



Down Syndrome News

NEWSLETTER OF THE



Volume 41, Number 1

First Quarter 2018

**"Be willing to compromise,
but never compromise your values."**

- SUSAN GOODMAN

After nearly two decades of steering our advocacy efforts in Washington, D.C., Susan Goodman became NDSC's first retiree at the end of 2017.

Susan has been at the forefront of impacting legislation not only affecting individuals with Down syndrome, but those with all disabilities. "One of the biggest threats to the Down syndrome community is the notion that we should be advocating only for people with Down syndrome. While there may be specific issues only affecting people with Down syndrome that need our attention, we must be very careful not to alienate all people with disabilities in our advocacy for equal opportunities. We need all advocates and they need us," Goodman said. The impact she has made on the disability community has been incredible. We thank her for her hard work and dedication!

"NDSC is proud of the advocacy support we have been providing families for 46 years," said David Tolleson.

Our Policy & Advocacy team, led by Heather Sachs, is continuing to build upon that foundation. Read more about what's happening in Washington inside.

In this issue

Letter from the President	2
Board Nominations	3
Developing speech while maintaining language and communication	4
Shine in the Hall of Stars!	7
NDSC Convention News	8
Advocacy in Action	9
Self-advocate Spotlight: Casey Barker	10
Desarrollar el habla mientras mantiene el lenguaje y la comunicación	12
Convención anual de NDSC	15



Letter from the President



Dear Families,

2018 has gotten off to a great start! From parent webinars to grassroots advocacy efforts, the NDSC staff has been working hard to bring you all the latest information you are looking for. Our website has been refreshed, as well as made mobile responsive, and convention plans are well underway.

We held our winter board and staff meeting in Dallas, TX in January, and as you can tell from my picture we are all getting ready to help you "Reach for Your Star" at our Annual Convention in July. This year's giant family reunion aims to be jam-packed with offerings to suit both families and professionals. Whether you are a first-timer or a seasoned attendee, there will be something for everyone this summer.

The NDSC board is continuing to build upon our strategic plan, and, along with the hardworking NDSC staff, we're expanding upon our existing programs and will introduce some new ones later this year. If you are interested in joining our engaged group of board members, or know someone who would be a great addition to support our mission and vision, the board nomination information can be found on page 3.

As always, the NDSC is here to serve you and your family. Don't hesitate to reach out to us!

Take care,


Kishore Vellody

Kishore

Down Syndrome News

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Mission

The mission of the NDSC is to provide information, advocacy and support concerning all aspects of life for individuals with Down syndrome.

Vision

The vision of the NDSC is a world with equal rights and opportunities for people with Down syndrome.

Statement of Policy and Disclaimer:

This newsletter reports items of interest relating to Down syndrome and provides a forum for others. The NDSC does not promote or recommend any therapy, treatment, etc. NDSC will not espouse any particular political or religious view. Individuals or organizations referred to are not necessarily endorsed by this publication or its editor. The National Down Syndrome Congress works to educate, advocate and empower. We are the leading national resource of support and information for people seeking to learn about Down syndrome.

The editor reserves the right to make corrections as are appropriate and in accord with established editorial practice in material submitted for publication. Submitting an item to the editor to use in *DSN* gives permission to do so.

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Board nominations are open through May 1

The NDSC Board is composed of 23 members from across the country, three of whom are self-advocates. Each year, we have board members who rotate off, many times after serving three terms, leaving us with room for new faces and new ideas to bring to our hardworking board of directors.

We hold two face-to-face meetings each year, one on a weekend in mid-winter and one on Thursday before the convention opens. Typically the mid-winter meeting is held in the upcoming convention city and hotel to familiarize the Board with the locale ahead of time. In addition to attending the board meetings, each board member is expected to serve on one or

You can read more and find the nomination form at –
<https://www.ndsccenter.org/about-ndsc/board-service-overview/board-nominating-process-information/>

Any member with Down syndrome, 22 years old or older, in good standing in the NDSC, and having attended three (3) of the last five (5) NDSC Annual Convention Y&A Conferences, is eligible for nomination to fill this year's self-advocate board member opening. The self-advocate nomination form can be found here – <https://www.ndsccenter.org/about-ndsc/board-service-overview/sa-board-nomination-form/> and is due by May 25.



more committees and/or strategic teams who meet by conference call periodically, most often, but not always, during daytime hours. The committees and teams are very active; some meet monthly, others, such as the convention committee, meet more often. Our strategic plan is very dynamic and is being actualized. In our face-to-face meetings we devote a 4-6-hour block of time to strategic planning. During the times the Board of Directors does not meet face-to-face, the Executive Committee (eight persons) meets monthly by conference call with the Executive Director.

Do you think you have what it takes?
Nominations are being accepted through May 1.



NDSC staff at Winter Meeting

Part 2 – Developing speech while maintaining language and communication

By Libby Kumin, Ph.D., CCC-SLP

Your child has been communicating with you from birth with gestures and eye gaze, crying and smiling. Your child has now mastered the pre-language skills, and is ready to communicate with you using language...but, he or she does not yet have the neurological and physiological skills to speak. The problem is that your child may not be developmentally ready to use speech. Your child may not have mastered all of the pre-speech skills, so there may be a period when he or she needs a transitional language system with which to communicate until he is ready and able to use speech. So, how do you help your child continue to progress in communication skills, language skills, and developing additional concepts? And, how do you help your child master the skills s/he will need to be able to speak?

What are the pre-speech skills?

- Respiration
- Feeding skills
- Hearing
- Vision
- Tactile skills
- Imitation skills
- Oral motor skills
- Motor planning skills
- Sound production skills

Once your child can use language, the skills above will enable him to be able to speak. At the same time that your child is using a transitional communication system to interact and to continue to learn language, you and the SLP are continuing to work on the skills that will lead to speech. Respiration and feeding address skills for speech output. Respiration is directed towards lengthening the exhalation (breathing out) phase of breathing. Feeding strengthens the muscles of the lips, face and oral cavity and provides practice in muscle movement. If your child is having difficulty nursing or bottle feeding, transitioning to solid foods, moving food around in the mouth and/or chewing, you want to seek help from a feeding specialist. Monitoring your child's hearing and vision is important because your child learns to speak by listening and watching the people around him. For hearing, the Down Syndrome Medical

Guidelines document the need for "brainstem auditory evoke response testing" and "otoacoustic emission testing" between birth and 3 months of age, additional hearing screening at 6 months of age, and the need for the pediatrician and otolaryngologist (ENT) and audiologist to monitor your child.

Through vocal play and babbling, your child learns what oral movements feel like (tactile skills), and develops feedback loops. Often, babies and young children with Down syndrome are uncomfortable (hypersensitive) with their face and lips being touched, or are hyposensitive to their face being touched and need more input through touch. Through vocal play, your child learns to imitate your movements, e.g. throwing a kiss or smacking their lips. It is best to work with a professional to help improve muscle strength, flexibility and range of motion. You need both muscle movement and planning of the movement to make speech sounds and words. Generally, through vocal play and practice, your child develops the ability to automatically program the muscle movements without thinking about the movements. The ability is out of awareness. When a child has difficulty with oral motor planning, it is known as verbal apraxia, a difficulty that requires direct speech intervention.

Your child learns to say the words that s/he already understands by imitating your words. That is why a child's native language is the language s/he learns in their environment. Since your child has already mastered the skill of referential knowledge, i.e. the connection between objects, people and the words that represent them, your child is on the road to beginning to say those words. S/he needs to learn how to imitate your movements and sounds. This is learned through play.

Imitation Skills

- Toy
- Body
- Oral Movements
- Speech Sounds
- Words/ Speech

When children learn language, they are imitating words that their parents and other adults and children in their environment say. To teach children how to imitate, start with a toy (e.g., show them how to move a toy car by putting your hands on their hands, and moving the truck).

Your child's first words will be the names and titles of people in the family and the names and titles of caregivers.

Words like mommy, daddy, papa, nana, bubbie, nona, and names of brother and sisters.

When they can imitate play with toys, move on to imitation of body movements such as clapping their hands when you clap your hands. If you can, use their older brother or sister as a model and have them imitate you clapping your hands. Then give your child a turn at imitating the clapping movement. You may need to put your hands around your child's hands and "walk" them through the movement. Then, move on to imitating oral movements such as throwing a kiss or popping your lips or clicking your tongue. Then add speech sounds, such as "lalala." And "bababa". Finally, help your child imitate real words.

Oral motor pre-speech skills

- Muscle Tone (low to high)
- Strength (weak to strong)
- Range of Motion (limited range of movement to free range of movement sufficient to make speech sounds)

When your child clicks their tongue, blows bubbles, and eats solid food, she is strengthening her tongue muscles. A speech-language pathologist can suggest exercises that will help your child increase muscle tone, strength and range of motion. The goal for the child is to be able to make these movements independently. The American Speech-Language-Hearing Association, the professional association for speech-language pathologists and audiologists states that only evidence-based methods should be used in treatment. SLPs and researchers have not collected sufficient data to demonstrate that oral motor skills therapy is effective, so school systems often will

not provide treatment for oral motor skill difficulty stating that the treatment methods are not evidence based. The research literature does not state that oral motor therapy is ineffective, just that it has not been proven to be effective. It leaves the decision on which treatment methods to use, to the clinical judgment of the SLP.

First Words

Your child's first words will be the names and titles of people in the family and the names and titles of caregivers. Words like mommy, daddy, papa, nana, bubbie, nona, and names of brother and sisters. There will be more names and nouns, and fewer verbs. His speech production of those words may not be exact; but he will be using the same sounds whenever he is saying the word, e.g. da or ti for daddy, and he will show recognition that the word means daddy. Your child will use high frequency, high information words that will get responses, actions and joy from people in the child's environment.

What can I do to improve my infant & toddler's ability to communicate?

The speech-language pathologist (SLP) is the professional who will work with you and your child on communication skills. In the first year, she will help you learn more about the pre-speech and pre-language skills and how to work with your child. She will work on the muscles for speaking through feeding therapy and through imitation and vocal play. Your child communicates from birth. During the first 12-18 months, your child masters the pre-language skills. Many children with Down syndrome begin to say words as early as 15 to 18 months of age, but it is more common for a child to master all of the prelanguage skills, use a transitional communication system such as sign language and then begin to speak between 3 and 4 years of age. If your child is ready to use language, but is not yet able to speak, it is important to use a transitional system such as sign language or the picture exchange system (PECS) so that your child can continue to communicate and learn more vocabulary and language skills until he is able to speak.

What are transitional communication systems? How do I know which system is right for my child?

Transitional communication systems are alternative communication systems that enable your child to communicate during the period when they have mastered all of the pre-language skills, i.e. they are ready to use

Continued on page 6

Developing speech

continued from page 5

language to communicate, but they cannot yet speak. You can request an AAC (augmentative and alternative) from your child's IFSP/IEP team. This evaluation may be done through the local school system, if they have an AAC team; through a state special education/rehabilitation agency; or, through a private outside agency. The goal of this evaluation will be to determine and prescribe the ideal system for your child's strengths and needs.

When your child is ready to communicate using language, they need a communication system that will enable them to continue communicating with you. It needs to be a system that is usable for your child and understandable by you and others in your child's environment. If your child does not have a way to communicate using language, and if you



don't understand his/her communication attempts, your child will get frustrated. So, there is a need for a transitional communication system (e.g. sign language, communication board or communication app) to bridge the gap when your child is able to use language, but is not yet able to speak. The most frequently used transitional language systems are sign language (total communication in which sign and speech are used to teach language), the Picture Exchange Communication System (PECS), communication boards, and electronic communication devices. Your child will be using a transitional communication system to enable your child to communicate.

Total communication is the communication system most frequently prescribed for children with Down syndrome. Total communication means that your child and you both learn sign language. When your child signs, you accept that as their means of communicating, but you say the words for them. When you sign, you also speak the words; you do both when you communicate with your child. The reason that total communication is preferred is that it uses no equipment that has to be carried around, and the child generates the signs that represent the words in a similar way that the brain would be encoding words.

Other communication systems that can be used are communication boards. In these systems, your child will point to a picture or photo to make requests, to communicate their needs. Low tech communication boards are simply paper picture boards. You would start out with the number of choices that your child is able to handle, e.g. 2-4 pictures to begin, e.g. a favorite toy and a favorite food. You also can use multiple communication boards, e.g. one in the kitchen to request food items, one in the bedroom to enable the child to request clothing that she likes, etc. There now are communication apps that you can use on an iPad, tablet, or smartphone. These systems will often use synthesized speech output. For example, your child will be pointing to a photo/image of a glass of water, and the system will say, "I'm thirsty". There also are high-tech systems, software programs on a computer or laptop that your child can be taught to use, that will provide a communication system that can substitute for speech until your child is able to speak.

When your child learned the early communication and pre-language skills, your child learned communicative intent, i.e. sounds or pointing had an effect on their environment, and turn taking, i.e. learning the roles of speaker and listener. What if your child does not understand how to request, or does not understand communicative intent? This is not usual for children with Down syndrome, but is often the case when a child has co-occurring DS-ASD. The AAC communication system that can teach a child how to communicate is the Picture Exchange Communication System (PECS). The child is taught that choosing and presenting a picture/photo (speaker) to a communication partner (listener) will result in the communication partner responding with what the child asked for, e.g. a pretzel. The SLP is teaching the child how to communicate by

using pictures/photos until they are able to speak. During the same period that your child is using a transitional communication system, you want to work with an SLP to teach your child the skills that s/he will need for speaking.

When children are not provided with a transitional system and are unable to communicate, they become frustrated. A system will also enable them to continue to progress in language. Your child will learn new vocabulary words and can progress from one-word to two-word phrases using a transitional communication system. At the same time, your child will continue with speech therapy to help them learn the pre-speech skills so they will be able to speak. The majority of children and adults with Down syndrome will use speech as their communication system, but the majority do require a transitional communication system before they are able to speak.

For further reading:

Kumin, L. (2012). *Early Communication Skills for Children with Down Syndrome* (third edition). Bethesda, MD: Woodbine House.

Parent resource information:

Go to <https://www.ndsccenter.org/programs-resources/speech-and-language/> and you can download:

- The Basis for Speech, Language and Communication in People with Down Syndrome
- Speech and Language Resource Guide for Parents of Infants and Toddlers with Down Syndrome: First Words to Phrases
- Resource Guide to Oral Motor Skill Difficulties in Children with Down Syndrome
- Resource Guide to Childhood Apraxia of Speech in Children with Down Syndrome



As the NDSC Annual Convention heads to Dallas, Texas we will be "Reaching For The Stars"! The focal point of the convention will be the Hall of Stars located in the main walkway leading to the convention center. This exhibit will feature beautifully decorated silver and white stars suspended from above, amidst original art work.

Individuals, families, civic groups, affiliate organizations, and corporations can show their support by purchasing stars in advance. Stars are available in 3 sizes and may be self decorated, self-advocate decorated (at the NDSC office), or may display a name, message or logo printed by the NDSC.



- Small Star, 13" \$25
- Medium Star, 17" \$75
- Large Star, 21" \$150

Each star to be self decorated will be mailed to the purchaser with return instructions. Self decorated stars must be ordered by June 1 and returned to the NDSC office by June 18. Orders for self-advocate and printed stars must be received by June 25, 2018.

To order, visit – <https://www.ndsccenter.org/support-join-be-involved/hall-of-stars/>

NDSC Convention News

46th Annual NDSC Convention

In addition to our jam-packed schedule of pre-conferences, workshops, exhibits and social events, we have these additional opportunities to learn!

ADVOCACY TRAINING DAY

Thursday, July 12, 2018, 8:00 am – 12:00 pm

Free to registered convention attendees, this introductory Advocacy Training Day will be presented by the NDSC Policy & Advocacy Team, NDSC's Self-Advocate Council and Global Down Syndrome Foundation. It is designed for inexperienced/beginner advocates, self-advocates and new parents. The team will address topics such as:

- What is advocacy?
- Effective ways to advocate
- How to engage with your legislators
- Basic overview of the legislative process
- An overview of key policy topics such as education, employment, research funding, Medicaid and healthcare
- How to join advocacy efforts



*Together with, Niagara University,
the NDSC will host*

First Responders Disability Awareness Training on Thursday, July 12.

This two-part training will feature one session for EMS and Fire Fighters and a separate session for Police Officers. For details or to register:

Law enforcement:

<https://frdat.niagara.edu/training/trainings/show/242>

Firefighter/EMS:

<https://frdat.niagara.edu/training/trainings/show/243>



RESEARCH & MEDICAL CARE ROUNDTABLE: **What parents, self-advocates & caregivers should know**

**Thursday, July 12, 2018
1:00 pm – 5:00 pm**

Co-organized with the NDSC, the Global Down Syndrome Foundation Roundtable is free for registrants of the NDSC Annual Convention and features renowned scientists and medical professionals.

*NDSC's Center for Educational Excellence
is also hosting its 3rd annual, full-day*

Educator Conference on Friday, July 13

Teachers, para professionals and administrators are invited to register. CEU's will be awarded. This workshop will engage participants in identifying and implementing strategies applicable to classrooms from kindergarten through 8th grades. Discussions will include ways to further include students in the general education classroom through effective literacy interventions, differentiated curriculum, technology, and behavioral practices.

<https://www.ndsccenter.org/centers-for-excellence/educationalexcellence/educator-conference/educator-conference-registration-form/>



Center for Educational Excellence

Advocacy in Action



**National Down Syndrome
Advocacy Coalition**



A member service of
**NATIONAL
DOWN SYNDROME
CONGRESS**



NDAC is a grassroots advocacy service that is designed to educate individuals with Down syndrome, their family members and other allies about policy issues and give them the advocacy tools and techniques they need to effectively engage with their legislators to advocate for change. NDAC aligns with NDSC's purpose since its founding in 1973: to promote the interests of people with Down syndrome and their families through advocacy, public awareness and information.

With this program, we bring together advocates of all abilities and levels of experience from across the country that have a passion for the Down syndrome community.

Through NDAC's education, training opportunities and engagement on social media, we cultivate a broad coalition of advocates who will be able to effectively engage with lawmakers, agencies and other key decision makers to promote policy change.

This program will also work to involve and engage more advocates, including individuals with

Down syndrome, their parents and other allies who support our community.

Since its launch in the fall, we have more than 100 NDAC individual members and 30 NDAC group members. We hope you will join NDAC and help us to fight for equal rights and opportunities for people with Down syndrome! For more information, visit <https://www.ndsccenter.org/political-advocacy/national-down-syndrome-advocacy-coalition/>

"NDSC's Policy and Advocacy Team has unparalleled expertise and experience in policy issues across the lifespan of people with Down syndrome such as early, elementary and secondary education, transition, postsecondary education, employment and the critical adult support systems such as Medicaid, health care and housing. NDAC provides a formal mechanism to engage individuals — regardless of level of advocacy experience — in these efforts in order to maximize the power of our community's voice."

— NDSC Executive Director, David Tolleson

Find us on Facebook:

[National Down Syndrome Congress](#)

SELF-ADVOCATE

Spotlight: Casey Barker



Casey Barker with his dad, mom and a local student in Kenya.

Habari Gani, my dear fellow self-advocates of NDSC,

I am Casey Barker. I am writing this from Kenya, East Africa. I lived in Columbus, GA and attended Kennesaw State University 2012 to 2014. My mom and dad are retired after working more than 30 years. My dad is a Hospital Administrator and my mom is a Speech Language Pathologist. We like to travel as a family and we have always volunteered at community outreaches to support people who are less fortunate.

My family decided to volunteer in another part of the world where people are extremely poor. We began to research and learn about many lay missioner organizations. We had to complete applications that had many questions. Some of them were very difficult! Others were easy. We applied to three organizations at the start. First, we heard from Fidesco, which is a French, Catholic organization based in Paris.

We had to interview on the phone, we waited for a long time to hear back from them. The people from Fidesco had to invite my family for the Discernment Weekend. It was held in Westchester County, New York. We stayed in a beautiful house on the Hudson River with a French family. They were lovely. During the weekend, we listened to the speakers from Fidesco, we ate meals together and we had individual interviews one to one. The people had very heavy French accents. There were nine or ten people attending. We went back to Columbus, GA to think about, pray and decide if this was the correct path for us. In one week, we got the call that we made it and we decided we wanted to go on mission.

We sold our home in Columbus, GA. There was a bunch of packing, donations to be delivered and to sort out our bigger stuff for storage. There were piles all around our house. Lots of our personal stuff needed to be separated to bring to Africa. It was a lot of decisions to make about what to keep. I kept some of my instruments, costumes, trophies, certificates and diplomas from Kennesaw State University.

In July, myself and my family went to a "Send Off Week" in Paray Le Monial in France. I was a bit unsure about what would be happening and understanding French people! At the end of the week, the new volunteers (about 40 to 50) attended a mass with about a thousand people and many priests and bishops. We each had to stand in front, introduce ourselves and announce where we were going for mission. My mom and dad introduced themselves and then I stood alone to introduce myself. Everyone began clapping and clapping.

That was one year and nine months ago! We have about five more months to complete our mission. Next summer, we will return to the United States. Let me tell you about my mission.

I work at St. Michael's School for the Deaf. It is a primary school where the students board. Here, school goes year-round. The school year begins in January. The students then have off and go home in April, August and Nov/December, after exams. There are 3 terms. I teach the pre-primary students sign language along with the teachers. I help them to learn colors, shapes, sizes, fruits, animals, etc. I have learned much Kenyan Sign Language (KSL). Some is the same as American Sign Language (ASL).

Sometimes Mom and I bring in apples, grapes or watermelons. The boys and girls were very excited! Many had never seen or tasted these fruits. I have introduced them to games like Charades, Bingo, Memory games, Flip Hats and table top basketball. I have also helped them to learn about painting, drawing and play dough. At PE, I have shown them bubbles, jump rope, hula hoops and bouncing balls. Football (soccer in America) is very popular here.

The schools here are very large and have very few supplies, no picture books or paper. They have taught me the lesson which is; they have so little and they are happy and do not complain! The government pays the teachers so little. The student's families have difficulty paying school fees.

We must write a mission report every 3 months that is sent to our sponsors. Following is my part of the report from November 2017:



CASEY'S CORNER

Casey, Rik and Diane have started a parent support group for families of kids with disabilities.

Casey organizes a play area for the children with various disabilities. Casey, along with Magdalene and Stephanie, set up alphabet mats and yoga mats to cover part of the concrete floor. They also distribute blocks, cars, trucks, various toys and books. Casey likes to show the children how to play with toys and he reads to them. The children really enjoy big picture books. Casey, Stephanie and Magdalene also pass out snacks and help moms to feed their children because many of them are unable to feed themselves. After the fun part when the meeting is over, they clean up the area. At home, Casey washes the mats and toys with Diane and Rik.

Some exciting news!!! Remember Casey had initiated a Best Buddies presentation to a local primary school, called Central Primary. During our current term 3, Casey and Diane gave a short presentation about Best Buddies, International to the staff at St. Michael's so everyone would be familiar with the organization and starting a BB chapter in Kitui. This was very new to everyone.

On Oct 12th, St. Michael's held their first BB hangout/social and it was a huge success!!! About 50 students came from Central Primary to meet and socialize with our students. The students, both deaf and hearing, played games like American Corn Hole, net ball, football (known in America as soccer) and frisbee. They teamed up for some games and enjoyed "buddying up." Some of the students were writing in the dirt with sticks to communicate. Many students quickly learned some signs.

Casey thinks that the staff enjoyed the day also. (I know I did a magnificent job!) Casey, Diane and Rik agreed that the teachers from the primary school are enthusiastic and want to continue BB.

Desarrollar el habla mientras mantiene el lenguaje y la comunicación

Libby Kumin, Ph.D., CCC-SLP

Su hijo se ha estado comunicando con usted desde el nacimiento con gestos y mirada, llorando y sonriendo. Su hijo ha dominado las habilidades de pre-lenguaje, y está listo para comunicarse con usted usando el lenguaje... pero, él o ella todavía no tiene las habilidades neurológicas y fisiológicas para hablar. El problema es que su hijo puede no estar preparado para usar el habla. Es posible que su hijo no haya dominado todas las habilidades previas al habla, por lo que puede haber un período en el que necesite un sistema de lenguaje de transición con el cual comunicarse hasta que esté listo y pueda usar el habla. Entonces, ¿cómo ayudará a su hijo a seguir progresando en habilidades de comunicación, habilidades de lenguaje y desarrollo de conceptos adicionales? Y, ¿cómo ayudar a su hijo a dominar las habilidades que él / ella necesitará para poder hablar?

¿Cuáles son las habilidades previas al habla?

- Respiración
- Habilidades de alimentación
- Audición
- Visión
- Habilidades táctiles
- Habilidades de imitación
- Habilidades motrices orales
- Habilidades de planificación del motor
- Habilidades de producción de sonido

Una vez que su hijo pueda usar el lenguaje, las habilidades mencionadas anteriores le permitirán poder hablar. Al mismo tiempo que su hijo está usando un sistema de comunicación transicional para interactuar y continuar aprendiendo el lenguaje, usted y el SLP continúan trabajando en las habilidades que llevarán al habla. Respiración y habilidades de dirección de alimentación para la salida del habla. La respiración se dirige hacia el alargamiento de la fase de exhalación (expiración) de la respiración. La alimentación fortalece los músculos de los labios, la cara y la cavidad oral y proporciona la práctica en el movimiento del músculo. Si su hijo está teniendo dificultad para amamantar o alimentar con biberón, la transición a alimentos sólidos, mover alimentos alrededor

de la boca y / o masticar, usted debe buscar ayuda de un especialista en alimentación. La supervisión de la audición y visión de su hijo es importante porque su hijo aprende a hablar escuchando y observando a la gente que lo rodea. Para la audición, las Directrices Médicas del Síndrome de Down documentan la necesidad de "pruebas de respuesta de evocación auditiva del tronco encefálico" y "pruebas de emisión otoacústica" entre el nacimiento y los 3 meses de edad, la detección auditiva adicional a los 6 meses de edad y la necesidad del pediatra y otorrinolaringólogo (ENT) y un audiólogo para supervisar a su hijo..

A través del juego vocal y el balbuceo, su hijo aprende cómo se sienten los movimientos orales (habilidades táctiles) y desarrolla bucles de retroalimentación. A menudo, los bebés y los niños pequeños con síndrome de Down son incómodos (hipersensibles) con la cara y los labios que se tocan, o son hiposensibles a su cara que se toca y necesitan más entrada a través del tacto. A través del juego vocal, su hijo aprenderá a imitar sus movimientos, por ejemplo, lanzar un beso o mover sus labios. Es mejor trabajar con un profesional para ayudar a mejorar la fuerza muscular, la flexibilidad y el rango de movimiento. Necesita movimiento muscular y planificación del movimiento para hacer sonidos y palabras.

Generalmente, a través del juego vocal y la práctica, su hijo desarrolla la capacidad de programar automáticamente los movimientos musculares sin pensar en los movimientos. La habilidad está fuera de la conciencia. Cuando un niño tiene dificultad con la planificación motora oral, se conoce como apraxia verbal, una dificultad que requiere intervención directa del habla.

El niño aprende a decir las palabras que él / ella ya entiende imitando sus palabras. Es por eso que el idioma nativo de un niño es el idioma que aprende en su entorno. Puesto que su hijo ya ha dominado la habilidad del conocimiento referencial, es decir, la conexión entre los objetos, las personas y las palabras que los representan, su hijo está en el camino de comenzar a decir esas palabras. El / Ella necesita aprender a imitar sus movimientos y sonidos. Esto se aprende a través del juego.

Habilidades de imitación

- Juguete
- Cuerpo
- Movimientos Orales
- Sonidos del habla
- Palabras/ El habla

Cuando los niños aprenden el idioma, están imitando palabras que dicen sus padres y otros adultos y niños en su entorno. Para enseñar a los niños a imitar, empiece con un juguete (por ejemplo, muéstreles cómo mover un coche de juguete poniendo sus manos sobre tus manos y moviendo el camión). Cuando pueden imitar el juego con los juguetes, pasar a la imitación de los movimientos del cuerpo, como aplaudir las manos cuando se aplaude las manos. Si puedes, usa a su hermano o hermana mayor como modelo y haz que te imiten aplaudiendo tus manos. Luego déle un turno a su hijo para imitarlo en el movimiento de aplausos. Puede que necesite poner las manos alrededor de las manos de su hijo y guiarlo a través del movimiento. Luego, pasar a imitar los movimientos orales, como lanzar un beso o hacer estallar sus labios o hacer clic en su lengua. A continuación, añadir sonidos de voz, como "lalala." Y "bababa". Por último, ayude a su hijo a imitar palabras reales.

Habilidades motoras orales del pre-habla

- Tono muscular (bajo a alto)
- Fuerza (débil a fuerte)
- El rango de movimiento (furia de movimiento limitado a la libre rango de movimiento suficiente para hacer que los sonidos del habla)

Cuando su niño hace clic en su lengua, sopla burbujas y come alimentos sólidos, ella/el está fortaleciendo sus músculos de la lengua. Un patólogo del habla y lenguaje puede sugerir ejercicios que ayudarán a su hijo a aumentar el tono muscular, la fuerza y el rango de movimiento. El objetivo para el niño es poder realizar estos movimientos de forma independiente. La American Speech-Language-Hearing Association, la asociación profesional para patólogos y auditólogos del habla, afirma que sólo los métodos basados en la evidencia deben ser utilizados en el tratamiento. Los SLPs y los investigadores no han reunido suficientes datos para demostrar que la terapia de las habilidades motoras orales es eficaz, por lo que los sistemas escolares a menudo no proporcionan tratamiento para la dificultad de la habilidad motora oral indicando que los métodos de tratamiento no están basados en pruebas. La literatura de investigación no indica que la terapia

motora oral es ineficaz, sólo que no ha demostrado ser eficaz. Deja la decisión sobre qué métodos de tratamiento utilizar, para el juicio clínico de la SLP.

Primeras palabras

Las primeras palabras de su hijo serán los nombres y títulos de las personas en la familia y los nombres y títulos de los cuidadores. Palabras como mamá, papá, papá, nana, bubble, nona, y nombres de hermano y hermanas. Habrá más nombres y sustantivos, y menos verbos. Su producción del discurso de esas palabras no puede ser exacta; pero utilizará los mismos sonidos cada vez que diga la palabra, por ejemplo, da o ti para papá, y mostrará reconocimiento de que la palabra significa papá. Su hijo usará palabras de alta frecuencia y alta información que obtendrán respuestas, acciones y alegría de la gente en el ambiente del niño.

¿Qué puedo hacer para mejorar la capacidad de mi hijo para comunicarse?

El patólogo del habla y el lenguaje (SLP) es el profesional que trabajará con usted y su hijo en las habilidades de comunicación. En el primer año, ella le ayudará a aprender más acerca de las habilidades del pre-lenguaje y cómo trabajar con su hijo. Trabajará en los músculos para hablar a través de la terapia de alimentación y a través de la imitación y el juego vocal. Su hijo se comunica desde el nacimiento. Durante los primeros 12-18 meses, su hijo domina las habilidades de pre-lenguaje. Muchos niños con síndrome de Down empiezan a decir palabras desde los 15 a 18 meses de edad, pero es más común que un niño domine todas las habilidades de preligación, utilice un sistema de comunicación transicional como el lenguaje de señas y luego comience a hablar entre 3 y 4 años de edad. Si su hijo está listo para usar el lenguaje, pero todavía no puede hablar, es importante usar un sistema de transición como el lenguaje de signos o el sistema de intercambio de imágenes (PECS) para que su hijo pueda continuar comunicándose y aprendiendo más vocabulario y hasta que pueda hablar.

¿Qué son los sistemas de comunicación de transición? ¿Cómo sé qué sistema es adecuado para mi hijo?

Los sistemas de comunicación de transición son sistemas de comunicación alternativos que permiten a su hijo comunicarse durante el período en el que han dominado todas las habilidades de pre-lenguaje, es decir, están listos para usar el lenguaje para comunicarse, pero aún

Continúa en la página 14

Desarrollar el habla

continuación de la página 13

no pueden hablar. Puede solicitar un AAC (aumentativo y alternativo) del equipo IFSP / IEP de su hijo. Esta evaluación se puede hacer a través del sistema escolar local, si tienen un equipo de AAC; a través de una agencia estatal de educación especial / rehabilitación; o, a través de una agencia externa privada. El objetivo de esta evaluación será determinar y prescribir el sistema ideal para las fortalezas y necesidades de su hijo.

Cuando su hijo está listo para comunicarse utilizando el lenguaje, necesitan un sistema de comunicación que les permita continuar comunicándose con usted. Necesita ser un sistema que sea utilizable para su niño y comprensible por usted y otros en el ambiente de su niño. Si su hijo no tiene una manera de comunicarse usando el lenguaje, y si no entiende sus intentos de comunicación, su hijo se sentirá frustrado. Por lo tanto, existe la necesidad de un sistema de comunicación transicional (por ejemplo, lenguaje de señas, tablero de comunicación o aplicación de comunicación) para colmar la brecha cuando su hijo pueda usar el lenguaje, pero aún no puede hablar. Los sistemas de lenguaje de transición más utilizados son el lenguaje de señas (comunicación total en la que se utilizan signos y palabras para enseñar el lenguaje), el PECS (Picture Exchange Communication System), las tarjetas de comunicación y los dispositivos de comunicación electrónica. Su hijo usará un sistema de comunicación de transición para permitir que su hijo se comunique.

La comunicación total es el sistema de comunicación más frecuentemente prescrito para los niños con síndrome de Down. La comunicación total significa que su hijo y usted aprenden el lenguaje de señas. Cuando su hijo use señas, usted acepta eso como su medio de comunicación, pero usted dice las palabras para ellos. Cuando usted use señas, usted también habla las palabras; usted hace ambas cosas cuando se comunica con su hijo. La razón que la comunicación total se prefiere es porque no utiliza ningún equipo que se tenga que llevar todo el tiempo, y el niño genera los signos que representan las palabras de una manera similar que el cerebro estaría codificando palabras.

Otros sistemas de comunicación que se pueden utilizar son las tarjetas de comunicación. En estos sistemas, su hijo señalará una imagen o una foto para hacer peticiones, para comunicar sus necesidades. Las tarjetas

de comunicación de baja tecnología son simplemente tableros de imagen en papel. Usted comenzaría con el número de opciones que su hijo es capaz de manejar, por ejemplo, 2-4 imágenes para comenzar, por ejemplo, un juguete favorito y un alimento favorito. También puede utilizar varias tarjetas de comunicación, por ejemplo, una en la cocina para solicitar los alimentos, una en el dormitorio para permitir que el niño pida ropa que le gusta, etc. Ahora hay aplicaciones de comunicación que se pueden utilizar en un iPad, o teléfono inteligente. Estos sistemas usan a menudo salida de voz sintetizada. Por ejemplo, su niño estará señalando una foto / imagen de un vaso de agua, y el sistema dirá: "Tengo sed". También hay sistemas de alta tecnología, programas en una computadora o computadora portátil que su hijo puede ser enseñado a usar, que proporcionará un sistema de comunicación que puede sustituir a la palabra hasta que su hijo es capaz de hablar.

Cuando su hijo aprendió las habilidades de comunicación y pre-tempranas del lenguaje, su hijo aprendió intención comunicativa, es decir, sonidos o apuntando teniendo un efecto en su entorno, y la toma de turnos, es decir, el aprendizaje de los roles de hablante y el oyente. ¿Qué pasa si su hijo no entiende cómo solicitar o no entiende la intención comunicativa? Esto no es habitual en niños con síndrome de Down, pero a menudo es el caso cuando un niño tiene co-ocurrencia de DS-ASD. El sistema de comunicación AAC que puede enseñar a un niño a comunicarse es el sistema de comunicación de intercambio de imágenes (PECS). Se enseña al niño que elegir y presentar una foto (orador) a un interlocutor (oyente) dará como resultado que el interlocutor responda con lo que el niño pidió, por ejemplo un pretzel. El SLP está enseñando al niño cómo comunicarse usando fotos hasta que puedan hablar. Durante el mismo período en que su hijo está usando un sistema de comunicación de transición, usted quiere trabajar con un SLP para enseñar a su hijo las habilidades que él / ella necesitará para hablar.

Cuando los niños no reciben un sistema de transición y son incapaces de comunicarse, se sienten frustrados. Un sistema también les permitirá seguir avanzando en el lenguaje. Su hijo aprenderá nuevas palabras de vocabulario y podrá progresar de frases de una palabra a dos palabras utilizando un sistema de comunicación transicional. Al mismo tiempo, su hijo continuará con la terapia del habla para ayudarles a aprender las habilidades previas al habla para que puedan hablar. La mayoría de los niños y adultos

con síndrome de Down usará el habla como su sistema de comunicación, pero la mayoría requiere un sistema de comunicación transicional antes de que puedan hablar.

Para más información:

Kumin, L. (2012). *Early Communication Skills for Children with Down Syndrome* (third edition). Bethesda, MD: Woodbine House.

Información de Recursos para Padres:

- Ir a: <https://www.ndsccenter.org/programs-resources/speech-and-language/>
- The Basis for Speech, Language and Communication in People with Down Syndrome
- Speech and Language Resource Guide for Parents of Infants and Toddlers with Down Syndrome: First Words to Phrases
- Resource Guide to Oral Motor Skill Difficulties in Children with Down Syndrome
- Resource Guide to Childhood Apraxia of Speech in Children with Down Syndrome



Dallas, TX • July 12–15, 2018

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¿Qué es la convención anual de NDSC?

Cada año, miles de personas de todo el mundo asisten a la Convención anual de síndrome de Down. La mayoría van para escuchar la información más reciente de expertos de renombre mundial. Para otros, son unas increíbles vacaciones. Sin embargo, para casi todos, es la sensación única de la gran reunión familiar del NDSC que contagia el fin de semana de la convención.

- Los padres aprenden de lo mejor, como de expertos de renombre internacional que vienen a Sacramento para compartir su conocimiento sobre la vida de las

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- Los autogestores se unen con más de 300 compañeros de todo el mundo para aprender, compartir, empoderarse y pasar un tiempo increíble!
- Los hermanos comparten y aprenden de sus compañeros, así como de los profesionales.
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El registro de la convención y el bloque hotelero se abrirán el lunes, 16 de abril de 2018.

Mesa Redonda de Investigación y Cuidado Médico. Lo que los padres, las personas con síndrome de Down y los cuidadores deben saber.

Disponible con interpretación simultánea al español.

En coordinación con el NDSC, y la Global Down Syndrome Foundation están ofreciendo a los asistentes de la Convención la entrada gratuita a ésta **mesa redonda de investigación** que contará con la presencia de reconocidos científicos y profesionales de la medicina. Los temas incluirán una revisión acerca del síndrome de Down y cáncer, enfermedad



autoinmune, y la enfermedad de Alzheimer. A quienes asistan se les ofrecerá el almuerzo y una bolsa de regalo. Pero deben de inscribirse con anticipación.

El cupo es limitado.

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