



A Promising Future Together

A Guide for New and Expectant Parents



The National Down Syndrome Society is the leading human rights organization for all individuals with Down syndrome.

About the National Down Syndrome Society

The National Down Syndrome Society (NDSS), established in 1979, is the leading human rights organization for all individuals with Down syndrome. NDSS was founded by Elizabeth Goodwin, following the birth of her daughter, Carson, who has Down syndrome. After Carson's birth, Elizabeth and her husband, Barton, discovered that support and resources available to parents of a child with Down syndrome were very limited.

NDSS supports the Down syndrome community across the lifespan. Our programs include:

- National Advocacy & Public Policy Center
- National Inclusive Health & Wellness Program
- Down Syndrome Community Outreach & Resources



OUR MISSION

The National Down Syndrome Society is the leading human rights organization for all individuals with Down syndrome.

OUR VISION

The National Down Syndrome Society envisions a world in which all people with Down syndrome have the opportunity to enhance their quality of life, realize their life aspirations and become valued members of welcoming communities.

Letter from Betsy Goodwin

Congratulations!

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:

- *How will Down syndrome affect my baby's development?*
- *What does the diagnosis mean for me as a parent?*
- *How will the addition of this baby 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 a child, a teen and an adult?*

My daughter, Carson, 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 in 1979 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.

All these 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 again on the recent or upcoming birth of your baby and may your new family member bring you the joy, love and laughter that Carson 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,

A handwritten signature in black ink that reads "Elizabeth Goodwin".

Elizabeth Goodwin
Founder

National Down Syndrome Society





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About Down Syndrome

Down syndrome is the most commonly occurring chromosomal condition, and occurs in people of all races, ethnicities and economic levels.

Each year, it is estimated that 1 in every 700 babies born in the United States has Down syndrome. This comes out to about 6,000 babies annually.¹

Today, individuals with Down syndrome are active participants in the educational, vocational, social and recreational aspects of our communities. Each year more teens and adults with Down syndrome are graduating from high school, going to college, finding meaningful employment and living independently. There are more opportunities than ever before for people with Down syndrome to develop their abilities, discover their talents and pursue their dreams.

WHAT IS DOWN SYNDROME?

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



Forms of Down syndrome

Type	% of Down Syndrome Cases	Description
1. Trisomy 21	95%	Trisomy 21 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, passing on both copies of the 21st chromosome instead of one. Individuals with trisomy 21 have 47 chromosomes instead of 46 in each of their cells.
2. Translocation	4%	In translocation there is an additional copy of chromosome 21, however, the copy attaches to another chromosome instead of being separate like in trisomy 21. The total number of chromosomes in each cell is 46.
3. Mosaicism	1%	Mosaicism (or mosaic Down syndrome) is diagnosed when there is a mixture of two types of cells, some containing 46 chromosomes and some containing 47. The cells with 47 contain an extra chromosome 21.

<https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/data.html>

The cause of the extra full or partial chromosome is still unknown. Maternal age is the only factor that has been linked to an increased chance of having a baby with Down syndrome. However, because younger women have higher fertility rates, 80% of babies with Down syndrome are born to women under the age of 35.

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 tests estimate the chance of the fetus having Down syndrome. These tests provide a probability, not a diagnosis.
- Diagnostic tests can provide a diagnosis with almost 100 percent accuracy.

Screening Tests

There are a number of prenatal screening tests available for pregnant women. Most of these screening tests involve a blood test and an ultrasound. The blood tests, maternal serum screening tests, measure quantities of various substances in the blood of the mother. Together with a woman's age, results are used to estimate her chance of having a child with Down syndrome. Typically offered in the first and second trimesters, maternal serum screening tests are only able to predict about 80 percent of fetuses with Down syndrome.

Maternal serum screening tests are often performed in conjunction with an ultrasound to check for physical features that are associated with Down syndrome in the fetus. Even with the ultrasound, the screening will not definitively diagnose Down syndrome.

Noninvasive prenatal tests (NIPT) involve blood being taken from the expectant mother as early as 10 weeks of gestation and rely on the detection of cell-free DNA that circulates between the fetus and the expectant mother. The American College of Obstetricians and Gynecologists recommends that doctors discuss all screening options with all pregnant women to determine which, if any, is appropriate.

Diagnostic Tests

The diagnostic procedures available for prenatal diagnosis of Down syndrome are chorionic villus sampling (CVS) and amniocentesis. These procedures, which carry up to a 1% risk of causing a

spontaneous termination (miscarriage), are nearly 100% accurate in diagnosing Down syndrome. CVS is usually performed in the first trimester between 9 and 14 weeks of gestation, and amniocentesis in the second trimester between 15 and 22 weeks. CVS and amniocentesis are also able to distinguish between trisomy 21, translocation Down syndrome and mosaic Down syndrome.

Whether or not to undergo prenatal screening or diagnostic testing is a personal decision, and expectant parents must make the choice that is best for them.

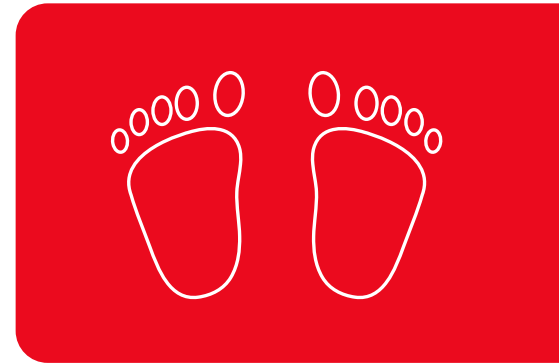
"Although it is important to offer all pregnant women, regardless of their age, screening or diagnostic testing for genetic disorders, there is no one test that is superior to all others. Furthermore, testing should be an informed patient choice, congruent with shared-decision making. Women also have the right to decline both genetic screening and testing, and all decisions should be supported."

- Nancy C. Rose, MD, previous chair of ACOG's Committee on Genetics

HOW IS DOWN SYNDROME DIAGNOSED?

Since some expectant parents forgo prenatal diagnostic tests, many 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
- a single deep crease across the center of the palm
- more flexible joints
- small skin folds on the inner corner of the eyes
- extra space between large and second toe



"Ob-Gyns Release Revised Recommendations on Screening and Testing for Genetic Disorders - ACOG." ACOG - Women's Health Care Physicians, www.acog.org/About-ACOG/News-Room/News-Releases/2016/Ob-Gyns-Release-Revised-Recommendations-on-Screening-and-Testing-for-Genetic-Disorders.

www.ndss.org | info@ndss.org | 800-221-4602

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 diagnosis. Therefore, doctors must perform a test called a karyotype before making a definitive diagnosis.

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

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 diagnosis 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. There are, however, certain health and developmental concerns commonly associated with Down syndrome. Individuals with Down syndrome are at an increased risk for certain health conditions. 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. 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. However, many children with Down syndrome learn to do these and many more activities, only possibly 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.

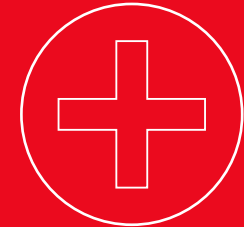
A Healthy Start

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 complications, it is important to be aware so that you can catch them early if they do occur.

New parents should also keep in mind that children with Down syndrome can have the same illnesses as other children. For example, they can develop ear infections, strep throat, or the flu.

WHAT HEALTH CONDITIONS ARE ASSOCIATED WITH DOWN SYNDROME?

Individuals with Down syndrome are at a higher risk for certain health problems compared to the general population, including: 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 can be frightening, keep in mind that your baby will not necessarily have all, or possibly any, of these conditions. If he or she does happen to have one or more of these complications, advances in medicine have rendered most conditions treatable.

For a complete list of co-occurring conditions, please visit <https://www.ndss.org/resources/cooccurring-conditions/>

ARE THERE HEALTH CARE GUIDELINES FOR CHILDREN WITH DOWN SYNDROME?

The American Academy of Pediatrics (AAP) has developed specialized health care information for families of children with Down syndrome that spans the prenatal period through age 21. Health Care Information for Families of Children with Down Syndrome provides information about potential health concerns at each stage of development. Checklists adapted from the AAP document can be found at the end of this booklet.

These 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, exercise and other issues across the lifespan.

By becoming familiar with the guidelines and communicating on a regular basis with your physician, you can ensure that your baby gets the best care possible.

In addition to visiting the AAP website, you can view and download the complete guidelines here:
<https://www.ndss.org/resources/healthcare-guidelines/>

WHAT SHOULD I LOOK FOR IN A PEDIATRICIAN?

For optimal health care, you may want to locate a developmental pediatrician or a specialist knowledgeable about Down syndrome, if any are available in your area.

Keep in mind that it is not always necessary to find an expert on Down syndrome. The most important thing to consider when you have a baby with special health care needs is finding a doctor who is willing to learn about Down syndrome and collaborate with you to ensure the best possible care for your child.

A good way to find a pediatrician is to ask families of other children with Down syndrome in your area for recommendations. Local parent support groups can be a good source of referrals. Find someone you feel comfortable with and with whom you can communicate freely.

To learn if there is a Down syndrome clinic near you or to find a local parent support group, please visit www.ndss.org or contact NDSS at 800-221-4602 or at info@ndss.org.

WHAT ABOUT ALTERNATIVE THERAPIES?

As you research Down syndrome, it is likely that you will come across 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. While this is understandable, be aware that although many therapies have been popular through the years, research studies are limited.

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 as safe and effective?
- What are the risks and side effects, and do they outweigh the potential benefits?
- 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?



SHOULD I BREASTFEED OR BOTTLE-FEED MY BABY WITH DOWN SYNDROME?

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

In addition, the physical process of breastfeeding strengthens babies' jaw and facial muscles, which helps lay a good foundation for speech and language development. It also 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 if you and your baby are able to. Some mothers breastfeed exclusively while others bottle-feed. Still others combine the two. Bottle-feeding can be through formula or expressed milk.

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 babies with Down syndrome 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.

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. 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 parent and 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.

Early Intervention

The first years of life are a critical time in a child's development. During these early years, children achieve the basic physical, cognitive, language, social and self-help skills that lay the foundation for future progress. Children with Down syndrome typically face delays in certain areas of development, so early intervention is highly recommended.

WHAT IS EARLY INTERVENTION?

Early intervention is a systematic program of therapy, exercises and activities designed to address any 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). This law requires states to 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 needs of their children. The most common early intervention services for babies with Down syndrome are speech and language therapy, physical therapy and occupational therapy.

WHEN SHOULD EARLY INTERVENTION START?

Early intervention can begin any time shortly after birth, and usually continues until the child reaches age three. An amendment to IDEA in 2004 allows states to have early intervention programs that may continue until the child enters, or is eligible to enter, kindergarten.

WHAT TYPES OF EARLY INTERVENTION ADDRESS EACH TYPE OF DEVELOPMENT?

Speech and language therapy is a key component of early intervention. Even though individuals with Down syndrome may not say 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 like "peek-a-boo"); visual skills (looking at speakers and objects); auditory skills (listening to music and speech for lengthening periods of time); tactile skills (learning about touch, exploring objects in the mouth); oral motor skills (using the tongue, moving the 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.

Physical therapy focuses on motor development. The abilities to explore one's surroundings, reach and grasp toys, turn one's head in order to follow a moving object with one's eyes, roll over, and crawl in pursuit of a desired objective foster understanding and mastery of the environment, stimulating cognitive, linguistic and social development. For example, during the first 3 to 4 months of life, an infant is 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. Appropriate physical therapy may assist a baby with Down syndrome, who may have low muscle tone, in achieving this milestone.

Occupational therapy helps children develop and master skills for independence. 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.

The goal of early intervention programs is to enhance and accelerate development by building on a child's strengths and by strengthening those areas that are weaker, in all areas of development.



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 find a local agency by visiting www.ectacenter.org. Once a referral has been made, the program staff must schedule and complete an initial evaluation within a specified time. After the evaluation, a caseworker will be assigned to coordinate the various services for which your baby and family qualifies. Early intervention services are individualized to meet the specific needs of each individual baby. The caseworker, therapists and family will determine the areas of focus and set goals based on the developmental milestones. These will be recorded in a document called the Individualized Family Service Plan, or IFSP. Parents can also find services privately if needed.

For more information about early intervention, visit <https://www.ndss.org/resources/early-intervention/>

Finding Support

If you have recently learned that your baby has or will have Down syndrome, you likely have questions and concerns. That's okay. There will be challenges in raising your child, but there will also be many, many joys.

IS WHAT I'M FEELING NORMAL?

After learning that your baby has Down syndrome, you may experience a roller coaster of emotions. While everyone handles the diagnosis in their own way, certain reactions are common in new or expectant parents of a child with a disability. For the majority of parents, the period immediately following the diagnosis is filled with uncertainty and doubt. 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 or have received a positive diagnosis, acceptance can be difficult.

Know that whatever you may be feeling is normal. More importantly, know that you are not alone. Many sources of support are available to new or expectant parents of children with Down syndrome. One of the best resources for encouragement and reassurance is other parents of children with Down syndrome. They have been through what you are going through, and can be an invaluable source of support.

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. 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 350 partner parent support groups, and can refer you to the group closest to your home. You can call or email NDSS to get this information or visit our website at www.ndss.org.

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 (such as a Buddy Walk®) to raise public awareness.

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. Alternatively, you may consider starting your own support group to network with others. NDSS can provide you with the information you need to get started.

WHAT ARE SOME OTHER THINGS I CAN DO TO TAKE CARE OF MYSELF?

Remember, it's also important to take care of yourself at this time. Doing so will keep you feeling healthy, strong and equipped to deal with your responsibilities as a parent. Here are some tips many new parents have found helpful for reducing anxiety and stress:

Be patient with yourself. 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, you may want 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.

Schedule some time to "recharge." Read a book, take a warm bath, go for a walk or just watch your favorite TV show. Do something you enjoy and find relaxing. This 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 to evaluate how your decision is working

Don't lose sight of the things that are important to you. Nurture your relationships with family and friends. Communicate with each other, laugh, do fun things together, celebrate traditions and enjoy spending time with your new baby that doesn't focus on his or her disability.



Caring for Your Family

It's natural for new parents of a child with Down syndrome to ask: 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?

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. 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 having a child with a disability, and that they are more focused on the things that really matter in life.

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 positive growth and character development. For example, children who have a brother or sister with Down syndrome 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 him or her.

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. Remind your children that while their brother or sister may have some physical differences, they will still look just like their parents and siblings. 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 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. Take a few minutes every day to talk with your partner about the diagnosis. 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.

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 diagnosis. 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. People may be uncomfortable because they don't have accurate information about Down syndrome or have never met someone with the diagnosis. It is possible 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 can also heal and begin to find joy in helping to raise their grandchild.

Don't be afraid of sharing your emotions with your trusted friends and family members. They are often 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.

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 expand our knowledge of 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. 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.

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 general education classrooms alongside their typically developing peers. Research has shown that this inclusion has only positive effects on the academic and social experiences of students with and without disabilities.

Many individuals with Down syndrome also graduate from high school and go on to post-secondary programs. The Individuals with Disabilities Education Act (IDEA) requires that teachers, related service providers and school administrators work with you to create a plan for your child to ensure a successful transition to life after high school. After high school, many new post-secondary programs for people with disabilities are available at colleges and universities throughout the country.

Individuals with disabilities now have more opportunities for employment in the community. These opportunities are diverse in nature with individuals with Down syndrome working in finance, sports, entertainment, fashion, customer service and many other industries. Employers are increasingly realizing that incorporating individuals with disabilities into their businesses is not only good for those individuals, but is also good for their bottom lines. We are seeing an increase in the amount of competitive, integrated employment opportunities available to people with Down syndrome and more options for independent living. Just like their typically developing peers, most individuals with Down syndrome have active social lives with friends with and without disabilities. Many people with Down syndrome live on their own, and some even get married.

To learn more about some of the amazing careers individuals with Down syndrome are having, check out:
<https://www.ndss.org/work/dsworks-success-stories/>

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!

HOW CAN I GIVE MY CHILD 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. Like all kids, children with Down syndrome have their own unique talents and abilities, and it is important to recognize and celebrate those accomplishments. Your child will likely receive many early intervention services, including physical, occupational and speech & language therapy. Still, instead of emphasizing what your child can't do, focus on what he or she can do!



Although your child with Down syndrome may need more attention from time to time, do your best to treat him or her same as your other children and have similar expectations. It's important to remember that inclusion starts in the family. By living life 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'll be able to share information with them about your child's abilities and the potential of people born with this diagnosis. 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 take your commitment to the next level!

The ABLE Act

For years, parents and families were told to not save money for their child with Down syndrome. Saving more than \$2,000 in their child's name would jeopardize vital benefits those with Down syndrome rely on, like Medicaid for healthcare and long term supports and services, Supplemental Security Income (SSI) and many others.

Today, self-advocates and families have access to ABLE accounts, thanks to the Stephen Beck Jr. Achieving a Better Life Experience (ABLE) Act, which was signed into law in 2014. ABLE accounts allow families to save money for their child's future without risking their vital benefits.

What is the ABLE Act?

The Stephen Beck Jr. Achieving a Better Life Experience (ABLE) Act (PL 113-295) added Section 529A to the federal tax code to enable eligible individuals with disabilities to save money in a tax-exempt account that may be used for qualified disability expenses while still keeping their eligibility for federal public benefits. This law has been heralded as one of the most significant pieces of disability legislation since the Americans with Disabilities Act. It was the result of nearly a decade-long cross-disability grassroots effort that originated with a group of parents of children with Down syndrome who recognized the unfairness of not being able to save funds in their child's name for fear of losing benefits. The ABLE Act was supported by 381 out of 435 US Representatives and 78 out of 100 US Senators – 85% of the entire US Congress.

What is an ABLE account?

An ABLE account is a tax-advantaged savings account that qualified individuals with disabilities may open as a result of the passage of the ABLE Act of 2014 and subsequent enactment of state ABLE laws. Contributions to ABLE accounts are made on an after-tax basis. Earnings from ABLE funds grow tax-deferred and are tax-free if used for qualified disability expenses. Contributions to the account may be made by any person (the account beneficiary, an employer, family and friends) and may or may not be tax deductible depending on the specifics of the state ABLE law. Funds in the account may be used for many different types of expenses. The beneficiary is the owner of the account, but legal guardianship and powers of attorney will permit others to control ABLE funds in the event that the beneficiary is unwilling or unable to manage the account.

For more information on ABLE accounts visit www.ndss.org

Why is there a need for ABLE accounts?

Individuals with disabilities can only have \$2,000 in assets at any given time in order to remain eligible for many federal means-tested benefits programs which provide much-needed supports, such as Supplemental Security Income (SSI). Under ABLE, eligible individuals and families may establish ABLE savings accounts that will not affect their eligibility for SSI (up to \$100,000), Medicaid and other public benefits. ABLE accounts provide a mechanism to essentially increase this \$2,000 asset limitation so that individuals with disabilities and their families can save money for their future and to improve their quality of life.

Who is eligible to open an ABLE account?

An individual must meet two requirements to be eligible for an ABLE account: an age requirement and a severity of disability determination. The onset of symptoms of the person's disability must have occurred before age 26. Additionally, the disabled individual must have "marked and severe functional limitations" (essentially, a Social Security definition of disability). An individual whose disability occurred prior to age 26 and is already receiving SSI and/or SSDI is automatically eligible to establish an ABLE account. Those who are not recipients of SSI and/or SSDI but still meet the age of onset disability requirement will be eligible to open an ABLE account upon obtaining a disability certification from their physician. All individuals with Down syndrome qualify because they are born with a disability.

What is a disability certification and how do you get one?

Depending upon the state ABLE program's procedures, the disability certification may be a form that a physician fills out or the ABLE program may simply require a letter from the physician providing certain information (such as the nature of the disability and date of onset). When a person opens an ABLE account, they do not need to submit a certification of eligibility at that time. Rather, they will certify (under penalty of perjury) that they are indeed eligible and have obtained some type of physician's note. The ABLE account owner keeps this certification in his or her own files and will only need to produce it if audited or eligibility is otherwise questioned.

How NDSS Can Help

NDSS COMMUNITY SUPPORT PROGRAMS

NDSS is committed to providing the Down syndrome community with quality support and informational services.

- NDSS leads a network of more than 350 local Down syndrome organizations across the country, consisting of local parent support groups and other organizations that provide services to the Down syndrome community.
- Through our helpline and email service, NDSS responds to more than 15,000 requests for information on Down syndrome each year. Our toll-free helpline and email service is supported by a translation service that can be accessed in over 150 languages.
- NDSS publications provide comprehensive information across the lifespan of individuals with Down syndrome. In addition to our Promising Future Together guide, our publications include: Aging and Down Syndrome: A Health & Well-Being Guidebook, and Alzheimer's Disease and Down Syndrome: A Practical Guide for Caregivers. All are available online and printed in English and Spanish.
- NDSS awards grants and scholarships to individuals with Down syndrome including the O'Neill Tabani Enrichment Fund, the #DSWORKS® Blake Pyron Entrepreneurship Scholarship, the Brandon Gruber Scholarship and the Ethan Saylor Memorial Scholarship.

NDSS NATIONAL ADVOCACY & PUBLIC POLICY CENTER

NDSS' National Advocacy & Public Policy Center advocates for federal, state and local policies that positively impact all people with Down syndrome across the country. Our comprehensive legislative agenda is centered around five important areas: healthcare & research, education, economic self-sufficiency, community integration and employment. We focus on legislation that would improve the lives of people with Down syndrome. These priorities have been shaped by self-advocates, families, affiliate leaders and others under the direction of the NDSS Board of Directors.

For more information on our current legislative agenda, please visit <https://www.ndss.org/advocate/ndss-legislative-agenda/>

INCLUSIVE EDUCATION PROGRAM

NDSS' Inclusive education program supports families through the individualized education plan (IEP) process including IEP development, implementation, mediation, independent educational evaluation, and due process. Supports schools in implementation inclusion, inclusive best practices, and create systemic changes at the school and district level.

For more information visit <https://www.ndss.org/advocate/ndss-legislative-agenda/education/>

#DSWORKS® EMPLOYMENT PROGRAM

NDSS' #DSWORKS® Program breaks down barriers to allow all individuals with Down syndrome to pursue their own hopes, dreams and aspirations in a more inclusive workforce. The #DSWORKS® Program achieves this by:

- Advancing a comprehensive federal and state legislation agenda that breaks down archaic legislative barriers to employment.
- Collaborating with private sector employers to promote best practices for hiring and supporting individuals with Down syndrome in employment.
- Creating resources, including webinars, to educate caregivers, parents, self-advocates, employers and other members of the community to promote employment for individuals with Down syndrome.

NDSS INCLUSIVE HEALTH AND WELLNESS PROGRAM

Our Inclusive Health and Wellness Program is dedicated to health, the most important and critical human right. The Inclusive Health and Wellness Program includes our National Buddy Walk® Program, Athlete Ambassador Program, Charity Racing Teams and Our Healthy Community Programs including Racing for 3.21 on World Down Syndrome Day.

- Since 1995, the National Buddy Walk® Program has become the premier awareness event for Down syndrome in the United States. It is also the world's most widely recognized public awareness program for the Down syndrome community. The program has grown from 17 walks in 1995 to almost 200 walks in 2020.

- The goal of NDSS' Athlete Ambassadors is to foster an inclusive community of like-minded individuals and athletes with a passion for helping local communities and the Down syndrome community live healthier.
- NDSS Charity Racing teams participate in races across the country including the TCS NYC Marathon, runDisney series, Marine Corps Marathon and other road and trail races and triathlons. Runners and triathletes gather to test their limits, summon their strength, and take on great challenges in support of individuals with Down syndrome. Every athlete has a racing story, let Down syndrome be yours.
- Racing for 3.21 on World Down Syndrome Day is a virtual event where participants and advocates run, walk, bike, hike, swim and/or move for 3.21 miles at any time, any place and at any pace on March 21 to celebrate World Down Syndrome Day and raise awareness for the Down syndrome community.
- As the life expectancy of individuals with Down syndrome continues to increase, NDSS is committed to ensuring our adults with Down syndrome, their families and caregivers have the best, most accurate information throughout adulthood.



Health Care Checklist

Health Care Information for Families of Children with Down Syndrome

Specialized health care guidelines for children with Down Syndrome have been published by the American Academy of Pediatrics. These guidelines are based on "Health Supervision for Children with Down Syndrome" published in PEDIATRICS (Vol. 128, No. 2, August 1, 2011. pp. 393 -406)

CHILD'S AGE: THE PRENATAL PERIOD (THE TIME BEFORE BIRTH)

Consider testing as desired

Prenatal testing for genetic conditions is recommended for families who wish information to help them make decisions about a pregnancy. This testing should be done only after information about the tests has been discussed between the doctor and the family, and the family understands the risks and benefits of the testing.

Counseling

If Down syndrome (trisomy 21) or any other chromosome change that causes Down syndrome is found by prenatal testing, the family should receive counseling to explain the issues and provide support for the family.

Prenatal heart testing

Because there is a high risk of heart problems at birth in Down syndrome, echocardiography (an ultrasound picture of the heart) done during the pregnancy can provide information that may be useful for the remainder of the pregnancy and for the delivery. This information may help with decisions such as where to deliver the baby and the medical services needed late in pregnancy or at delivery.

CHILD'S AGE: BIRTH TO 1 MONTH

Complete physical examination

If the diagnosis of Down syndrome was made before birth or suspected after birth, a complete physical examination should be done to confirm the known physical features and to check for any possible associated conditions.

Genetic testing

If prenatal testing gave a diagnosis of Down syndrome and if the exam after birth agrees, then no further testing is probably needed in the newborn period. If the physical examination after birth raises the possibility of Down syndrome, testing by rapid (FISH) confirmation and a complete chromosome analysis are needed. The rapid analysis results are typically available within 48 hours, whereas the complete analysis might take 3-5 days for the results. A complete chromosome analysis is needed to provide full information, but to ensure prompt results, both should be obtained unless the complete analysis can be done as quickly as the rapid analysis.

Counseling

The prenatal or newborn diagnosis of Down syndrome can cause many concerns for parents. Talking with a medical genetics team (medical geneticist and genetic counselor) or others recommended by your child's doctor may be helpful.

Feeding

Infants with Down syndrome sometimes have low muscle control, which can cause feeding problems. For this reason, infants should be closely watched for slow feeding or choking and for good weight gain. Breast feeding is strongly encouraged, but extra attention may need to be given to positioning and to keeping the baby awake or alert.

Heart

An echocardiogram (an ultrasound picture of the heart) is needed to check for any evidence of heart disease. This should be done even if a prenatal echocardiogram was done. If issues exist, it is very important to act early. Breathing that is too fast or cyanosis (a bluish color of the skin) are signs for possible concern.

Hearing and vision

Infants with Down syndrome are at risk for sensory issues, such as eye problems leading to vision loss or ear problems leading to hearing loss. It is important to have both vision and hearing checked by specialists (ophthalmology and ENT).

Thyroid

Thyroid hormone levels can be too low in newborns and need to be checked (a TSH test). Thyroid hormone imbalance can cause a variety of problems that might not be easy to detect without a blood test.

Blood test

After birth, white and red blood counts can be unusually high in infants with Down syndrome. These blood counts need to be checked.

Stomach or bowel problems (reflux, constipation, blockages)

Intestinal issues can occur. Spitting up, stomach swelling, or an abnormal stool pattern can be signs that there is an issue.

Infection

Because of an increased risk of infections (especially respiratory infections), infants should be protected from any unnecessary exposures to sick siblings, relatives, or others. It is also recommended to get checked quickly when any infection is suspected.

Developmental services

It is not too early in the first month of life to start to look for the developmental services (sometimes called "Early Intervention") that will be very important in early childhood.

Resources

Families of children with Down syndrome will need multiple resources, and now is a good time to start lining them up. Such resources might include specialized medical care, early intervention, physical therapy, and family counseling services.

CHILD'S AGE: 1 MONTH TO 1 YEAR

Regular well-care visits (check-ups)

While infants with Down syndrome might need multiple special visits to their doctor and specialty physicians, it is very important that they get regular well-care visits (check-ups). These visits will include checking your child's health, giving immunizations (shots), and building the relationships between the doctor and the family. Developing these relationships will help support the medical and other needs of the child and the family.

Monitor growth

It is important to check growth at every visit. Measurements include height, weight, weight for height, and head circumference. Discuss your child's diet, activity level, bowel and urine patterns, and growth. Your child's doctor can help with questions about any need for vitamins or supplements.

Immunizations (shots)

Your child's doctor should follow the same shot schedule as for any other child. This includes yearly influenza (flu) shots. It may include other shots, too, depending on your child's health history.

Heart

If there were any signs of heart disease in the first month of life, heart monitoring is probably already in place. Heart problems could still worsen or new ones could arise. If concerns exist, it is very important to act early. Breathing that is too fast or cyanosis (a bluish color of the skin) are signs for possible concern.

Hearing and vision

Infants with Down syndrome are at risk for eye problems leading to vision loss or ear problems leading to hearing loss. It is important to have both vision and hearing checked by specialists (ophthalmologist and otolaryngologist/ear, nose, and throat doctor or ENT). The eyes should be tested at birth and again at 1 year or sooner if there are concerns. Hearing should be tested at birth and again every 6 months in early childhood to be sure that the baby's hearing is the best possible.

Thyroid

Thyroid hormone levels can be too low in infants and need to be checked (a TSH test). Low thyroid levels can cause a variety of problems that might not be easy to detect without a blood test. A TSH should be obtained at birth and again at age 6 months and 1 year.

Stomach or bowel problems (reflux, constipation, blockages)

Intestinal issues can occur. Spitting up, stomach swelling, or an abnormal stool pattern can be signs that there is an issue.

Neck instability

Bones in the neck or spine can be unstable in some people with Down syndrome. There are almost always visible signs when there are problems. Daily physical activity is important to your child and should not be limited by unneeded worries. X-rays are not needed unless there is pain or changes in the use of hands, walking, or bowel or bladder function. If x-rays are done and the results are abnormal, your child may be referred to a spine or neck specialist. It is recommended that the neck be positioned properly for any medical procedures.

Developmental services

Developmental services (for example, early intervention programs) can be of great benefit to the family with a child with Down syndrome. Developmental services can also help arrange for other related services. These services should provide information to your child's doctor to maintain a close working relationship with the doctor and the family.

Social support services

Many families need additional help with the issues that can arise with the care of children with Down syndrome. All families should discuss with their doctor the social services that may be available and their benefits.

Recurrence risk counseling

Families should get counseling about the possible risk of having another child with Down syndrome, if they choose to have more children. While the risk is usually low, other factors in the family history might be present, so counseling should be done after a complete review of the family history.

CHILD'S AGE: 1 YEAR TO 5 YEARS

Regular well-care visits (check-ups)

At the one-year check-up, you should look at the checklists for newborns and infants to be sure everything has been done as recommended. Follow-up on known problems with specialists and be sure that reports are sent to your child's primary doctor.

Monitor growth

It is important to check growth at every visit. Measurements include height, weight, body mass index (BMI), and head circumference. Discuss your child's diet, activity level, and growth. Your child's doctor can help with questions about any need for vitamins or supplements.

Immunizations (shots)

Your child's doctor should follow the same shot schedule as for any other child. This includes yearly influenza (flu) shots. It may include other shots, too, depending on your child's health history.

Heart

The need to see a cardiologist during this age is based on the child's health history and examination. Children with cardiac lesions may need to be monitored even after repair for remaining lesions and development of pulmonary hypertension (high pressure in blood vessels of the lungs).

Hearing

Hearing should be checked every 6 months, with audiogram and tympanometry tests until normal hearing is documented by testing of both ears separately (usually by 4-6 years of age). Children with hearing loss should be referred to an otolaryngologist (ear, nose, and throat doctor or ENT). Higher risks of hearing problems can go with middle ear fluid and ear infections. Treatment of middle ear fluid often includes the use of ear tubes.

Vision

Vision should be checked at each visit to the doctor and with yearly checkups by a pediatric ophthalmologist (special eye doctor) or a general ophthalmologist who is good with children with disabilities. Crossing eyes or blocked tear ducts might be reasons for quicker action. Early use of eye patches, glasses, or both may help to fix eye crossing while lowering the need for surgery and the risk of vision loss.

Thyroid

The thyroid gland is usually normal in babies with Down syndrome. It can stop working normally for half of people with Down syndrome by adulthood. The symptoms of low thyroid can be hard to notice in people with Down syndrome, so a blood test (TSH) is needed every year, or sooner if symptoms change. When there is a problem, treatment is safe and can often be started by your primary doctor.

Blood tests

Tests for low iron or anemia (hemoglobin and other tests if needed) should be done every year.

Stomach or bowel problems (diarrhea, constipation)

Discuss toilet patterns at each visit, especially any ongoing problems with loose stools or constipation. These are common in children with Down syndrome. Some children with Down syndrome have celiac disease, which is a problem with tolerating some grains, including wheat. Testing can help to identify that condition, and may lead to changes in diet. Celiac disease can affect growth, stooling patterns, and behavior. Let your child's doctor know if your child is having:

- Very loose stools
- Hard to treat constipation (hard or painful stools)
- Slow growth/weight loss
- Belly pain or stomach swelling
- New or challenging behavior problems

Neck instability

Bones in the neck or spine can be unstable in some people with Down syndrome. There are almost always visible signs when there are problems. Daily physical activity is important to your child and should not be limited by unneeded worries. X-rays are not needed unless there is pain or changes in the use of hands, walking, or bowel or bladder function. If x-rays are done, and the results are abnormal, your child may be referred to a spine or neck specialist. Special neck positioning may be needed for some medical procedures. Let your child's doctor know if your child is having:

- Stiff or sore neck
- Change in stool or urination pattern
- Change in walking
- Change in use of arms or legs
- Numbness (loss of normal feeling) or tingling in arms or legs
- Head tilt

Sleep issues

Obstructive sleep apnea is a common problem for people with Down syndrome, especially those with low muscle tone. Some symptoms are obvious (snoring, restless waking at night, daytime sleepiness), but it can be hard to tell just by watching. AAP guidelines recommend that every child with Down syndrome have a sleep study by the age of 4 years. (That testing may be hard to find in some parts of the country.) Treatment can include special breathing equipment or surgery.

Skin

Discuss with your child's doctor if your child has very dry skin or other skin problems.

Brain and nervous system

Discuss with your child's doctor concerns about neurologic problems, such as seizures.

Dental

Delayed and missing teeth are common. Teeth often come in unusual order.

New treatments

Talk to your doctor about any new treatments or medications you may consider.

Recurrence risk counseling

Talk to your doctor about future pregnancy planning and chances of recurrence of Down syndrome and where prenatal diagnosis is available.

Developmental services (early intervention)

Review your child's development with your doctor. Referral to local early intervention services and other options for therapy may be needed. Speech progress can be very delayed in children with Down syndrome, but after some delays, most will learn to talk well. Until speech is easier for your child, he or she might need help finding other ways to communicate, such as using sign language, pictures, reading, or using electronic communication tools. Behavior problems are often linked to problems with communication, but may reflect other issues, including ADHD or autism. Language delays or hidden abuse are more common than autism but may be misdiagnosed. Talk with your doctor about how to explain social safety and "good and bad touch" as your child grows older



National Down Syndrome Society

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