once your child is a toddler and has more independent mobility, occupational therapy can help with abilities such as opening and closing things, picking up and releasing toys of various sizes and shapes, stacking and building, manipulating knobs and buttons, experimenting with crayons, etc. Therapists also help children learn to feed and dress themselves, and teach skills for playing and interacting with other children.

Early intervention programs also offer many benefits to parents, including information, encouragement and support. Your therapist can teach you exercises and activities you can do at home with your baby to meet his or her specific needs and enhance development. He or she can also provide reassurance that your baby is on track developmentally. Furthermore, early intervention centers give parents the opportunity to share their concerns with other parents.

### How do I sign up for early intervention services?

Each state has its own set of laws governing early intervention services. You can get a referral from your baby's doctor, or you can find a local agency by visiting [www.nectac.org](http://www.nectac.org). Once a referral has been made, the program staff must schedule and complete an initial evaluation within a specified time. Once the assessment is done, a caseworker is assigned to coordinate the various services for which your baby and family qualify. Early intervention services are individualized to meet the specific needs of your baby. The caseworker, therapists and family members will determine the areas to focus on and set clear, measurable goals based on the developmental milestones. These will be recorded in a document called the Individualized Family Service Plan, or IFSP.

### Who pays for early intervention?

The evaluation to determine whether your child is eligible for free early intervention services is performed by a state authorized entity. No child deemed eligible can be denied services based on ability to pay, but insurance companies may be billed and/or a sliding scale payment may be required, depending on the state you reside in. Check with your state's early intervention center for information about authorized service providers and financial obligations. Frequently, there is little or no cost to parents for these services.

### What about the future?

IDEA, which regulates early intervention, also mandates that local school districts provide free preschool services for children with disabilities starting at the age of 3. Your service coordinator or a local parent group can help you access these services and, if necessary, advocate for your child's needs when the time comes.



"His eyes would light up when he got something right. You just fill up with love and accomplishment at a moment like that."



“You have to forget the timetable you reserve for your other kids. This child will succeed at his own pace.”

## Developmental Milestones

Milestone	Range for Children with Down Syndrome	Typical Range
<b>GROSS MOTOR</b>		
Sits Alone	6 -30 Months	5 -9 Months
Crawls	8 -22 Months	6 -12 Months
Stands	1 -3.25 Years	8 -17 Months
Walks Alone	1 -4 Years	9 -18 Months
<b>LANGUAGE</b>		
First Word	1 -4 Years	1 -3 Years
Two-Word Phrases	2 -7.5 Years	15 -32 Months
<b>PERSONAL/SOCIAL</b>		
Responsive Smile	1.5 -5 Months	1 -3 Months
Finger Feeds	10 -24 Months	7 -14 Months
Drinks From Cup Unassisted	12 -32 Months	9 -17 Months
Uses Spoon	13 -39 Months	12 -20 Months
Bowel Control	2 -7 Years	16 -42 Months
Dresses Self Unassisted	3.5 -8.5 Years	3.25 -5 Years

## Additional Resources

### BROCHURES

#### **Speech & Language Skills in Infants, Toddlers and Young Children with Down Syndrome.**

Kumin, L. (1995). New York, NY: National Down Syndrome Society.

Discusses speech and language development in infants, toddlers and young children with Down syndrome. Provides information on how you can help your child develop speech and language skills and how to locate a qualified speech-language pathologist.

Contact us at (800) 221-4602 or [info@ndss.org](mailto:info@ndss.org).

#### **Speech and Language Skills in Children and Adolescents with Down Syndrome.**

Kumin, L. (1995). New York, NY: National Down Syndrome Society.

Discusses speech and language characteristics of children and adolescents with Down syndrome. Provides information on how you can help your child's speech and how to locate a qualified speech-language pathologist.

Contact us at (800) 221-4602 or [info@ndss.org](mailto:info@ndss.org).

#### **Accessing Programs for Infants, Toddlers, and Preschoolers with Disabilities (ages 0-5).**

Ed. Lisa Küpper (1994). Washington, D.C.: National Dissemination Center for Children with Disabilities (Also known as NICHCY).

Provides more in-depth information on child evaluations for early intervention, the Individualized Family Service Plan (IFSP), and services for rural, Native American, adoptive/foster, and military families & their young children with disabilities.

Available for download at [www.nichcy.org/pubs/parent/pa2txt.htm](http://www.nichcy.org/pubs/parent/pa2txt.htm). To order by mail, contact NICHCY at (800) 695-0285 or [nichcy@aed.org](mailto:nichcy@aed.org)

### BOOKS

#### **Early Communication Skills for Children with Down Syndrome.** Kumin, L, Ph.D. (2003). Bethesda, MD: Woodbine House.

Explains the role of a speech-language pathologist, how certain characteristics of Down syndrome affect speech and language development, and the stages of communication development.

Available from Woodbine House at [www.woodbinehouse.com](http://www.woodbinehouse.com) or (800) 843-7323.

#### **Enhancing Children's Communication: Research Foundations for Intervention.**

Kaiser, A. & Gray, D.(Eds.) (1993). Baltimore, MD: Paul H. Brookes.

Discusses the practical and theoretical issues raised by pre-linguistic intervention, language intervention by parents, and teaching generalized communication skills to children with a range of abilities.

Available from Brookes Publishing at [www.brookespublishing.com](http://www.brookespublishing.com) or (800) 638-3775.

#### **Teaching Reading to Children With Down Syndrome: A Guide For Parents and Teachers.**

Oelwein, P. (1995). Bethesda, MD: Woodbine House.

Presents a step-by-step reading program specifically tailored to children with Down syndrome, with an emphasis on visual learning.

Available from Woodbine House at [www.woodbinehouse.com](http://www.woodbinehouse.com) or (800) 843-7323.

#### **The New Language of Toys: Teaching Communication Skills to Special-Needs Children.**

Schwartz, S. & Miller, J. (1996). Bethesda, MD: Woodbine House.

Presents a language learning program based on play, and explains how parents can stimulate their special-needs child's learning development through fun and educational exercises involving toys.

Available from Woodbine House at [www.woodbinehouse.com](http://www.woodbinehouse.com) or (800) 843-7323.

### VIDEOS

#### **Emma's Gifts.** Endless Horizon Productions.

This beautiful documentary follows one family's journey through the preschool years and illustrates the power of advocating for a child's rights and the importance of early intervention. Emma's parents share their stories to provide a very touching, realistic view of having a child with Down syndrome.

Available from Endless Horizon Productions at [www.endlesshorizonproductions.com](http://www.endlesshorizonproductions.com) or (704) 374-1778.

### ORGANIZATIONS

#### **Division for Early Childhood of the Council for Exceptional Children**

[www.dec-sped.org](http://www.dec-sped.org)  
27 Fort Missoula Road, Suite 2  
Missoula, MT 59804  
(406) 543-0872  
[dec@dec-sped.org](mailto:dec@dec-sped.org)

One of seventeen divisions of the Council for Exceptional Children, this organization supports policies and practices that support families and enhance development in children with disabilities and learning delays.

#### **Early Childhood Outcomes Center**

[www.the-ECO-center.org](http://www.the-ECO-center.org)  
[staff@the-ECO-center.org](mailto:staff@the-ECO-center.org)

Promotes the development of child and family outcome measures for young children with disabilities, and the implementation of these measures on a local, state, and national level.

#### **National Early Childhood Technical Assistance Center (NECTAC)**

Campus Box 8040, UNC-CH  
Chapel Hill, NC 27599-8040  
(919) 962-2001  
[www.nectac.org](http://www.nectac.org)  
[nectac@unc.edu](mailto:nectac@unc.edu)

Supports the national implementation of the Individuals with Disabilities Education Act (IDEA) by working with each state to improve outcomes for children and families of children with disabilities. Web site provides a list of early intervention programs by state.

### OTHER RESOURCES

#### **"Communicating Together,"**

Kumin, L. (Ed.). Newsletter.

Discusses speech and language issues in infants, toddlers, children, and adolescents with Down syndrome. Each issue includes a major topic article, questions and answers, home activities and reviews of current research articles. No longer published, but past issues are available on request by writing P.O. Box 6395, Columbia, MD 21045-6395 or calling (410) 995-0722.

#### **Education Resources Information Center (ERIC) Database**

[www.eric.ed.gov](http://www.eric.ed.gov)

Sponsored by the Institute of Education Sciences of the U.S. Department of Education, this is a free online database of journal and non-journal education literature.



# finding support

If you have recently learned that your baby has Down syndrome, you probably have a million questions, concerns and fears right now. That's okay. The most important thing to keep in mind is that the diagnosis is not as life-changing as the fact that you have a new baby. There will be challenges in raising your child, but there will also be many, many joys. This section discusses some of the sources you can turn to for support and reassurance at this time.

## Is what I'm feeling normal?

Learning that your baby has Down syndrome is not an easy thing for anyone to face, and right now, you may be experiencing a roller coaster of emotions. While everyone handles the diagnosis in their own way, certain reactions are common in new parents of a child with a disability.

For the majority of parents, the period immediately following the diagnosis is filled with uncertainty and doubt. For example, you might worry about how the condition will impact your child's life and whether or not you are equipped to handle all the responsibilities of raising a child with a disability. If your child has health complications, you may have additional fears and concerns. It is natural to experience denial, anger, depression and other stages of grief as you adjust to the news that your baby has Down syndrome. Even for parents who knew they were at a higher risk of having a child with Down syndrome, acceptance can be difficult or, at first, seem impossible.

Know that whatever you may be feeling is normal. More importantly, know that you are not alone. There are many sources of support available to new parents of children with Down syndrome. In time and with the right support, you can expect the intensity of painful emotions to subside, and new, positive feelings to take their place. One of the best places to turn to for encouragement and reassurance is other parents of children with Down syndrome. Often, other parents can help you look beyond your baby's diagnosis and delight in the joys of parenthood. They have been through what you are going through, and can be an invaluable source of support.



## The NDSS Goodwin Family Information and Referral Center

Contact us toll-free at (800) 221-4602 or by email at [info@ndss.org](mailto:info@ndss.org). We can provide information on Down syndrome, referrals to local parent support groups and other resources, and a wide variety of educational materials.

“We have become wonderful friends with other parents from our support group. Initially, it was just comforting to be with other people who were walking in our shoes and learning with us. We didn't have to explain our feelings or hide them.”

## How can I get in touch with other parents of children with Down syndrome?

One of the best ways to meet other parents is to get involved in a local Down syndrome parent support group. These groups can provide you with an excellent forum for sharing your feelings and concerns as a new parent, and an opportunity to learn from the experiences of others who have been in your shoes. Learning more about Down syndrome can also help ease some of your uncertainty, and support groups are a great place to start gaining knowledge. In addition to providing emotional support, other parents can recommend useful Down syndrome resources and organizations and help you understand the new terminology.

NDSS has a network of more than 200 affiliated parent support groups, and we can refer you to the group closest to your home. You can call or email our Information and Referral Center to get this information. In addition to having support group meetings, most of our affiliates offer a wide range of other programs and services for individuals with Down syndrome and their families, such as sibling workshops, expert-speaker presentations, early intervention programs, social activities, and events to raise public awareness. Support group membership can provide benefits to you and your family now and in the future, so we encourage you to contact your local group and explore this option.

If there is not a Down syndrome-specific support group in your area, your hospital or pediatrician may be able to provide contact information for other parents who have agreed to serve as a resource. There may also be a general support group for parents of children with disabilities that you can join. Alternately, you may consider starting your own support group to network with others. NDSS can provide you with information on how to get started.

## What are some other things I can do to take care of myself?

Right now, you are very focused on taking good care of your baby. But remember that it's also important to take good care of yourself at this time. Doing so will keep you feeling healthy, strong and well-equipped to deal with your responsibilities as a new parent. It can also help you develop and maintain a positive frame of mind, which is necessary for meeting new challenges successfully. Here are some tips many new parents have found helpful for reducing anxiety and stress:

***Be patient with yourself.*** The road to acceptance is a process, so give yourself time to deal with your emotional responses. Some days you might feel like you're taking steps backward, but recognize that this doesn't mean you aren't making progress. If you feel it would be helpful, do not hesitate to contact a therapist. A therapist can help you find ways to cope and develop confidence in your ability to handle challenges.

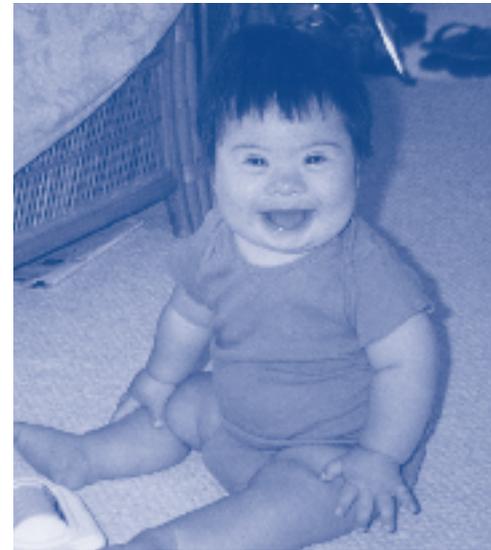
***Build a support system.*** It may be tempting to keep to yourself at this time, but doing so can result in feelings of isolation. Reach out to trusted friends or family members. This allows your loved ones to understand what you're going through and gives them a chance to offer comfort and support. You can always let them know how much help you need or desire, and if you want time alone, don't hesitate to say so.

***Schedule some alone time regularly,*** and use this time to "recharge." Read a book, take a warm bath, go for a walk, or just watch your favorite T.V. show. Do something you enjoy and find relaxing, and let yourself enjoy it. Alone time may sound like a luxury, but it is necessary for good health and can do wonders for your productivity and mood.

***Take care of your physical health.*** Research shows that a healthy eating and exercise plan can reduce fatigue, irritability, and risk for certain diseases and health complications. Develop a plan that works for you and make an effort to stick to it, especially during times of high stress. Be sure to get regular medical check-ups, too.

***Practice "living in the moment."*** While it is important to plan ahead, worrying about the future can easily lead to anxiety. Although it may be hard, try to focus only on what you can do realistically in the present. If you find yourself getting anxious about a particular situation, try this strategy: 1) Identify the problem. 2) Research your options. 3) Make a decision. 4) Set a date in the future to evaluate how your decision is working. In the meantime, just go with the decision you made and trust that it will work out.

***Don't lose sight of "the important things in life."*** Nurture your relationships with your partner, children, friends and family. Communicate with each other, laugh, do fun things together, celebrate traditions, and be sure to spend quality time with your new baby that doesn't focus on his or her disability. The fact that your baby has Down syndrome is life-changing. But it doesn't change the things that are truly important in life!



"My son has helped me to grow as an individual, be more aware of others, and see what is really important in life. He has taught me the beauty of unconditional love."



## A Wealth of Information Online

Visit the NDSS Web site [www.ndss.org](http://www.ndss.org) to get answers to commonly asked questions about Down syndrome, read in-depth articles, search our database of Down syndrome organizations and other resources, and much more!

To locate a parent support group near you, visit the “Resources” tab on the top of the homepage.

## A Parent’s Perspective on Having a Child With a Disability

### Welcome to Holland

by Emily Perl Kingsley

©1987 by Emily Perl Kingsley. All rights reserved.

I am often asked to describe the experience of raising a child with a disability – to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It’s like this...

When you’re going to have a baby, it’s like planning a fabulous vacation trip – to Italy. You buy a bunch of guidebooks and make wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It’s all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, “Welcome to Holland.”

“Holland!?” you say. “What do you mean Holland?? I signed up for Italy! I’m supposed to be in Italy. All my life I’ve dreamed of going to Italy.”

But there’s been a change in the flight plan. They’ve landed in Holland and there you must stay.

The important thing is they haven’t taken you to a horrible, disgusting, filthy place full of pestilence, famine and disease. It’s just a different place.

So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you never would have met.

It’s just a different place. It’s slower-paced than Italy, less flashy than Italy. But after you’ve been there for a while and you catch your breath, you look around...and you begin to notice Holland has windmills...and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy...and they’re all bragging about what a wonderful time they had there. And for the rest of your life, you will say, “Yes, that’s where I was supposed to go. That’s what I had planned.”

And the pain of that will never, ever, ever, ever go away...because the loss of that dream is a very, very significant loss.

But...if you spend your life mourning the fact that you didn’t get to go to Italy, you may never be free to enjoy the very special, the very lovely things...about Holland.

## Additional Resources

### BOOKS

***A Special Kind of Hero: Chris Burke's Own Story.*** Burke, C., & McDaniel, J. B. (2001). Lincoln, NE: iUniverse.

This is the story of Chris Burke and his family; how their love and support helped him to achieve the seemingly impossible goal of a career in show business; and his tireless work to help other people with special needs.

Available from iUniverse at [www.iuniverse.com](http://www.iuniverse.com) or (877) 288-4737.

***Common Threads: Celebrating Life with Down Syndrome.*** Kidder, C. S., Skotko, B., and Dew, K. (2001). Rochester Hills, MI: Band of Angels Press.

Through the common thread of belief that runs throughout the various stories and pictures, Band of Angels demonstrates how the similarities outweigh the differences between children with Down syndrome and their peers.

Available from Band of Angels Press at [www.bandofangels.com](http://www.bandofangels.com) or (800) 963-2237.

***Count Us In: Growing Up with Down Syndrome.*** Kingsley, J. & Levitz, M. (1994). New York: Harcourt Brace & Company.

Two men give their personal accounts of life with Down syndrome. Topics discussed include friendship, school, and independence.

Available from Harcourt Brace & Company at [www.harcourtbooks.com](http://www.harcourtbooks.com) or (212) 592-1000.

***Expecting Adam: A True Story of Birth, Rebirth, and Everyday Magic.*** Beck, Martha (1999). New York, NY: Berkeley Books.

A busy couple learns that the child they will have has Down syndrome and grapple with the question of whether or not to have the baby. This struggle challenges the couple's ideas about what is truly important.

Available from Penguin Group USA at [www.penguinputnam.com](http://www.penguinputnam.com) or (800) 788-6262.

***Family Makers: Joyful Lives With Down Syndrome.*** MacDonell Mandema, J. (2002). Menlo Park, CA: The Mandema Family Foundation.

Through its beautiful pictures and inspirational stories, this book helps anyone understand the joys and hardships of raising a child with Down syndrome.

Available from Kepler's Books at [www.keplers.com](http://www.keplers.com) or (650) 324-4321.

***Uncommon Fathers: Reflections on Raising a Child with a Disability.*** Meyer, D.J. (Ed.) (1995). Rockville, MD: Woodbine House.

This book, written by fathers for fathers, gives the rare view of being the father to a child with developmental disabilities.

Available from Woodbine House at [www.woodbinehouse.com](http://www.woodbinehouse.com) or (800) 843-7323.

### VIDEOS

***Down Syndrome: A Parental Perspective.*** Dartmouth-Hitchcock Medical Center.

This video features the opinions and views of parents in a support group.

Available from Learner Managed Designs, Inc., P.O. Box 747, Lawrence, KS 66044; (800) 467-1644.

# caring for your family

It's natural for new parents of a child with Down syndrome to wonder how this new person will impact family members and relationships. You might be asking yourself: How will having a brother or sister with Down syndrome affect my other children? Will having a child with a disability alter my relationship with my partner? How will my relationships with friends and relatives change? While each family's situation is unique, it may be helpful and encouraging to know that both personal accounts and research studies provide solid evidence that families of children with Down syndrome can be stable, successful and happy. This section provides information on things you can do to meet the needs of your entire family.

## **How will having a baby with Down syndrome affect my family?**

One of the best ways to find an answer to this question is by speaking to family members of individuals with Down syndrome. In addition, there are many books and articles written by family members about their personal experiences. These accounts can offer a great deal of comfort and reassurance because, as you hear or read other people's stories, you will find that there is a consistent theme throughout the varied experiences. A message you'll encounter time and time again is that the positive impacts of having a family member with Down syndrome far outweigh any difficulties or challenges that may come up. The majority of families share that they are stronger and closer as a result of the experience of dealing with a disability, and that they are more focused on the things that really matter in life.

There have also been many research studies that explore how having a child with Down syndrome affects families. These have shown that while these families do experience additional challenges, their levels of well-being are comparable to those of families who do not have a child with Down syndrome. Researchers say that what seems to determine if families are resilient and able to thrive is their ability to access individual, family and community resources. By contacting NDSS, you have taken an important first step in ensuring that your family has the support it needs to adapt successfully and stay strong. Be sure to also take advantage of all the resources available in your local community, and focus on building a support network to get you and your family through any tough times.



“We were both afraid of how our new baby would affect our family. As it turns out, she is the light of our lives.”

“My sister has taught me more about life and how to live it than anybody. She motivates me because I know how hard she works.”

### How will having a sibling with Down syndrome affect my other children?

While having a sibling with Down syndrome may present unique challenges, it also provides many opportunities for children’s positive growth and character development. Studies have shown that children who have a brother or sister with Down syndrome can benefit in many ways. For example, these children often exhibit a level of maturity above that of their peers and tend to have more highly-developed communication and social skills. The experience and knowledge gained by having a sibling with Down syndrome also seems to make children more accepting and appreciative of differences. They tend to be more aware of the difficulties that others might be going through, and often surprise parents, teachers and others with their wisdom, insight and empathy.

Brothers and sisters of individuals with Down syndrome are also very much aware of their sibling’s challenges and thus, often take a tremendous amount of pride in his or her accomplishments. In addition, parents often report that, no matter what issues siblings may have with their brother or sister with Down syndrome at home, outside the home they are typically very loyal to their sibling and do their best to defend and protect them.

### How do I explain Down syndrome to my other children?

When telling your children that their new little brother or sister has Down syndrome, tailor your explanation to their age and ability to comprehend. An older child might be able to understand the genetics of Down syndrome, while a younger sibling might need a simpler explanation. Encourage your children to ask questions about whatever they don't understand and be sure to emphasize that the new baby will be able to do all the same things other babies do. Most children are able to grasp that a baby with Down syndrome may learn a little more slowly and need extra care, and they often take special pride in helping their new sibling.

Remember that your children will take their cue from you. If you are able to communicate excitement about their new sibling, they will be excited, too. Try to keep up family routines and traditions, and don't curb family activities out in the community any more than is necessary. This will help your other children come to terms with their sibling's condition while giving your new baby many new varied experiences. Brothers and sisters are often the first to realize that their new sibling is more like other kids than different, with his or her own unique personality, and that like all members of the family, he or she will have strengths, challenges and much to contribute.



## What are some tips for taking care of my other children's needs?

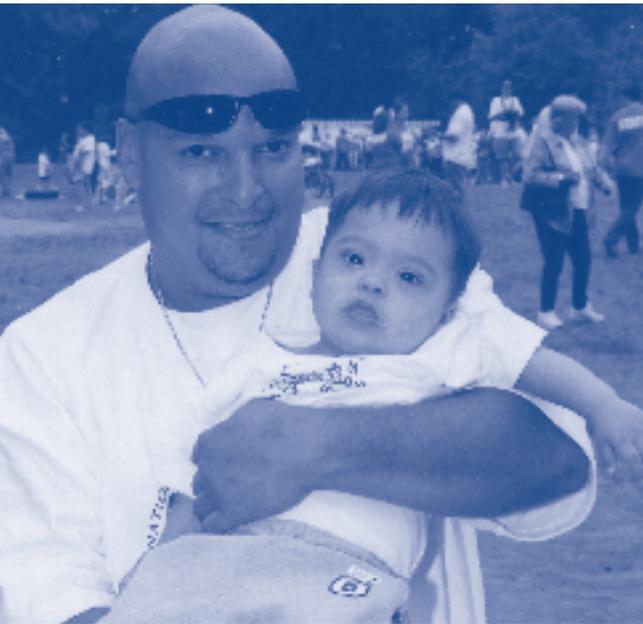
As discussed, your children may be doing an excellent job of helping with their brother or sister, but you want to make sure you are doing all you can to meet their needs as well. Here are some tips for caring for siblings:

- Be sure to acknowledge all emotions, not just the positive ones. If your children know that it is okay to express any feelings they may be having about their sibling with Down syndrome, negative emotions are less likely to turn up in other ways, such as behavior problems.
- While it can be beneficial for your other children to feel they can play an important role in caring for their sibling with Down syndrome, don't give them too many responsibilities in this area.
- Although your responsibilities may pull you in many different directions, pay attention to your children and any changes in their moods. If you notice symptoms of anxiety or depression, get your child the help he or she needs as early as possible.
- Make an effort to spend time with each of your children on a regular basis. Each child is unique, so don't worry about dividing your time equally. Instead, focus on what's important to an individual child, and dedicate time to those things that would make him or her feel loved and special. Remind your children that all members of your family are special in their own way.

## How can I keep my relationship with my partner strong?

There are many things you can do to keep your relationship strong amidst the added stresses that may come when raising a child with a disability. Two key strategies often mentioned by parents are maintaining good communication and spending time alone together. So take a few minutes every day to talk with your partner. Plan a regular "date night." Or, take a vacation together. Even if you can't get away as often as you might like make an effort to keep your romance alive. Don't let anniversaries or other special occasions go uncelebrated, and do little things to show your partner that you care and appreciate all of his or her hard work. A loving relationship is one of the best sources of strength and support for dealing with any challenges that come your way.

"I actually think having a child with Down syndrome has strengthened our relationship. We are in this together."



“Other relatives see my son as a person. They accept and encourage him in the same way that they would other family members.”

### How do I share the diagnosis with other family members and friends?

New parents sometimes worry about telling friends and family members about their baby’s condition. However, it is recommended that you do it as early as possible. Parents report that the longer you wait, the harder it gets. Not only will waiting add to the stress that you may already be dealing with, but you will likely miss out on the comfort and support your loved ones might be able to provide during this time. Keep in mind, too, that others will follow your lead. Family and friends will usually want to support you, and if you are able to focus on positive aspects of caring for your new baby, they will likely want to share in your joy! You should also consider offering friends and family members information about the developmental aspects of Down syndrome so that they, too, can share in celebrating your baby’s accomplishments.

If someone does not react in the way you would hope, remember that he or she may have personal reasons for doing so that have nothing to do with you or your baby. The person may be uncomfortable because they don’t have accurate information about Down syndrome, or have never met someone with the condition. It is also a possibility that they may also be dealing with their own grief or pain. Grandparents, for example, may be dealing not only with the news that their grandchild has a disability, but also with the knowledge that their child is in pain. Just as new parents often go through the stages of grief, grandparents may also go through shock, denial and other emotions before they are able to accept the news. It is important to let them deal with their emotions at their own pace so they, too, can heal and begin to find joy in helping to raise their grandchild. Support group membership is usually open to grandparents and other relatives, so you might consider letting them know that it’s an option available to them.

Don’t be afraid of sharing your emotions with your trusted friends and family members. Often, these people are eager to provide emotional support or other assistance. If you share your feelings honestly and openly, you create opportunities for them to do so. Remember that whenever you do turn to others for assistance, it’s a good idea to be specific about how much help you want or need, and what your needs are.

## Additional Resources

### BOOKS

***Living With a Brother or Sister with Special Needs: A Book for Sibs.*** Meyer, Donald J. and Patricia Vadasy (1996). University of Washington Press.

A resource for young readers with special needs siblings.

Available from University of Washington Press at [www.washington.edu/uwpress](http://www.washington.edu/uwpress) or (800) 441-4115.

***Oh Brother! Growing up with a Special Needs Sibling.*** Hale, Natalie (2004). Illustrated by Kate Sternberg.

With humor and honesty, Becca learns to deal with the challenges of living with Jonathan, her special needs brother.

Available from Magination Press at [www.maginationpress.com](http://www.maginationpress.com) or (800) 374-2721.

***Our Brother Has Down's Syndrome: An Introduction for Children.*** Cairo, S. (1985). Ontario: Firefly Books, Ltd.

Through the personal account of Jai, as told by his two sisters, this book explains Down syndrome to young children.

Available from Firefly Books at [www.fireflybooks.com](http://www.fireflybooks.com) or (800) 387-5085.

***The Sibling Slam Book: What It's Really Like To Have A Brother or Sister with Special Needs.*** Ed. Meyer, Donald J. (2005). Bethesda, MD: Woodbine House.

A candid, complex collection of responses from teenagers who have grown up with a special needs sibling.

Available from Woodbine House at [www.woodbinehouse.com](http://www.woodbinehouse.com) or (800) 843-7323.

***Views from Our Shoes: Growing up with a Brother or Sister with Special Needs.*** Ed. Meyer, Donald J. (1997). Bethesda, MD: Woodbine House.

In 45 essays, siblings ranging in age from 4 to 18 share their observations and experiences growing up with a brother or sister with a disability. Honest and heart-felt, their essays will be meaningful to other kids who have a sibling with special needs. A glossary of disabilities provides easy-to-understand definitions of many of the conditions mentioned.

Available from Woodbine House at [www.woodbinehouse.com](http://www.woodbinehouse.com) or (800) 843-7323.

***We'll Paint the Octopus Red.*** Stuve-Bodeen, Stephanie (1998). Bethesda, MD: Woodbine House.

Six-year-old Emma has big dreams for her new baby brother, but when she learns that he has Down syndrome, she worries that he won't be able to do many of the fun things she's imagined. A reassuring story for young children bewildered by Down syndrome and what it means for their relationship with their sibling, it concludes with a set of questions and answers about Down syndrome commonly asked by children.

Available from Woodbine House at [www.woodbinehouse.com](http://www.woodbinehouse.com) or (800) 843-7323.

### ORGANIZATIONS

**National Dissemination Center for Children with Disabilities**

P.O. Box 1492  
Washington, DC 20013  
(800) 695-0285  
[www.nichcy.org](http://www.nichcy.org)  
[nichcy@aed.org](mailto:nichcy@aed.org)

Also known as NICHCY, this organization serves the nation as a central source of information on disabilities in infants, toddlers, children, and youth. NICHCY offers the a wide range of publications dealing with finding support, including Accessing Parent Groups, Parent to Parent Support, Parent Training and Information Centers, Parenting a Child with Special Needs, A Guide to Children's Literature and Disability and Children with Disabilities: Understanding Sibling Issues. Publications can be downloaded on the Web site or ordered by contacting NICHCY at the phone or email above.

**Sibling Support Project of the Arc of the United States**

6512 23rd Ave NW, #213  
Seattle, WA 98117  
(206) 297-6368  
[www.thearc.org/siblingsupport](http://www.thearc.org/siblingsupport)  
[donmeyer@siblingsupport.org](mailto:donmeyer@siblingsupport.org)

The Sibling Support Project, believing that disabilities, illness, and mental health issues affect the lives of all family members, seeks to increase the peer support and information opportunities for brothers and sisters of people with special needs and to increase parents' and providers' understanding of sibling issues.

The project's mission is accomplished by training local service providers on how to create community-based peer support programs for young siblings; hosting workshops, listservs, and Web site for young and adult siblings; and increasing parents' and providers' awareness of siblings' unique, life-long, and ever changing concerns through workshops, Web sites and written materials.



WC  
CAVIS

Ken

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# a promising future

Your child has been born, or is about to be delivered, into a world that offers more opportunities than ever before for people with Down syndrome to reach their full potential. Every day, we are expanding our knowledge about how individuals with Down syndrome learn and the best ways to support their development. Scientific research is constantly yielding new information about the causes of Down syndrome and associated conditions. Also, NDSS and many local and national advocacy organizations are working tirelessly to promote legislation that advances the rights of individuals with disabilities. All these efforts have opened up many doors for people with Down syndrome to pursue their dreams. This section discusses looking ahead to the future.

## **What does the future hold for people with Down syndrome?**

There is still much progress to be made, but with the positive developments we've seen in recent years, you have every reason to be optimistic about your baby's future. For example, today the majority of children with Down syndrome are included in regular education classrooms alongside their peers, and research has shown that this inclusion has positive effects on both the academic and social experiences of students with and without disabilities.

Many individuals with Down syndrome are also graduating from high school and going on to college. The Individuals with Disabilities Education Act requires that your child have a plan in place to ensure a successful transition to life after high school, and many new postsecondary programs especially for people with disabilities are available. In addition, we are seeing an increase in the amount of meaningful, satisfying employment opportunities available to people with Down syndrome and more options for independent living. Many people with Down syndrome are employed, live on their own and some even get married.

The fact that these options are available today gives us reason to believe that for the next generation of people with Down syndrome – including your child – the future is even brighter.



“The greatest words of encouragement that I have received and lived by in raising my son are: ‘Do not let yourself be a barrier to him. You need to have the courage to allow him to try.’ Whenever I’m afraid for him, I remember this.”

### How can I give my baby the best chance at a promising future?

No one can tell you your child’s potential, but there are many things you can do to give your child the best chance at a successful and happy life. First and foremost, your child will need lots of love, affection and support for healthy development. Just like all kids, children with Down syndrome will have their own unique talents and abilities, and it is important to recognize and celebrate those accomplishments. During the first few years of life, your child will likely receive many early intervention services, including physical, speech and language, and occupational therapy. Still, instead of emphasizing what your child can’t do, focus on what he or she *can* do! We are used to doing this with typically-developing children, and it should be no different for kids with disabilities.

Of course, babies and children with Down syndrome will have certain developmental challenges that will need special attention. In addition to providing your baby with varied experiences and constant opportunities for growing and learning, you’ll also want to learn as much as you can about Down syndrome. There are many successful strategies for addressing specific challenges, but often, it’s up to parents to track them down. Fortunately, there are many organizations and resources available to you that can provide information on specific topics.

Lastly, although your child with Down syndrome may need more attention from time to time, do your best to treat him or her the same as your other children and have similar expectations. Inclusion starts in the family. By going out into the community and enjoying all the same activities that other families enjoy, you will be teaching your child that he or she has the same right as everyone else to live a full and active life. You will also be showing others that people with Down syndrome are more like the rest of us than they are different.

As a parent, you are a natural advocate for your child. You will probably come across many people who do not know very much about Down syndrome, and you’ll be able to share information with them about your child’s abilities and the potential of people born with this condition. As you become more comfortable in your role, you may find that you want to advocate for people with Down syndrome in more formal ways, and there are many opportunities to get involved!

## Resources

### BOOKS

*Believe in My Child with Special Needs. Helping Children Achieve Their Potential in School.*

Falvey, M. (2005). Baltimore, MD: Brookes Publishing.

First and foremost a book about celebrating abilities, this book arms parents with an invaluable perspective with which to approach their child's education and tips and tools for collaborating with education professionals.

Available from Brookes Publishing at [www.brookespublishing.com](http://www.brookespublishing.com) or (800) 638-3775.

### WEB SITES

**The National Policy Center at NDSS.org**

<http://www.ndss.org> Click on "National Policy Center" on the left directory.

This section of the NDSS Web site provides the latest information about legislation that impacts individuals with Down syndrome and their families, and provide tips and tools for getting involved in advocacy.

**Wrightslaw**

[www.wrightslaw.com](http://www.wrightslaw.com)

Web site provides accurate, up-to-date information about special education law and advocacy for children with disabilities.



A Promising Future Together

# how ndss can help

The mission of the National Down Syndrome Society is to benefit people with Down syndrome and their families through national leadership in education, research and advocacy. We accomplish our mission by developing and disseminating quality educational materials and programs; initiating and advancing basic, clinical and applied research; shaping and advocating for improved public policy, increased public resources and services for people with Down syndrome; and working in partnership with our affiliates and other support organizations. Some of our current programs and services are listed below.

## Education

- Books on Down Syndrome
- *Changing Lives* Program for Health Care Professionals
- Clinical Care Brochure Series
- Club NDSS Web site
- Educational Materials and Videos
- *Everyone Counts: Teaching Acceptance and Inclusion* Curriculum for Grades K-6
- Goodwin Family Information and Referral Center
- *Joshua O'Neill and Zesban Tabani Enrichment Fund*
- NDSS.org Web Site
- Model Postsecondary Education Programs
- NDSS Electronic Newsletter



## Research

- Charles J. Epstein Down Syndrome Research Award
- Down Syndrome Research Coalition
- International Research Conferences
- Scientific Symposia and Published Proceedings

## Advocacy

- Advocacy Training for Individuals with Down Syndrome, Parents and Professionals
- Buddy Walk Program and Web site
- Governmental Affairs Committees
- Grassroots Advocacy Initiatives
- Media and Public Relations
- Online Advocacy Center and E-mail Alerts
- National Policy Center

**With these and many other programs and services,  
NDSS is here for you and your family now and in the future!**

# Down Syndrome Health Care Guidelines

*Based on 1999 Down Syndrome Health Care Guidelines\*7*

## Neonatal (Birth-1 Month)

- Review parental concerns. Chromosomal karyotype; genetic counseling, if necessary.
- If vomiting or absence of stools, check for gastrointestinal tract blockage (duodenal web or atresia or Hirschsprung disease).
- Evaluation by a pediatric cardiologist including echocardiogram. Subacute bacterial endocarditis prophylaxis (SBE), in susceptible children with cardiac disease.
- Exam for plethora, thrombocytopenia.
- Review feeding history to ensure adequate caloric intake.
- Thyroid function test – check on results of state-mandated screening at birth.
- Auditory brainstem response (ABR) or otoacoustic emission (OAE) test to assess congenital sensorineural hearing (at birth or 3 months).
- Pediatric ophthalmological evaluation (by 6 months) for screening purposes.
- Discuss value of early intervention (infant stimulation) and refer for enrollment in local program.
- Referral to local Down syndrome parent group or family support and resources, as indicated. Referral to NDSS.

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# Down Syndrome Health Care Guidelines

Based on 1999 Down Syndrome Health Care Guidelines\*

## Infant (1-12 Months)

- General neurological, neuromotor and musculoskeletal examination.
- TSH and T4-Thyroid Function Test (6 and 12 months).
- Evaluation by pediatric cardiologist including echocardiogram (if not done at birth). Consider progressive pulmonary hypertension if VSD or atrioventricular septal defect and little or no symptoms of heart failure.
- Subacute bacterial endocarditis prophylaxis (SBE) (as indicated).
- Well child care: immunizations.
- Feeding consult, especially if constipated. Consider Hirschsprung disease.
- Auditory brainstem response (ABR) or otoacoustic emission (OAE) test to assess congenital sensorineural hearing (by 3 months if not already or if suspicious).
- Ear, nose and throat exam (as needed), especially if suspicious of otitis media.
- Well-balanced, high-fiber diet.
- Vision exam (by 6 months and annually; earlier if nystagmus, strabismus or indications of poor vision).
- Discuss early intervention and refer for enrollment in local program.
- Application for supplemental Security Income (SSI), depending on family income.
- Consider estate planning and custody arrangements; continue family support.

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# Down Syndrome Health Care Guidelines

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## Childhood (1-12 Years)

- TSH and T4-Thyroid Function Test (annual).
- Echocardiogram by a pediatric cardiologist if not done previously.
- Behavioral Auditory Testing (every 6 months to age 3, then annually).
- Lateral cervical spine x-rays (neutral view, flexion, extension) to rule out atlanto-axial instability. Radiologist to measure atlanto-dens distance and neural canal width (at 3-5 years, then as needed).
- Pediatric and neurological exam with evaluation for spinal cord compression: deep tendon reflexes, gait, Babinski sign.
- Use Down Syndrome Growth Charts and head circumference charts with others.
- Eye examination (annually, or as indicated).
- Screen for celiac disease, IgA antiendomysium antibodies and total IgA (between 2 and 3 years).
- Question about obstructive sleep apnea; ENT exam (as needed).
- Dental exam (2 years; follow up exams every 6 months after). Twice daily brushing.
- Reinforce need for subacute bacterial endocarditis prophylaxis (SBE) for cardiac problems (as indicated).
- Brief vulvar exam for girls.
- Well child care: immunizations; pneumococcal vaccine (2 years).
- Evaluation by speech/language pathologist.

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## Down Syndrome Health Care Guidelines

Based on 1999 Down Syndrome Health Care Guidelines\*

### Adolescence (12-18 Years)

- TSH and T4-Thyroid Function Test (annual).
- Auditory testing (annually).
- Monitor for obstructive airway; sleep apnea.
- General physical and neurological exam; check for atlanto-axial dislocation. Cervical spine x-ray (as needed for sports).
- Eye examination (annually).
- Monitor for obesity by plotting height for weight on growth charts for typical children.
- Clinical evaluation of the heart to rule out mitral/aortic valve problems. ECHO-Echocardiogram (as indicated by findings).
- Reinforce need for subacute bacterial endocarditis prophylaxis (SBE) in susceptible adolescents.
- Adolescent medicine consult for puberty/sexuality issues; health, abuse prevention, and sexuality education. Pelvic exam (only if sexually active).
- Low-calorie, high fiber diet; regular exercise.
- Smoking, drug and alcohol education.
- Begin functional transition planning (16 years). Monitor independent functioning.

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## Down Syndrome Health Care Guidelines

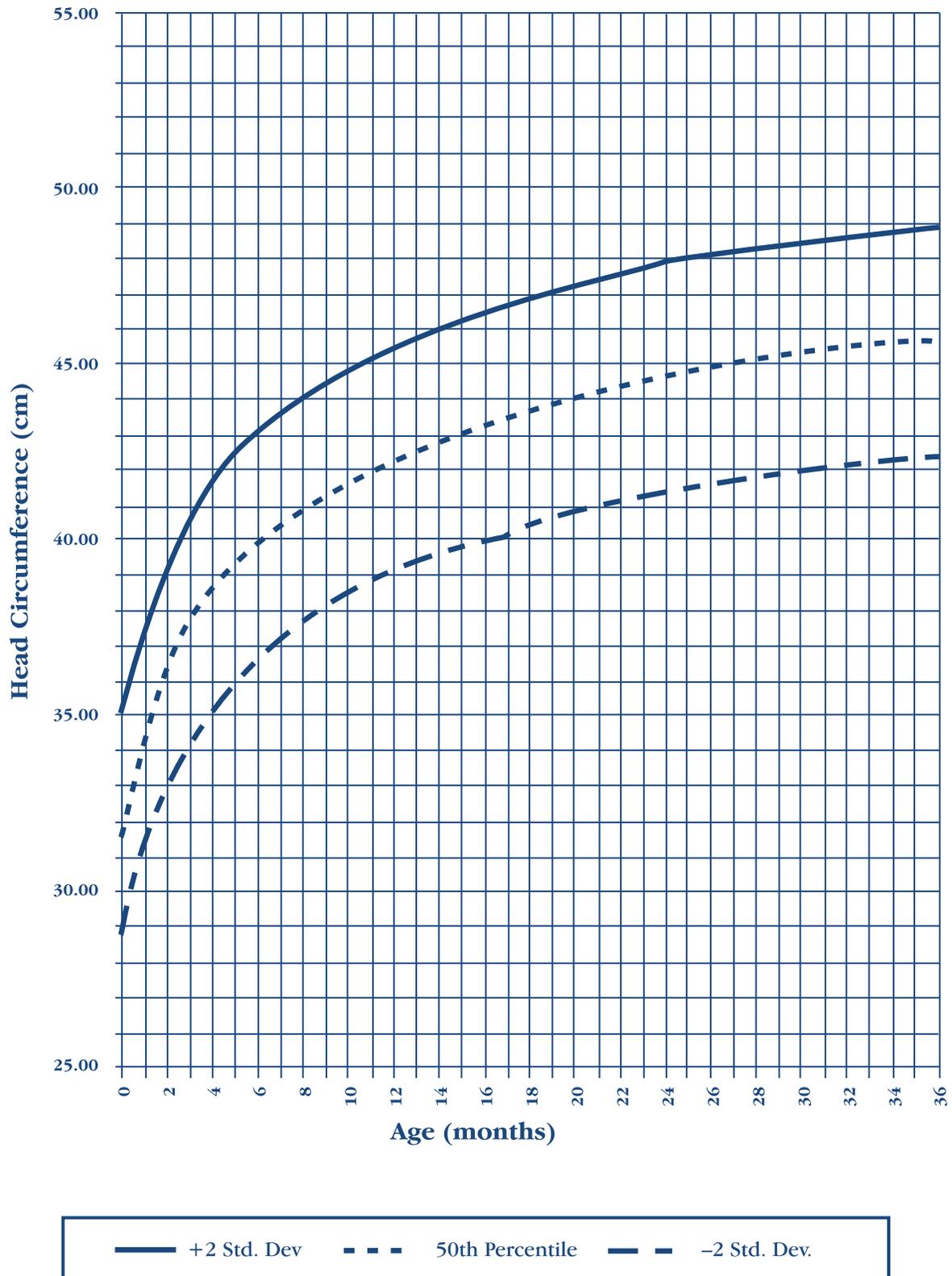
Based on 1999 Down Syndrome Health Care Guidelines\*

### Adulthood (More than 18 Years)

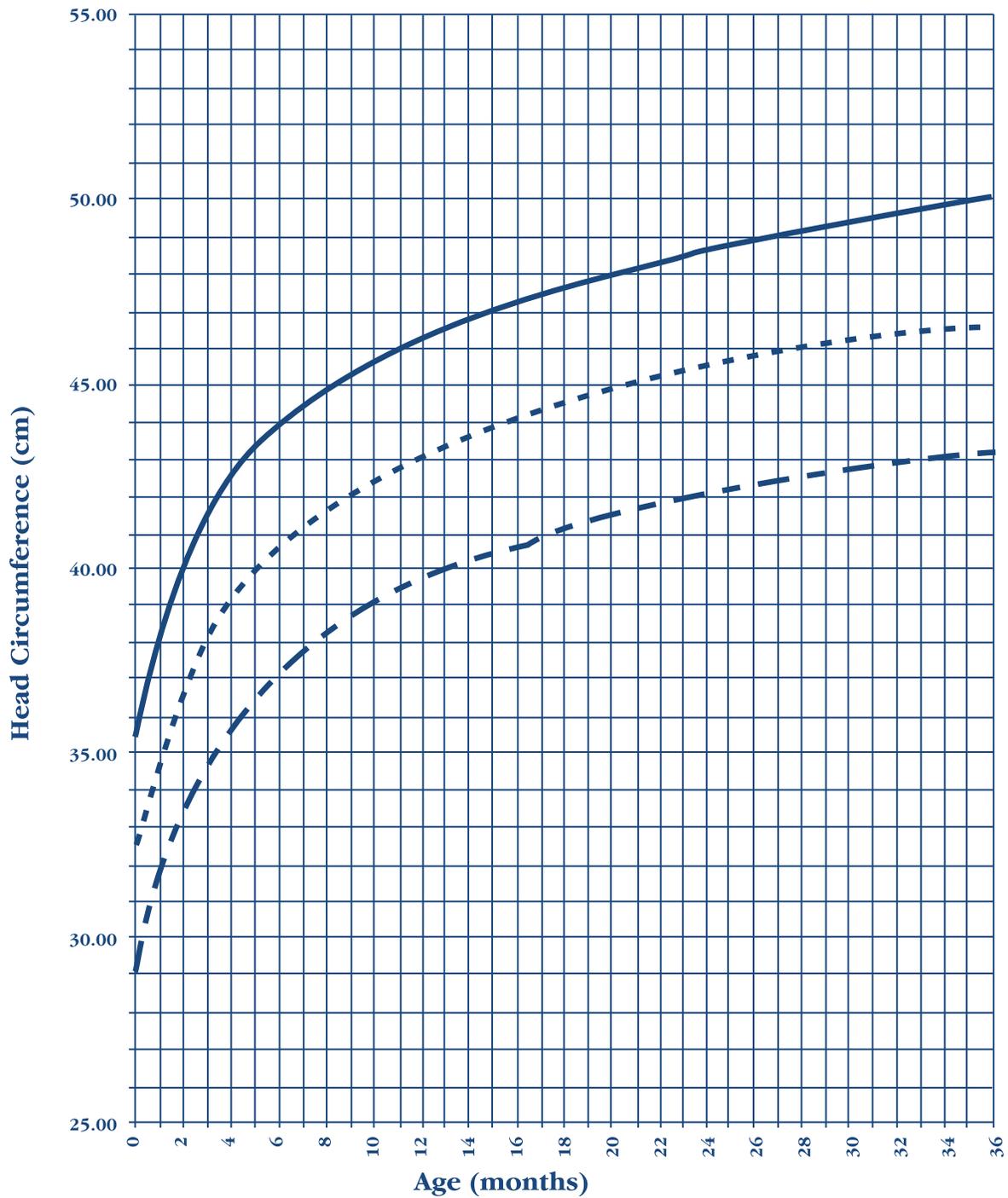
- TSH and T4-Thyroid Function Test (annual).
- Auditory testing (every 2 years).
- Cervical spine x-rays (as needed for sports); check for atlanto-axial dislocation.
- Ophthalmologic exam, looking especially for keratoconus and cataracts (every 2 years).
- Clinical evaluation of the heart to rule out mitral/aortic valve problems. Echocardiogram-ECHO (as indicated).
- Reinforce the need for subacute bacterial endocarditis prophylaxis (SBE) in susceptible adults with cardiac disease.
- Baseline mammography (40 years; follow up every other year until 50, then annual).
- Pap smear and pelvic exam (every 1-3 years after first intercourse). If not sexually active, single-finger bimanual exam with finger-directed cytology exam. If unable to perform, screen pelvic ultrasound (every 2-3 years). Breast exam (annually).
- General physical/neurological exam. Routine adult care.
- Clinical evaluation for sleep apnea.
- Low calorie, high-fiber diet. Regular exercise. Monitor for obesity.
- Health, abuse-prevention, and sexuality education. Smoking, drug and alcohol education.
- Clinical evaluation of functional abilities (consider accelerated aging); monitor loss of independent-living skills.
- Neurological referral for early symptoms of dementia: decline in function, memory loss, ataxia, seizures and incontinence of urine and/or stool.
- Monitor for behavior/emotional/mental health. Psych referral (as needed).
- Continue speech and language therapy (as indicated).

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# Head Circumference for Girls with Down Syndrome (0-3 years)

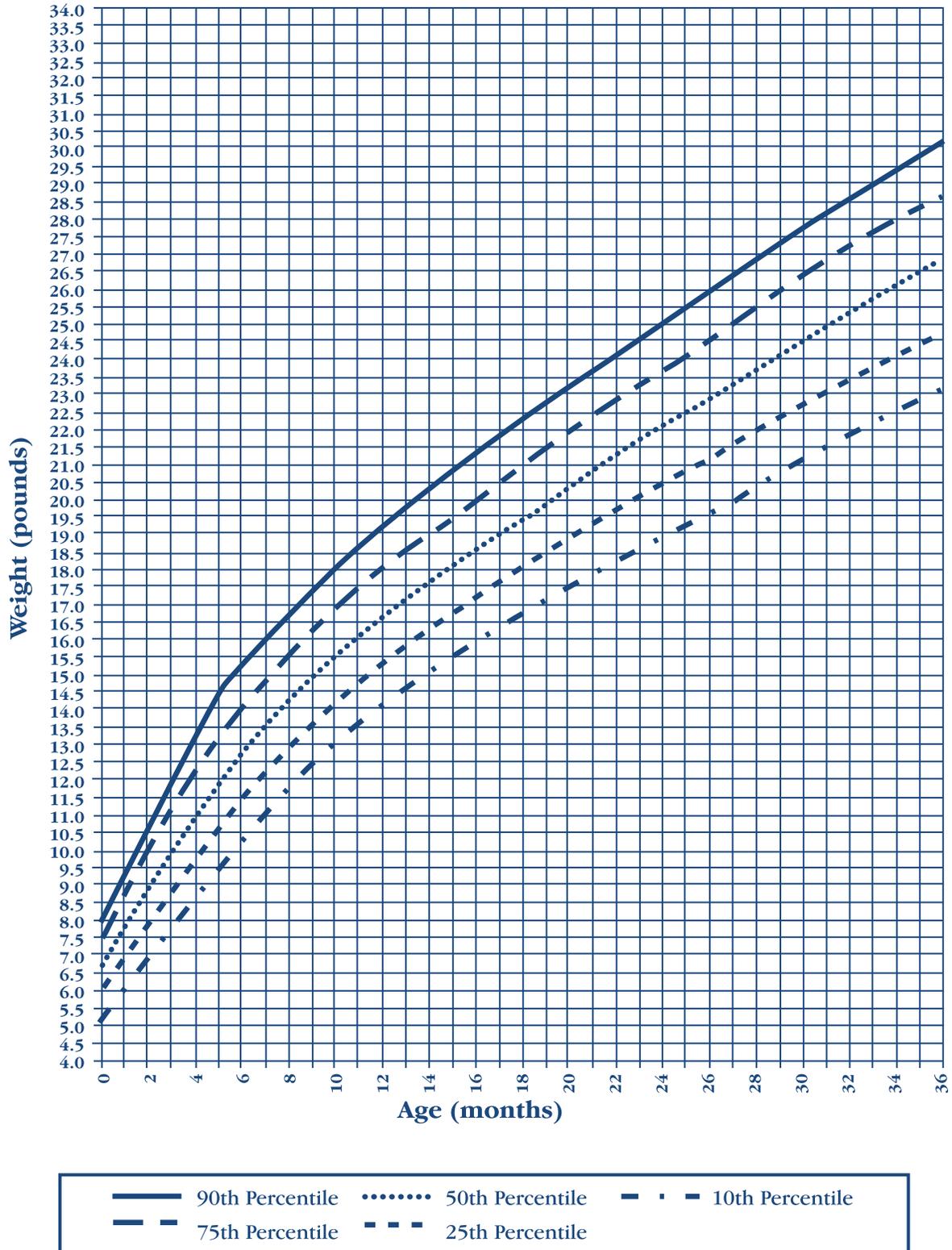


## Head Circumference for Boys with Down Syndrome (0-3 years)



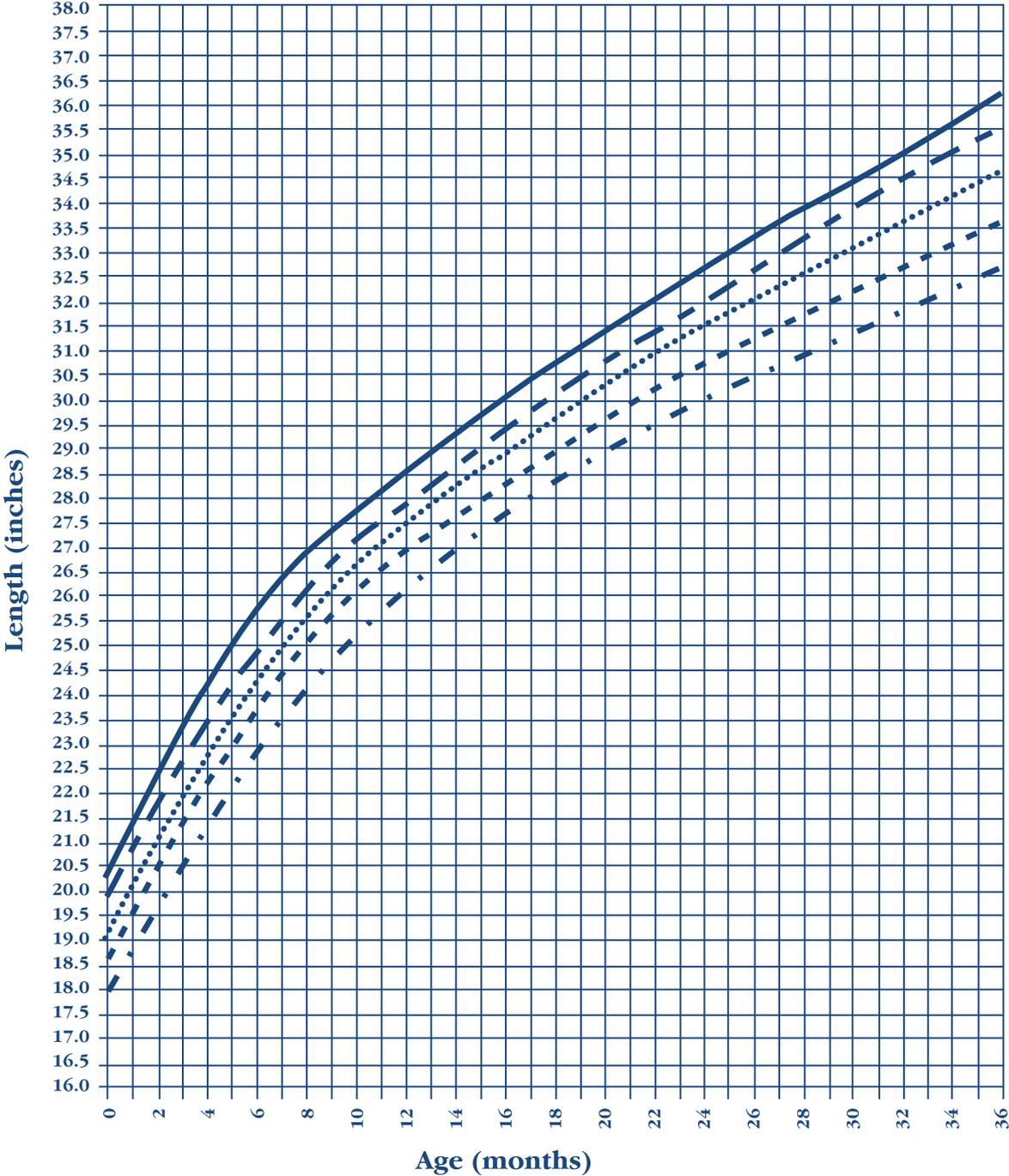
# Growth Chart for Girls with Down Syndrome (0-3 years)

## WEIGHT



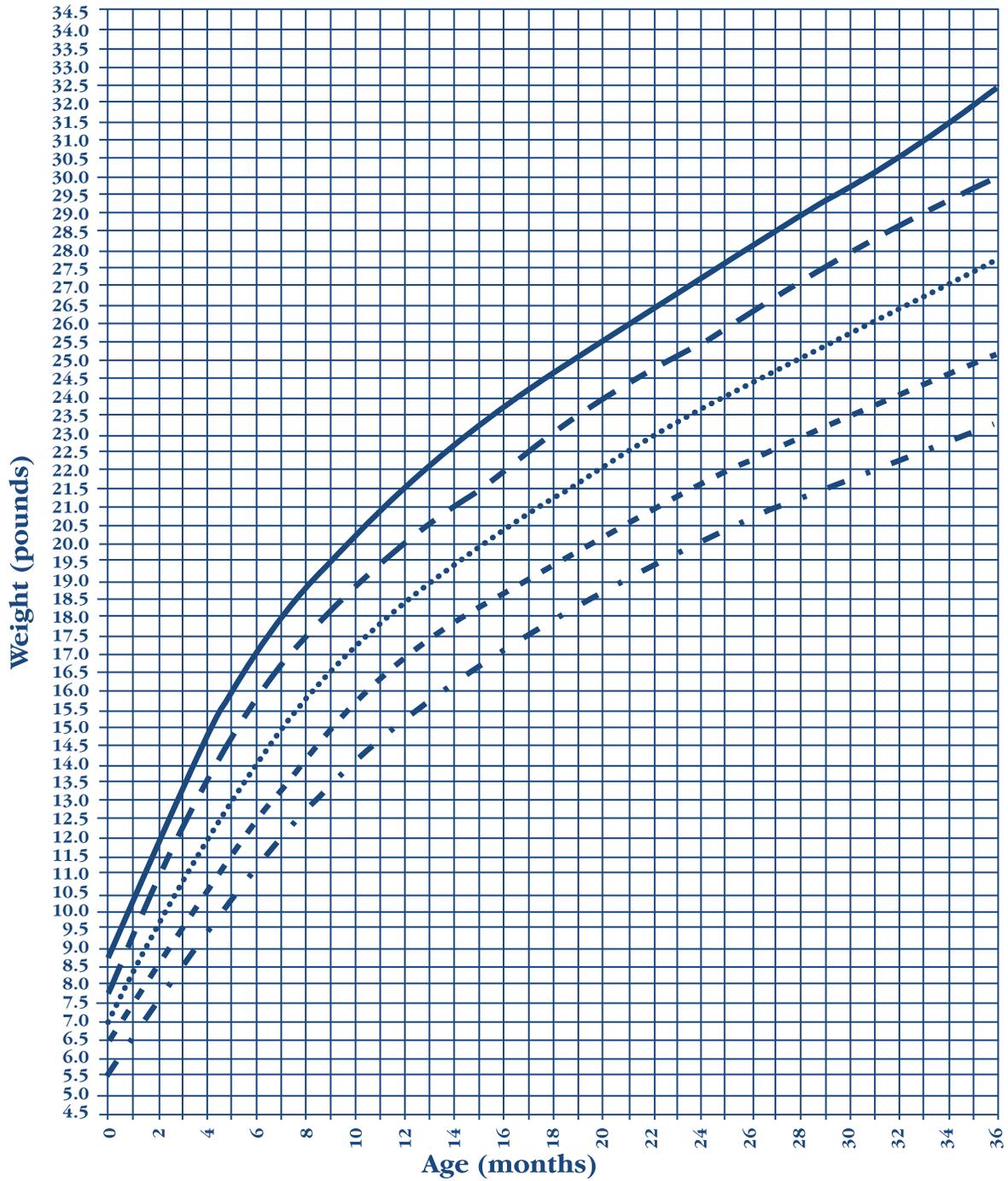
# Growth Chart for Girls with Down Syndrome (0-3 years)

## LENGTH



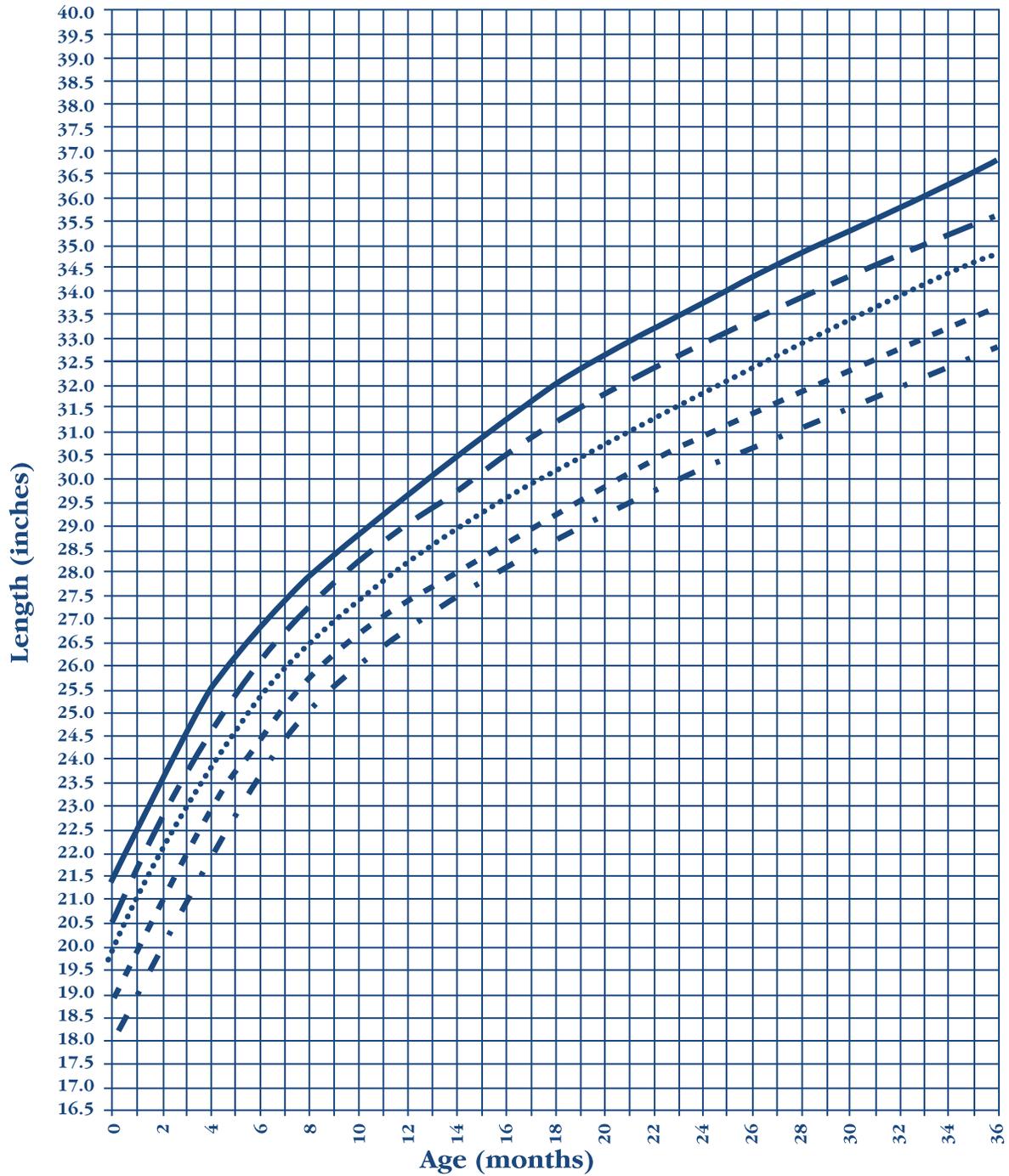
# Growth Chart for Boys with Down Syndrome (0-3 years)

## WEIGHT



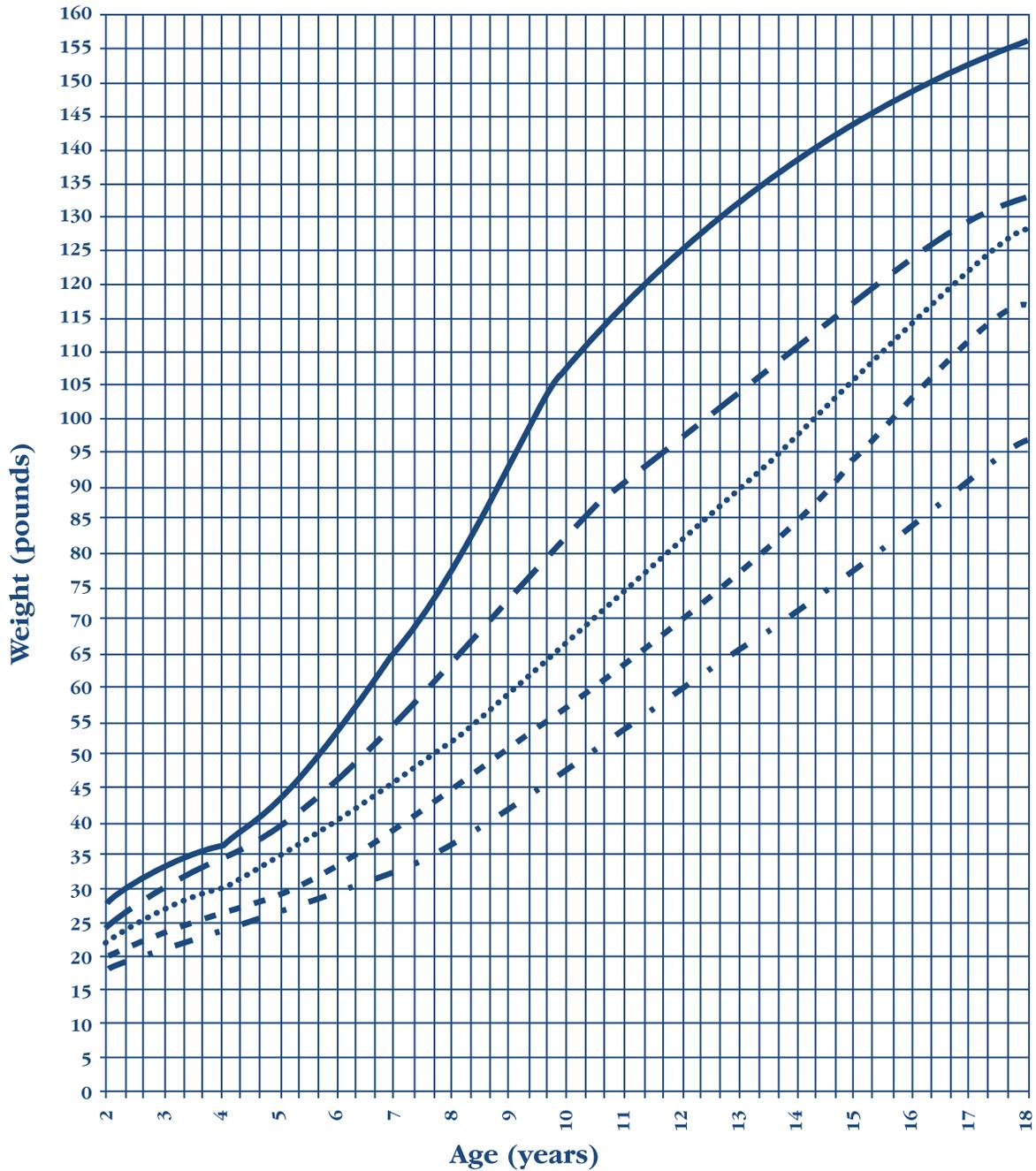
# Growth Chart for Boys with Down Syndrome (0-3 years)

## LENGTH



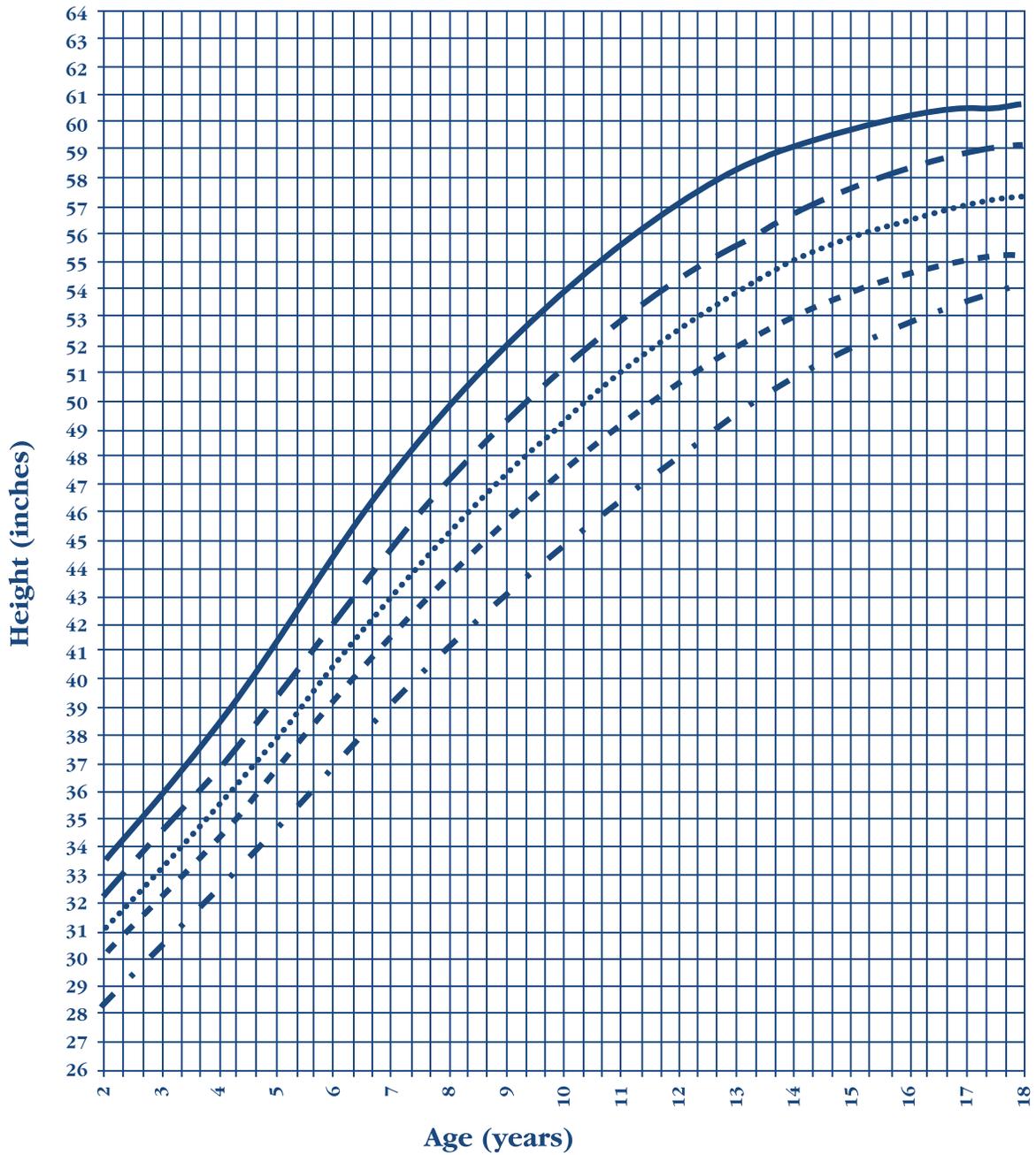
# Growth Chart for Girls with Down Syndrome (2-18 years)

## WEIGHT



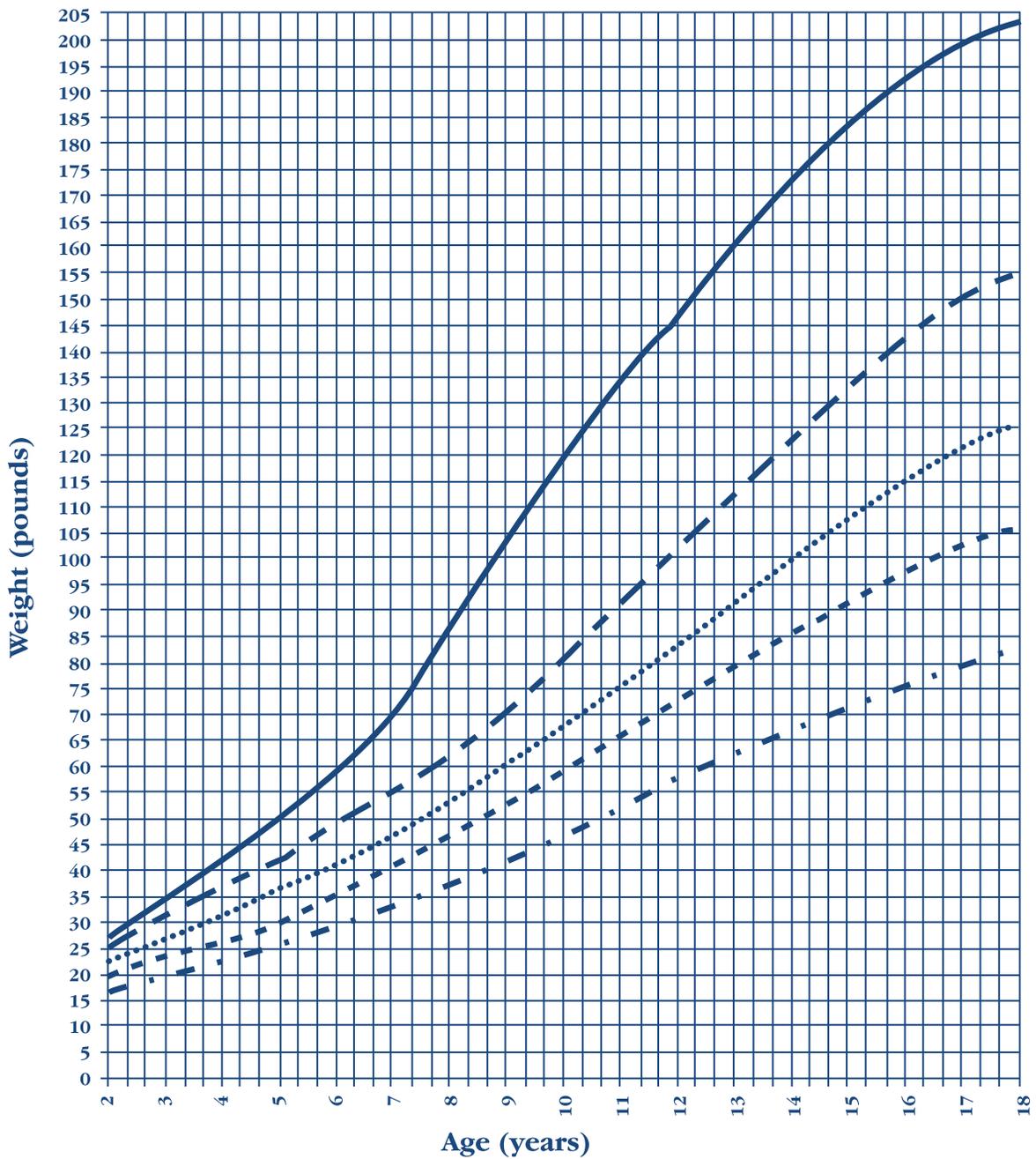
# Growth Chart for Girls with Down Syndrome (2-18 years)

## HEIGHT



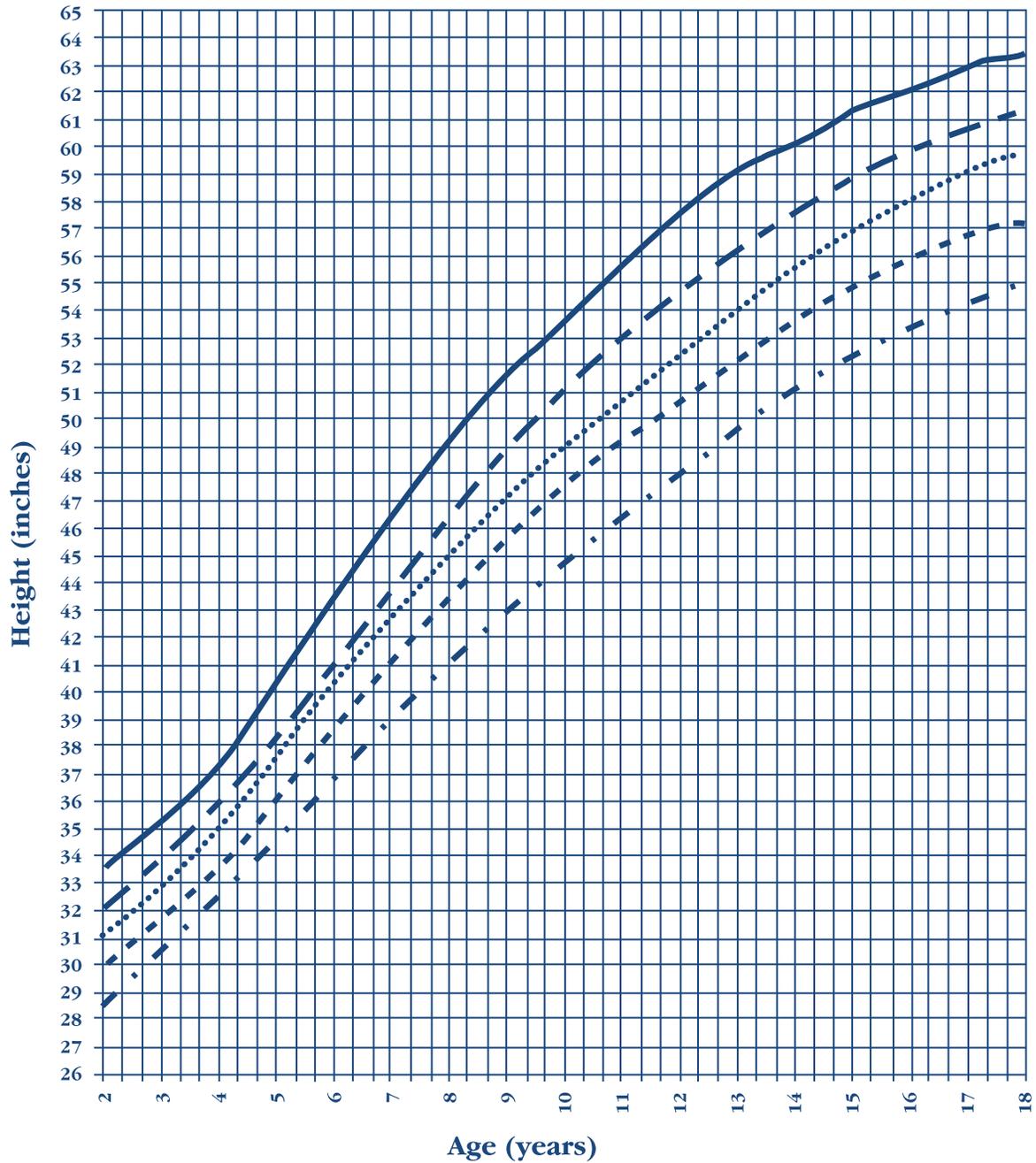
# Growth Chart for Boys with Down Syndrome (2-18 years)

## WEIGHT



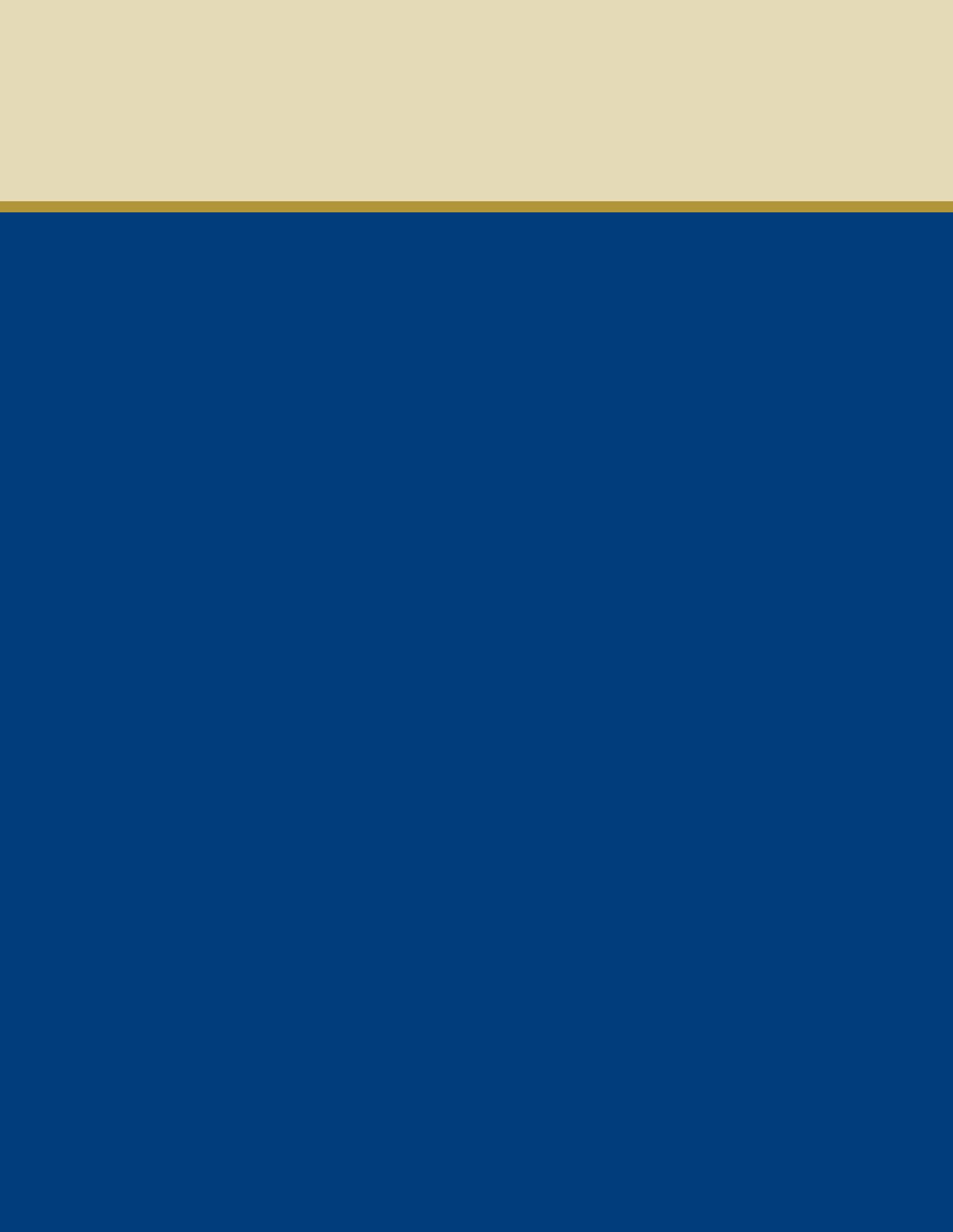
# Growth Chart for Boys with Down Syndrome (2-18 years)

## HEIGHT



A Promising Future Together

# notes





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