

DOWN SYNDROME

News

SPEECH INTELLIGIBILITY:**Helping Children and Adults Develop and Maintain Understandable Speech (Part 2)**

Libby Kumin, Ph.D., CCC-SLP

CHILDHOOD APRAXIA OF SPEECH

Childhood Apraxia of Speech (CAS) is a motor speech disorder where children have difficulty planning, coordinating, producing and sequencing speech sounds. CAS interferes with the child's ability to say sounds and to combine them into syllables, words, phrases and conversations. Other terms such as developmental apraxia, dyspraxia, pediatric verbal apraxia or just apraxia all refer to the same problem. Some children with Down syndrome have characteristics of CAS, but many do not.

Children who have childhood apraxia of speech are very inconsistent. One time, a child may be able to say his brother's name clearly; another time, he may have great difficulty. Typically, children with apraxia also make many

Speech Intelligibility, *continued on page 20*

*In this issue*

FROM THE PRESIDENT:
THANK YOU 18

NDSC 2014 ANNUAL
GENERAL MEMBERSHIP
MEETING 19

JOIN THE 321 DANCE
MOVEMENT 23

CIVIL RIGHTS
BREAKTHROUGH FOR
WORKERS WITH
DOWN SYNDROME! 24

INTELIGIBILIDAD DEL HABLA:
FACTORES QUE AFECTAN
A LA COMPRENSIÓN DEL
HABLA – PRIMERA PARTE 25

NO GREATNESS
WITHOUT GOODNESS 27

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This newsletter reports items of interest relating to Down syndrome and will provide 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. We wish to bring together those interested in Down syndrome and attempt to create an optimistic outlook and attitude.

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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.

From the President: THANK YOU

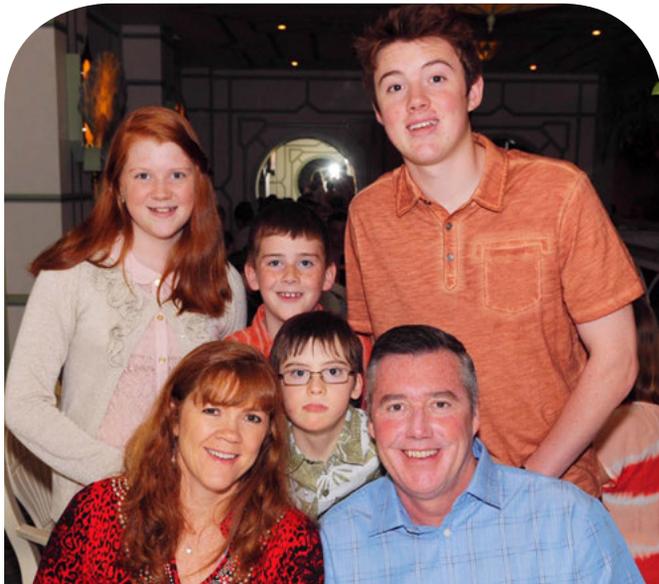
Thank you for allowing me to serve as your President over the past three years. It has been a tremendous honor. My term will officially end this July at our annual convention in Indianapolis, but I will continue to serve on the board of directors as the immediate past President, for a final three year term. The National Down Syndrome Congress and the national and international Down syndrome movement have come such a long way in a short period of time. Yes, we still have a long way to go and much more work to do, but we should also celebrate the successes and progress we have made in creating a better world for individuals with Down syndrome. Here are a few accomplishments in just the past few years:

National DS Movement

Since starting monthly collaboration calls three years ago, I am happy to report that the state of the national Down syndrome movement is stronger than ever. These monthly calls include representatives from seven national organizations, who cover everything from providing information, training, conferences and support to families; research related to Trisomy 21; Washington policy, advocacy and governmental affairs; support and training for local affiliate partners; and collaboratively, speaking with a unified voice on issues of the greatest importance to our community. The future is bright for the “DS Movement” and we will only get stronger and more unified as these partnerships strengthen, and communication continues in an honest, open, and transparent manner. Let me assure you, our national organizations are all focused on creating a better life for individuals with Down syndrome.

NDSC’s Annual Convention

Now in our 42nd year, the NDSC Convention is the largest Down syndrome convention in the world. Each year, we bring the most comprehensive group of medical professionals, researchers, educators, and public policy experts together with parents, self-advocates, and siblings anywhere on earth. The NDSC convention has seen 10% growth year-over-year in attendance since 2011, and we expect this year’s convention in Indianapolis to grow yet again. We have added an additional workshop cycle on Friday this year, as well as more specific “tracks” to better serve the needs of our members. In addition, the NDSC Convention now has representatives in attendance from nearly every U.S. State, and we have an average of 11 countries represented every year.



JIM AND SUZANNE FABER WITH
THEIR CHILDREN NATALIE, WILLIAM,
ALEXANDER AND BEN.

Limitless Possibilities

In the past three years I have been privileged to visit many local parent organizations around the country, meeting with DS affiliate leaders. I have spoken at conferences, met with researchers and school district officials, and have talked about the “Limitless Possibilities” for individuals with Down syndrome. I have traveled across the country and overseas, working to increase awareness and shift paradigms, to show the world the extraordinary capabilities of

individuals with intellectual disabilities. The message was very simple — we all need to focus on ability, not disability. People with Down syndrome truly are “More Alike Than Different.” The NDSC and, I am certain, the next President, will continue to reinforce this important message.

The Future

In 2013 the NDSC embarked on a very aggressive three-year strategic plan, focusing on everything from creating new programs to better serve our members, to enhanced communications and advocacy for greater information sharing, to programs for self-advocates and much more. I am pleased to report that great progress has been made in all areas, and the NDSC is excited about the future and confident in our ability to continue serving as your national organization focused primarily on families, and creating a better world for individuals with Down syndrome.

Thank you again for allowing me to serve as your President. It has been a true honor and privilege. Together we are changing lives every single day!

Cheers!

Jim Faber

NDSC 2014 Annual General Membership Meeting

For the election of board members
and the conduct of other business

Saturday, July 12, 2014, 5:30 p.m. ET

JW Marriott Indianapolis
Room 309/310
10 South West Street
Indianapolis, IN 46204



Speech Intelligibility

continued from page 18

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sound reversals in their words. They might say “aminal” or “hopsital” or “efelant.” They may be physically capable of producing all the speech sounds, but have trouble putting them in the proper sequence. As words get longer, children with motor programming problems such as apraxia start to have difficulty. So, a child might be able to say “light,” but “lightning bug” may be difficult. Or “eel” might be fine, but “electricity” will be difficult.

Formal tests that can be used to diagnose apraxia are The Apraxia Profile and the Kaufman Speech Praxis Test for Children (KSPT). For younger children, diagnosis is often made by observed speech difficulties.

What are the symptoms of childhood apraxia of speech?

Speech Development Patterns

- Quiet as a baby. Parents report children did not coo or babble a lot.
- Late talkers.
- Speech sounds develop at a much slower rate.
- Children develop gesture systems to communicate their needs.
- Omit the first sound in a word, e.g. “up” for “cup” or “oos” for “juice.”
- Words appear and disappear. Many say a word once and then not use the word again for months.
- May say a word correctly and not be able to say it again.

Oral Motor Patterns

- No direct impairment of the muscles for speech. (This may be present, but is not part of CAS.)
- Often have difficulty with movements needed for feeding, eating, and swallowing.
- Oral apraxia: has trouble with mouth movements such as puckering lips or throwing a kiss.

- Limb apraxia: has trouble with voluntary hand movements which may make it difficult to use sign language.
- Voluntary movements for imitating sounds are difficult.
- Voluntary movements for speech are difficult.

Speech Sound Production Characteristics

- Problems producing, omitting, or distorting vowel sounds.
- Sound additions, for example adding an “L” to “cat,” saying “clat.”
- Sound prolongations.
- Leaves out sounds or syllables.
- May move their tongues or lips into place (silent posturing) but can’t make the sound correctly.
- Multiple articulation errors, meaning they have difficulty making *many* speech sounds, not just one or two sounds.
- Omit beginning sounds, e.g., /up/ for cup, /at/ for cat.
- Make the most errors on sounds that occur later in speech development such as /s/ and /z/.
- Problems using the correct voicing for a sound, such as /p/ and /b/.
- The greatest number of errors in articulation are made on sound clusters (more than one consonant pronounced together, e.g., glass, crown); followed by fricatives, affricates, stops, and nasals.

Language Development/ Language Production Patterns

- Children with CAS appear to understand (receptive language) more than they can produce (expressive language). This is also common for most children with Down syndrome.
- Vocabulary size may be reduced.
- Grammar or syntax errors are present.
- Organizational problems when relaying messages or retelling a story.

- Produces a limited number of speech sounds, often vowels with few consonants.
- Has difficulty combining consonants and vowels and may omit or distort vowel sounds.
- Inconsistently produces speech sounds and sometimes, but not always, says a sound or word clearly.
- Struggles or gropes when speaking.
- Has unimpaired muscle movements for non-speech tasks such as raising the tongue to lick the lips, but cannot make the same movement for speech sounds.
- Has more difficulty with longer words or sentences (from key to monkey to monkey bars and light to lightning to lightning bug).
- Has difficulty combining and sequencing phonemes (efelant for elephant).
- Omits some speech sounds and syllables, and adds others (hamburgurger).
- Finds automatic speech is easier, such as counting, reciting the alphabet or saying “I don’t know.”
- Has difficulty saying unfamiliar words or imitating words.
- May move the tongue or lips into place (silent posturing), but can’t make the right sound.
- Has difficulty with speech rhythm, stress and timing, speaking very fast or accelerating.
- Connected speech in conversation is often unintelligible, and the child is frustrated that people can’t understand what he says. In his mind, he is saying the sounds and words right.

For children with CAS, therapy needs to be frequent, and there should be a home practice program. Your child will need lots of practice making sounds, but this can be done as part of play, singing and daily activities. The basic difference in CAS treatment is that therapy moves from teaching your child individual speech movements (a consonant-vowel combination) to sequences of movements, from shorter to longer, less to more complex. Therapy may also provide physical

cues that remind the child where and how the sound is made, such as touching the lips for “m”, and the throat for “k”. Or, a combination of approaches may be used, including:

- Oral motor (practicing the movements for speech sounds)
- Phonemic and articulation (teaching your child how to make the sounds and combine sounds into syllables)
- Visual cueing (providing a hand cue that your child can see).

Some approaches are visual-tactile (Strode and Chamberlain); others use physical cues (PROMPT) where the therapist touches the facial area where the sound is made. Multimodal or Total Communication approaches are often used, meaning that you always use the word in addition to signs or cues. Prosodic approaches (melodic intonation therapy) use singing and rhythm to help the child learn sound combinations. Shaping approaches, which deconstruct and construct words (e.g. the Kaufman Praxis Treatment Kit) break words down to the level of complexity that your child can say, moving the word immediately into functional expressive vocabulary use, and then building the word up through shaping procedures. For example, your child can say “na,” but cannot say “banana.” You would show the child “banana” many times, having him say “na,” and then building up to “nana,” and finally to “banana.”

Successful speech treatment for CAS usually involves a home practice program. You can work with your speech language pathologist, and ask for home practice material on a weekly basis. Since your child needs lots of practice making sounds, one or two sessions a week is not enough. **Daily practice at home is needed.** The SLP can keep you updated on what to do at home each week. You also want to be sure that at every age and stage, your child has a communication system that works for him. If he is not understandable through speech or sign, he may need a communication board or

Continued on page 22

Speech Intelligibility

continued from page 21

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a high tech computer device to use as he continues to work on speech.

Home Activities

Regular practice is critical for children with apraxia, and the SLP should provide a home practice program for you and your child to work on together. Here are examples of activities and strategies the SLP might suggest for you to use at home:

- Use singing and melody, especially songs with hand movements or songs with repeated choruses. The repetition will make it easier for your child.
- Encourage vocal play and sound making.
- When you read with your child, use repetitive books or books with predictable phrases. *Chicken Soup with Rice; Four Furry Feet;* and *Are You My Mother?* are examples of this type of book. Children know what the repeated phrase is and can practice it in advance and say it in a singsong manner. If they cannot say the phrase, they can say some of the words. This will give them successful experiences saying words.
- Use familiar verbal routines with gestures (*Eensy Weensy Spider* and other hand rhyme songs).
- During daily routines, use scripts and phrases that are repeated. For example: “Hi, how’re you doing?” or “See you later!” This will also provide successful experiences, and opportunities to practice familiar phrases.
- If your child is having difficulty speaking, never insist that he say a word in order to receive a reward or receive a desired item. Don’t say, “I won’t give you this ice cream until you ask for it.”
- To promote communication when your child cannot speak, Total Communication using signs or picture communication systems can be used. You use speech and the sign or picture, but your child can respond using just the sign or picture, if necessary, to request things that he wants or to communicate with you in

other ways. For children who are having difficulty speaking, this can cut down on frustration.

- Many of the therapy methods suggest helping children practice with slowed-down speech. You can slow down songs and sing them together with your child like a choir in slow motion. Or play *Time to Sing!*, a CD that contains slowed-down versions of popular children’s songs. It has been helpful for children with apraxia who want to sing along, but can’t sing the words at fast speeds.

HEARING:

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Children with Down syndrome are at high risk for ear infections, middle ear fluid and hearing problems, and research has demonstrated that hearing ability is related to language development. Hearing testing should include:

- assessment of middle ear function and fluid in the ear;
- pure tone testing (to determine how well your child hears a variety of sound frequencies or pitches);
- speech reception (to determine how loudly words need to be spoken for your child to identify them accurately);
- speech sound discrimination (testing the ability to distinguish between different speech sounds, such as light, might, tight, sight); and
- central auditory processing (testing the ability to understand and make sense out of what is heard).

Perceptual/Speech Symptoms:

What does the listener hear?

The SLP should do formal and informal testing to evaluate articulation, phonological processes, voice, resonance, rate, fluency and prosody, and will treat difficulties in any or all areas, as needed.

Articulation

When children have articulation difficulty, they have problems producing specific speech sounds. The SLP will evaluate all of the sounds and determine what methods and techniques to use to help your child improve articulation.

Phonological Processes

These are sound simplifications or substitution patterns all children use as they are developing speech sounds and learning their native language. It's just that children with Down syndrome use the phonological processes for a longer time. For example, a child may leave off all of the final consonant sounds in words, saying /ca/ for both /cat/ and /cap/. Or he may say /tootie/ instead of /cookie/ because he still can't make back of the mouth sounds.

Home Activities

These are very basic activities to help your child develop foundation skills for articulation.

- Give each sound a name. For example, /z/ is the “buzzing sound” or /p/ is the “motorboat sound.” Play with a toy that makes that sound.
- For sound awareness, have a “sound” day. If it's /p/ day, have pizza for lunch and pork, potato, pasta, and peas for dinner. Make popcorn, or have peanuts or potato chips as a snack. Buy pirate hats and have a

treasure hunt outside to name as many things as you can starting with the sound.

- If your child is having difficulty with multisyllabic words such as “railroad train” or “birthday cake,” try having him practice words of similar length he can say while he pounds lightly on a drum. For example, “pancake house,” “rock and roll,” and “hamburger.”
- Pretend that you are parrots and play a parroting game. You say a word with the sound to be practiced while looking in the mirror. Your child keeps looking in the mirror and tries to say the word exactly the way you did.

This is the second in a series of three articles that discuss speech intelligibility for children and adults with Down syndrome. Dr. Libby Kumin serves on the NDSC's Professional Advisory Council and is a frequent speaker at our annual convention. You can see Dr. Kumin in person at our convention in Indianapolis, where she will present workshops on development of communication skills in young children, and communication and employment.

Join the Movement!

321 Dance™ is a pledge-based fundraising event designed to raise funds for the mission of the National Down Syndrome Congress, to create a climate in which people with Down syndrome are accepted and valued. The premier 321 Dance!™ event each year is held at the NDSC national convention. You can sign up today to get involved.



Two Ways to Help

Attending the NDSC Convention?

Sign up to participate in the 321 Dance

<http://ndsc.donordrive.com/event/321dance-indy>

The NDSC 321 Dance!™ fundraising website allows you to create and personalize a fundraising page. Then, you can email your friends and family members, to let them know that they can support your fundraising efforts.

Everyone who raises \$100 or more will receive a 321 Dance!™ t-shirt at the convention.

For help getting started or for more information, call Rebecca Davis 770-604-9500 or email: rebecca@ndsccenter.org

No dancing skill required!

Our fundraising goal: \$25,000

Not attending the Convention?

Sign up to be a Virtual Dancer



Civil rights breakthrough for workers with Down syndrome!

by Bob Lawhead

On April 8, 2014 the U.S. Department of Justice (DOJ) announced “a landmark settlement agreement between the United States and the state of Rhode Island, vindicating the civil rights of approximately 3,250 individuals across the state with intellectual or developmental disabilities.” **This case constitutes the nation’s first statewide settlement involving the unnecessary segregation of people with disabilities in segregated sheltered workshops and day facilities,** in violation of the Americans with Disabilities Act (ADA). It is well known that this same kind of unnecessary segregation is presently supported by nearly every state in the union.

The Rhode Island – DOJ settlement agreement states that Rhode Island will redirect state funding from segregated to integrated services over a ten year period. The settlement demands a shift from segregated facilities to supported employment programs resulting in real jobs with real wages—typical jobs out in the community, the kind of jobs available to people without disabilities. These are jobs that pay a competitive wage and that are individual jobs (not “group” employment, as we see sometimes with respect to people with intellectual and developmental disabilities). Supported employment programs are designed for people with Down syndrome, intellectual disabilities and other significant disabilities so workers can be employed in the community. Supported employment refers to paid work, in integrated settings with ongoing support. It is a strategy for locating jobs that match a person’s skills, abilities and preferences. Once hired, job training is provided for the new employee with a disability. The new employee and their employer then receive ongoing consultation and support on an as-needed basis. These supports are provided for the life of the employment relationship, include training and consultation to assure employment success, and are provided at no cost to the employer.

We must move forward to correct the injustice of state-sponsored work segregation for people with Down syndrome and other intellectual disabilities. People are tired of being placed in these sweatshops where pay is below minimum wage and demeaning tasks do not match up with individual worker aptitude or ability. Professionals currently understand how to provide effective supports to people who desire regular employment. Recent research has found that integrated employment options actually cost the state less than ongoing segregated work programs. Most importantly, people with disabilities and their families are telling us in increasing numbers that they want to take their rightful place in the regular workforce. It’s time to take advantage of the contribution people with Down syndrome can make to the workplace and their local communities. The individual states should do the right thing and eliminate this needless segregation which has been referred to as “economic servitude and social exile” (*New York Times* editorial, *Doubly Disabled in Life*: April 11, 2014).

During her announcement of the Rhode Island settlement agreement, Acting Assistant Attorney General Jocelyn Samuels stated, “This year, we are celebrating the 50th anniversary of the Civil Rights Act of 1964, the landmark legislation that outlawed discrimination on the basis of race, color, religion, sex and national origin. It ended segregation in schools, at the workplace, and by facilities that served the general public. Similarly, the ADA calls for an end to segregation based on disability. Yet, approximately 450,000 people with intellectual or developmental disabilities across our nation spend their days in segregated sheltered workshops or in segregated day programs.” She went further to say, “Unnecessary segregation of people with disabilities is harmful to people with disabilities and to our communities. We cannot wait another day to change. And we won’t.”

The states should wake up and embrace “Employment First” before DOJ comes knocking on their door!

Bob Lawhead serves on the NDSC Professional Advisory Council. He has served as CEO of Community Link in Boulder, Colorado since 1989. Bob is Public Policy Chair for the Colorado Association of People Supporting Employment First (CO-APSE)

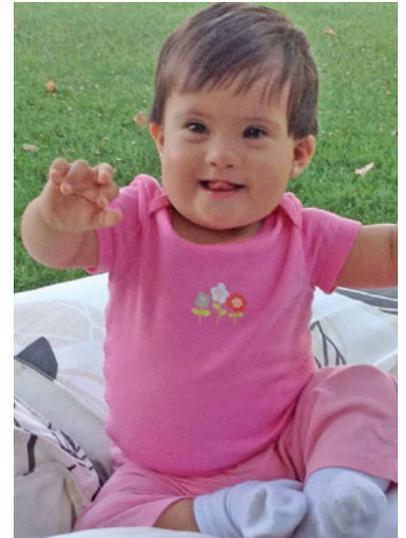
and Co-Chairs the National Association of People Supporting Employment First (APSE) Public Policy Committee. Bob also serves as the Colorado Project SEARCH Statewide Director, is a member of the TASH Employment Committee and is an advisor to Self-Advocates Becoming Empowered (SABE) of Boulder County.

INTELIGIBILIDAD DEL HABLA: Factores que afectan a la comprensión del habla – Primera parte

Dra. Libby Kumin, Certificado de Competencia Clínica -
Patología del Habla y el Lenguaje (CCC-SLP por sus siglas en inglés).

Tanto los niños como los adolescentes y los adultos con síndrome de Down tienen mucho que contarnos. Pero muchas veces no podemos entender lo que nos dicen. La inteligibilidad del habla es un término que se utiliza para describir si el discurso de una persona es comprensible para el receptor. La palabra inteligibilidad puede sonar a término científico y objetivo, sin embargo no lo es. Es más bien un juicio subjetivo que el receptor realiza y en el que pueden influir muchos factores. El interlocutor y su discurso no son los únicos factores importantes, sino que también lo son la familiaridad que existe con el receptor, el tipo de mensaje que se está transmitiendo y otros factores del entorno como pueda ser el ruido externo. Por esa razón mamá, papá y los hermanos pueden entender mejor al niño que cualquier otra persona con la que hable por primera vez. Por eso a un adulto con síndrome de Down es fácil entenderle cuando pronuncia "hola" y "¿qué tal?", pero se le entiende menos cuando intenta contarnos cualquier anécdota cotidiana del colegio o el trabajo. La inteligibilidad no es estática; puede variar mucho de una situación a otra. Es muy frustrante para un niño el hecho que no entendamos lo que intenta contarnos. Del mismo modo resulta también frustrante para los padres y las familias, así como para profesores y amigos, intentar adivinar lo que la persona intenta decir, fingir que le entienden, asentir con la cabeza y

responder, cuando en realidad no están seguros de haber entendido correctamente el mensaje.



Hasta mediados de los años 90, las investigaciones que se publicaban apenas mencionaban las dificultades de la inteligibilidad del habla en personas con síndrome de Down. Aunque los padres constataban pruebas de las dificultades diarias, era muy difícil encontrar ayudas para la inteligibilidad del habla porque no estaba documentada como un problema. En 1994, mediante una encuesta llevada a cabo entre familias, tuve la posibilidad de documentar que la inteligibilidad del habla era un problema importante para las personas con síndrome de Down. Más del 95% de las casi 1000 familias que participaron afirmaron que sus hijos encontraban dificultad para ser entendidos por personas de fuera de su entorno más inmediato bien en ocasiones o con frecuencia.; (El 58,2% de los padres informaron que sus hijos hallaban dicha dificultad con frecuencia y el 37,1% informó que sus hijos encontraban tal dificultad en ocasiones). Por lo tanto contamos con documentación que demuestra que la inteligibilidad del

Continúa en la página 26

Inteligibilidad del habla

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habla es un problema generalizado entre los niños con síndrome de Down. La pregunta es si este hecho nos ayuda de algún modo a saber qué podemos hacer para mejorar la inteligibilidad.

La "dificultad de la inteligibilidad del habla" es un diagnóstico general. Catalogarla como "dificultad de inteligibilidad del habla" no nos proporciona información sobre qué debemos hacer para ayudar al niño. No existe un patrón típico del habla común a todos los niños con síndrome de Down. Como ejemplo, para un niño, una voz suave y muchos errores de articulación pueden provocar que su habla resulte difícil de entender. Mientras que podemos encontrar el caso de otro niño que hable muy rápido y tartamudee además de omitir los sonidos finales de las palabras. A su vez podríamos encontrar un tercer niño que reproduzca sonidos incoherentes; siendo capaz de pronunciar los sonidos de las letras /b/ y la /f/ en ocasiones y en otras no. Podría incluso omitir sílabas e invertir sonidos (por ejemplo, "efelante" en lugar de "elefante"). Las dificultades específicas del lenguaje que afectan a la inteligibilidad del habla se deben evaluar individualmente y se deben tratar para cada persona en particular.

¿Cómo puede ayudar el logopeda (SLP, por sus siglas en inglés) a un niño con inteligibilidad del lenguaje? Es necesario realizar un esquema / lista de control para evaluar cada uno de los factores que podrían afectar a la inteligibilidad del lenguaje y de ese modo determinar cuáles de ellos están afectando al habla en ese niño. El logopeda tiene la capacidad de diseñar un plan integral de tratamiento para solucionar las dificultades específicas encontradas en el individuo. El plan de tratamiento para la inteligibilidad puede también incluir la participación de otros especialistas además de los logopedas. Por ejemplo el especialista de la audición podría examinar la pérdida auditiva. Por otro lado, los médicos y terapeutas ocupacionales pueden tratar los problemas de procesamiento sensorial o de integración sensorial. El habla es un sistema de emisión, pero está

basado en el oído, la vista y otros sistemas sensoriales de recepción. Por lo tanto, para que la persona sea capaz de hablar, los sistemas de recepción han de funcionar bien. Los padres han relatado magníficas sesiones de tratamiento en las cuales han colaborado logopedas y terapeutas ocupacionales.

El primer y más importante paso en la planificación del tratamiento es una evaluación completa de los factores que afectan a la inteligibilidad en el niño. Por ejemplo, si el niño encontrase dificultades con el sonido /s/, la terapia de articulación se centraría en el sonido /s/. Si el factor fuese el bajo tono muscular, la terapia se centraría en fortalecer el tono muscular en cara, labios y mejillas mediante entrenamiento con silbato, haciendo burbujas y con ejercicios de labios y lengua. En el caso de que el niño no mantuviese la mirada del interlocutor, la terapia se centraría en el contacto visual. Si el problema fuese seguir la conversación, la terapia de lenguaje se centraría en mantener la conversación. No existe un plan de tratamiento específico recomendado para el tratamiento de la inteligibilidad. El plan de tratamiento debería más bien incluir propuestas para abordar cada uno de los factores que repercuten en la inteligibilidad del habla en cada niño, y establecer referencias para medir el progreso de cada factor que influye en el habla. Una prueba formal que se puede utilizar es la *Medición de la Inteligibilidad del Habla en Niños*. Habitualmente la evaluación es informal y prueba todos los factores que podrían influir en la inteligibilidad de la persona.

Para continuar leyendo el artículo "Inteligibilidad del habla" ingrese al blog del NDSC → <http://blogenespanol.ndscenter.org/>

Este es el primero de una serie de 3 artículos que debatirán los factores que pueden afectar a la inteligibilidad del habla para los niños y adultos con síndrome de Down, con el objetivo de ayudar a las familias y a los logopedas a identificar y trabajar los factores específicos que afectan a la falta de comprensión del habla de su hijo.

Traducción realizada para el National Down Syndrome Congress por Pilar Rozalén dentro del marco de la iniciativa PerMundo y con el apoyo de la empresa de traducción Mondo Agit. Enlace desde "PerMundo" a www.mundo-lingua.com Enlace desde donde dice "empresa de traducción" a www.mondoagit.es

No Greatness without Goodness

Editor's Note: This interview is reprinted with permission from BLOOM, a magazine and blog on parenting children with disabilities at Holland Bloorview Kids Rehab Hospital, Toronto Ontario Canada: <http://bloom-parentingkidswithdisabilities.blogspot.ca/>

In 2006 Randy Lewis changed the way Walgreen Co. does business.

As senior vice-president of supply chain and logistics for the U.S. drug store chain, Lewis oversaw 10,000 employees and up to a thousand new hires each year. As a father to Austin, who has autism, he knew the difference a job could make in the lives of young people with disabilities.

In *No Greatness Without Goodness* Lewis explains how he brought his corporate and personal worlds together, transforming Walgreen's distribution centers into inclusive workplaces where people with all kinds of physical and mental disabilities, many deemed unemployable, work to the same standards and earn the same pay as other staff.

The company's new mindset is proclaimed in a giant sign when you enter the building with the words "No 'them'" in a circle and a line drawn through it.

BLOOM: What is the message of your new book?

Randy Lewis: It's the story of how I got involved with disability hiring, why we did it as a company and how we were able to go from essentially zero to 10 per cent of the workforce in five years.

The reason I wrote it was one, so that people could understand that people with disabilities could work effectively and have a positive impact on the work

environment. It wasn't just as good, it was better.

And two, that we all tend to underestimate our power to effect change and that everyone, I think, at their core really does want to change the world. As leaders, if we can tap into that in ourselves, that we want to do good things, we can unleash that in others.

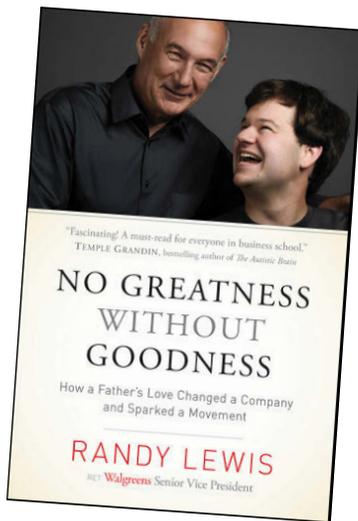
BLOOM: How did you get the idea to hire people with disabilities?

Randy Lewis: I have a son with autism and so watching him grow up, I shared the same dream of other parents like me—to live one day longer than my child because you wonder what will happen to them after you're gone. We'd go to these IEP conferences at school and I realized disability plays no favorites. It strikes traditional and non-traditional families, rich and poor. I got to thinking: 'What is going to happen to all of these other kids and parents?' If we're hiring over here at Walgreen and there's a need over there, why can't we bring those two worlds together?

BLOOM: How did you sell the idea to the company?

Randy Lewis: I said we're not going to lower any of our performance standards, we're a business, not a charity, and if it didn't work out, we wouldn't do it. What I discovered as an employer was we had lots of invisible walls around us—systems that we thought were giving us the best performers, but weren't.

We were screening out a whole class of people who would never get through the Internet job application, or interview well, or look and talk like everyone else, or have all of their limbs. That was a huge turning point.



Continued on page 28

No Greatness without Goodness

continued from page 27

BLOOM: How did you get buy-in from existing staff?

Randy Lewis: We'd had some experience with enclaves, where we contract with another company and they bring people in with disabilities, typically to do janitorial or ancillary tasks, and they supervise them. All our employees liked it, management liked it. Here we are helping these people, but they weren't integrated.

One day a team member told the group about how important this work was to her and she showed a picture of these people with disabilities. They were all wearing the same shirts and she was in the picture with them, also wearing the same shirt. She made a point of telling me she was not 'one of them,' but their sponsor. I knew that was a problem. We had not embraced people with disabilities as equals.

After that we hired a young man with Asperger's to work on the line at one of our centers and he did a fantastic job. We had two women he worked with and I talked to them and asked 'How are things working with Chuck? Are people accepting him?' They said: 'If they don't, they have to deal with us,' and I thought now we're making progress.

Each of our buildings has different colored plastic totes for shipping, and in this building they were grey. A couple of times every day a purple tote would get mixed up and come down the line and Chuck loved those purple totes. He would dance every time he saw one. At one point we said 'Is that appropriate behavior for the workplace?' But then we got to thinking 'Why not?' We'd rather have him dancing than complaining.

So we started learning about inclusion and we were about to build a new generation of building. We had experience with the enclaves, we knew Chuck could work on the line, so I thought maybe this is time. Why don't we develop our automation with people with disabilities in mind?

BLOOM: How did you decide on what proportion of staff would have disabilities?

“We underestimated them, it's as simple as that. When we measure performance, the people with disabilities perform as well statistically as the others.”

Randy Lewis: When it came time to plan a new-generation distribution center 10 years ago to handle our growing business, I believed it was an opportunity to 'go big' with disability hiring in an intentional manner. We were designing new equipment and we thought let's make it effective for people with disabilities if we can do that with negligible cost.

We talked to a fellow who worked with people with autism. We knew we couldn't afford a lot of job coaches and we asked him how many typically abled people would we initially need to provide support to a person with autism, thinking the person with autism might be the most difficult to employ. He said maybe two people. So we decided one-third of the workforce is going to be a person with a disability.

No one had ever done this anywhere in the world in a production environment. If we don't get orders shipped accurately we're not in business. This was a clear and elevating goal. We would hire 200 people with disabilities out of 600 to staff this new-generation center we were building in South Carolina.

Two years later we opened up a similar center with the same goals near Hartford, Conn.

BLOOM: What did you learn?

Randy Lewis: We discovered that people with disabilities could do all of the jobs, not just the jobs we'd designed the equipment in mind for. The automation we put in helped everyone, not just the people with disabilities. We brought in managers from our other centers to show them that it wasn't about the automation. That they didn't have to have specialized equipment that we had in the new center to be successful at this. They liked what they saw and were ready to try it out in their less automated buildings.

And I asked them to set a clear and elevating goal and they said let's hire 1,000 people by the year 2010.

BLOOM: Why were the staff with disabilities so effective?

Randy Lewis: We underestimated them, it's as simple as that. When we measure performance, the people with disabilities perform as well statistically as the others. The standard is not that they have to be Superman or Jackie Robinson. But the employees with disabilities also have fewer accidents, better retention, less absenteeism and they make people better managers and create greater teamwork.

BLOOM: So it sounds like overall there were definite advantages.

Randy Lewis: Yes.

BLOOM: Did the culture in these environments change for the better?

Randy Lewis: I asked people in our South Carolina and Connecticut centers who'd worked in other buildings without disability hiring, 'How did you rank engagement when you were there?' And they'd say probably a seven or eight out of 10. Then I asked them to compare that level of engagement with what they saw in the building they were in now. They said the eight would drop to a two.

'We didn't know what engagement was until we got here,' they said. 'We didn't know what teamwork was like.'

If you ask managers in the buildings with a large percentage of people with disabilities what is their number one job, they'll say 'My job is to make everybody who works for me successful.' When you have that kind of attitude the workforce notices and they respond to it.

BLOOM: How has the experience created better managers?

Randy Lewis: We've learned to 'manage in the grey' and by that I mean we want to manage with values or principles, not rules. People like rules, bosses like rules because they're easier to administer. For some of our

supervisors that was uncomfortable at first, but I said if it's just about administering rules I can get my own children to come in and run this place. We asked people to look at the purpose of rules and apply what were the principles of the rule, rather than the rule itself. This caused us to look at a lot of our policies.

We changed the way we hire and recruit because a lot of people can't get through the Internet application system or need help applying. If there's a discipline problem, we let the employee bring in a parent or advocate because we want to make sure they understand and we understand.

Sometimes we make exceptions to a rule. For example, I remember a situation where a young man became frustrated because he had to work overtime and he was going to miss a doctor's appointment. He punched a computer screen and broke it.

The rule is that if you break something intentionally, you're fired forever and forever banned from the company. We got to thinking: 'Is that a good rule? Is there ever an exception?' Even Aristotle way back when noted that human behavior is not mathematics, it's not finite reasoning, there are exceptions to all things.

So we went back and had to look at that policy as it applied to all of our staff. We needed a framework. And it was: 'Is there an extenuating circumstance? Is there a reason to expect the person won't do it again? And what's the likelihood that they'll be able to find employment elsewhere?' We don't decide in favor of the employee in every case, but we did in that one.

Our managers say this idea of managing in the grey is the most powerful thing that's made them better managers.

BLOOM: It sounds like they feel empowered in a new way.

Randy Lewis: The change is huge. They talk about managing with love, a word we've never used in the workplace.

A few years back we had the president of a Best Buy division come through for a tour and afterwards he sat down with our managers to ask questions. I've heard all

Continued on page 30

No Greatness without Goodness

continued from page 29

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the good things about this place,' he said. 'What's a bad day like?'

And essentially the supervisors said: 'A bad day is when I come in with my own problems and I'm not focused on my staff and the work. You know that saying 'You come home and you want to kick the dog?'' If I do that at work my staff will either shut down or start acting out or they'll confront me and tell me why I'm being a jerk. Or they'll come up and give me a hug. One thing I've learned is that when I'm here, it's about them, not me.'

BLOOM: How costly is it to train people with disabilities?

Randy Lewis: It was negligible. What we did was go out in the community and get partners. We demanded that disability agencies in the community form a coalition and work together with us. We built a training room in a community-rented space and for a year the community screened and trained people and taught them how to use our equipment. Now we have training rooms within our buildings.

Typically a new employee has 60 days' probation and by 60 days they have to be up to full productivity. We anticipated that people with disabilities might need longer because our training might not be right for everyone. So we created an alternative pipeline into the company. If you have a disability and want to come in that route you are paid as a temporary employee, with no benefits, and you can stay in that group as long as you're progressing towards full productivity. It might take 60 days or less, some may take 90. One person took a year. Once they're at full productivity they're hired as permanent staff.

BLOOM: In a news story I saw you talked about an accommodation where you name, as well as number, stations. Can you explain that?

Randy Lewis: For someone who has difficulty with numbers and directions, we've named stations as a

group of animals in a zoo. So we might say 'You'll be working at rhinoceros in zoo.' We also have a race-cart alley and a hamburger alley. So perhaps you'll be working at the hot dog station in hamburger alley. These are simple things that help some people. Most of our accommodations cost less than \$20 and most are paper and pencil.

BLOOM: What's been the greatest challenge in implementing this model?

Randy Lewis: The biggest impediment to overcome is fear.

BLOOM: How did you manage that?

Randy Lewis: To outsiders in the organization I said: 'We're here to make money, we're here to make it work. If people with disabilities can't do the job, they won't be working here.'

To those who reported to me I said, 'Our standard is to give it our very best, so if it doesn't work, we can tell the world this is not possible. Give it your very best, and if it doesn't work, we know no one else could have done it better than us.' That was very freeing for everyone.

We also said, 'We don't have all the answers. There are going to be problems we can't anticipate, so let's not worry about those. If you anticipate a problem, let's figure out a way around it. And you can't bring a "What if?" unless you've thought of a way around it. Most of the problems we anticipated never happened.'

BLOOM: What was a problem you didn't anticipate?

Randy Lewis: We thought all of our systems were great for getting us the best employees. We thought we'd build this and as soon as we put an ad in the paper all of the people with disabilities would come flocking to us. We didn't think about the fact that this is a group that doesn't read the paper every morning looking for places to work. It's not a group that trusts employers. It's a group that may have difficulty in even getting to the job site for the interview. We didn't realize we had so many invisible walls.

It took some work for us to say gee whiz, we're going to have to do something different. We worked

“We discovered that people with disabilities could do all of the jobs, not just the jobs we’d designed the equipment in mind for.”

with community agencies. We’ve had to teach them to understand our jobs and send us people that they believe will be successful.

BLOOM: What are common myths about hiring people with disabilities?

Randy Lewis: That they can’t do the job, it’s going to cost me more to make them effective and when they fail I will get punished.

BLOOM: Has Walgreen hired people who were considered unemployable?

Randy Lewis: Lots of them. For most of them it’s their first job.

BLOOM: What does the average person get paid?

Randy Lewis: They make close to \$30,000 on the production line.

BLOOM: I heard that in a couple of your distribution centers as many as half of all employees have disabilities.

Randy Lewis: In our original center in South Carolina, 40 per cent have disabilities. In our newer center in Connecticut, 50 per cent have disabilities. In 2011 we achieved our goal of having 10 per cent of the workforce made up by people with disabilities. Before I retired 14 months ago, the center managers from across the country met and set a new goal to reach 20 per cent.

BLOOM: What kind of impact do these jobs have on people with disabilities?

Randy Lewis: For many a world of possibility, opportunity and responsibility is opened to them for the

first time. They have relationships they’ve never had before. They have money they never had before. And there are some unanticipated consequences, too. For instance, some become like teenagers: they stay up too late at night playing video games because they can afford them now. It’s a whole village of people working together that’s expanded everyone’s way of thinking.

BLOOM: What advice would you give a parent who’s concerned that their child won’t be able to get a job due to disabilities?

Randy Lewis: The words we hear as parents of a child with a disability are ‘always’ and ‘never.’ We have found that that’s not necessarily true. I was in Canada yesterday with a new organization of employers called SensAbility. They’re going to look for employers in Canada who will help spread this model. Ontario’s Lieutenant Governor David Onley has taken employers to visit our site and is very active in helping Canada advance on this front. So I’m very hopeful about Canada.

BLOOM: What about your son. What are his dreams?

Randy Lewis: I wish I knew. I wish he could tell me. He’s 25 and he works about 12 hours a week in a Walgreens store. There’s a Michigan company building a distribution center about an hour from here in Chicago and the owner has talked about how one day he wants Austin to be their employee. So we’re going to go up and see it.

BLOOM: What impact do you hope your book will have?

Randy Lewis: I hope people read it and believe it’s possible and try it. There are enough models out there to do it. We make only three cents on the dollar, so our margins are razor thin. If Walgreen could do it—and we didn’t have any models to work from—anyone can do it.

Walgreen Company was awarded the NDSC Employer of the Year Award in 2007 and has been nominated again in 2014.

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The NDSC's annual convention provides the opportunity to learn from experts on issues that cover the lifespan of individuals with Down syndrome. Our Giant Family reunion brings together self advocates, parents, siblings and other family members, along with professionals to learn, grow, connect and celebrate. We hope we'll see you this July at the JW Marriott in Indianapolis!

