Comprehensive speech and language treatment for infants, toddlers, and children with Down Syndrome

by Libby Kumin

Libby Kumin is a Professor and Department Chair of the Speech-Language Pathology Department at Loyola College in Baltimore.

This text is from the book Down Syndrome: A Promising Future, Together, Edited by Terry J. Hassold and David Patterson. This material is used with permission of Wiley-Liss, Inc., a subsidiary of John Wiley & Sons, Inc. Copyright 1998 by Wiley-Liss, Inc. This article by Libby Kumin is just one chapter of this comprehensive text on Down syndrome.

This chapter discusses a comprehensive approach to speech and language treatment from infancy through elementary school, which considers the communication strengths and challenges for children with Down syndrome, as well as the specific needs of the individual child with Down syndrome.

Speech and language are complex and present many challenges to the child with Down syndrome that need to be addressed through a comprehensive approach to speech and language treatment. There have been major historical, legislative, and financial influences on speech and language services and service delivery for children with Down syndrome; these are summarized below.

LEGISLATIVE BACKGROUND

The Education for All Handicapped Children Act (Public Law 94-142) was passed in 1975 and resulted in special education services in separate classrooms as the model for helping children with disabilities. The Individualized Education Plan (IEP) became the blueprint for each child's educational program for the school year. The law has been amended and renewed to the present day. The most recent legislation is the Individuals with Disabilities Education Act Amendments of 1997 (IDEA 97).

The important ramifications of IDEA for communication in school-age children are that speech-language pathology is a related service and is based on a remediation model. Related services are developmental, corrective, and other supportive services, as may be required to assist a child with a disability to benefit from special education, and includes the early identification and assessment of disabling conditions in children. A remediation model means that the child receives services only when there is a documented problem based on test results, in order to address that problem. With inclusion becoming more common and the regular education initiative, the child's needs for speech-language pathology services may be greater, and the goals may be higher.

Public Law 99-457 provided funding to extend services to children ages 3 to 5 years using the IEP as the child's service plan, and provided for early intervention services to children ages birth to 2 years who are experiencing developmental delays or who have a diagnosed condition that will place them at risk for developmental delay, using the Individualized Family Service Plan (IFSP) as the family's service plan. Children with Down syndrome would qualify for evaluation for services from the time of diagnosis, based on the guidelines in PL 99-457. Important ramifications of PL99-457 for speech and language treatment are that speech-language pathology services are based on a prevention model and that the family is included as central to the treatment process. When the child is 3 years of age, the educational plan changes from the IFSP to the IEP, and this represents a shift from a prevention model to a remediation model, and a shift in service delivery.

IDEA 97 has continued the funding for early intervention services for children under age 3, which was first mandated under PL 99-457. The sections related to early intervention are under Part C in IDEA 97. Whereas speech-language pathology is defined as a related service for children age 3 and older, it is defined as an early intervention service for infants and toddlers younger than 3 years. Early intervention services "are designed to meet the developmental needs of an infant or toddler with a disability in any one or more of the following areas: physical development, cognitive development, communication development, social or emotional development, or adaptive development" (Section 632(C)).

Under IDEA 97, it appears that children under age 3 with Down syndrome would be eligible for early speech-language evaluation and treatment services, audiological evaluations including hearing testing, feeding therapy, assistive communication devices, and transportation and related costs.

IDEA 97 considers several issues that have a direct impact on where services should be delivered. Part A deals with elementary through secondary school. For elementary-school-age children through high-school age, services are most likely to be delivered on site within the school. According to the statutes of IDEA 97, services should be provided in the natural environment, and the interpretation appears to be that "the natural environment" means within the classroom. There is a recognition within the legislation that inclusion within regular classrooms is increasing, and that classroom teachers in regular education settings and specialists (such as speech-language pathologists) in special education roles are working together more frequently. For example, the legislation mandates that the regular education teacher in a child's classroom be part of the IEP team for that child and provides funding for regular educators, classroom assistants, and special education and related services personnel to receive training regarding children with disabilities.

FINANCIAL BACKGROUND

Funding issues often drive service delivery in schools and community settings. Most available funding is through health insurance or through federal and state legislation that provides funding for educational budgets. Many health insurance plans do not fund long-term speech and language treatment for children with developmental disabilities. School systems are mandated to provide services based on specific criteria that they have developed to ensure compliance with federal funding. It is essential to become familiar with the entrance and exit criteria, eligibility for services through the local schools, and the criteria and guidelines through the health insurance agency.
Although every child is a unique individual and therapy must be designed for the individual child, there are some general considerations that form the foundation for a speech and language treatment program.

Communication skills are important and contribute to inclusion and integration. Communication includes not only speech, but also facial expressions, smiles, gestures, pointing, high five signs, and alternative systems such as sign language and computer-based systems. Children and adults are more likely to interact when they can understand and be understood. At home, in school, and in the community, a functional understandable communication system facilitates relationships.

Although there are common speech and language problems, there is no single pattern of speech and language common to all children with Down syndrome. There are, however, speech and language challenges for most children with Down syndrome. Many children with Down syndrome have more difficulty with expressive language than they do with understanding speech and language, that is, receptive language skills are usually more advanced than expressive language skills. Certain linguistic areas, such as vocabulary, are usually easier for children with Down syndrome than other areas, such as grammar. Sequencing of sounds and of words may be difficult for many children. Many children have difficulties with intelligibility of speech and articulation. Some children have fluency problems. Some children use short phrases, while others have long conversations. All of the speech and language problems that children with Down syndrome demonstrate are faced by other children as well. There are no speech and language problems unique to children with Down syndrome. This means that there is a great deal of knowledge and experience that can be applied to helping a child with Down syndrome with his/her specific areas of challenge.

The speech and language treatment program should be individually designed based on a careful evaluation of each child's communications patterns and needs. It is especially important to include the family as part of the treatment team. The child, family (including siblings and extended family), teacher, friends, and community members can all contribute to the child's communication success. The speech-language pathologist can guide, inform, and help facilitate and enhance the process of learning to communicate effectively. But language is part of daily living and must be practiced and reinforced as part of daily life.

During the school years, speech and language treatment must relate to the child's educational setting and the communication needs of the classroom and the curriculum. Speech and language treatment should also consider the child's needs in relation to community activities such as religious groups and scouting. Communication goes on outside of therapy sessions, as well as inside the sessions. Inclusion and community involvement promote interactive communication and provide models and communication partners.

On the path from infancy to adulthood, the child may need speech-language treatment at various points, and the family may need ongoing information, resources, and guidance to work with the child at home. At different developmental stages, the child may need periods of treatment and/or a home program.

What is a comprehensive speech and language treatment program? It is an individually designed program that meets all of the communication needs for a specific child. Let's examine some of the areas that could be targeted in a comprehensive program at different speech and language learning stages.

During the birth to one-word period, the most important intervention occurs at home. Families need to be the focus of the treatment program. In the program at Loyola College, families observe the therapy sessions 100% of the time, and discuss all of the activities with a clinical supervisor. For each session, they are provided with home activities so that speech and language experiences will continue in the home environment (Kumin et al., 1991). For infants, one focus of the treatment program will be sensory stimulation: providing activities and experiences to help the infant develop auditory, visual, and tactile skills, including sensory exploration and sensory feedback and memory. The child will experience what a bell sounds like, or the different sensations while touching velvet or sandpaper. It is essential to monitor the child's hearing status for every infant with Down syndrome, since they are at high risk for otitis media with effusion (Roberts and Medley, 1995). The most recent literature (Gravel and Wallace, 1995) is finding strong relationships between OME (otitis media with effusion, or fluid in the middle ear without signs or symptoms of ear infection), language development, and academic achievement in typically developing children. Some of the delays in language that we see in children with Down syndrome may be related to the presence of OME. The pediatrician or otorhinolaryngologist and the audiologist will be able to monitor hearing status and treat fluid accumulation in the ear.

Speech is an overlaid function in the human body. Feeding and respiration involve many of the structures and muscles used in speech. Therefore, feeding therapy, sensory integration therapy, and other complementary therapies may have a positive impact on speech function.

Many infants and toddlers whom we see are very sensitive to touch. They do not want to be touched, don't want their teeth brushed, or do not like certain textures of foods or perhaps mixed food textures. The term "tactilely defensive" is sometimes used. We have found that by using oral massage, direct muscle stimulation, and an oral normalization program (using the NUK massager), infants and toddlers are able to learn to tolerate touch in the lip and tongue area. The massage program begins with the arms and legs and gradually moves toward the face and intra oral area. A detailed description of the program is included in an article by Kumin and Chapman (1996). We find that babbling and sound making increase after the oral normalization activity. Once the child can tolerate touch and can freely move the articulators, an oral motor skills program is introduced. This might include blowing whistles, blowing bubbles, making funny faces, and sound imitation activities. Generally, the clinician will imitate the child rather than providing a model to imitate.

The basis for communication is social interaction, and certain conversational skills such as turn taking can be developed at a very young age through play (MacDonald, 1989). Peek-a-boo games and handing a toy or musical instrument back and forth are ways of developing turn taking. There are many pre-language skills that can be addressed in treatment before the child is able to talk, so therapy should begin early, before the child speaks the first word (Kumin et al., 1991).

Infants with Down syndrome, by 8 months to 1 year, have a great deal to communicate with the people around them. If they do not have some way of communicating their messages, young children become frustrated by their inability to be understood. A transitional communication system is very important until the child is neurophysiologically able to speak (Gibbs and Carswell, 1991). Although speech is the most difficult communication system for children with Down syndrome, more than 95% of children with Down syndrome will use speech as their primary communication system. Total communication (use of sign language plus speech), communication boards or computer communication systems may be used as communication systems until the child is ready to transition to speech. (Kumin, 1994; Kumin et al., 1991; Meyers, 1994). Research has shown that children with Down syndrome will discontinue using the sign when they can say the word so that it is understandable to those around them.

**GENERAL CONSIDERATIONS FOR SPEECH AND LANGUAGE TREATMENT**

**ONE-WORD TO THREE-WORD PERIOD**

Once the young child begins to use single words (in sign or speech), treatment will target horizontal as well as vertical growth in language. Treatment may address single word vocabulary (semantic skills) in many thematic and whole language activities, such as cooking, crafts, play, and trips (Kumin et al., 1996). So there may be a great deal of horizontal vocabulary growth. Treatment will also target increasing the length of phrases, the combinations of words that the child can use; this is known as increasing the mean length of utterance (Manolson, 1992). There are many meaningful relations that the child learns in two word phrases (e.g., agent-action, possession, negation), and then
We have found that the pacing board provides a visual and motoric cuing system that capitalizes on the strengths of children with Down syndrome, and helps children to expand the length of their utterances (Kumin et al., 1995). The pacing board is usually a rectangular piece of tag board with separate circles that represent the number of words in the desired utterance (e.g., "throw ball" would have two circles). The pacing system concept can also be implemented by putting a dot under each word in a book.

Pragmatics skills such as making requests and greetings, as well as conversational skills would be taught during this period.

Vocabulary, pragmatics, and other language activities would generally be approached through play activities. Play would also be used to increase auditory attending and on task attention skills (Schwartz and Miller, 1996). Language skills would be supported through the use of appropriate computer activities, such as First Words or First Verbs by Laureate or Living Books or Bailey's Book House by Edmark (Kumin et al., 1996).

The basis for developing speech during this period is sensory integration (translating auditory to verbal messages) and oral motor abilities. Most children with Down syndrome understand messages, and are able to produce language (through signs) well before they are able to use speech. So sensory integration and oral motor skills therapy are used to strengthen the readiness for speech during this period.

**PRESCHOOL THROUGH KINDERGARTEN**

The young child is usually far more advanced in receptive language skills than in expressive language skills, but both areas are targeted in therapy. During this stage, receptive language work may focus on auditory memory and on following directions, which are important skills for the early school years. It will also focus on concept development such as colors, shapes, directions (top and bottom), prepositions through practice, and play experiences. Expressive language therapy will include semantics, expanding the mean length of utterance, and will begin to include grammatical structures (word order) and word endings (such as plural or possessive). Pragmatics skills such as asking for help, appropriate use of greetings, requests for information or answering requests, as well as role playing different activities of daily living may be addressed. Again, play activities such as dressing andundressing a doll, crafts activities such as making a card, or cooking activities such as making cupcakes may be used. The same activity may target semantic, syntactic, and pragmatics skills, for example, how many cupcakes should we make, what color frosting should we use, and following the directions to make the cupcakes. Many children with Down syndrome learn to read effectively, and this can help in learning language concepts (Buckley, 1993).

During this stage, sounds and specific sound production would be targeted; articulation therapy could begin. But the therapy would also include oral motor exercises and activities on an ongoing basis to strengthen the muscles and improve the coordination of muscles. Intelligibility is the goal of the speech component of therapy.

**ELEMENTARY SCHOOL YEARS**

During the years in elementary school, there is a great deal of growth in language and in speech. Speech-language pathology may involve collaboration with the teacher and may be based in the classroom. Often, the curriculum becomes the material used for therapy, both proactively, to prepare the child for the subject and reactively, to help if problems occur. This makes sense, because school is the child's workplace, and success in school greatly affects self esteem.

Receptive language work becomes more detailed and advanced (Miller, 1988), including following directions with multiple parts, similar to the instructions given in school. Receptive language might include comprehension exercises, reading and experiential activities, and specific comprehension of vocabulary, morphology (word parts such as plurals), and syntax (grammatical rules).

Expressive language therapy would also focus on more advanced topics in vocabulary, similarities and differences, morphology, and syntax. Expressive language work might also include work on increasing the length of speech utterances. The pacing board, rehearsal, scaffolds, and scripts have been found helpful in facilitating longer speech utterances.

Pragmatics becomes very important during this stage; using communication skills in real life in school, at home, and in the community is the goal. Therapy might address social interactive skills with teachers and peers, conversational skills (discourse), how to make requests, how to ask for help when the child does not understand material in school, how to clarify statements that people do not understand, and so forth. As the child matures, the communicative activities of daily living will change. Treatment and/or home practice must keep pace with the child's communication needs at every stage.

Speech skills with emphasis on articulation and intelligibility would be targeted in therapy during this period (Swift and Rosin, 1990). An individual analysis of oral motor strengths and challenges is important to determine what specific skills need to be addressed, for example, does the child have low muscle tone or muscle weakness in the oral facial area? difficulty with motor coordination? difficulty with motor planning? Are other speech areas such as voice and fluency affecting intelligibility? Each of these areas can be worked on if they are affecting communication ability for an individual child.

There are many different approaches to speech and language treatment that can be used, and some may be used simultaneously as part of a comprehensive individually designed program.

Therapy may be programmed based on linguistic skills, that is, there may be individual goals for semantics, morphology and syntax, pragmatics, and phonology. Therapy may also focus on different channels. So the goals for therapy may target auditory skills or speech and oral motor skills, or encoding a language message or producing a language message. One channel, such as reading, may be used to assist another channel such as expressive language or written language. Therapy may also be approached through the needs of the curriculum. In this approach, vocabulary would be taught based on the vocabulary that the child needs for success in science or social studies. The therapy may be proactive, teaching in advance the language skills that the child will need for the official curriculum, formal and informal classroom interactions, following directions in class and learning the rules and routines, and skills for interacting with peers. Curriculum-based therapy may also be reactive, targeting areas of difficulty as they occur and providing assistance with study skills and strategies to meet classroom expectations or to overcome difficulties when they occur. The speech-language pathologist can also suggest adaptive and compensatory strategies such as seating in front of the room, using a peer tutor, and visual cue sheets.

Whole language is a current approach in which reading, understanding, writing, and expressive language are taught as a whole. This approach is very real-world oriented. Therapy might work on scripts and may further expands into three word phrases.
provide assistance through scaffolds (e.g., fill-in sentences) to help the child learn to communicate more effectively with specific people or in specific settings based on a variety of objectives.

Speech and language treatment is complex and can include different approaches, a variety of goals, and many different activities. The goal is to find treatment approaches and methods which will enable each child to reach his communication potential.

RESOURCES

Communicating Together
PO Box 6395
Columbia, MD 21045-6395
Telephone: 888-816-8501, or 410-995-0722
FAX: 410-997-8735

Communicating Together provides workshops for parents and professionals and a subscription newsletter devoted to speech and language issues in infants, toddlers, children, and adolescents with Down syndrome. Workshops are held in different parts of the country throughout the year. Local workshops can be arranged. The newsletter is published six times per year. Written and edited by Dr. Libby Kumin, each issue includes a major topic article (e.g., IEPs/IFSPs, oral motor skills, intelligibility), questions and answers, home activities and reviews of current research articles. Call Dr. Martin Lazar for more information.

REFERENCES


Children with Down syndrome may also send more positive emotional signals than may other children with mental retardation. At 17.5 months, infants with Down syndrome show responses to maternal requests that are similar to those responses made by typically developing infants (Bressanunuti, Sachs, & Mahoney, 1992). In a modified strange situation, 24-month-olds with Down syndrome show distress when their mothers are absent, with increased crying and noncrying distress and increased looks at the doorâ€’behavior described as similar to that observed in typically developing children (Berry, Gunn, & Andrews, 1980; see also Vaughn et al., 1994). Toddlers and preschoolers with Down syndrome also do Libby Kumin is a Professor and Department Chair of the Speech-Language Pathology Department at Loyola College in Baltimore. This article by Libby Kumin is just one chapter of a comprehensive text on Down Syndrome: A Promising Future, Together, Edited by Terry J. Hassold and David Patterson. Read the chapter "Comprehensive Speech and Language Treatment for Infants, Toddlers, and Children with Down Syndrome" HERE. Children with Down syndrome may not age emotionally/socially and intellectually at the same rates as children without Down syndrome, so over time the intellectual and emotional gap between children with and without Down syndrome may widen. Complex thinking as required in sciences but also in history, the arts, and other subjects can often be beyond the abilities of some, or achieved much later than in other children.Â “Comprehensive speech and language treatment for infants, toddlers, and children with Down syndrome” Hassold, T.J. and D. Patterson Down Syndrome: A Promising Future, Together, New York: Wiley-Liss. â†’ Development of Fine Motor Skills in Down Syndrome. URL accessed on 2006-07-03.