A Guide for NEW PARENTS

Resources for new parents of a child with Down syndrome.

the upside of downs

Supporting & Celebrating Down Syndrome in Northeast Ohio
USOD’S MISSION

To provide support, education and advocacy for people with Down syndrome, their families and communities.
Dear Parent,

Twenty years ago, I was pregnant with my second child. We knew that he was going to be a boy and we had already named him Alex. We were so excited because our family, we thought, would be complete. We already had a three year old daughter and now a boy—how perfect!

What we didn’t expect, however, was to be told that our baby had Down syndrome. I remember the shock and sadness those first few days after he was born. I was fearful of what the future would hold for Alex and for our family. As I held him I knew though that he was such a sweet and precious little thing and I loved him dearly no matter what.

Well, I cannot even imagine our lives without Alex in them. He has brought so much joy, love, pride and hope into our lives that it is hard to even put into words. When he smiles and laughs, the whole world lights up! He has not only touched our lives, but so many others around him.

A big fear that we had when he was born was how this would affect our daughter. I can tell you that it has affected her, but only in a positive way. She is the most patient and compassionate young adult that I have ever known. She is studying to become an Occupational Therapist ans was inspired by her brother to follow this path. I believe that having Alex in her life has been a large part of who she is and who she will become in the future.

Alex enjoys the same things that teens his age do including sports, movies, video games, and girls! He attends regular classes at school and has many friends. He has been on the high school swim team and has made great friends over the years. He is an altar server at our church and really enjoys it!

Alex has been a joy in our lives and our family would not be complete without him. My hope is that your baby will bring you the same love and joy that we have experienced.

Thank you,

Laurie

Laurie Kowalski
New and Expectant Parent Support
The Up Side of Downs
Congratulations on the birth or expected birth of your baby! We understand that your baby may have Down syndrome. You probably have a million questions, concerns and fears right now. That is OK. The most important thing to keep in mind is that this diagnosis is not as “life changing” as the fact that you have a new baby. And in most ways, your baby will be just like other infants. Every baby needs to be fed, held, and most of all, loved.

There will be challenges in raising your child, but there will also be many, many joys. It’s normal to be nervous about what lies ahead, but remember that Down syndrome is a condition your baby has, it is not who your baby is. Now is the time to begin learning all you can about Down syndrome and the local services available to you. This New Parent Guide is a great place to start.
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 guide books and make your 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 flight attendant 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 that 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 guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never 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 that 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 go away... because the loss of that dream is a very significant loss.

But... if you spend your life mourning the fact that you didn’t get to Italy, you may never be free to enjoy the very special, the very lovely things... about Holland.
If you have recently learned that your child is developmentally delayed or has a disability (which may or may not be completely defined), this message may be for you. It is written from the personal perspective of a parent who has shared this experience and all that goes with it.

When parents learn about any difficulty or problem in their child’s development, this information comes as a tremendous blow. The day my child was diagnosed as having a disability, I was devastated—and so confused that I recall little else about those first days other than the heartbreak. Another parent described this event as a “black sack” being pulled down over her head, blocking her ability to hear, see, and think in normal ways. Another parent described the trauma as “having a knife stuck” in her heart. Perhaps these descriptions seem a bit dramatic, yet it has been my experience that they may not sufficiently describe the many emotions that flood parents’ minds and hearts when they receive any bad news about their child.

Many things can be done to help yourself through this period of trauma. That is what this paper is all about. In order to talk about some of the good things that can happen to alleviate the anxiety, let us first take a look at some of the reactions that occur.

By Patricia McGill Smith

You are not alone

When Parents Learn that their Child has a Disability
Common Reactions

On learning that their child may have a disability, most parents react in ways that have been shared by all parents before them who have also been faced with this disappointment and this enormous challenge. One of the first reactions is denial—“This cannot be happening to me, to my child, to our family.” Denial rapidly merges with anger, which may be directed toward the medical personnel who were involved in providing the information about the child’s problem. Anger can also color communication between husband and wife or with grandparents or significant others in the family. Early on, it seems that the anger is so intense that it touches almost anyone, because it is triggered by the feelings of grief and inexplicable loss that one does not know how to explain or deal with.

Fear is another immediate response. People often fear the unknown more than they fear the known. Having the complete diagnosis and some knowledge of the child’s future prospects can be easier than uncertainty. In either case, however, fear of the future is a common emotion: “What is going to happen to this child when he is five years old, when he is twelve, when he is twenty-one? What is going to happen to this child when I am gone?” Then other questions arise: “Will he ever learn? Will he ever go to college? Will he or she have the capability of loving and living and laughing and doing all the things that we had planned?”

Other unknowns also inspire fear. Parents fear that the child’s condition will be the very worst it possibly could be. Over the years, I have spoken with so many parents who said that their first thoughts were totally bleak. One expects the worst. Memories return of persons with disabilities one has known. Sometimes there is guilt over some slight committed years before toward a person with a disability. There is also fear of society’s rejection, fears about how brothers and sisters will be affected, questions as to whether there will be any more brothers or sisters in this family, and concerns about whether the husband or wife will love this child. These fears can almost immobilize some parents.

Then there is guilt—guilt and concern about whether the parents themselves have caused the problem: “Did I do something to cause this? Am I being punished for something I have done? Did I take care of myself when I was pregnant? Did my wife take good enough care of herself when she was pregnant?” For myself, I remember thinking that surely my daughter had slipped from the bed when she was very young and hit her head, or that perhaps one of her brothers or sisters had inadvertently let her drop and didn’t tell me. Much self-reproach and remorse can stem from questioning the causes of the disability.

Guilt feelings may also be manifested in spiritual and religious interpretations of blame and punishment. When they cry, “Why me?” or “Why my child?”, many parents are also saying, “Why has God done this to me?” How often have we raised our eyes to heaven and asked: “What did I ever do to deserve this?” One young mother said, “I feel so guilty because all my life I had never had a hardship and now God has decided to give me a hardship.”

Confusion also marks this traumatic period. As a result of not fully understanding what is happening and what will happen, confusion reveals itself in sleeplessness, inability to make decisions, and mental overload. In the midst of such trauma, information can seem garbled and distorted. You hear new words that you never heard before, terms that describe something that you cannot understand. You want to find out what it is all about, yet it seems that you cannot make sense of all the information you are receiving. Often parents are just not on the same wavelength as the person who is trying to communicate with them about their child’s disability.

Powerlessness to change what is happening is very difficult to accept. You cannot change the fact that your child has a disability, yet parents want to feel competent and capable of handling their own life
Getting Started
<table>
<thead>
<tr>
<th><strong>Milestone</strong></th>
<th><strong>Range for Children with Down Syndrome</strong></th>
<th>** Typical Range**</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>GROSS MOTOR</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sits Alone</td>
<td>6 - 30 Months</td>
<td>5 - 9 Months</td>
</tr>
<tr>
<td>Crawls</td>
<td>8 - 22 Months</td>
<td>6 - 12 Months</td>
</tr>
<tr>
<td>Stands</td>
<td>1 - 3.25 Years</td>
<td>8 - 17 Months</td>
</tr>
<tr>
<td>Walks Alone</td>
<td>1 - 4 Years</td>
<td>9 - 18 Months</td>
</tr>
<tr>
<td><strong>LANGUAGE</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>First Word</td>
<td>1 - 4 Years</td>
<td>1 - 3 Years</td>
</tr>
<tr>
<td>Two-Word Phrases</td>
<td>2 - 7.5 Years</td>
<td>15 - 32 Months</td>
</tr>
<tr>
<td><strong>PERSONAL/SOCIAL</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Responsive Smile</td>
<td>1.5 - 5 Months</td>
<td>1 - 3 Months</td>
</tr>
<tr>
<td>Finger Feeds</td>
<td>10 - 24 Months</td>
<td>7 - 14 Months</td>
</tr>
<tr>
<td>Drinks From Cup Unassisted</td>
<td>12 - 32 Months</td>
<td>9 - 17 Months</td>
</tr>
<tr>
<td>Uses Spoon</td>
<td>13 - 39 Months</td>
<td>12 - 20 Months</td>
</tr>
<tr>
<td>Bowel Control</td>
<td>2 - 7 Years</td>
<td>16 - 42 Months</td>
</tr>
<tr>
<td>Dresses Self Unassisted</td>
<td>3.5 - 8.5 Years</td>
<td>3.25 - 5 Years</td>
</tr>
</tbody>
</table>
Speech Therapy

Speech & Language Skills in Infants, Toddlers & Young Children with Down Syndrome
By Libby Kumin, PhD, Professor of Speech-Language Pathology/Audiology, Loyola College

Speech and language present many challenges for children with Down syndrome but there is information that can help infants and toddlers begin learning to communicate, and help young children progress in speech and language. Although most children with Down syndrome learn to speak and will use speech as their primary means of communication, they will understand language and have the desire to communicate well before they are able to speak. Total communication, using sign language, pictures, and/or electronic synthesized speech can serve as a transitional communication system.

Are hearing problems common in children with Down syndrome?

Ear infections occur frequently in infancy and early childhood in all children. But, because of anatomic differences in the ears of children with Down syndrome (narrow and short canals), they are more susceptible to accumulations of fluid behind the eardrum. This is known as Otitis Media with Effusion (OME). These problems result from fluid retention and inflammation in the middle ear; sometimes with infection. The presence of fluid makes it more difficult for the child to hear, resulting in fluctuating conductive hearing loss. Children should be followed by their pediatrician and otolaryngologist (ENT) and visit an audiologist for auditory testing. This testing can be done soon after birth. Hearing testing should also be done every six months until three years of age and annually through age 12 years. Treatment usually involves either an antibiotic regimen or the insertion of tubes to drain the fluid. These recommendations follow the schedule found in the Down Syndrome Medical Interest Group Healthcare Guidelines, available through NDSS.

What effect does hearing loss have on speech and language development?

Speech and language are learned through hearing, vision and touch. Hearing is very important to speech, and studies have shown that speech and language development are negatively affected by chronic fluid accumulation. Children with Down syndrome often have fluctuating hearing loss due to the frequency of fluid accumulation. When fluid is present, hearing is affected; as fluid drains, hearing improves. When children do not consistently hear well, it is difficult to learn how sounds and events are related, e.g. the ring of the telephone or someone calling you. So, it is important to ensure that your child is hearing well. Pediatricians and otolaryngologists have great success in treating fluid accumulation, but treatment requires close monitoring.


How is feeding related to speech and language?

Speech is a secondary function that uses the same anatomic structures used for feeding and respiration. Low muscle tone (hypotonia) affects feeding and will also affect speech. In feeding, children gain practice with strengthening and coordinating the muscles that will be used for speech. If your child has difficulty feeding, it is important to seek guidance from a feeding specialist, a speech-language pathologist or occupational therapist who has advanced training. Feeding therapy can help strengthen the oral muscles. This can also have a positive effect on speech.

What other skills are related to speech and language development?

Other important pre-speech and pre-language skills are 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 looking at objects); auditory skills (listening to music and speech for lengthening periods of time, 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, cause and effect relationships). The family can stimulate these pre-speech and language skills at home. Contact Child Find in your area, and ask for speech-language pathology services for your child. The SLP can help you learn the skills that you need to help your child move along the journey to learning language and using speech. For more information, see:

When will my child say his first word?
Children with Down syndrome frequently begin to use single words between the ages of two and three, but the age of the first word varies, and the first true word may not be a spoken word, but it may be a signed word. Most children with Down syndrome communicate from birth through crying, looking and gesturing. They have the desire to communicate and learn that crying or making sounds can affect their environment and bring them help and play and attention. Many children with Down syndrome, by 10-12 months of age, understand the relationship between a word and a concept. However, at that age, the child generally does not have sufficient neurological and motor skills developed to be able to speak. That’s why it is important to provide another system so that the child can communicate and learn language before they are able to speak.

What is total communication?
Total communication (TC) is the combined use of signs and gestures with speech to teach language. Total communication provides the child with an output system to communicate when he or she has not yet developed the skills needed for speech. In total communication, the adult uses sign and speech when talking with the child. The child learns signs in conjunction with speech and uses the signs to communicate. Sign language is a transitional system for children with Down syndrome. Other choices for transitional communication systems are pictures used on a communication board or in a communication exchange system, and/or electronic communication systems which use synthesized speech. Most children with Down syndrome are ready to use a language system many months or even several years before they are able to use speech effectively to communicate. Therefore, a transitional communication system such as sign language, pictures or synthesized voice is frequently needed. A speech-language pathologist and/or augmentative communication specialist (AAC) can help design a transitional communication system for your child. Most children with Down syndrome will use speech as their primary system for communication.

What can parents do to help infants and young children learn speech and language?
Parents are the primary communicators interacting with their babies and young children; thus, parents can do a great deal to help their children learn to communicate. Many of the pre-speech and pre-language skills are best learned in the home environment.

- Remember that language is more than spoken words. When you are teaching a word or a concept, focus on conveying meaning to the child through play or through multisensory experiences (hearing, touch, seeing).
- Provide many models. Most children with Down syndrome need many repetitions and experiences to learn a word. Repeat what your child says, and give him a model to help him learn words.
- Use real objects and real situations. When you are teaching a concept, use daily activities and real situations as much as possible. Teach the names of foods as your toddler is eating, names of body parts while you are bathing your child, and concepts such as under, in and on while your child is playing. Communication is part of daily life.
- Read to your child. Help your child learn concepts through reading about them, field trips in the neighborhood and daily experiences.
• Follow your child’s lead. If your child shows interest in an object, person or event, provide him or her with the word for that concept. There are many milestones as the child progresses toward using speech. The child responds to a familiar voice, recognizes familiar faces, experiments with many different sounds, produces strings of sounds over and over and makes a sound to mean you (dada, mama). Many children enjoy looking in a mirror, and increase their sound play and babbling when vocalizing in mirrors. Effective ways to work on these skills at home can be learned through early intervention sessions, through books, workshops and speech and language professionals. For more information, see:


When should speech-language pathology services begin? What is early language intervention?

Speech-language pathology services can begin in infancy. Treatment may involve sound stimulation, language stimulation accompanying play, feeding, oral motor exercises and/or other techniques. It should always include the family as a partner in treatment because the family is the primary teacher of speech and language. Early language intervention (ELI) is the designation given for services provided to infants and toddlers from birth through the end of age two. Speech-pathology services should be part of a comprehensive overall treatment plan for infants and toddlers. It may involve sessions at home or in a center, and may be part of a team approach involving physical, occupational and other therapists working together with the family.

A government-sponsored early intervention program is available in all communities in the United States. In Ohio, this program is called Help Me Grow. Speech-language and other therapy services are often provided at these programs for eligible children under age three, based on disability and an evaluation. Most children with Down syndrome qualify for speech-language services. After age three, there are continuing services provided by the child’s school system. Other speech services are available through community agencies, private practitioners, university clinics, medical centers and other sources.

How do you find a qualified speech-language pathologist?

Qualified SLPs are certified by the American Speech-Language-Hearing Association and licensed by the state. When a professional is certified, they can use CCC-SLP (Certificate of Clinical Competence in Speech-Language Pathology) following their name. This means they have completed a master’s degree in an accredited program, have completed required hours of clinical practice internship and passed a national certification examination. If you are receiving services through Child Find (a federal program that identifies the needs of children with disabilities), the health department or school system in your local area, they will have professionals working with them or they can refer you to local professionals. Members of local Down syndrome support groups can often refer you to speech-language pathologists in your area who have experience working with children with Down syndrome.

*Reprinted from the National Down Syndrome Society website: www.ndss.org
There are more than 400,000 people with Down syndrome in the United States.
Feeding the Infant with Down Syndrome
By Rebecca B. Saenz, M.D.

An infant with Down syndrome can be breast-fed. Breast milk is generally easier to digest than formulas of all types. Furthermore, breast-fed infants have fewer upper and lower respiratory infections, as well as a lower incidence of otitis media, atopic diseases and respiratory allergy. Breast feeding also enhances oral motor development, which is the foundation of speech. The psychological benefit derived from the bonding of mother and infant can be extremely important at a time when, because of the infant’s disability, the mother may be questioning her own adequacy. Even if the infant is unable to breast feed directly, expressed breast milk given another way may be beneficial for the child’s health and the mother’s emotional wellbeing.

Sucking problems related to hypotonia or cardiac defects may make breast feeding initially difficult, particularly in the premature infant. In this situation, the mother can be encouraged to feed the infant expressed milk by other means, such as a nursing supplementary or a bottle, or, occasionally, by gavage (forced feeding, especially through a tube passed into the stomach). After several weeks, the infant’s sucking ability often improves, and the infant becomes capable of nursing effectively. A nursing supplement may be used to encourage the infant who has a weak suck.

Occupational therapists, speech therapists, lactation consultants and breastfeeding support groups usually have specific resources for the mothers of infants with Down syndrome. Mothers may find these resources invaluable. If the breastfeeding infant is not gaining enough weight, consideration should be given to partial supplementation with formula or additional expressed breast milk. A nursing supplement may also be used to provide additional caloric intake while the infant continues to breast feed.

Many infants with Down syndrome tend to be “sleepy babies” in the early weeks. Consequently, feeding only on demand may be inadequate for both the caloric and the nutritional needs of the infant and stimulation of the mother’s milk supply. In this situation, the infant should be awakened to feed at least every three hours, or every two hours if only breast feeding is being used. The mother may need to pump her breasts to stimulate the production of an adequate supply of milk.

The mother who prefers formula feeding should also be encouraged to awaken her infant at least every three hours to ensure adequate caloric and nutritional intake. Reflux may be reduced by holding the feeding infant in a semi-upright position and keeping the bottle appropriately angled to prevent the swallowing of air.

Unless weight gain is a problem or an infant with Down syndrome has a particular medical disorder, no specific formula is currently recommended. Formula additives or gavage feeding may be necessary in infants with very poor weight gain.

The diet of an infant with Down syndrome should be advanced according to the usual schedule for food groups. However, delayed eruption of teeth may put off the introduction of hard solids. Parents should be reminded that a great deal of patience is required to teach a child with Down syndrome to feed from a spoon and to drink from a cup.

This article was reprinted with the permission of Dr. Rebecca Saenz.
Is it possible to breastfeed my baby who was born with Down syndrome?

How wonderful that you want to give your baby the precious gift of your milk! Babies with Down Syndrome experience special benefits from breastfeeding beyond the many advantages to typical newborns.

- Breast milk provides extra protection against infections and bowel problems, which are more common in babies with Down Syndrome.
- Breastfeeding improves mouth and tongue coordination, giving a child with Down Syndrome a real developmental advantage.
- The act of breastfeeding provides additional stimulation for your baby.
- Breastfeeding promotes closeness between mother and baby, and enhances mothering skills.
- Extra patience and reasonable expectations are critical when breastfeeding a baby with Down Syndrome. Low muscle tone and a weak suck can impede the baby's ability to breastfeed.

Here are a few tips that may help you breastfeed your baby:

- Because babies with Down syndrome are often sleepy and placid, you may need to interest your baby through frequent breast feedings throughout the day, wake him fully before breastfeeding, or provide extra touch and stimulation to keep him alert.
- Pay extra attention to positioning your baby at your breast. Try to keep your baby's body elevated near your breasts with his ear, shoulder and hip in a straight line and use extra pillows for support.
- If gulping and choking are a problem, try positioning your baby so that his neck and throat are slightly higher than your nipple.
- If poor muscle tone makes it difficult for your baby to latch on well, try supporting your baby's chin and jaw while nursing using the “Dancer Hold.” (The name of this position was coined by Sarah Coulter Danner, RN, CPNP, CNM, IBCLC and Ed Cerutti, MD. “Dancer” comes from the first letters of their last names (Dan + Cer).) Hold your baby with the arm opposite the breast you'll be offering. Using the hand on the same side as the breast you are offering, cup your breast with your thumb on one side of the breast, palm beneath, index finger pointing outward, and the other three fingers on the other side of the breast. Use your index finger to support your baby's lower jaw while nursing. As your baby’s muscle tone improves through breastfeeding and maturity, he will become able to support himself and breastfeed more effectively.

Resources for Additional Information

These publications may be available from your La Leche League Leader or http://store.lli.org/.

*Breastfeeding a Baby with Down Syndrome.*
Provides education and support for the mother who is breastfeeding a baby with Down Syndrome.

*Defining Your Own Success: Breastfeeding after Breast Reduction Surgery*
By Diana West: This thoroughly researched book has useful information far beyond what its title suggests. It contains extensive information about supplementation as well as increasing milk supply. Some mothers of babies with Down Syndrome will find this very useful.

La Leche League’s classic book, *The Womanly Art of Breastfeeding*, has lots of good information on breastfeeding your baby.

Many mothers find it helpful to call a local La Leche League Leader or attend a La Leche League meeting. The support and information of other breastfeeding mothers may make a big difference for you.

**Lactation Consultant who has experience with babies with Down syndrome:**
Cheryl Devonshire RN, MSN, IBCLC
Cleveland Clinic Hillcrest Hospital
(440) 312-5332
The Oral-Motor Myths of Down Syndrome
By Sara Rosenfeld-Johnson, M.S., CCC-SLP
Published in ADVANCE Magazine August 4, 1997

There is a visual impression that each of us holds in our mind when we think of a child or adult with Down syndrome. As a Speech Pathologist in private practice for twenty-five years and as a continuing education instructor for speech and language pathology classes on Oral-Motor Therapy, I have learned that this impression is a powerful teaching aid. When I teach, I ask the participants to tell me what they consider to be the characteristics of a Down syndrome child, or any low-tone child from an oral-motor point of view; without fail, I get the same responses. Their portrayals have become so predictable I have come to refer to them as the “Myths of Down syndrome”. This is what these professionals see:

**Myth #1**: A high narrow palatal vault

**Myth #2**: Tongue protrusion

**Myth #3**: Mild to moderate conductive hearing loss

**Myth #4**: Chronic upper respiratory infections

**Myth #5**: Mouth breathing

**Myth #6**: Habitual open mouth posture

**Myth #7**: Child’s tongue is too big for its mouth

These seven structural/functional disorders have been plausibly associated with Down syndrome, so why label them myths? Because the children my associates and I have worked with over the past fifteen years no longer exhibit these characteristics. The therapeutic community has inadvertently allowed these myths to flourish because we didn’t recognize that they could be prevented. These abnormalities emerge in most children by the time they enter early-intervention programs. What has been missing in our treatment that has allowed them to develop? How do we pursue prevention?

A quick review of some oral motor development basics. Children are born with two cranial soft spots. One on the top of the skull at midline and the other under the skull at the midline. Soft spots facilitate the birth process, allowing plates in the skull to overlap, easing the infant’s downward progress. After birth, the plates return to original position, eventually joining between 12 and 18 months of age. When the plates meet at the top of the skull, they take the shape of the brain’s contour, giving us a round-headed shape. In the Down’s population, this closing of plates may not occur until 24 months of age.

The identical closing of plates occurs under the brain in the plates of the hard palate. Just as the brain lends shape to the top of the head, the tongue shapes the palate. During the closing of the palate, if the tongue is not resting habitually inside the mouth, there is nothing to inhibit plate movement toward midline. The result:

**Myth #1**, a high, narrow palatal vault. Can this be prevented? Let’s return to the infant at birth. What is not commonly known is that even children with severe low tone at birth, including Down syndrome, are
nose breathers. They maintain their tongues in their mouth and upon examination their tongues are not abnormally large. Orally, these children look pretty much like any other infant with the exception that they have a weak suckle. This critical observation draws us to the connection between feeding muscles and muscles of speech.

In quick order, a cascade of events unfolds for these babies with weak suckle. Many mothers tell me they genuinely wanted to breast feed their newborn but were unable because the child had a weak suckle and/or the mother did not produce sufficient milk. Absent a medical problem, the difficulty is often that the child’s suckle was not strong enough to stimulate the mammary glands into producing adequate milk flow.

In this scenario mothers are traditionally encouraged by physicians to use a bottle. Bottle feeding is fine, when done therapeutically, but mothers should be given meaningful choices. Further, when bottle feeding is suggested for these infants, the hole in the nipple is often cross-cut or enlarged to make it easier for the infant to suckle. The child is held in the mother’s bent elbow and the bottle is held on a diagonal, nipple down. Visualize this - the milk flows easily into the infant’s mouth, but what stops the flow, allowing the child to swallow?

Myth #2: Tongue protrusion; Excessive tongue protrusion is a learned behavior that creates a physical manifestation. Keep visualizing this infant with low tone/muscle strength. There is a sphincter muscle at the base of the Eustachian tube whose function is to allow air to enter the middle ear. If weak muscle tone reduces the effectiveness of this sphincter muscle, then in the described feeding position, milk is able to enter the middle ear. The result: chronic otitus media; a primary causative factor in conductive hearing loss.

Myth #3: Fluid build-up in the middle ear, and the resulting infection, circumfuses throughout mucous membranes of the respiratory system and frequently becomes the originator of chronic upper respiratory infections.

Myth #4: The nasal cavity becomes blocked, the child transfers from nose breathing to mouth breathing.

Myth #5: The jaw drops to accommodate the mouth breathing, encouraging a chronic open mouth posture.

Myth #6: Because the tongue is no longer maintained within the closed mouth, the palatal arches have nothing to stop their movement towards midline and we end up with a high, narrow palatal vault, making full circle back to Myth #1. The child’s tongue remains flaccid in the open mouth posture, at rest.

Myth #7: Lack of a properly retracted tongue position. This enlarged appearance of the tongue is therefore not genetically coded, but rather the result of a series of care-provider related responses to the very real problem of weak suckle.

Understanding this scenario provides insight into the characteristics seen in these children when speech and language therapists begin to work on correcting their multiple articulation disorders. Addressing the oral muscles/structure from birth offers a more effective, preventative therapy than the wait-and-see approach taken today. These physical features are not predetermined. Our therapeutic goal should be to normalize the oralmotor system through feeding beginning in infancy. In infancy, nutrition is of primary concern. Our job is to balance nutrition, successful feeding and therapy.
Goal one is to change the position in which the child is being fed. Mouths must always be lower than ears to prevent milk flow into Eustachian tubes. The bottle position is altered to introduce the nipple from below the mouth, vertically encouraging a slight chin tuck. In this position the child draws the milk up the nipple predominately with tongue retraction. This position and retractive action prevents milk from flowing freely into the child’s mouth. The child no longer needs strong tongue protrusion to enable swallowing. It is also important not to make the hole in the nipple larger. Can children with weak suckle draw the milk into their mouths in this position? Yes, if you don’t use standard glass bottles. Bottles with the disposable liners, in either 4-ounce or 8-ounce sizes, can be filled with either pumped breastmilk or any variety of formula, and the air can be forced out causing a vacuum. This type of bottle can then be fed to the child in an upright position. If the child has trouble drawing the milk up because of weak suckle, you can facilitate the draw by pushing gently on the liner. When I have used this technique with even the most severely impaired children, it has been successful. After a week or so you will be able to push less as the muscles will begin to get stronger.

Facilitation is generally eliminated within 3-6 weeks. Breastfeeding mothers follow the same principles. Hold the child in a position where its mouth is lower than its ears. Stimulate the mammary glands while the child is suckling to increase milk flow. This also enables the mother’s milk to come in stronger. As the child’s suckle strength increases, the need for gland stimulation will be eliminated. A simple change in the position relationship of the child’s mouth to the bottle/breast can improve long-term oral-motor skill levels. That one change prevents a series of abnormal compensatory patterns to develop. It is so significant that I have incorporated feeding intervention into the treatment of all my clients with oral-motor issues regardless of age or diagnosis. Even my third-grade “regular” kids who are seeing me for an interdental lisp work on developing muscle strength and tongue retraction through feeding. If Speech and Language Pathologists accept the premise that normal speech is superimposed on normal oral structures and functions, then the call to provide early therapeutic feeding intervention takes on an importance that we must both acknowledge and affect.

Copyright © 1997 Sara Rosenfeld-Johnson, M.S., CCC-SLP, reprinted with permission. Sara Rosenfeld-Johnson has a website at: www.talktools.net.
Down syndrome occurs in people of all races and economic levels.
Health Care Information for Families of Children with Down Syndrome

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.
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.

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.
Life expectancy for people with Down syndrome has increased dramatically in recent decades - from 25 in 1983 to 60 today.
HELPING PROVIDE THE BEST FUTURE FOR YOUR CHILD WITH SPECIAL NEEDS

Your child has so many needs. Your time is very precious. You want the best for your child but it’s difficult to take that first step and start talking about these issues.

www.skylightfinancialgroup.com/financial-planning/special-needs-planning

Special Needs Planning: Information you need to know about Wills, Trusts, Guardianships and the ABLE Act

People with Down syndrome attend school, work, participate in decisions that affect them and contribute to society in many wonderful ways.
Medical/Financial Resources

Supplemental Security Income (SSI) payments for children with disabilities:
SSI makes monthly payments to people with low income and limited resources who are 65 or older, or blind or disabled. A child younger than age 18 can qualify if he or she meets Social Security’s definition of disability for children, and if his or her income and resources fall within the eligibility limits. The amount of the SSI payment is different from one state to another because some states add to the SSI payment. Your local Social Security office can tell you more about Ohio’s total SSI payment.

SSI rules about income and resources:
To determine eligibility for SSI, the Social Security Administration (SSA) office decides considers your child’s income and resources. Income and resources of family members living in your child’s household are also considered. These rules apply if your child lives at home. They also apply if he or she is away at school but returns home from time to time and is subject to your control.

If your child’s income and resources, or the income and resources of family members living in the child’s household, are more than the amount allowed, we will deny the child’s application for SSI payments. We limit the monthly SSI payment to $30 when a child is in a medical facility where health insurance pays for his or her care. Here is a benefits calculator to see if your family qualifies: www.livestrong.com/article/250112-how-to-calculate-a-childs-social-security-disability-benefits/

SSI rules about disability:
• Your child must meet all of the following requirements to be considered disabled and therefore eligible for SSI.
• Your child must not be working and earning over a determined dollar amount, which is adjusted each year. If he or she is working and earning this amount of money, SSA will find that your child is not disabled.
• The child must have a physical or mental condition, or a combination of conditions, that results in “marked and severe functional limitations.” This means that the condition(s) must very seriously limit your child’s activities.
• The child’s condition(s) must have lasted, or be expected to last, at least 12 months; or must be expected to result in death.
• If your child’s condition(s) results in “marked and severe functional limitations” for at least 12 continuous months, we will find that your child is disabled. But if it does not result in those limitations, or does not last for at least 12 months, we will find that your child is not disabled.

Providing information about your child’s condition:
When you apply for benefits for your child, we will ask you for detailed information about the child’s medical condition and how it affects his or her ability to function on a daily basis. We also will ask you to give permission for the doctors, teachers, therapists and other professionals who have information about your child’s condition to send the information to us. If you have any of your child’s medical or school records, please bring them with you. This will help speed up the decision on your application.

What happens next?
We send all of the information you give us to the Disability Determination Services in your state. Doctors and other trained staff in that state agency will review the information, and will request your child’s medical and school records, and any other information needed to decide if your child is disabled. If the state agency cannot make a disability decision using only the medical information, school records and other facts they have, they may ask you to take your child for a medical examination or test. We will pay for the exam or test. We may make immediate SSI payments to your child It can take three to five months for the state agency to decide if your child is disabled. However, for some medical conditions, we make SSI payments right away and for up to six months while the state agency decides if your child is disabled.
Following are some conditions that may qualify:

- HIV infection
- Total blindness
- Total deafness
- Cerebral palsy
- Down syndrome
- Muscular dystrophy
- Severe mental retardation (child age 7 or older)
- Birth weight below 2 pounds, 10 ounces

If your child has one of the qualifying conditions, he or she will get SSI payments right away. However, the state agency may finally decide that your child’s disability is not severe enough for SSI. If that happens, you will not have to pay back the SSI payments that your child got.

SSI disability reviews:

Once your child starts receiving SSI, the law requires that we review your child’s medical condition from time to time to verify that he or she is still disabled. This review must be done:

- At least every three years for children younger than age 18 whose conditions are expected to improve; and
- By age 1 for babies who are getting SSI payments because of their low birth weight, unless we determine their medical condition is not expected to improve by their first birthday and we schedule the review for a later date.

We may perform a disability review even if your child’s condition is not expected to improve. When we do a review, you must present evidence that your child is and has been receiving treatment that is considered medically necessary for your child’s medical condition.

What happens when your child turns age 18:

- For disability purposes in the SSI program, a child becomes an adult at age 18, and we use different medical and non-medical rules when deciding if an adult can get SSI disability payments. For example, we do not count the income and resources of family members when deciding whether an adult meets the financial limits for SSI. We count only the adult’s income and resources. We also use the disability rules for adults when deciding whether an adult is disabled.
- If your child is already receiving SSI payments, we must review the child’s medical condition when he or she turns age 18. We usually do this review during the one-year period that begins on your child’s 18th birthday. We will use the adult disability rules to decide whether your 18-year-old is disabled.
- If your child was not eligible for SSI before his or her 18th birthday because you and your spouse had too much income or resources, he or she may become eligible for SSI at age 18.

How can I get ready for the disability interview?

- Request a disability starter kit from the social security website or local office. It includes a checklist and a worksheet to help you gather the information you need. Have this information with you at the time of the interview.
- If you have access to the Internet, you can complete an online Child Disability Report at www.socialsecurity.gov/childdisabilityreport.
- For more information, visit our website at www.socialsecurity.gov/disability/ or call toll-free 1-800-772-1213 (for the deaf or hard of hearing, call TTY 1-800-325-0778).

Early Intervention/Help Me Grow

The state of Ohio’s Early Intervention services program is called Help Me Grow. It is designed to meet the developmental needs of each child eligible for Early Intervention, and the needs of the family related to enhancing the child’s development. In addition to the services below Early Intervention also provides early identification, screening and assessment services.
The following are types of Early Intervention Services:

1. Assistive Technology Device and assistive technology services means any items, equipment, product or system used to increase, maintain, or improve the functional capabilities of children with disabilities, along with the services necessary to use them.

2. Audiology means providing services for children with auditory impairment; determining the range, nature, and degree of hearing loss; and auditory training, aural rehabilitation, speech, reading and listening device orientation and training.

3. Family Training, Counseling and Home Visits means services provided, as appropriate, by social workers, psychologists, and other qualified personnel to assist the family of an eligible child in understanding the special needs of the child and enhancing the child’s development.

4. Health Services necessary to enable the infant or toddler to benefit from the other Early Intervention Services.

5. Medical Services only for diagnostic or evaluation purposes means services provided by a licensed physician to determine a child’s developmental status and need for Early Intervention Services.

6. Nursing Services includes assessment of health status for the purpose of providing nursing services, provision of nursing care to prevent health problems, restore or improve functioning and promote optimal health and development.

7. Nutrition Services includes assessment and development of appropriate plans to address nutritional needs of children and making referrals to appropriate community agencies.

8. Occupational Therapy includes services to help the child develop and improve self-help skills and adaptive behavior and play. The occupational therapist also addresses the young child’s motor, sensory, and postural development.

9. Physical Therapy is designed to prevent or alleviate movement dysfunction through a program tailored to the individual child.

10. Psychological Services address issues related to learning, mental health, and development.

11. Service Coordination means the activities carried out by a service coordinator to assist and enable a child and his family to receive the rights, procedural safeguards, and services.

12. Social Work Services includes assessment, individual and family group counseling and coordination of community resources.

13. Special Instruction includes the design of learning environments and activities that promote the child’s acquisition of skills in a variety of developmental areas.

14. Speech-Language Pathology includes identification of children with disorders or delays in communication skills, referrals for medical or other professional services and provision of services. Also includes sign language and cued-language services where necessary.

15. Transportation and related costs necessary for an infant or toddler and the infant’s or toddler’s family to receive a service.

16. Vision Services means evaluation and assessment of visual functioning, referral for medical or other professional services, and communication skills training.

Other Services means services the Individualized Family Service Plan (IFSP) team deems necessary.