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Infant Development and Early Intervention Services

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

Early Intervention

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

Benefits to My Child

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

Each type of early intervention addresses specific aspects of your baby’s development.

Physical therapy focuses on motor development. For example, during the first three to four months of life, infants can be expected to gain head control and the ability to pull to a sitting position (with help) with no head lags and enough strength in the upper torso to maintain tone, and a physical therapist can illustrate exercises that you can do with your baby to help him or her achieve this milestone.

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

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

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

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

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

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

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

**Early Intervention Services in Michigan**
The Early Intervention program in Michigan is called Early On (see Section 3, page 4) You can obtain a referral from your baby’s doctor, or you can call Early On directly at (800) EARLYON. Once a referral has been made, the program staff must schedule and complete an initial evaluation within a specified time. Once the assessment is done, a caseworker is assigned to coordinate the various services for which your baby and
family qualify. Early intervention services are individualized to meet the specific needs of your baby. The caseworker, therapists and family members will determine the areas to focus on and set clear, measurable goals based on the developmental milestones. These will be recorded in a document called the Individualized Family Service Plan, or IFSP.

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

### Developmental Milestones

<table>
<thead>
<tr>
<th>Milestone</th>
<th>Range for Children with Down Syndrome</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 ¼ 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 ½ 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 ½ - 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 ½ - 8 ½ years</td>
<td>3 ¼ - 5 years</td>
</tr>
</tbody>
</table>

What is Early On?

*Early On* is a statewide, comprehensive, coordinated interagency system of early intervention services for infants and toddlers birth to age three years with disabilities and their families. In Michigan, *Early On* is coordinated by the Michigan Department of Education and provides services under Part-C of the Individuals with Disabilities Education Act (IDEA).

Every local health department has at least one professional in place that is designated as its liaison to help families access Early On services. Any family concerned about the development or health of their child can access the system by contacting a local agency or by calling 1-800-Early On.

Local communities receive funding through their local Intermediate School District (ISD) to implement Early On. Each local ISD jurisdiction has an interagency coordinating council (comprised of individuals from human service agencies, parents, educators, and other agency personnel who serve families) that guides implementation locally. Implementation is also guided through local memoranda of understanding between education, mental health, public health and social services.

Infants and toddlers from birth through age two who need early intervention services because they are experiencing developmental delays and/or have a diagnosed physical or mental condition that has a high probability of resulting in developmental delay are eligible.

Your *Early On* coordinator may recommend or you may request the coordination of the following services with other community agencies:

- √ assistive technology devices
- √ family training
- √ health services
- √ nursing services
- √ physical therapy
- √ referrals to community agencies
- √ service coordination services
- √ specialized instruction
- √ transportation & related costs
- √ audiological services
- √ feeding & nutrition services
- √ diagnostic medical services
- √ occupational therapy
- √ psychological services
- √ respite
- √ social work services
- √ speech-language pathology
- √ vision services

To the maximum extent appropriate to the needs of the child, *Early On* services will be provided in natural environments including the home and community settings.

*Early On* is a family-focused process, with emphasis on family strengths and abilities, which requires the development of an individualized family service plan specific to each enrolled family, based on the findings of a multidisciplinary evaluation of the child and family.
What services does Early On offer?

Early On Coordinators are located in each county and are available to help a parent decide if they want to enter the Early On system. Children with Down syndrome automatically qualify for these services.

1. Evaluation: Children with developmental delays are evaluated. Early On may refer you to other agencies for your initial evaluation and service coordination (e.g. Ken-o-Sha in Kent County).
2. Individualized Family Service Plan: Through the initial evaluation, an Individualized Family Service Plan (IFSP) is developed. The IFSP addresses the developmental needs of the baby as well as the needs of the family in helping the baby (see listing of available services above). See sample copy of IFSP at Section 3, Page 6.
3. Service Coordination: An Early On Service Coordinator helps the parent coordinate the services outlined in their baby's plan.
4. Implementation: Services outlined in the IFSP are implemented with the permission of the parent.

What Information will be included in the IFSP?

The IFSP will include the results of the evaluation and will describe what will happen to help your child grow and learn. If you choose intervention services, your IFSP also will contain information relative to the services to be performed.

You and your Early On team will work together to make the plan. The final choices of the plan are a team decision. You may not agree with the team. If you don’t agree, see the Early On Family Rights brochure or call 1-800-327-5966 to learn what you can do.

What is the cost? Are there any income restrictions?

There is no charge to families for an evaluation, the development of an IFSP or service coordination. Most services outlined in IFSP are available at no cost, but that is determined by the agency’s budget and your family’s needs (i.e. income, number of family members, etc). As agency budgets and family needs change, it may be beneficial to reapply for services that had been previously denied. Early On is available regardless of income.

Why is Early On a leader in developing relationships?

Family-centered care is the set of beliefs and principles that are the foundation for Early On. Family-centered care is a new way of thinking about and working with children and their families. At the heart of family-centered care is the recognition that the family is the constant in the child’s life. Family-centered care builds equal partnerships between families and professionals and promotes trust and respect. Family-centered care honors the priorities, choices, and resources of the family.

Both families and professionals think that working with this set of beliefs and principles will create the brightest futures for our children and families.

See the New and Expectant Resource Guide at Appendix 1 for a listing of county-by-county phone numbers, call 1-800-EARLY ON or visit http://www.cenmi.org/pair/coordinators.asp to locate your Early On coordinator.
The Oral-Motor Myths of Down Syndrome®

By Sara Rosenfeld-Johnson, M.S., CCC-SLP

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 child with Down syndrome, 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: a high narrow palatal vault, (Myth #1), tongue protrusion (#2), mild to moderate conductive hearing loss (#3), chronic upper respiratory infections (#4), mouth breathing (#5), habitual open mouth posture (#6), and finally, the impression that the child's tongue is too big for its mouth (#7).

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 which 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 children with Down syndrome, 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 breastfeed 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? Tongue protrusion; myth #2. 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 and we have 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. Lack of a properly retracted tongue position is myth #7. 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 oral-motor 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.

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Visit www.talktools.net for more articles on oral-motor speech therapy, feeding therapy and Down syndrome
Helping Babies with Down Syndrome
Develop Speech and Language
By Libby Kumin, Ph. D., CCC-SLP

Welcome to the great adventure of helping your baby learn to speak. It is exciting to get to know your baby and to watch them learn about their world. While your newborn cannot talk to you, they can communicate with you through cries, smiles, gestures, sound and body language. Your baby wants to communicate with you and they begin communicating right from birth. When your baby cries, he is often sending a message that he wants attention. When your baby smiles and looks at you, he is sending you a message that he is happy and content, and maybe that he wants to play with you or be held. The way that you react to these messages can foster further communication. If you respond by coming to the baby and taking care of their needs, the baby will gradually become aware that making noises and sounds affects the environment. You are the most important person in your child’s life, and you will be instrumental in helping your baby learn language.

There are many things that we can do to help children move along the road to speech. Speech involves coordinating breathing, voice, and rapid and precise movements of the lips, tongue, palate and jaw. We use the same structures and muscles for speech that we also use for breathing, eating, drinking, blowing bubbles, and making clicking, popping, and “throwing a kiss” sounds. Through feeding and play, we can begin to work early on some of the same skills and movements that your child will need to speak. Here is what you can do to help your infant develop language and speech:

LOOK
Infants look all around, taking in the many sights of their new world. To learn language, infants need to learn 3 visual skills:

 To look at you
 To look at an object together with you
 To focus on an object and explore it

You can help your baby learn these skills through play. Encourage your baby to look at your face by making funny faces and smiling. Hold objects up to your face so that your baby looks right at you, but also hold objects in your hand and look at the object together with your infant. When you look at an object together, take time to explore it. Use sound effects and look interested in the toy. Touch the toy, smell it, look at it and comment on what you see and feel. That will increase your baby’s interest in exploring.

LISTEN
In order to listen, your baby needs to have adequate and reliable hearing. Children with Down syndrome often have fluid in the middle ear and fluctuating hearing loss. Hearing needs to be checked frequently. The Healthcare Guidelines for Individuals with Down Syndrome (see Resources) recommend hearing testing by three months of age, with follow-up testing every six months to three years of age and annually.
throughout childhood. The pediatrician or otolaryngologist (ear, nose and throat medical specialist) working with the audiologist (specialist in hearing testing and treatment) can develop a treatment program to ensure your baby’s hearing will be the best possible.

You can teach your child to pay attention to sound, and to listen longer to sounds. Musical tapes and CDs and musical toys (such as bells and xylophones) are terrific! Comment on sounds and look for the source of the sound, e.g., “Do you hear an airplane? Look, there it is!” or “I hear a meow. Let’s look for the cat.” When you come into your child’s room, call his name and wait for him to turn to you. Sing songs and play with musical toys. Sway back and forth, dance with your child, and respond to the rhythm. Many of the speech rhythm concepts can be learned through music.

**INTERACT**
You want to help your infant develop the awareness that making noises or using gestures will get results from the environment. This is known as *communicative intent*. How can you help your child develop this skill? Interpret anything that your child does as communicative and respond to it in that way. So, if your baby kicks her feet, play a game with her toes or put a balloon or even a tambourine near her feet that she can kick. If she looks over at the front door, ask her if she wants to go outside. If she makes a “mmm” sound, react to it as if she said “mama” and respond. Say the word “mama” and point to mama. If she makes a “b-b-b” sound, react as if she said “ball.” Point to the ball and play with it. Engage your baby in the play. Show by your actions how delighted you are at your child’s attempt to communicate.

**TOUCH**
Infants respond to touch. They may find it comforting, or they may find it uncomfortable. Some infants with Down syndrome are hypersensitive to touch, i.e. they don’t like being touched especially around the mouth. Current thought is that children who are hypersensitive need lots of sensory experience with touch through massage and play. Use a washcloth and lotion to massage your child’s skin. Rub cotton, velvet, wool, and burlap on your child’s skin during play. You might use different types of teething toys, which have different surface designs and shapes. Put together samples of all kinds of textures for your child to explore. For example, you might hide small toys in a shoebox filled with pasta or rice and help your child find the toys. You might have pieces of sandpaper, cotton balls, aluminum foil, Velcro, sponge, and velvet in a bag for your child to feel and learn about different textures (be sure to supervise; safety first). Provide interesting toys for your child to bite, mouth, and explore. Infant massage specialists and occupational therapists can provide assistance, when needed.

**FEEDING/STRENGTHENING MUSCLES**
Feeding uses many of the same muscles and structures that are used for speaking. Sometimes, infants with Down syndrome have difficulty with feeding because of low muscle tone (floppy muscles) or tongue or lip strength and control. If your child is experiencing any difficulty with feeding, ask for help. Many hospitals and/or early intervention programs have feeding specialists, and a feeding evaluation can be done within the first week after birth, if needed.
PLAY WITH SOUND
Your baby makes sounds during the course of the day. When your baby makes a sound, such as *pa-pa-pa*, imitate that sound and smack your lips together making the *p* sound. Follow your child’s lead, and repeat the sounds or movements (lip puckers and throwing a kiss) that your child makes. Repeat the same sound that your child made, but then vary it a bit. For example, sing the *p-p-p* up and down the scale. Or say it in a very high voice, then a very low voice; shout the sound then whisper the sound. Make it fun! Make a variety of sounds – use lip-popping sounds, click the tongue on the roof of your mouth, say *cha-cha-cha* to exercise your jaw.

ORAL MOTOR EXERCISES
Oral massage, oral exercises and sound play can help your child learn skills that will be needed for speech. A speech-language pathologist who specializes in working with muscles of the facial area is known as an oral motor specialist. A complete oral motor evaluation is recommended before one year of age. The specialist can develop a home treatment exercise program that will help your child prepare for speech.

LANGUAGE-RICH ENVIRONMENT
Create a language-rich environment for your infant. In the course of the day, label any objects or people in whom your child shows interest. Make this a part of your daily activities, and follow your child’s lead. Certain activities lend themselves to stimulating specific vocabulary. For example, eating lends itself to talking about food and drink, utensils, kitchen items, and verbs (*drink, eat, open*). Bathtime lends itself to talking about body parts, water, soap, shampoo, and hot and cold. When you go outside, there are trees and flowers, vehicles, stores, community workers, and neighbors. Use short phrases, so your child will learn the important words in his environment. Wait and see if your child will try to say words and sounds; take time to give him a chance to participate. A language evaluation is recommended by or before one year of age.

We learn language by watching and listening to people around us. Babies learn to make connections between the words they hear and the objects and people they see. Most children with Down syndrome make that connection and are ready to use language on or before one year of age. At that age, they can usually understand words, but they are not ready to speak. But it is important that they continue to learn new language concepts, and that they have a more complex way of letting you know their needs than just crying, smiling, or looking. Babies and toddlers with Down syndrome have a lot to tell us and they become frustrated if they cannot make their needs known. Therefore, babies and toddlers need to use a system other than speech as a transitional system to communicate their needs until their muscles, nerves, and coordination skills are ready for speech.
SYSTEMS OF COMMUNICATION
The research has shown that children with Down syndrome begin to use speech anywhere from nine months to eight years of age. That is a wide range, but we don’t need to passively wait for speech to happen. We can provide a pre-speech communication system and help the child learn skills that they need to be able to speak. The speech-language pathologist can help by providing information, and teaching you the skills that you need to help your child. Books and newsletters can provide helpful information for you. Some suggested readings are included in the resources section.

The systems that are generally used by children with Down syndrome to communicate until they are ready to use speech are sign language, communication boards, picture exchange communication, and electronic communication systems

- **Sign language** systems are symbolic hand gestures. Gestures that resemble actual real life situations, e.g., pointing to the mouth for eating or pretending to drink from a cup for drinking, may be used. Formal sign language systems such as American Sign Language (ASL) and Signed Exact English (SEE) may be taught. They may be used as a short-term transitional communication system until the child develops speech.

- **Communication boards** are individually designed communication systems made up of pictures, photographs, line drawings, or words (for older children). Your child points to the pictures that represent what he is requesting. Communication boards may be made of tagboard, or may be plastic sheets with pictures tucked into pockets, photo albums with communication pictures, or magnets on the refrigerator with pictures of apples, juice, milk, water and soda. There are many varieties of communication boards and they are inexpensive and individualized.

- **Picture exchange systems** may also be used where parent and child physically exchange photographs or line drawings as the basis for communication, much like a speaker and listener.

- **Electronic communication systems** can also be used. They are more costly, but provide an early “voice” for your child.

In all of these systems, you will be using speech along with the sign or picture, so your child will continue to hear and learn speech. Although your child will be communicating through the sign or picture, you will always accompany that sign or picture with speech. This combination is known as *Total Communication*.

The speech-language pathologist can work with you and your child to help you learn the signs, and to choose materials for the communication board or exchange system that will be useful for you and your child. Why is it important to use a transitional communication system until your child is ready to use speech? Through the signs and pictures:

- Your child will be able to communicate his messages to you.
- You will be able to understand the communication, lessening frustration for you and your baby.
- *Your child will be able to continue progressing in language, learning new words and concepts and using them.*
- You will be able to get to know your child’s personality and sense of humor through his communication.
SPEECH AND LANGUAGE SERVICES

School systems have speech-language pathologists who work with children with special needs. According to the guidelines in IDEA 97 (Individuals with Disabilities Education Act Amendments of 1997), children who are at risk for delays in communication (speech, language, and hearing) are eligible for special education services. Although the educational plan is supposed to be individualized and designed to meet the needs of the individual child, many school systems do not provide speech and language evaluations and/or treatment until a child with Down syndrome is older (three years of age) or is speaking. In countries outside of the United States, early intervention services may or may not include speech and language.

Speech and language information and help is available. A speech-language pathologist has professional training in communication development and disorders. The American Speech-Language-Hearing Association awards professional credentials when the speech-language pathologist has successfully completed undergraduate and master’s degree accredited programs, completed extensive clinical practicum, and a clinical fellowship year, and passed a national certification examination. Speech-language pathologists who have been awarded professional credentials will use CCC-SLP after their names. The local school system is a good starting place to look for speech and language help.

References & Resources

Speech Sound Cues

Initially, a child or infant may be more “aware” of hand movement than sound to be eventually produced. Cueing will help your child begin the process of making sounds by associating the cue with the sound.

<table>
<thead>
<tr>
<th>SPEECH SOUND</th>
<th>CUE</th>
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<tbody>
<tr>
<td>P, B</td>
<td>Point index finger into your cheek near the corner of your mouth</td>
</tr>
<tr>
<td>T, D, N, L</td>
<td>Touch the tip of your index finger just above the center of your upper lip</td>
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<tr>
<td>M</td>
<td>Pull the tip of your index finger across closed lips</td>
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<tr>
<td>K, G</td>
<td>Place one finger under the chin back by the voice box</td>
</tr>
<tr>
<td>F, V</td>
<td>Place tip of index finger on the center of your lower lip</td>
</tr>
<tr>
<td>O, OO</td>
<td>Move index finger around pursed lips</td>
</tr>
<tr>
<td>EE</td>
<td>Push tips of thumb and index finger into the corners of your mouth</td>
</tr>
<tr>
<td>SH</td>
<td>Place index finger up to lips and say, “Shhh…”</td>
</tr>
<tr>
<td>CH, J (sometimes SH)</td>
<td>Place thumb and index finger around jaw with fingertips into the corners of your mouth</td>
</tr>
<tr>
<td>TH (voiced and unvoiced)</td>
<td>Stick out your tongue to touch your index finger, which is held vertically, slightly away from your mouth</td>
</tr>
<tr>
<td>“ER”</td>
<td>Place two fingers under your chin, back by your voice box, using a slight vibrating motion</td>
</tr>
<tr>
<td>H</td>
<td>Point your thumb at the center of your chest. Move it up and out to show the direction of the airflow.</td>
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Sensory Integration

What is Sensory Integration?
Sensory integration is the brain’s ability to organize sensations from the body and the environment, thus making it possible for a person to function effectively. The brain uses information from all of the sensory systems, which include tactile (touch), taste, smell, visual, vestibular (sense of movement) and position in space. When sensory integration dysfunction occurs within the system, an individual may have difficulty with every day activities, such as dressing, grooming, social interaction, attention, and school work to mention a few. For example, a child may cry uncontrollably or hide when it’s time to have their hair washed or brushed. In severe cases, a person may have a limited diet due to texture defensiveness or exhibit great difficulty with social touch or interaction.

An occupational therapist trained in sensory integration can provide therapy using sensorimotor activities to aid a person to integrate the sensory systems. Assessment begins with a thorough evaluation of how each system is functioning. Using the information gained in the evaluation process, a therapist will aid and guide an individual and family in developing a specifically designed program to facilitate improved integration. Activities to improve a child’s sensory integration may include brushing, deep pressure, swinging or cross crawling. As the sensory systems begin to function in harmony with each other, the individual is better able to interact and explore their environment.

Who might need help with Sensory Integration?
Individuals with sensory integration dysfunction, learning disabilities, developmental disabilities, fine motor difficulties, syndromes and genetic disorders, physical disabilities, prematurity or high risk and autistic spectrum disorder are examples of those who could benefit from this therapy.

Other signs that this therapy may be helpful for a child are when a child has irregular sleeping patterns, difficulty accepting changes in routine, limited diet (avoids certain textures), inability to play well with other children, clumsy or uncoordinated movements, poor balance, frequent falls, difficulty calming as an infant, illegible/labored handwriting, limited or no awareness of safety issues, emotional/aggressive reactions, overreactions to touch, decreased awareness of pain and/or temperatures, accident-prone tendencies, strong clothing preferences, or difficulty developing skills for fine motor activities (i.e., tying shoes, buttoning, opening containers), difficulty engaging in social interactions/activities with other children, prefer for playing alone, or being rigid or controlling with belongings and routines.

How do you learn if someone needs this help?
The Sensory Integration and Praxis Test (SIPT) is one standardized assessment tool that may be utilized when a detailed breakdown of sensory processing is needed. This assessment is appropriate for children from the ages four through eight. A detailed sensory history including parental input and clinical observation/interview is involved in the evaluation of individuals with suspected sensory integration dysfunction. A SIPT certified therapist is qualified to administer and interpret the results of the SIPT.

(From Families at Heart newsletter, March/April 2004 & DVCH Pediatric News, April 2002)
# Glossary of Special Education Terms and Common Abbreviations

<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
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<tbody>
<tr>
<td>ADA</td>
<td>Americans with Disabilities Act</td>
</tr>
<tr>
<td>ARC</td>
<td>Organization that advocates with and/or on behalf of persons with developmental disabilities and their families</td>
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<tr>
<td>ASD</td>
<td>Autism Spectrum Disorder</td>
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<tr>
<td>AT</td>
<td>Assistive Technology</td>
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<tr>
<td>CI</td>
<td>Cognitive Impairment</td>
</tr>
<tr>
<td>CP</td>
<td>Cerebral Palsy</td>
</tr>
<tr>
<td>CMH</td>
<td>Community Mental Health</td>
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<tr>
<td>DCH</td>
<td>Department of Community Health</td>
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<tr>
<td>DD</td>
<td>Developmental Disability</td>
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<tr>
<td>DS</td>
<td>Down Syndrome</td>
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<tr>
<td>ECDD</td>
<td>Early Childhood Developmentally Delayed (also referred to as ECSE)</td>
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<tr>
<td>ECSE</td>
<td>Early Childhood Special Education (also referred to as ECDD)</td>
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<tr>
<td>EI</td>
<td>Emotionally Impaired</td>
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<tr>
<td>ESY</td>
<td>Extended School Year</td>
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<tr>
<td>FAPE</td>
<td>Free Appropriate Public Education</td>
</tr>
<tr>
<td>FBA</td>
<td>Functional Behavior Assessment</td>
</tr>
<tr>
<td>HI</td>
<td>Hearing Impaired</td>
</tr>
<tr>
<td>ICC</td>
<td>Interagency Coordinating Council (LICC – Local; RICC – Regional; SICC – Statewide)</td>
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<tr>
<td>IDEA</td>
<td>Individuals with Disabilities Education Act</td>
</tr>
<tr>
<td>IEE</td>
<td>Independent Educational Evaluation</td>
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<tr>
<td>IEP</td>
<td>Individualized Educational Program (age 36 months and up)</td>
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<tr>
<td>IEPT</td>
<td>Individualized Education Planning Team</td>
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<tr>
<td>IFSP</td>
<td>Individual Family Service Plan (age birth to 36 months)</td>
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<tr>
<td>ISD</td>
<td>Intermediate School District (e.g. Kent ISD, Ottawa ISD, etc.)</td>
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<tr>
<td>LD</td>
<td>Learning Disability</td>
</tr>
<tr>
<td>LEA</td>
<td>Local Education Agency</td>
</tr>
<tr>
<td>LOF</td>
<td>Letter of Finding</td>
</tr>
<tr>
<td>LRE</td>
<td>Least Restrictive Environment</td>
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</table>
MDE, OSE/EIS  Michigan Department of Education, Office of Special Education and Early Intervention Services
MET  Multi-disciplinary Evaluation Team
NCLB  No Child Left Behind
OCR  Office of Civil Rights
OSEP  Office of Special Education Programs
OSERS  Office of Special Education and Rehabilitation Services
OT  Occupational Therapy
P&A  Protection and Advocacy
PA 451  Michigan Special Education Regulations
PAC  Parent Advisory Committee
Priority Person  This is the professional (OT, PT or speech therapist) assigned to your family to provide service coordination while in the Early On program
PT  Physical Therapy
SLI  Speech and Language Impaired
SLP  Speech-Language Pathologist
SPD  Sensory Processing Disorder
SSI  Supplemental Security Income
TC  Teacher Consultant
VI  Visually Impaired
WISC  Weschler Intelligence Scale for Children