



# Down Syndrome News

NEWSLETTER OF THE

Volume 40, Number 2

Summer 2017



## Part 1 – Beginning the Journey to Speech, Language and Communication

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

### How does my infant and toddler learn to speak?

Babies can't speak to us, but they communicate their needs to their families by crying, laughing, pointing and other gestures. They learn that when they make a sound or cry, someone will come and help meet their needs.

Speech uses the structures and movements used for breathing and feeding, and this is good news because you don't need to wait until your child is speaking to work on the skills needed for speaking. There isn't a separate speech system in the body. Early on, infants move their lips, tongue and jaw for sucking, nursing or bottle-feeding, and then eating solid foods. Infants cry and babble and play with sounds. They play with their lips and tongues and make sounds, improving their muscle strength, range of motion, and feedback system. They test their voice, and make loud and soft sounds. They babble strings of sounds. In English and Spanish, all speech is made during exhalation. If a person is speaking while inhaling, they are choking and gasping. So, one of the skills babies are learning when they cry or babble sounds is to lengthen the time that they exhale, preparing them for speech.

*Thank you, Libby,  
for this wonderful  
3-part article!  
In our next  
issue, Part 2 –  
"Developing Speech  
While Maintaining  
Language and  
Communication"*



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# Letter from the President

Dear Families,

As the final days of Spring wind down and everyone begins planning for the Summer, many of us are preparing for our annual convention in July. Sacramento, California promises to be a weekend filled with fun, friends, families and lots of opportunities for educational workshops, networking and celebration. It is our Sapphire Year and we will certainly be "Livin' the Dream"! If it will be your first time attending, you will not be disappointed! If you have been coming for many years, you know what a wonderful experience it is and what an awesome weekend it will be!

This past year, your Board of Directors and NDSC staff have been hard at work enhancing current programs and adding new programming to enrich the lives of people with Down syndrome. Our Governmental Affairs staff are in Washington, DC working on your behalf on all the issues that affect

people with Down syndrome. Our Strategic Plan initiatives are moving forward and we will have our 2nd Annual Educator's Conference in combination with the Convention this year. We look forward to sharing updates with you in July!

As we look toward our "Family Reunion" in July, don't forget that we are here for you 365 days a year to provide resources and support. YOU are the NDSC and we look forward to working with you and meeting you soon.

As a final note, thank you for allowing me to serve as your Board President for the past three years. It has been a tremendous honor and nothing short of amazing! It has been my privilege and I so appreciate everyone's support and encouragement. My term will officially end in July at our annual convention in Sacramento. It will be bittersweet but know that I, alongside many



others, will continue to work to create a better world for individuals with Down syndrome.

We are making a difference every single day. I hope to see many of you in Sacramento!

My best,

Marilyn

## 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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# California, here we come!



In a few weeks, the NDSC staff and Board of Directors will travel to Sacramento to present our 45th annual convention! Each year, thousands of people from across the globe attend the NDSC Convention. For most, it's to hear the latest information from world-renowned experts. For others, it's a great vacation. However, for nearly all, there's the one-of-a-kind NDSC "giant family reunion" feeling that permeates the convention weekend.

- PARENTS learn from the best, as internationally known experts come to Sacramento to share their knowledge across the life span of individuals with DS.
- SELF-ADVOCATES join together with over 350 friends from across the world to learn, share, become empowered and have an amazing time!

- SIBLINGS share and learn alongside peers, from each other, as well as from professionals.
- VOLUNTEERS have the experience of a lifetime by volunteering in any number of capacities available.

Not making the trip to Sacramento? You can purchase the recordings! These audio recordings include the presenter's PowerPoint with synced audio for a virtual recreation of each presentation. There are three options to choose from:

1. **Fast Pass** – 12-month, streaming-only online access – \$69 now through July 10 (\$129 after the convention)
2. **Season Pass** – 12-month, streaming online access, plus download access – \$99 now through July 10 (\$159 after the convention)
3. **USB Works** – USB Flash Drive and 12-month, streaming online access, plus download access – \$129 now through July 10 (\$199 after the convention)

<https://www.ndsccenter.org/the-convention/conference-recordings/>

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## Speech, language & communication

*continued from page 17*

Speech is an output system but it is based on the input that the child receives. So, it is important to ensure that the child's input systems: hearing, vision and touch, are functioning well. If there are sensory input difficulties (hearing or seeing), it is important to treat those difficulties early.

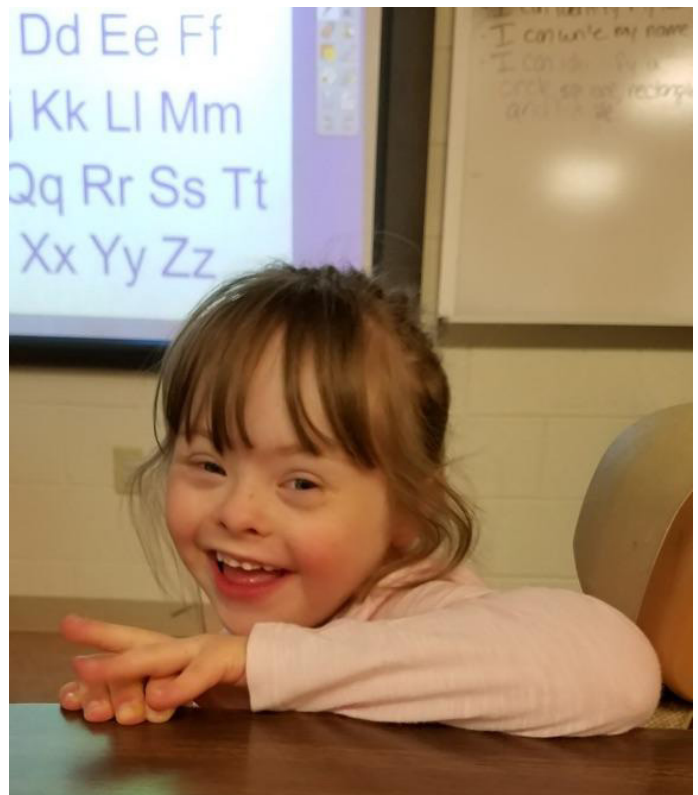
The power for speaking comes from exhalation. Through feeding, crying, cooing and babbling, infants learn to coordinate breathing and the movements that they will use for speaking. Through hearing, vision, and touch, they listen to the language of their families and they learn the words in their language. So, babies are learning and practicing the input and output skills they will need for speech, language and communication early in their development.

### **How early do you need a speech and language evaluation? What type of speech and language evaluation and treatment are needed?**

You should not passively wait for your child to begin to speak. You should seek information and education about speech, language, and communication as soon as you can. Early intervention programs may or may not include a speech and language evaluation as part of their program. Many school system special education programs will not evaluate speech and language until age 3, or even until your child is beginning to speak. Pre-speech and pre-language evaluations may be available through university clinics or private practices, if they are not available to you through the schools. There are books, talks, and conferences (local, regional, and national/international such as the NDSC Convention), that will provide information to help you and your child get started on the journey to speech and language. During the first year of life, speech and language evaluation and treatment focus on the pre-speech and pre-language skills. Evaluation can determine which skills your child has already mastered and which skills would be best to work on next. Therapy can teach you how to work with your child at home and model how to use play activities (rolling a ball back and forth) and activities of daily living (feeding, bathing) to promote speech and language.

### **What are the pre-language skills?**

From birth to approximately 1 year of age, your child learns many skills that help him/her get ready to use language.



These are skills that you can work on at home while you are playing with your child.

### **Interactive Communication Skills**

- A. Communicative intent:** This is when the baby realizes that s/he can get attention by crying or making noises. His family come to help him when he cries. She lifts her arms and mom takes her out of the crib. She points to her toy bear, and her sister gets it for her. What can you do to help your infant learn this skill? Respond to your child! Your infant will learn this skill because you respond to her initiations. She will realize that her family and caregivers respond to her sounds and gestures.
- B. Turn taking:** Your baby learns that communication is two-way. He can initiate communication and he can respond to communication. How do you teach this skill? When your child makes a sound, you talk back to him. You can roll a ball to your baby and teach him to roll the ball back. You can take turns banging on a drum or playing a xylophone with a wand and passing the wand back and forth. Turn taking in play transfers to taking turns in communication.
- C. Engaging attention:** Respond when your baby looks at you or tugs on your arm. Show the baby that he can get your attention.



- D. Requesting:** When your baby “asks” for something by pointing, respond to the request. Later on, when your baby crawls over to a toy but can’t get it off the shelf, help him. He needs to know that his requests get results. Requesting begins with pointing, gestures and signs.
- E. Protesting:** When your baby cries when he doesn’t want to do something, or pushes a food that he does not like away, let him know that you got his message even when you can’t do what he wants. Say, “Do you want a piece of banana” or “I know that you don’t like to eat a banana, but you need to eat this little piece of banana.”
- F. Social communication:** Encourage your baby to wave hi and bye, to smile and interact with people.

## Attentional Skills

To learn language, your baby needs to listen to you speaking, watch you, and pay attention. How can you help your baby learn this skill? Explore toys together. Show your baby how to touch, squeeze, turn over and learn more about a toy ball, or a toy giraffe. Comment as you look at the toy together. Play music and sing songs with your child and increase the amount of time that your child listens. Read a book to your child, and progress from very short books to longer books. You are teaching your child to focus and to attend for longer periods of time.

## Visual Skills

- Seeing/vision
- Visual attention
- Reciprocal gaze
- Shared gaze
- Visual tracking

Work with the pediatrician and the eye specialist to make sure that your child can see well. Teach your child to look around at the environment: watch birds flying, the puppy moving around, airplanes overhead. Teach your child to watch moving things; this is known as visual tracking. Teach your child to look you in the face, for you and he to look at each other. This is known as reciprocal gaze or eye contact. *(Sometimes, I even put stickers on my face, or funny eyeglasses, or make funny faces to get a child to look at me.)* Look at the pictures in a book together, or look at the clouds, or the snow falling outside. Looking at something together is known as shared gaze, joint attention, or referential gaze. Infants and toddlers need to be able to look at an object, person, or event with you

so that they can learn the words that identify that object, person, or event.

## Auditory Skills:

- Hearing
- Auditory Attention
- Auditory Localization
- Auditory Processing
- Auditory Integration

Work with the pediatrician and the hearing specialist to monitor your child’s hearing. Environmental sounds are all around us. Comment on sounds, e.g. Did you hear that? The dog is barking. Did you hear that? The ambulance has the siren on. It’s really loud. Help your child learn to listen longer; this is auditory attention. Listening to music and using finger and hand movements with songs (e.g. the eensy weensy spider) is good practice. Teach your child where the sound is coming from. That is called auditory localization. I hear some birds chirping. Where are they? Or the car in back of us is honking his horn. Auditory processing means making sense out of the sounds that you hear. When you talk to your child about the sounds he hears and when you read with your child, you are teaching

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him about words and what they mean. Some children are uncomfortable with loud noises, or with a lot of background noise around them. They cover their ears with their hands at baseball games or when folks are cheering or screaming loudly; this means that they have difficulty with auditory integration. The audiologist can evaluate whether your child has difficulty in this area, and there are specialized treatment methods for auditory integration difficulties.

*Continued on page 22*

## Speech, language & communication

continued from page 21

### Cognitive/linguistic pre-language skills

- Object permanence
- Cause and effect
- Means-end
- Referential communication

To learn language, children must realize that when they can't see something, it still exists. We put a toy ball behind our back. The child looks for the toy, and tries to get it back. He knows that even though he no longer can see it, it is still there. He has mastered the skill of object permanence. How can we teach this skill? We can cover a musical toy with a scarf. The child cannot see the toy, but he hears it and he knows that it is there. Put a baby blanket over daddy as he curls up on the floor. Your child will still know that daddy is there even if he is partially or fully covered with the blanket. Say, "Where's daddy?" Then remove the baby blanket and say "There he is!" A game that teaches this skill is Peek-a-Boo, and we play the game many, many times to help the baby learn about object permanence.



In play, infants and toddlers learn that actions have results. They love to flip the light switch and turn the lights on and off. They love to push a button on a toy and see it move. They are learning that when you do something, there is a reaction, an effect. This is the skill of cause and effect. Sometimes, you need to make a plan to accomplish your goal. For example, you want to reach the bowl of cookies on the counter, but you can't reach the counter, so you pull a chair over to the counter. You climb on the chair, reach the counter, and get the cookies. Your plan worked and you accomplished your goal. This skill is known as means-end.

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Speech uses the structures and movements used for breathing and feeding...you don't need to wait until your child is speaking to work on the skills needed for speaking.

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For many months, you label objects, e.g. door, people, e.g. daddy, and events, e.g. it's raining. At some point, your child makes the connection between the words you have said, and the object, person or event that the word represents. That is known as referential knowledge or referential communication.

Now, your child has mastered all of the skills that will enable them to use language. Your child knows how to learn about his environment. Your child can use vision to learn. She can look at you and look with you at a toy or book. He can listen to music and to the sounds in his environment. He understands cause and effect and that communication can get results. She can be social and interact with people in her environment. He understands that objects, people and events have names and that these words (symbols) are meaningful. But often, your child is not yet ready to speak. What do we do to bridge the gap, to continue to help your child learn new words and more language skills? What can we do so that your child can continue to communicate and use the language skills s/he has already mastered? What can we do to help your child learn the skills s/he will need to begin speaking?

### 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/speech-and-language/>

- Speech and Language Resource Guide for Parents of Infants and Toddlers with Down Syndrome: Birth to First Word
- Speech and Language Resource Guide for Parents of Infants and Toddlers with Down Syndrome: First Words to Phrases

# Effective practice for students with Down syndrome: Tools for today's classroom

Join the National Down Syndrome Congress and world-renowned speakers for a special workshop for educators working to enhance outcomes for their students with Down syndrome and other intellectual disabilities, as well as autism.

This workshop will engage participants in identifying and implementing strategies applicable to classrooms from kindergarten through 12th grades. Discussions will include ways to further include students in the general education classroom through effective literacy interventions, differentiated curriculum, technology, and behavioral practices.

Practical in nature, the workshop will equip participants with ideas, solutions, and tools to implement in the classroom.

For more information, including speaker bios, presentation abstracts, learning objectives and to register:

<http://www.ndsccenter.org/educationalexcellence/>

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*Center for Educational Excellence*

NDSC members attending the convention are invited to attend the **Annual General Membership Meeting on Friday, July 21st, at 3:30 PM, at the Sacramento Convention Center located at 1400 J Street, Sacramento, CA.** 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!

## WORKSHOP DETAILS:

**Friday, July 21**

**8:45 am – 4:15 pm**

**Sacramento Convention Center  
1400 J Street, Sacramento, CA 95814  
Room 315, 3rd Floor**

**Fee: \$100**

*includes CEU credits, handouts and lunch*

### Presentation Schedule

8:45 am ..... Check-in  
9:00 am ..... Teach Literacy  
10:45 am ..... Technology Innovation  
12:15 – 1:00 pm ... Networking Lunch  
1:00 ..... Behavior Management  
2:45 pm ..... Differentiated Instruction  
4:15 pm ..... Concludes

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# Advocacy in Action

By Raquel Ross



Advocacy can appear daunting. A task best left to those who know what they are doing, right? But here is the secret: No one knows how to do this better than you and me, the parents.

In April, I received an email from a staff member for Congressman Glenn “GT” Thompson (R-PA), senior member of the House Education and the Workforce Committee, to attend an invite-only panel discussion on the implementation of the Every Student Succeed Act (ESSA) in Pennsylvania. The panel included Matt Stem, Deputy Secretary for the Pennsylvania Department of Education; Jacki Ball, Director of Government Affairs for the National PTA; and Erin Duncan, Government Relations for the National Education Association. The staff member thought I would really enjoy the panel since I had discussed ESSA implementation with Congressman Thompson, specifically asking Congressman Thompson to help make sure that disability advocates (or stakeholders) were involved in the creation and implementation of the ESSA Plan in Pennsylvania.

Flattered, I immediately responded yes. Soon thereafter, I became filled with a certainty that I would make a fool out of myself. I had only a cursory understanding of ESSA and no knowledge of where Pennsylvania was in the implementation process. The last thing I wanted to do was embarrass myself in a room full of professionals and educators. So I contacted NDSC’s Senior Education Policy Advisor, Ricki Sabia, and asked for her guidance. Ricki spent several hours with me on the phone, providing me with an advanced understanding of ESSA and its implementation process. With this new tutelage, I reviewed the Pennsylvania Department of



Education’s website and prepared questions in advance for the panelists.

The event was held in a small, beautiful room at the Alumni Center at Lock Haven University. The audience consisted of principals and superintendents from surrounding school districts as well as directors and presidents of national associations mainly focused on educator rights. Each panelist presented a short presentation and afterwards an informal question and answer period transpired. After a brief moment of hesitation, I asked my two questions to the panelists. I was relieved when my questions were understood and my relief turned to joy when questions elicited notable responses.

Following the question and answer period, the Congressman, audience and panelists mingled. I used this time to thank the panel members and talk more intimately with them about the Pennsylvania ESSA Plan. Through these interactions, I was introduced to members of the Pennsylvania PTA, as well as the Director of the Pennsylvania NEA. Moreover, the Deputy Secretary invited me to meet with him and key members of the Pennsylvania Department of Education as a stakeholder in Pennsylvania to help with the ESSA Plan development in Pa.

A huge thank you to NDSC and Ricki Sabia for preparing me so I could ask the right questions at the right time.





**SUSAN GOODMAN** is currently the Senior Policy Advisor for NDSC, with over thirty-five years of experience in disability law and policy, in education and community living. Ms. Goodman served as Director of Governmental Affairs for the NDSC from 2001 - 2017. In that role, she collaborated closely with other national organizations to bring a strong emphasis on people with Down syndrome and other intellectual and developmental disabilities.

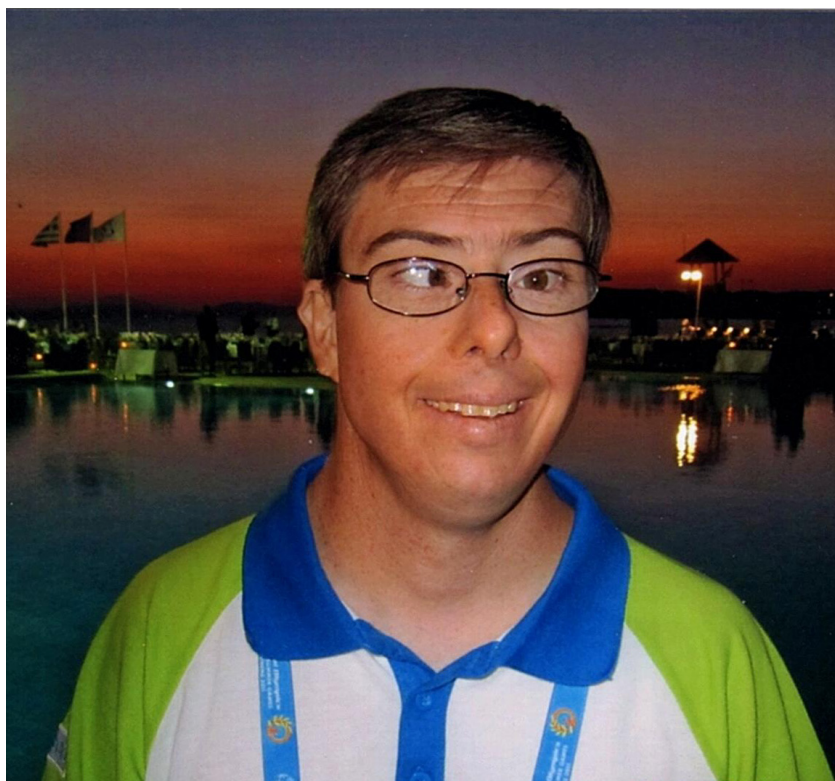
Her advocacy experience began after her son, David, was born with autism and led to tireless advocacy for inclusion in school and in employment for him, and all people with disabilities. Susan was an expert consultant for the Associate Commissioner of Disability and Income Support Services for the Social Security Administration, focusing on employment issues for people with disabilities. She was also project director at the United Cerebral Palsy Association and practiced law representing families and people with disabilities in education and civil rights issues, winning a one of the first victories in a federal court cases involving both restraints and seclusion of a student with disabilities in schools. She was part a group of five organizations that was responsible for Medicaid HCBS services adding "self-determination" waivers, giving people with disabilities (and/or families) the right to control spending of their Medicaid funding.

Her current emphasis is community living and employment services for adults, focusing on the Home and Community Based Services Medicaid waiver program (HCBS), the Workforce Innovation and Opportunity Act (WIOA), and Social Security and Supplemental Security Income (SSI) program.

## SELF-ADVOCATE Spotlight

My name is Edward Barbanell. I am 39 years old and I live in Florida. I was born with Down syndrome. It is a meaningless word. I believe, I can, and I will do whatever it takes to follow my dream of acting. I was blessed to have been in the movie "The Ringer" in 2005, and have been in several episodes of "Workaholics."

I am a self-advocate. I served on the board of Special Olympics and I campaigned to make people aware that using the R-word was hurtful. I led a rally at a local high school and had everyone sign a petition to ban the R-word. My goal is to have people with Down syndrome appear in commercials, TV shows and corporate advertising. We have the same needs as all of you — love, respect and camaraderie. I would like to create awareness for individuals with Down syndrome to be in the media, too.



# A Parent's Challenge: She CAN live alone...She CAN'T live alone...She CAN...

Written by Bernadette Moran, author and Moira's Mom

This is a dilemma faced by parents all over the country that becomes magnified each year as your child with developmental disabilities grows and reaches that frightening point of exiting school! My husband and I faced that dilemma many times over as the magical age of 22 approached and we knew we could not stop the clock. Our daughter, Moira, had surprised and delighted us over the years as she grew and participated in regular scouting, went to the local Catholic middle school, became a cheerleader and even ran for class president! Her cousin had run for that office in another school and Moira had heard her rehearse her address to the class. Unbeknownst to us, Moira had it memorized and gave the very same speech to her class – the teachers were bowled over – we knew what had happened but never let on that it was actually her cousin's speech! But for all of her accomplishments, we knew that her reasoning skills were poor, her trust in strangers was potentially dangerous, her money management was non-existent, and household maintenance seemed a distant goal. So, what could we do? What would her future hold?

We knew that Moira's desire for independence was strong and we were fast approaching the new reality of losing our child with disabilities and gaining our adult with disabilities. The child that wanted, and deserved,

all the excitement and challenges of adulthood. Those very same challenges faced by her cousins, yet she didn't seem ready for adulthood, although her desire was so strong. As we struggled with this dilemma and talked with numerous friends facing the same issues, we heard about a new program being run by The Arc Jacksonville, Inc., right in our hometown of Jacksonville, FL. The program was offering an opportunity for young adults over 18 to spend four summer weeks living in student housing with others with intellectual and developmental disabilities. It had been years since Moira had been to camp and it seemed perhaps too juvenile for my adult child to be going to summer camp but as we delved into the concept, it became clear that this was not a camping experience but rather a time for young adults – and their families – to really assess their strong and weak points and begin to evaluate the potential for their future. What would be the best approach for the child? Is a group home the option? Foster family? Live-in supports in a home environment? What about cooking? Shopping? Getting to work! Getting a job! Public transportation? Getting along with others? A myriad of questions that my husband and I had asked one another a hundred times but never answered. The same



questions our family and friends asked us year after year, and every year we would say we just were not sure!

## A wonderful opportunity...

Now we had an opportunity to have others help Moira to evaluate her own potential for success in independent living. She would live, for four weeks, with two other adults with developmental disabilities and a peer-aged support person. She would live in a four-bedroom, four-bathroom apartment so she would have her own room and bath and be responsible for keeping her area clean and organized. She would manage her schedule, choose her own clothes, and keep them clean. She would help with the common chores as well as shop and cook. We went to visit the complex where the apartment was located

and met some of the other families considering this unique opportunity. We were so impressed! The complex was beautiful with a pool, hot tub, volleyball and basketball courts, a community center with a pool table, exercise room and giant televisions. The apartment seemed perfect for this experiment, a place I would like to go to get away for four weeks! As we listened to the presentation by the staff, we became more and more convinced it was something we had to try to help us answer that unrelenting question — CAN she...CAN'T she?

The staff explained that as part of the cost of the program, each person would receive a gift card each week that would be theirs to budget and use. In other words, Moira would have to pay attention to the costs of groceries, movies, incidentals, bus or taxi fares, and entertainment. Each person participating in the program would be planning their own meals and progressive dinners, planning social engagements, and choosing their daily events and activities from a roster of opportunities. Staff would provide an overarching level of support but the goal would be for each person to begin to see what is required to be an adult and take responsibility for their own entertainment, friends, transportation, planning, cooking, cleaning, and safety. Staff would run workshops on household safety, simple sewing, taking transportation, setting an alarm, and handling household repairs...like turning the water off to an overflowing toilet...something I had never even thought to mention to Moira!

We were sold on giving this summer experiment a try! We met families from South Florida and even New York whose children had attended the previous year and were enthusiastic about the value of the

experience. It would be expensive, but we hoped it would help us to answer that nagging question of Moira's capabilities if/when we were not around.

### **Yes, she CAN...**

Well, we were right! Not only did the summer experience teach Moira how much is entailed in taking responsibility for yourself as an independent adult, we also learned how much we had grown accustomed to doing things for her without ever realizing it. We had always bragged about how Moira was good with her own personal grooming without ever realizing that every night we would ask if she had taken her shower. In the morning, it was a reminder to take her medications and suggest a wardrobe for the day based upon where we would be going and what the weather looked like. There were so many small things that had just become part of our routine that we didn't know how much she relied on those little prompts to get into action. The summer was an exciting opportunity for Moira because she found out how to make friends and live with others that were not family. She had the opportunity make her own mistakes and live with them, like the week she bought a DVD which didn't leave enough money on her weekly gift card to go to the movies with the rest of the gang! But, as important, we realized what we had been doing that was not helping Moira to learn to care for herself. We also learned how others saw her strengths and weaknesses and what we could do, as a family, to increase her overall abilities.

Moira completed her four weeks in what seemed like days and came home with a maturity we did not know was possible. Instead of riding in the car without thinking, she paid attention to the route. Instead of just



eating dinner, she asked questions about what was in the meatloaf. And, she took on more responsibility for household chores. I don't mean to say she suddenly grew up but the subtle changes were notable for both of us. We backed off of much of what we had been doing and allowed Moira to choose her clothes for the day without a word of warning. We let her pick out some of the week's menu items. We encouraged her participation in planning some social events.

In short, we were finally able to answer the question of "CAN she?" We KNOW SHE CAN! Not today and maybe not next year...but she CAN! And we have a much better idea of how to help her get there!

### **You can experience this opportunity too...**

If anyone is interested in learning more about the summer program at The Arc Jacksonville, Inc., it is called LIFE (Living Independently, Finding Enrichment). The contact person is Bernadette Gismonde and can be reached at 904.620.3892 or [bgismonde@arcjacksonville.org](mailto:bgismonde@arcjacksonville.org). You can also visit Arc's website at [arcjacksonville.org](http://arcjacksonville.org).



# Parte 1 – El comienzo del viaje hacia el habla, el lenguaje y la comunicación

Libby Kumin, Ph.D., CCC-SLP

## ¿Cómo aprende mi niño a hablar?

Los bebés no pueden hablar con nosotros, pero ellos le comunican sus necesidades a su familia gritando, riendo, señalando y haciendo otros gestos. Aprenden que cuando hacen un sonido o lloran, alguien vendrá y los ayudará a satisfacer sus necesidades.

Al hablar se usan las mismas estructuras y movimientos que para respirar y alimentarse, y eso buena noticia porque no hay necesidad de esperar hasta que su hijo esté hablando para trabajar en las habilidades de habla necesarias. No hay un sistema de habla separado en el cuerpo. Desde el principio, los bebés mueven los labios, la lengua y la mandíbula para chupar, tomar del seno o el biberón, y luego comer alimentos sólidos. Los bebés lloran y balbucean y juegan con los sonidos. Juegan con los labios y la lengua y producen sonidos, mejorando su fuerza muscular, amplitud de movimiento y sistema de retroalimentación. Ponen a prueba su voz, y hacen sonidos suaves y fuertes. Balbucean cadenas de sonidos. En inglés y en español, todo lo que se habla se hace durante la exhalación. Si una persona habla mientras inhala, se ahoga y se fatiga. Así que, una de las habilidades que los bebés aprenden cuando lloran o balbucean es alargar el tiempo que exhalan, preparándolos para el habla.

El habla es un sistema de salida pero se basa en la entrada que recibe el niño. Por lo tanto es importante asegurarse de que los sistemas de entrada del niño: audición, visión y tacto, están funcionando bien. Si hay dificultades sensoriales de entrada (audición o visión), es importante tratar esas dificultades pronto.

El poder de hablar proviene de la exhalación. A través de la alimentación, llorando, arrullándose y balbuceando, los bebés aprenden a coordinar la respiración y los movimientos que van a utilizar para hablar. A través de la audición, la visión y el tacto, escuchan el lenguaje de sus familias y aprenden las palabras en su idioma. Por lo tanto, los bebés están aprendiendo y practicando desde temprano, las habilidades de entrada y salida que necesitarán para el habla, el lenguaje y la comunicación en su desarrollo.



*¡Gracias Libby, por este maravilloso artículo de 3 partes!  
En nuestro próximo número, Parte 2 "Desarrollando el habla mientras Mantenemos el lenguaje y la comunicación"*

## ¿Qué tan pronto necesita una evaluación del habla y el lenguaje? ¿Qué tipo de evaluación y tratamiento del habla y el lenguaje son necesarios?

No debe esperar pasivamente a que su hijo comience a hablar. Usted debe buscar información y educación sobre el habla, el lenguaje y la comunicación lo más pronto posible. Los programas de intervención temprana pueden o no incluir una evaluación del habla y del lenguaje como parte de su programa. Muchos programas de educación especial del sistema escolar no evaluarán el habla y el lenguaje hasta los 3 años, o incluso hasta que su hijo empiece a hablar. Las evaluaciones del pre habla y pre lenguaje pueden estar disponibles a través de clínicas universitarias o prácticas privadas, si no lo están a través de las escuelas. Hay libros, charlas y conferencias (locales, regionales y nacionales/internacionales, como el Congreso Nacional del Síndrome de Down), que le proporcionarán información para ayudarlo a usted y a su hijo a comenzar el viaje hacia el habla y el lenguaje. Durante el primer año de vida, la evaluación y el tratamiento se enfocan en las habilidades de pre habla y pre lenguaje. La evaluación puede determinar las habilidades que su hijo ya ha dominado y las que sería mejor trabajar a continuación. La terapia puede enseñarle a trabajar con su hijo en casa y mostrarle cómo usar las actividades de juego (balancear una bola hacia adelante y hacia atrás) y las actividades de la vida diaria (alimentación, baño) para promover el habla y el lenguaje.



## ¿Cuáles son las habilidades del pre lenguaje?

Desde el nacimiento hasta aproximadamente el año de edad, su hijo va aprendiendo muchas habilidades que lo ayudan a prepararse para usar el lenguaje. Estas son habilidades que usted puede trabajar en casa mientras está jugando con él.

## Habilidades Interactivas de Comunicación

- A. Intención comunicativa:** Es cuando el bebé se da cuenta de que puede llamar la atención llorando o haciendo ruidos. Su familia viene a ayudarlo cuando llora. El bebé levanta los brazos y mamá lo saca de la cuna. Señala su oso de juguete, y su hermana se lo alcanza. ¿Cómo puede ayudarlo a aprender esa habilidad? ¡Respóndale a su hijo! Su bebé aprenderá esa habilidad porque usted responde a sus iniciaciones. Él se dará cuenta de que su familia y las personas que lo cuidan responden a sus sonidos y a sus gestos.
- B. Tomar turnos:** Su bebé aprende que la comunicación va en dos direcciones. Él puede iniciar o responder a la comunicación. ¿Cómo se enseña esta habilidad? Cuando su hijo haga un sonido, respóndale. Puede rodarle una pelota a su bebé y enseñarle a rodarla de nuevo. Turnarse tocando un tambor o jugando con un xilófono con una varita y pasando la varita de un lado al otro. El tomar turnos jugando se transforma en tomar turnos en la comunicación.
- C. Atraer la atención:** Respóndale a su bebé cuando la mire o tire de su brazo. Enséñele que puede llamar su atención.
- D. Pedir:** Cuando su bebé “pida” algo señalándolo, responda a la solicitud. Más adelante, cuando pueda gatear hasta un juguete pero no pueda sacarlo del estante, ayúdelo. Necesita saber que sus peticiones obtienen resultados. Las peticiones comienzan con señas, gestos y signos.
- E. Protestar:** Cuando el bebé llora porque no quiere hacer algo, o empuja un alimento que no le gusta, hágale saber que entendió el mensaje incluso así no pueda hacer lo que él quiere. Dígame: “¿Quieres un pedazo de banano” o “Sé que no te gusta el banano, pero tienes que comerte este pedacito”.
- F. Comunicación social:** Anime a su bebé a decir hola y adiós con la mano, y a sonreír e interactuar con la gente.

## Habilidades de Atención

Para aprender el idioma, su bebé necesita escucharla hablar, observarla y prestar atención. ¿Cómo puede ayudarlo a aprender esta habilidad? Explorando los juguetes juntos. Muéstrole al niño cómo tocar, apretar, voltear y aprender más sobre una pelota, o una jirafa. Hágale comentarios mientras miran juntos el juguete. Escuchen música y cántele canciones, y aumente la cantidad de tiempo que él pueda concentrarse en escuchar. Léale libros a su hijo, comience con libros cortos y luego va aumentando a otros más largos. Está enseñándole a concentrarse y a prestar atención por períodos más largos de tiempo.

## Habilidades Visuales

- Ver/visión
- Atención visual
- Mirada recíproca
- Mirada compartida
- Seguimiento visual

Consulte con el pediatra y el oftalmólogo para asegurarse de que su hijo puede ver bien. Enséñele a su hijo a mirar el paisaje alrededor: A ver los pájaros volando, al perrito dando vueltas, los aviones arriba. Enséñele a su hijo a ver cosas en movimiento; esto se conoce como seguimiento visual. Enséñele a que la mire a la cara, para que juntos se miren el uno al otro. Esto se conoce como mirada recíproca o contacto visual. A veces, incluso me pongo pegatinas en la cara, o lentes divertidos, o hago caras graciosas para atraer la mirada de un niño. Mirar juntos las fotos en un libro, o mirar las nubes, o la nieve que cae afuera. Mirar algo juntos se conoce como mirada compartida, atención conjunta o mirada referencial. Los bebés y los niños pequeños deben ser capaces de mirar un objeto, una persona o un evento para que puedan aprender las palabras que los identifican.

## Habilidades Auditivas

- Audición
- Atención auditiva
- Localización auditiva
- Procesamiento auditivo
- Integración Auditiva

Consulte con el pediatra y el otorrinolaringólogo para monitorear la audición de su hijo. Los sonidos ambientales

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## El habla, el lenguaje y la comunicación

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están a nuestro alrededor. Hacer comentarios sobre los sonidos, por ejemplo: ¿Escuchaste eso? El perro está ladrando. ¿Lo escuchaste? La sirena de la ambulancia está sonando. Es muy ruidosa. Ayúdele a su hijo para que aprenda a escuchar por más tiempo; Eso se conoce como atención auditiva. Escuchar música y con las canciones hacer movimientos con los dedos y las manos es una buena práctica. Enséñele a su hijo de dónde viene el sonido. Eso se denomina localización auditiva. Escucho algunos pájaros trinando. ¿Dónde están? O, El carro de atrás está tocando su bocina. El procesamiento auditivo significa dar sentido a los sonidos que escucha. Cuando habla con su hijo sobre los sonidos que escucha y cuando lee con él, le está enseñando acerca de las palabras y lo que significan. Algunos niños se sienten incómodos con ruidos muy fuertes, o con mucho ruido de fondo alrededor de ellos. Se cubren las orejas con las manos en los juegos de béisbol o cuando la gente está animando o gritando en voz alta; eso significa que tienen dificultad con la integración auditiva. El fonoaudiólogo puede evaluar si su hijo tiene dificultad en esa área. Existen métodos de tratamiento especializados para las dificultades de integración auditiva.



### Habilidades del pre lenguaje cognitivas / lingüísticas

- Objeto permanente
- Causa y efecto
- Medio final
- Comunicación referencial

Para aprender el idioma, los niños deben darse cuenta de que así no puedan ver algo, todavía existe. Ponemos una pelota de juguete detrás de nuestra espalda. El niño busca el juguete e intenta recuperarlo. Sabe que, aunque ya no puede verlo, sigue ahí. Él ha dominado la habilidad de la permanencia del objeto. ¿Cómo podemos enseñarle esta habilidad? Podemos cubrir un juguete musical con

una bufanda. El niño no puede ver el juguete, pero lo oye y sabe que está allí. Ponga una cobija de bebé sobre papá mientras se acurruca en el suelo. El niño sabe que papá está ahí todavía, incluso si él está total o parcialmente cubierto con la cobija. Pregúntele: "¿Dónde está papá?". Luego retírele la cobija y diga "¡Ahí está!" Un juego que enseña esta habilidad es el cucú- tras, y jugamos el juego



muchas veces para ayudar al bebé a aprender sobre la permanencia del objeto.

En el juego, los bebés y los niños pequeños aprenden que las acciones tienen resultados. Les encanta subir y bajar el interruptor de la luz y encender y apagar las luces.

Presionar un botón en un juguete y verlo moverse. Están aprendiendo que cuando haces algo, hay una reacción, un efecto. Esta es la habilidad de causa y efecto. A veces, se necesita hacer un plan para lograr una meta. Por ejemplo, desea coger el frasco con galletas del mostrador, pero no lo alcanza, entonces coloca una silla en frente de éste para alcanzarlo. Sube a la silla, llega al mostrador y coge las galletas. Su plan funcionó y logró su objetivo. Esa habilidad se conoce como medio final.

Por algunos meses, etiqüete los objetos, como la puerta, las personas, por ejemplo papá y algunos eventos, como, está lloviendo. En algún momento, su hijo hará la conexión entre las palabras que ha dicho y el objeto, la persona o el evento que la palabra representa. Eso se conoce como conocimiento referencial o comunicación referencial.

Ahora, su hijo ha dominado todas las habilidades que le permitirán usar el lenguaje. Su hijo sabe cómo aprender acerca de su entorno. Puede usar la visión para aprender. Puede mirarla y pueden mirar juntos un juguete o un libro. Puede escuchar música y los sonidos a su alrededor. Entiende la causa y el efecto y que la comunicación puede dar resultados. Puede ser social e interactuar con la gente en su ambiente. Entiende que los objetos, las personas

y los eventos tienen nombres y que esas palabras (símbolos) son significativas. Pero a veces, no está todavía listo para hablar. ¿Qué hacemos para tapar la brecha, y seguir ayudando a nuestro hijo a aprender nuevas palabras y más habilidades de lenguaje? ¿Qué podemos hacer para que su hijo pueda continuar comunicándose y usando las habilidades de lenguaje que ya ha dominado? ¿Qué podemos hacer para ayudar a que su hijo aprenda las habilidades que necesitará para comenzar a hablar?

### Para lectura adicional:

Kumin, L. (2012). *Síndrome de Down: habilidades tempranas de comunicación (Tercera edición)*. Bethesda, MD: Woodbine House.

- Información de Recursos para Padres: <https://www.ndsccenter.org/informacion-para-padres/>

# California, aquí vamos!



¡Dentro de unas semanas, el personal de NDSC y la Junta Directiva viajarán a Sacramento para presentar

nuestra 45a convención anual! Cada año, miles de personas de todo el mundo asisten a la Convención NDSC. Para la mayoría, es para escuchar la información más reciente de expertos de conocimiento mundial. Para otros, son unas grandes vacaciones. Sin embargo, para casi todos, es la sensación única de una «reunión familiar gigante» del NDSC que impregna el fin de semana de la convención.

- LOS PADRES aprenden de los mejores, como expertos de conocimiento internacional vienen a Sacramento para compartir su conocimiento a lo largo de la vida de las personas con DS.
- AUTO-GESTORES se unen con más de 350 amigos de todo el mundo para aprender, compartir, ser empoderados y pasar un tiempo increíble!
- Los HERMANOS comparten y aprenden junto con sus compañeros, entre ellos, así como entre profesionales.
- Los VOLUNTARIOS pasan por una experiencia única ofreciéndose como voluntarios en cualquier número de capacidades disponibles.

Los miembros del NDSC que asisten a la convención están invitados a asistir a **la Reunión General Anual de Membresía el viernes, 21 de julio, a las 3:30 PM, en el**

**Sacramento Convention Center ubicado en 1400 J Street, Sacramento, CA.** La Reunión General de Miembros incluirá la presentación de nuestro nuevo miembro de la Junta de Auto-Gestores (elegido por sus compañeros en el inicio de la Conferencia de Jóvenes y Adultos); Informes del Tesorero del NDSC, Fiduciarios de la Fundación NDSC y un resumen 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 del consejo del NDSC. Otros asuntos se llevarán a cabo según sea necesario. ¡Todos los miembros del NDSC están invitados a asistir!

No puede viajar a Sacramento? Usted puede comprar las grabaciones! Estas grabaciones de audio incluyen PowerPoint del presentador con audio sincronizado para una recreación virtual de cada presentación. Hay tres opciones para elegir:

1. **Pase rápido** – acceso en línea de sólo 12 meses, precio de \$ 69 hasta el 10 de julio (\$ 129 después de la convención)
2. **Pase de temporada** – 12 meses, acceso en línea de streaming, además de acceso de descarga - precio de \$ 99 hasta el 10 de julio (\$ 159 después de la convención)
3. **USB Works** – USB Flash Drive y 12 meses, acceso en línea de streaming, además de acceso de descarga - precio de \$ 129 hasta el 10 de julio (\$ 199 después de la convención)

<https://www.ndsccenter.org/the-convention/conference-recordings/>

## Down Syndrome News

is a benefit of your annual membership in the NDSC.

To renew or join, visit [ndsccenter.org](http://ndsccenter.org).

To update your contact information, call 800-232-6372 or email [info@ndsccenter.org](mailto:info@ndsccenter.org).

When we **empower** individuals and families from all demographic backgrounds, we **reshape** the way people understand and experience Down syndrome.



NATIONAL  
DOWN SYNDROME  
CONGRESS

30 MANSELL COURT, SUITE 108

ROSWELL, GA 30076

[NDSCCENTER.ORG](http://NDSCCENTER.ORG)

## Down Syndrome News

A newsletter published throughout the year  
by the National Down Syndrome Congress

# Research Opportunity

In order for children with Down syndrome to thrive, caregivers also need support. To find out what support is needed researchers are creating a new measure that will help society understand the impact of providing care for a child with Down syndrome on the lives of caregivers. They want to learn about your experiences with caring for a child with Down syndrome age younger than 18 years by responding to questions about both the challenges and benefits of caregiving. With this information, communities can provide better support for caregivers and find out what works well.

### WHO CAN PARTICIPATE?

In order to participate you must:

- be at least 18 years of age;
- be able to speak, read, write, and understand English;
- care for a child with Down syndrome (age younger than 18 yrs)

<http://uwcorr.washington.edu/caregiving-usa>

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The University of Washington Center on Outcomes Research in Rehabilitation