



Down Syndrome News

NEWSLETTER OF THE

Volume 41, Number 2

Second Quarter 2018



Looking for inspiration? Our featured keynote speakers are bringing it to Dallas!

Filmmaker and Producer, **Dan Habib**, who you may know from his award-winning films, *Including Samuel* and *Who Cares About Kelsey?*, is premiering a new documentary this year – *Intelligent Lives* – which will examine our society’s narrow perceptions of intelligence. Habib’s films have been featured in dozens of film festivals, broadcast internationally, nominated for Emmy awards and translated into 17 languages for worldwide distribution. He is a filmmaker at the University of New Hampshire’s Institute on Disability. Habib gave a widely viewed TEDx talk, “Disabling Segregation,” received the Champion of Human and Civil Rights Award from the NEA, and the Justice for All Grassroots Award from the American Association of People with Disabilities.



If you saw his impassioned speech to Congress earlier this year, you know **Frank Stephens**. Frank’s business card describes him as “Actor, Author, Advocate.” He truly is all of these things. As an actor, Frank is a member of a wonderful local theater group known as Artstream, where he has appeared in original plays for over a decade, and recently guest starred in the Emmy-winning television show *Born This Way*. As an author, Frank’s work has been printed in publications ranging from the *New York Times* to the *London Daily Mail*. He has contributed to a book of stories of outstanding young advocates called *Stand Up*, which is a best seller on Amazon. He is also a frequent contributor to the *Huffington Post* on-line. As an advocate, he has spoken all over North America and Europe promoting the inclusion of individuals with intellectual disabilities. Frank speaks often of how lucky he feels to live in a generation where all these things are possible for a man with Down syndrome.

There’s still time to register and join us in July! Read more inside...

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Letter from the President



Dear Families,

Spring has sprung (although it took a bit longer in some places this year) and Summer is right around the corner. Before we know it, many of us will be coming together in Dallas, TX, for the 46th Annual NDSC Convention. The staff has pulled together an amazing lineup. I am looking forward to all the programs and workshops being offered this year; there really is something for everyone: Parents, Educators, First Responders, Self-advocates, Siblings, Affiliate Leaders, Grandparents and Caregivers. If you haven't made plans to join us yet, there is still time to register.

I hope that you're enjoying the great Parent Webinar Series we've been bringing you over the past year. We are fortunate to have some amazing speakers willing to share their

timely and up-to-date information with our constituents. If you've missed any, you can revisit them in the archived recordings on the website. We've got more lined up starting in August, so stay tuned. We continue to grow and expand our programs and resources and want to hear from you. Please contact our Center staff with your comments or questions.

Thank you for all you do to make the NDSC what it is — the oldest organization educating, advocating, empowering, and inspiring individuals with Down syndrome and their families.

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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Part 3 – Speech, language and communication: after the first word

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

My child is saying some single words. What comes next? What can I do to help?

When your child is using single words, there are three paths that you will need to follow:

- oral motor skills/speech
- horizontal language development
- vertical language development

One path is to work on oral motor skills and sound making so that your child's speech is understandable. This is known as speech intelligibility. The speech-language pathologist can help your child learn to speak more clearly.

Second is horizontal language development, i.e. you want to help your child develop more concepts and increase vocabulary skills. You can do that by involving your child in many language experiences and labeling with vocabulary words what is happening at the time. For example, when you walk outside, labeling trees, flowers, birds and clouds, looking at them, listening, smelling, engaging your child's senses in learning the words for what he is seeing. When you are at the playground, provide words for the equipment your child is playing on, and use the words slide, down, on, under, up and behind to describe what is happening. Read books with your child about their experiences, e.g. walking in the city, going to the beach, snow and winter.

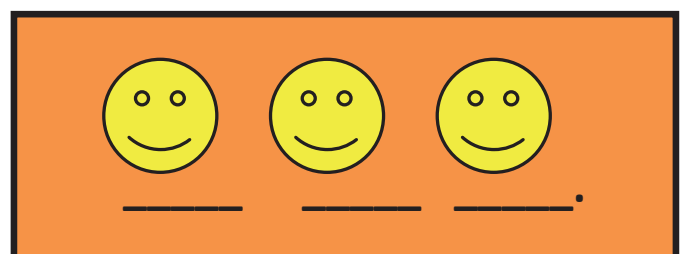
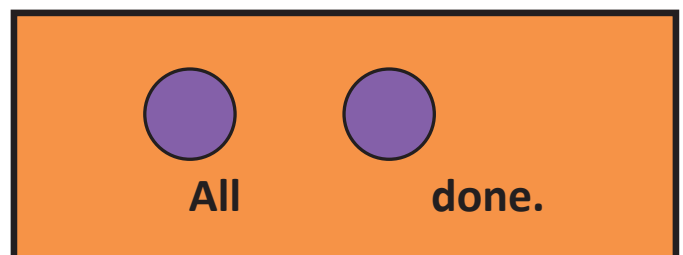
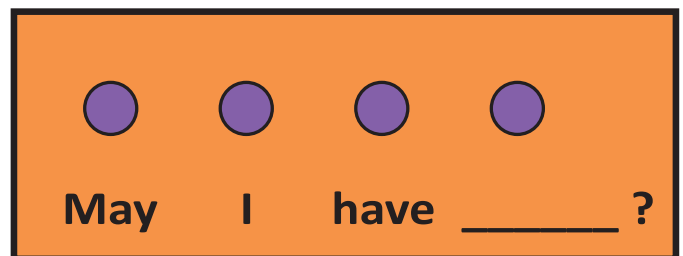
Third is vertical development, i.e. helping your child learn to combine words and use 2 word phrases. Research tells us that children with Down syndrome are ready to combine words when they have a 100 word vocabulary (either signs or speech). Then they can combine the single words that they already know and use, and learn to say *big car* instead of *car*.

The best method for helping your child combine words into multi-word phrases is using imitation with expansion and a pacing board. To use imitation with expansion:

1. Repeat what your child says. By repeating the word, you show that you understand him and that he used a correct word.
2. Expand what your child says by one word.

You may present the imitation with expansion many times before your child begins to use two words; just keep at it. This type of activity lends itself well to play and to activities of daily living, for example, your child says *sock*, you say *sock on*; your child says *ball*, you say *roll ball* or *throw ball*.

Using a pacing board will help your child learn to say 2 word and 3 word combinations, such as *go out* and *go out now*. The pacing board is a cueing system that provides a visual and tactile reminder of the number of words your child is able to use in combination (see below). The pacing board may consist of two colored dots on a piece of cardboard, or a square of velvet and a square of sandpaper mounted on a board, two colorful stickers mounted on a piece of cardboard – or anything else that your child likes. When you use imitation with expansion, point to the dots on the pacing board as you say each word. For example, point to the first dot when you say *roll* and the second dot when you say *ball*. Place your hand over your child's hand and guide him to point to the dots. Children catch on to using the pacing board very quickly.



Continued on page 4

After the first word

continued from page 3

Once your child is using 2 word phrases consistently, you want to help him learn to use 3 word phrases, such as “daddy throw ball.” You can use the same techniques, imitation with expansion and the pacing board with 3 dots. What we find effective in therapy is to use a 2 sided pacing board with 2 dots on 1 side (what your child can say) and 3 dots on the flip side (what you are stimulating). Another way to practice multiword phrases is using children’s books with predictable phrases. When you read children’s books with your child, choose books that have phrases that are repeated, e.g. all gone, chicken soup with rice, the sky is falling, Where’s Spot?. That way, your child can learn the phrase and say it when it comes up in the book. You can also use carrier phrases such as “I see” or “I want,” so that your child learns the phrase and just needs to add the one word that will complete the message, e.g. I see daddy or I want ball. You can use a pacing board to teach carrier phrases. When you child is able to say phrases, ask questions, and use early sentences, you can write the words on the pacing board. Your child may even be able to read the words.

What speech and language skills prepare your child for preschool?

A. Comprehension (also called understanding, or receptive language skills)

This includes understanding language as well as following directions. When you read books with your child, talk about the characters and what happens in the book. Point to the pictures. Reading together is a good way to practice comprehension. When you have finished reading the book, go back over the pictures in the book, and ask your child questions. If your child cannot answer, you answer the question, and ask your child to repeat the answer. Following directions is an important skill in preschool and the early school years. Practice at home in everyday activities. For example, begin with a 1 stage command. “Get your jacket,” and progress to “We’re going outside. It’s cold. Get your jacket and hat and gloves.”

B. Semantics (vocabulary and meaning)

Help your child learn more and more vocabulary words. Talk with your child, and give them the words for everything that they see. Sometimes, your child will ask, “what’s that?” but even when they don’t ask, provide new



words. You can also describe what your child is doing when they are playing, e.g. you are taking the cow out of the barn. You put the cow on the grassy field so that he can eat and rest. Language practiced in preschool includes, colors and numbers and shapes. Preschool teachers are usually in close touch with parents. They let you know what concepts and vocabulary were worked on, so that you can reinforce the concepts in daily life at home and in the community. For example, for Halloween, they may work on orange and black and round; for Valentine’s Day, red and hearts.

C. Morphosyntax (grammar and word parts)

When your child learns concepts such as past tense and plural, they also learn the word endings that go with those concepts, e.g. dog and dogs, walk and walked, run and ran, child and children. When your child begins putting sentences together, he learns about word order, e.g. I am going. Are you going? It is snowing. Yesterday, it snowed.

D. Expressive Language Skills (spoken language)

Receptive language skills involve listening and understanding. Expressive language skills involve speaking and formulating messages. If your child cannot yet speak, it might involve sign, language, or pictures or a high tech device to help your child communicate. If your child is having difficulty with speaking, a speech-language pathologist can evaluate your child to determine whether the difficulty is with formulating and expressing messages, or with the motor production of speech. Then, she can work on expressive language and oral motor skills and speech, as needed.

E. Pragmatics (social language in daily living)

This includes greetings, hellos and goodbyes, and daily conversation, such as giving your name and asking the other person’s name. When you talk with your child,

and when they watch you talking with others, you are practicing conversations and social language. During daily living, we often use the same phrases, e.g. Hi, How are you doing? High five. Let's go now. These conversational words and phrases can be taught as a unit. They are known as scripts, and once your child learns scripts for daily living, you will hear her using those scripts.

F. Pre-literacy skills **(the skills that prepare you for reading)**

These skills are generally worked on in preschool and kindergarten, and mastering these skills will prepare your child to read.

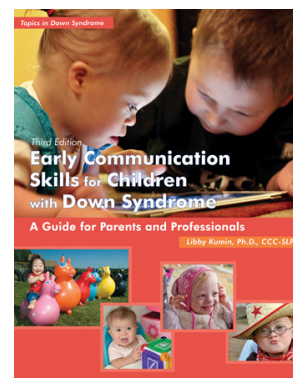
Phonological Awareness Skills:

- Taking words apart (map is m-a-p)
- Putting words together (d-o-g is dog)
- Counting the syllables in words (may clap or bang a drum, e.g. railroad is 2 syllables)
- Rhyming words (in school, sometimes called word families, such as cake, bake, rake)
- Identifying initial sounds in words

During the period from 1-4 years of age, your child is mastering concepts and words for language, skills for speaking, social skills, and early conversational skills. By the time of preschool, your child will be using single words and multiword phrases. Your child will be able to recognize and respond to his/her name, and follow simple directions. Your child will be interacting with parents, siblings, relatives, teachers, and other important people in their environment. Your child will be on the road to more complex and advanced language skills during the school years.

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

Thank you to Libby Kumin for this wonderful 3-part series. To download the articles in PDF format, visit our website:

<https://www.ndsccenter.org/programs-resources/speech-and-language/>

Glasgow welcomes the 13th Annual World Down Syndrome Congress

Held every two years, the World Down Syndrome Congress allows families, professionals and people with Down syndrome to access the latest medical research, educational developments and best practices related to the condition. Hosted by Down's Syndrome Scotland, on behalf of Down Syndrome International (DSi), the WDSC takes place at the Glasgow SEC's Scottish Event Campus, July 25th-27th. For event information, or to register, visit <http://wdsc2018.co.uk/>

DSi is a UK based international charity, comprising a membership of individuals and organizations (including



WDSC GLASGOW 2018
Experience, Research and Practice, widening opportunities, improving lives
25th - 27th July 2018, SEC, Glasgow, Scotland

NDSC) from all over the world, who are committed to improving quality of life for people with Down syndrome worldwide and promoting their inherent right to be accepted and included as valued and equal members of their communities. Down's Syndrome Scotland is the only charity in Scotland focused solely on the needs of people with Down syndrome and their families. They provide information, support and services for people with Down syndrome, their families, caregivers and those with a professional interest. They also seek to improve awareness, knowledge and understanding within society.



Self-Advocate Book Project

This project began in 2003 when self-advocate Tracy Hile introduced the idea of self-advocates presenting books on Down syndrome to the NDSC convention host community. Self-advocates and friends donate money for books that positively portray individuals with Down syndrome. They present these books to libraries in the NDSC Convention host city.

How can you help?

During on-line convention registration, check the box to have \$1 or more added to your registration fee to be donated to the Self-Advocate Book Project. For a donation of \$100, you will receive a "bundle" of all the books listed below to take back to your local community.

If you would like to make a donation to the Book Project, or purchase a bundle for your community, visit the website donation page — <https://www.ndsccenter.org/donate/> and write "Book Project" in the Comments box.

- **ABC Building Blocks for Growing Up With Down Syndrome**, by self-advocate Meredith Martin — Nicely outlines some of the key components that led her to independent living.
- **The Little King and His Marshmallow Kingdom**, by Louis Rotella III — This beautiful book encourages children to be themselves with confidence, and challenge pressures to conform.

- **Donovan and the Big Hole**, by Nancy Lambert Davenport — This delightful, fictional Texas adventure is narrated by fourteen-year-old Donovan, who happens to have Down syndrome. He and his neighborhood friends don't ask for trouble, but manage to find it!
- **Sam's Top Secret Journal (3 Book Series)**, by Sean Adelman — This is a set of three short novels about the adventures of Sam, a middle school girl with Down syndrome. They solve mysteries, have adventures, and deal with the world and its conflicts.
- **Stealing First: the Teddy Kremer Story**, by T Kremer with D Lang & M Buchanan — "Nothing — can top that night — I was batboy for the Cincinnati Reds!"
- **Why Are You Looking At Me?**, by Lisa Tompkins — A child with Down syndrome only wants to be a friend and have friends. She wants them to learn she "is more alike than different!"

Self-advocates present book bundles to librarian of Sacramento's St. Michael's Day School in 2017.



Last Call for Registration!

46th Annual
NDSC Convention



Dallas, TX • July 12–15, 2018

If you haven't made your plans yet, there's still time to join us at the 46th Annual NDSC Convention at the Sheraton Dallas Hotel and Convention Center, July 12 to 15. With all that is being offered this year you will find something for everyone.

All things convention can be found on our website, at <https://www.ndsccenter.org/annual-convention/>. Please take a few minutes to check it out: abstracts of our fantastic pre-conference workshop line-up, tips for planning your trip, and so much more — with all the details and many downloadable documents for you to review. First Responders and Educators, we've got you covered too! Our first-ever Disability Awareness Training for law enforcement personnel, firefighters and EMS will be held on July 12. July 13, Educators can attend an all-day conference, *Effective Practice for Students with Down Syndrome: Tools for Today's Classroom*.

Kids' Camp reached capacity at a record pace this year, but don't let that keep you from coming. Bring along an extra caregiver, take turns with your spouse or family member, or think about coming alone to learn and network.

As always, children are welcome to accompany you to the workshops (we just ask that you bring quiet activities to keep them engaged and to step out into the hallway if need be, so as not to distract our hard-working speakers or fellow attendees).

For those of you who have already registered, please be sure to review your confirmation to ensure you have included everything you need. If you've forgotten to add something, or someone, please call the NDSC office so we can get your registration adjusted while space is still available. Online registration closes on June 22.

NDSC members attending the convention are invited to attend the **Annual General Membership Meeting:**

Friday, July 13th, at 3:30 PM

Sheraton Dallas Hotel and Convention Center

400 North Olive Street

Dallas, TX 75201

The General Membership Meeting will include the introduction of our newest self-advocate board member (elected by his/her peers at the Youth & Adults Conference kick-off); reports from the NDSC Treasurer, NDSC Foundation Trustees and an overview of activities by our Executive Director. The Nominating Committee will present its slate of candidates and the election of new NDSC board members will take place. Other business will be conducted as warranted. All NDSC members are invited to attend!



Have you always wanted a Star named after you?

As the NDSC Annual Convention heads to Dallas, Texas, we will be "Reaching For The Stars"! A focal point 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. 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-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

Not coming to Dallas? You can still be a star in our sky!

<https://www.ndsccenter.org/support-join-be-involved/hall-of-stars/>

Orders for stars must be received by June 25, 2018.



We've added a new Facebook page: National Down Syndrome Congress - Engage

This is the page for people who want to make a difference, who want to get involved, who want to attend events, who ENGAGE with the National Down Syndrome Congress.



Did Someone Say Shopping?

The NDSC E-Commerce Store is open!

Get your NDSC apparel and accessories by clicking

<https://squareup.com/store/NDSC/>.

Advocacy in Action



Achieving a Better Life Experience (ABLE) Act Update

Spring has been busy for ABLE: three new state programs launched (Arizona, Wyoming and Texas), and the Social Security Administration updated its guidance on ABLE (for a summary on these guidance updates, click here: <http://www.ablenrc.org/news/social-security-administration-releases-updated-guidance-able>). There are now thirty-four ABLE programs around the country, many of which are available to qualified individuals nationwide.

NDSC is a founding member of the ABLE National Resource Center (ANRC) and continues to actively participate in ANRC's informational campaigns and outreach. NDSC staff is at the forefront of strategy discussions and policy relating to ABLE. NDSC Policy & Advocacy Director Heather Sachs formerly served as the Senior ABLE Advisor to ANRC, and she is currently a co-chair of the Consortium for Citizens with Disabilities Financial Security Task Force, which oversees cross-disability advocacy efforts relating to ABLE.

ANRC recently selected a group of ten ABLE Advisors to act as national spokespersons for ABLE accounts. We would like to congratulate National Down Syndrome Advocacy Coalition (NDAC) Member **Rachel Mast** on being selected as one of these ABLE Advisors.

(<http://www.ablenrc.org/meet-our-2018-able-advisors>).

A longtime advocate for passing ABLE legislation on the national and state level, we know that Rachel will do

a fantastic job representing the Down syndrome community and discussing the benefits and possibilities of having an ABLE account.

We encourage you to sign up for updates from ANRC and take advantage of the free resources and webinars that ANRC offers, and check out its website at www.ablenrc.org.



Every Student Succeeds Act

The Every Student Succeeds Act (ESSA) is the law that replaced the No Child Left Behind Act as the main elementary and secondary education law in 2015. ESSA works alongside IDEA with the purpose of creating a significant opportunity for all children to receive a fair, equitable and high quality education and to close achievement gaps. Every state has developed an ESSA implementation plan and submitted it to the US Department of Education for approval. Some states have sought waivers from certain ESSA provisions, especially the cap on the number of students who can take an alternate assessment. Local school districts also must develop ESSA plans. The resources found at the link below will help you determine what is happening in your state and show you how to use ESSA in your advocacy efforts.

<https://www.ndsccenter.org/wp-content/uploads/ESSA-Resources.pdf>

Find us on Facebook:

[National Down Syndrome Congress](#)

SELF-ADVOCATE

Spotlight: Christopher Bennett



Hi I'm Christopher Bennett. I work with Wine Bev Services of the UCP of the North Bay, Inc and the Meritage Resort and Spa. I'm proud to be employed in a work-related relationship with Wine Bev Services and the Meritage Resort and Spa in Napa, California, and also proud to be in a relationship outside of work for over 5 years with my girlfriend Theresa.

Wine Bev Services with UCPNB is enrolled with nearby Solano College, for work-related classes on the job, for job training on-site and off-site. They teach us the value of being employed. I learned my work skills and my work ethic from my parents, by working in the family business with them in the past and watching them at work. I learned about being employed and the value of making money for the future. Also to always work with the employer to make good first impressions, learn about their companies, how they work with you to accommodate your needs that fit with your abilities and skill levels. Not focused on what we can't do, due to our

disabilities. Moving Forward, an organization in Napa, introduced me to NVSS, NPS, and the Department of Rehab for employment opportunities, assessments, employment support with the Regional Center.

Wine Bev and The Meritage opened more work opportunities for me, I learned a lot about working in a five-star resort with their resort management support in working with us, our crews. They provide us with uniforms, discounts, lunches, and our equipment to do the jobs at their resort. I provide five-star, guest-first treatment to the resort guests, making them feel welcomed during their stay in the hotel. Supervisors come with us to oversee our groundskeeping crew on the parking lot, known as the "Lot Crew" for short, for six months to a year. I'm very helpful to my Wine Bev Supervising Staff and clients, supporting and encouraging the clients at work every day to have work opportunities for work with Wine Bev and Meritage. We have other crews at the Meritage too with the kitchen, laundry, and the hotel. The Meritage Resort and Spa is expanding to another hotel property across the street opening in 2018. I like my managers, my crew I work with every day, and I speak Spanish with my Spanish hotel managers, being the worker the resort likes to have around.

From attending my National Down Syndrome Congress Annual Conventions I learned to mentor self-advocates about our conferences, how to be active at our conferences and with NDSC. As of January 2018 to start out the New Year, I started the Wine Bev Mentors Program of Wine Bev Services with UCP of the North Bay. Mentoring new clients starting out a new job with Wine Bev Services, learning about Wine Bev and the Meritage, learning what we do for work opportunities for them, creating a safe working environment for them too. Making client binders for their supervisors to have for them for when they meet with them too.

I grew up with Down syndrome which challenged me to where I am now today. I became a successful public speaker, presenter, and mentor, educating other families about what helped us as a family. To inspire other families of people with Down syndrome and other disabilities, to learn more resources that can be helpful resources to them, for family supports in schools



and being actively involved in the schools too. I learn a lot from social media and the news even though Down syndrome is not always a daily news topic. How employers can hire employees with disabilities, accommodate their employment abilities to work like everyone else, be accepted everywhere they go, be productive members of today's society, accessing their communities, healthcare, research for more resources. It's about promoting Down syndrome awareness month in October and World Down Syndrome Day in March. Volunteering, serving on the NDSC Board and Self-Advocate Council, being empowered self-advocates in our local cities and states, learning new skills at our conference workshops each year at our conferences. I hope to see you at the 2018 NDSC Convention, our giant family reunion in Dallas, Texas! As we gather our group knowledge together — as one NDSC, one family — networking, research, employment, education, advocacy, medical providers, all in one place.

Are You Ready to Be in the Spotlight of Our Self-Advocate Corner?

We love to share stories and articles written about and by people with Down syndrome. If you, or someone you know, has something to share with our members, please send it our way. People all over the country will read it!

Send your original story or article, or article that we can reprint to:

Editor, Down Syndrome News
National Down Syndrome Congress
30 Mansell Court, Suite 108
Roswell, GA 30076
or tamara@ndsccenter.org

Don't forget to send your name, age, address, phone number and a photo of yourself to go with your article.

NDSC's National Partner – Comfees!

We are excited to announce our new corporate partnership with Comfees Premium Diapers! Not only will we be working together to get the word out about their products, and about the great company behind the diaper, but Comfees will sponsor our 321 Dance on Friday night, at the 46th Annual NDSC Convention.

Visit their website today — <https://www.mycomfees.com/>



El habla, el lenguaje y la comunicación después de la primera palabra

Libby Kumin, Ph.D., CCC-SLP

Mi hijo está diciendo pocas palabras. ¿Qué viene después? ¿Qué puedo hacer para ayudar?

Cuando su hijo usa pocas palabras, hay tres pasos que usted deberá seguir:

- habilidades motoras orales/habla
- el desarrollo del lenguaje horizontal
- desarrollo vertical del lenguaje.

Un paso es trabajar en habilidades motoras orales y sonidos haciendo que el habla de su hijo sea comprensible. Esto se conoce como inteligibilidad del habla. El patólogo del habla y el lenguaje puede ayudar a su hijo a aprender a hablar con más claridad.

El segundo es el desarrollo horizontal del lenguaje, es decir, desea ayudar a su hijo a desarrollar más conceptos y aumentar las habilidades de vocabulario. Puede hacerlo involucrando a su hijo en muchas experiencias lingüísticas y señalando con palabras de vocabulario lo que está sucediendo en ese momento. Por ejemplo, cuando caminas afuera, señale árboles, flores, pájaros y nubes, y asegúrese de mirarlos, escucharlos, olerlos e interactuar con los sentidos de tu hijo para aprender las palabras de lo que está viendo. Cuando esté en el patio de recreo, proporcione palabras para el equipo en el que su hijo está jugando y use las palabras desliza, abajo, encima, por debajo, arriba y atrás para describir lo que está sucediendo. Lea libros con su hijo sobre sus experiencias, por ejemplo, caminar en la ciudad, ir a la playa, jugar en la nieve.

El tercero es el desarrollo vertical, es decir, ayudar a su hijo a aprender a combinar palabras y usar frases de 2 palabras. La investigación nos dice que los niños con síndrome de Down están listos para combinar palabras cuando tienen un vocabulario de 100 palabras (ya sean signos o palabras). Luego pueden combinar las palabras que ya conocen y usan, y aprender a decir coche grande en lugar de coche.

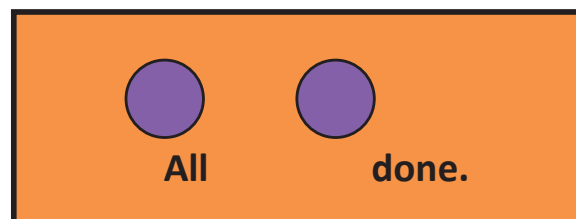
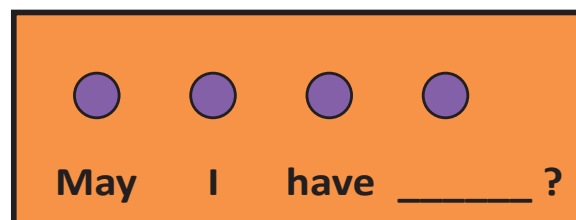
El mejor método para ayudar a su hijo a combinar palabras en frases de varias palabras es usar imitación con expansión y una tabla de ritmo. Para usar imitación con expansión:

1. Repite lo que dice tu hijo. Al repetir la palabra, muestras que lo entiendes y que usó una palabra correcta.

2. Expande lo que dice tu hijo con una palabra.

Puede presentar la imitación con expansión muchas veces antes de que su hijo comience a usar dos palabras; solo manténlo. Este tipo de actividad se presta bien para jugar y para las actividades de la vida diaria; por ejemplo, su hijo dice "calcetín", tu dices "ponte el calcetín"; tu hijo dice "pelota", tu dices "rueda la pelota o tira la pelota".

Usar una tabla de ritmo le ayudará a su hijo a aprender a decir combinaciones de 2 palabras y 3 palabras, como salir o salir ahora. La tabla de estimulación es un sistema de localización que proporciona un recordatorio visual y táctil de la cantidad de palabras que su hijo puede usar en combinación (ver a continuación). La placa de ritmo puede consistir en dos puntos de colores en un pedazo de cartón, o un cuadrado de terciopelo y un cuadrado de papel de lija montado en un tablero, dos adhesivos coloridos montados en un pedazo de cartón, o cualquier otra cosa que le guste a su hijo. Cuando use la imitación con la expansión, señale los puntos en la tabla de ritmo mientras dice cada palabra. Por ejemplo, señale el primer punto cuando diga rueda y el segundo cuando diga la pelota. Coloque su mano sobre la mano de su hijo y guíelo para que señale los puntos. Los niños se acostumbran a utilizar la tabla de ritmo muy rápidamente.



Una vez que su hijo use frases de 2 palabras consistentemente, debe ayudarlo a aprender a usar frases de 3 palabras, como "papa tira la pelota". Puedes usar las mismas técnicas, la imitación con expansión y la placa de ritmo con 3 puntos. Lo que encontramos efectivo en la terapia es usar una placa de estimulación de 2 lados con 2 puntos en un lado (lo que su hijo puede decir) y 3 puntos en el lado opuesto (lo que está estimulando). Otra forma de practicar frases de palabras múltiples es usar libros para niños con frases predecibles. Cuando lees libros para niños con tu hijo, elige libros que tengan frases que se repitan, por ejemplo, "todo se ha hido, sopa de pollo con arroz, el cielo esta cayendo". De esa forma, su hijo puede aprender la frase y decirla cuando aparezca en el libro. También puede usar frases portadores como "Yo veo" o "Quiero", para que su hijo aprenda la frase y solo tenga que agregar la palabra que completará el mensaje, por ejemplo, veo a papá o quiero pelota. Puede usar una tabla de ritmo para enseñar frases de operador. Cuando su hijo es capaz de decir frases, hacer preguntas y usar oraciones tempranas, puede escribir las palabras en la tabla de ritmo. Su hijo incluso puede leer las palabras.

¿Qué prepara el habla y las habilidades lingüísticas a su hijo para el preescolar?

A. Comprensión (también llamada comprensión o habilidades del lenguaje receptivo)

Esto incluye entender el lenguaje y seguir las instrucciones. Cuando lea libros con su hijo, hable sobre los personajes y lo que sucede en el libro. Señala las imágenes. Leer juntos es una buena forma de practicar la comprensión. Cuando haya terminado de leer el libro, vuelva a revisar las imágenes del libro y hágale preguntas a su hijo. Si su hijo no puede responder, responda la pregunta y pídale a su hijo que repita la respuesta. Seguir las instrucciones es una habilidad importante en preescolar y en los primeros años de escuela. Practica en casa en actividades cotidianas. Por ejemplo, comience con un comando de 1 etapa. "Consigue tu chamarra", y avanza hacia "Vamos afuera. Hace frío. Consigue tu chamarra, sombrero y guantes".

B. Semántica (vocabulario y significado)

Ayude a su hijo a aprender más y más palabras de vocabulario. Hable con su hijo y dele las palabras para todo lo que vean. A veces, su hijo preguntará "¿qué es eso?", Pero incluso cuando no pregunten, brinde nuevas palabras. También puede describir lo que está haciendo su hijo cuando están jugando, por ejemplo, si está sacando la vaca del establo, pones la vaca en el campo de hierba para que pueda comer y descansar.

El lenguaje practicado en preescolar incluye, colores y números y formas. Los maestros de preescolar suelen estar en contacto cercano con los padres. Le permiten saber en qué conceptos y vocabulario se trabajó para que pueda reforzar los conceptos en la vida diaria en el hogar y en la comunidad. Por ejemplo, para Halloween, pueden utilizar el naranja, negro y redondo; para el Día de San Valentín, rojo y corazones.

C. Morfosintaxis (partes gramaticales y vocales)

Cuando su hijo aprende conceptos tales como el pasado y el plural, también aprenden las terminaciones de palabras que corresponden a esos conceptos, por ejemplo, perro y perros, caminar y caminé, correr y corrimos, niño y niños. Cuando su hijo comienza a juntar oraciones, aprende sobre el orden de las palabras, por ejemplo, voy. ¿Vas a ir? Está nevando. Ayer, nevó.

D. Habilidad lingüística expresiva (lenguaje hablado)

Habilidades del lenguaje receptivo involucrar a la escucha y la comprensión. Habilidades lingüísticas expresivas implican hablar y formular mensajes. Si su hijo aún no puede hablar, puede incluir signos, lenguaje o imágenes o un dispositivo de alta tecnología para ayudar a su hijo a comunicarse. Si su hijo tiene dificultades para hablar, un patólogo del habla y el lenguaje puede evaluar a su hijo para determinar si la dificultad está en formular y expresar mensajes o en la producción motora del habla. Luego, puede trabajar en el lenguaje expresivo y las habilidades orales y motoras, según sea necesario.

E. Pragmática (lenguaje social en la vida diaria)

Esto incluye saludos y adiós, y conversaciones diarias, como dar su nombre y preguntar el nombre de la otra persona. Cuando hablas con tu hijo y te miran hablar con otros, estás practicando conversaciones y lenguaje social. Durante la vida diaria, a menudo usamos las

Gracias a Libby Kumin por esta maravillosa serie de 3 partes. Para descargar los artículos en formato PDF, visite nuestro sitio web:

<https://www.ndsccenter.org/bienvenidos/informacion-para-padres/>

Continúa en la página 14

Después de la primera palabra

continuación de la página 13

mismas frases, por ejemplo, Hola, ¿Cómo estás? Vamos ahora. Estas palabras y frases de conversación se pueden enseñar como una unidad. Son conocidos como guion, y una vez que su hijo aprenda los guiones para la vida diaria, lo escuchará usar esos guiones.

F Habilidades de pre-alfabetización: (las habilidades que te preparan para la lectura)

Estas habilidades generalmente se trabajan en preescolar, y el dominio de estas habilidades prepara a su hijo para leer.

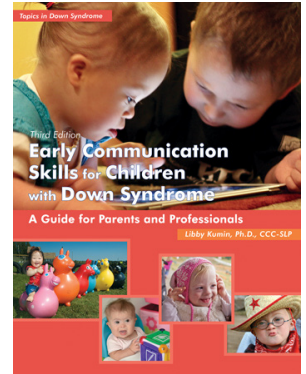
Habilidades de Conciencia Fonológica:

- Separando palabras (el mapa es un m-a-p-a)
- Poner palabras juntas (p-e-r-r-o es perro)
- Contar las sílabas en palabras (puedo aplaudir o golpear un tambor, por ejemplo, el ferrocarril es de 4 sílabas)
- Palabras que riman (en la escuela, a veces llamadas familias de palabras, como pastel, hornear, rastrillo)
- Identificar sonidos iniciales en palabras

Durante el período de 1-4 años de edad, su hijo domina conceptos y palabras para el lenguaje, habilidades para hablar, habilidades sociales y habilidades iniciales de conversación. En el momento del preescolar, su hijo utilizará palabras sueltas y frases de palabras múltiples. Su hijo podrá reconocer y responder a su nombre, y seguir instrucciones simples. Su hijo interactuará con sus padres, hermanos, parientes, maestros y otras personas importantes en su entorno. Su hijo estará en el camino hacia habilidades de lenguaje más complejas y avanzadas durante los años escolares.

Para lectura adicional:

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



Parent Resource Information:

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



Los miembros del NDSC que asisten a la convención están invitados a asistir a la **Reunión Anual de Membresía General:**

Viernes, 13 de julio, a las 3:30 p.m.

Sheraton Dallas Hotel and Convention Center

400 North Olive Street

Dallas, TX 75201

La Reunión de Membresía General incluirá la presentación de nuestro nuevo miembro de la junta autogestora (elegido por sus pares en la inauguración de la Conferencia de Jóvenes y Adultos); informes del Tesorero del NDSC, Fideicomisarios de la Fundación NDSC y una descripción general de las actividades de nuestro Director Ejecutivo. El Comité de Nominaciones presentará su lista de candidatos y se llevará a cabo la elección de nuevos miembros de la junta de; NDSC. Se realizarán otros negocios según lo justifique. ¡Todos los miembros del NDSC están invitados a asistir!



Dallas, TX • July 12–15, 2018



Pre-Conferencia H

**“Ella Tiene Síndrome de Down, Pero yo no”:
Cuando el Autorreconocimiento es difícil y
su falta se transforma en barrera para
la Inclusión**

MACARENA LIZAMA

Directora Ejecutiva del Centro UC Síndrome de Down en Chile, Dra. Lizama será nuestra ponente para la Pre-Conferencia de nuestra convención este año en Dallas, TX. Ella discutirá cómo las personas con síndrome de Down pueden ganar autoestima y aprender a amarse a sí mismos. El objetivo del workshop será reconocer el proceso de autorreconocimiento de las personas con síndrome de Down en su condición, identificar cuando su falta se transforma en barrera de inclusión y discutir herramientas para trabajarlo.

Regístrese para nuestra conferencia y añada la Pre-Conferencia “H” o si ya se registró todavía tiene tiempo para añadir esta Pre-Conferencia. Para más información nos puede llamar a: 770-604-9500

Down Syndrome News

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