

DOWN SYNDROME

News

BUILDING A STRENGTHS MINDSET

Ryan M. Niemiec, Psy.D., VIA Institute on Character, Cincinnati, OH

Sometimes we all need a little push toward the positive. Parenting a child with special needs often presents challenges other families don't face and scenarios in which no template for management exists.

The good news is that new discoveries by scientists have revealed a set of positive qualities called character strengths that all human beings have. Each person has a unique recipe of these strengths within them. See pages 5 and 6 for a list of these character strengths. This list is important for at least 3 reasons:

1. It is a "common language" for describing your best qualities and your child's best qualities.
2. It offers a template for what to look for, what to talk about, and what to help your child improve upon.
3. Using these strengths can help your child (and you) become happier, less stressed, more accepting, and find more meaning in life.

Our brains are wired to focus on what is wrong...to see limitations, to find flaws. This is our mind's default mode. We can break through this pattern by looking for and developing our strengths. What follows are typical scenarios families face. Many of these are common concerns parents inquire the National Down Syndrome Congress about. The responses that follow are not intended to be cures or final answers, but help you instead think of each as a way you might further build a "strengths mindset" with yourself and your family.

***Struggling with your child's communication issues
(e.g., my child is nonverbal; my child is hard to understand)?***

Try this...

Character strengths come forth *loudest* in our actions, not our words. Strengths-spotting—the practice of deliberately looking for strengths being expressed and sharing them aloud or making a mental note when you see

In this issue

LETTER FROM
THE PRESIDENT2

ACCEPTING NOMINATIONS
TO SERVE ON NDSC'S
BOARD OF DIRECTORS.....7

ANA CRUZ JOINS
NDSC STAFF7

WELCOME RICKI SABIA
AS SENIOR EDUCATION
POLICY ADVISOR7

WHERE IN THE WORLD WILL
THE NDSC CONVENTION
MEET NEXT?8

DS (DAILY SMILES) CAN
CHANGE EVERYONE'S DAY ... 10

INTELIGIBILIDAD DEL HABLA:
CÓMO AYUDAR A NIÑOS Y A
ADULTOS A DESARROLLAR Y
A MANTENER UN HABLA
COMPREENSIBLE
(PARTE 3 DE 3) 12



**NATIONAL
DOWN SYNDROME
CONGRESS**

ISSN 0161-0716

Publisher: National Down Syndrome Congress

Executive Director: David Tolleson

General Correspondence and Memberships:

National Down Syndrome Congress
30 Mansell Court, Suite 108
Roswell, GA 30076

phone: 800.232.NDSC fax: 770.604.9898

email: info@ndsccenter.org

website: ndsccenter.org

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.

Reprints From DSN:

We invite editors of other newsletters to reprint items from *Down Syndrome News*, provided proper credit is given to the source. Please delineate clearly the material you are reprinting and indicate that it comes from *Down Syndrome News*, newsletter of the National Down Syndrome Congress, 30 Mansell Court, Suite 108, Roswell, GA 30076, ndsccenter.org

Please note that for material which the DSN reprinted with permission you must contact the original source.

Board of Directors:

Marilyn Tolbert – President

Bret Bowerman – Vice President

Andrew Bean – Vice President

Carole Janine Guess – Vice President

Lori McKee – Vice President

Shawn W. Hardister – Treasurer

Julie Harmon – Secretary

Jim Faber – Past President

Bruce Bennett • Christopher Bennett

Regina Britt • George T. Capone, M.D.

Daniel Chaplin • Kate Dougherty

Chandra Torry, Pharm.D. • John T Farley

Tonia Ferguson, Esq. • Viviana Fernandez

Kathleen Forney • Dana Halle, Esq.

Nadine C. Maes • Kishore Vellody, MD

LETTER FROM THE PRESIDENT

I hope you all have recovered nicely from the holidays and those in the northeast are beginning to thaw. Spring is right around the corner and, of course, that means the NDSC Convention is not too many months away! The Convention Planning Committee has been working all winter to ensure that the convention is full of hot topics, interesting workshops and exciting speakers! I know you will be pleased at the variety and diversity.



Phoenix is a beautiful area and the conference hotel and convention center are exquisite! The hotel block filled quickly, but a waitlist is available. Add your name to the waitlist right away, and your chances of getting a room are very good. We don't want you to miss a single minute or chance to network and visit with friends—old and new.

We have joined with other Down syndrome organizations to celebrate World Down Syndrome Day by celebrating “Random Acts of Kindness.” We hope you'll be joining in the fun all month long. “Like” the Facebook page “WDSO Random Acts of Kindness,” share your acts of kindness, and raise awareness for Down syndrome.

The NDSC Board of Directors met in January for our annual Board meeting. New and exciting ideas and plans are in the works and we can't wait to share them with you in June! We continue to grow and expand our resources and want to hear from you as to how we can better serve you and your community.

Thank you for all you do to make the NDSC what it is—people supporting, educating, advocating and empowering people with Down syndrome.

As you begin to make your plans for spring and summer, don't forget to reach out to the NDSC—we are here for you! I look forward to seeing you in Phoenix!

My best,

Marilyn

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.

Building a Strengths Mindset

continued from page 1

.....

them—can start with newborns. Even though newborns are nonverbal, character strengths are present in some form. For example, when my son with Down syndrome was less than one year of age, I began looking for strengths. He would often start to cry when I laid him down and then when I picked him back up, he stopped crying and was attentive and warm; I spotted this as the character strength of love. Looking for strengths of character early on is a way of training yourself, the parent, to take on a mindset of looking for strengths for a lifetime.

We can also take notice when others are spotting strengths in our child. Open your mind to the good that others say directly and indirectly and you'll be surprised at how plentiful the strengths are. During one hospitalization for my son when he was an infant, there were many doctors and medical staff that popped in and out of our medical room. One physician, an Irish woman, made an impression when she described my son's behavior throughout the day. She described him as hardworking, inquisitive, and energetic. Catching on that she was using positive-oriented words, I asked her to say more about each of these descriptions. She went on to say that despite his bronchiolitis, he works very hard to breathe right and just keeps trying and trying

(perseverance/hard-working); he is interested and watchful of every person that walks in the room quickly turning his head toward the person and he eagerly explores each new toy (curiosity/inquisitive); and he shows a lot enthusiasm and energy as he seems to communicate with his whole body, arms and legs (zest/energetic).

I was glad I asked this physician to share more about the positive she observed as it helped my wife and I feel more comfortable with the medical situation, seemed to improve our dialogue with the medical staff, and led to our feeling an increase in optimism about the situation.

Frustrated with your school's IEP situation?

Try this...

First, know this: Teachers love working with these character strengths but not all teachers know this "language." Most teachers already think they take a "strengths-based" approach, so this means you have something you can build upon in your conversation with them.

Tell your child's teachers that you are doing an experiment. Give each teacher the list of character strengths and ask each of them to share the top five strengths they view in your child. Have them tell you about classroom examples of how they've seen each of these strengths in action. Ask the teachers for advice about how you can extend this work with your child's strengths into your home-life. (Even if you don't really need the advice, this will get the

teachers more invested in your child's strengths and may expand upon the ways they view your child).

For those really adventurous parents, make the case to the principal/school board that in addition to IEP's, each child should receive an ISP (Individual Strengths Plans). An ISP would include observations, insights, and plans around boosting each child's strengths. For example, the child's character strengths commonly displayed (offered by each teacher), examples for each, goals for how the teacher plans to build from these character strengths, a list of the child's interest areas, examples of the child's talents (what they are best at), comments about the main friendships/relationships they have cultivated, and so on.

Note: you can also download different user-friendly versions of the character strengths, such as handouts, posters, and wordles at www.viacharacter.org

Dealing with a family member, case worker, support staff, or someone who is very negative and only talks about problems?

Try this...

Shift the conversation. Each time I went to pick up one of my kids from daycare, I would ask the daycare workers how the day was for them. One particular daycare worker always offered negative comments, many trivial and minor. After several days of this pattern, I asked her my standard question about how the day went and again she noted something negative and trivial (e.g.,

Continued on page 4

Building a Strengths Mindset

continued from page 3

.....

“He didn’t listen the first time when I called him in from playing outside.”) I then said, “OK, thank you for sharing that. And, what did you notice that went right for him today? What was best about his day?” She was surprised at this question, thought for a moment, and offered two positive behaviors he displayed during the day. That question caused a shift in her. From that point forward, every day I came in, she shared positive observations. She shared other behaviors too, but it was clear she had made a shift, at least in discussions with me, to offer balanced feedback.

The offering of balanced feedback applies to EVERY child, regardless of age, diagnosis, and behavior. And to elicit more balanced feedback, it might be as straightforward as asking others the right question:

- What is best about my child?
- What did they do well today?
- What character strengths did you see them display today?
- What do you like most about my child?
- When did my child seem most engaged today?

Finding yourself in a difficult medical scenario where there’s nothing but medical issues, procedures, and diagnoses thrown your way?

Try this...

**I then said,
“OK, thank you for
sharing that. And,
what did you notice
that went right for
him today?
What was best
about his day?”**

In difficult medical situations, we are inundated with diagnoses, worries, complex procedures, and most scary—the unknown. Hospitals and clinics are entrenched in a world of deficit-based language and a correct-the-problem mentality. Character strengths are often the last thing on people’s minds. However, isn’t this when we need our character strengths the most? Who reading this that has faced a challenging surgery or doctor’s visit did not turn to strengths, consciously or unconsciously, such as hope, perseverance, prudence/caution, bravery, spirituality, or love? Strengths are what help us, the parents, face challenges with grace and still maintain mental energy to ask the right questions and stick with our children through the difficult times.

My aunt, whose son has Down syndrome, has helped him through brain surgeries, thousands of seizures, countless medical procedures you couldn’t pronounce the name of, and dealt with hundreds of medical professionals over the decades. Do you think she has ever once left her son’s side

through everything? Not once. How could she possibly have done this without turning to love (unconditional devotion for her son), perseverance (“I will keep going no matter what”), bravery (facing the unknown, the horrifying, the difficult), spirituality (prayer), teamwork (support of her husband, other children, and close friends), and probably all of the other character strengths from time to time?

Once we recognize that we have all 24 of these strengths, we can turn to any of them to help us find that extra morsel of resilience. Any moment. Any situation.

Conclusion

Take on a “character strengths mindset.” Build this “language” into your conversations. Get creative with your family as you use it. Be the first to bring it to your schools, IEP meetings, and community gatherings. Realize you have an incredibly helpful toolkit right by your side. It’s up to you to decide when to open it.

About the author

Dr. Ryan Niemiec is a psychologist and international presenter on well-being, happiness, strengths, and mindfulness meditation. He is involved in research studies that are creating a survey of character strengths, inclusive for people with disabilities, and the use of character strengths interventions for people with disabilities. He’s the author of several books including Mindfulness and Character Strengths: A Practical Guide to Flourishing.

The VIA Classification: The 24 character strengths found in all human beings, with real examples of people with Down syndrome.

©The VIA Classification is copyright of the VIA Institute. All rights reserved. www.viacharacter.org

VIRTUE CATEGORY	CHARACTER STRENGTH	DESCRIPTION	EXAMPLE
Wisdom	Creativity	You like to create unique things that are of use. You can think of many different ways to solve a problem.	A young man plays the guitar for live shows and wears a unique outfit for each show.
	Curiosity	You like to explore things. You are very interested in trying out new activities and meeting new people.	A young child asks her parents many questions about each new place she goes to around the city.
	Judgment/ Critical Thinking	You are logical and like to think. When someone gives an opinion you like to examine it in many different ways.	An adolescent tries different approaches to program a TV remote, thinking through all his options.
	Love of Learning	You want to keep learning. You love to deepen your knowledge. You spend a lot of time learning as much as you can.	An adult has an interest in learning a lot on a particular topic & takes college classes.
	Perspective	You are wise. You learn from your mistakes. You offer guidance to others who are struggling.	A friend is upset after his basketball team loses. His friend tells him: "It's OK. It's only a game."
Courage	Bravery	You face your fears. When there is a problem, you go right toward it to solve it. You stand up for what is right.	A young woman is nervous about public speaking. She takes a deep breath, faces her fear, and walks up front.
	Perseverance	When you have a goal, you keep going. You overcome anything that might get in your way. You finish what you start.	A young adult repeats her personal motto to herself when she is stressed: "Just keep going... keep trying."
	Honesty	You tell the truth. You are viewed by others as sincere and genuine.	A little girl exclaims that even though it's not always comfortable, she chooses to tell the truth to people.
	Zest	You are full of energy. You are enthusiastic about life. You always seem to be talking to people.	A friendly adolescent is always the first to greet people at each activity and sporting event.
Humanity	Love	You are loving toward others and you receive love from others. You value being close to people.	An adolescent hugs others in a warm, caring way following a positive interaction.
	Kindness	You often do good things for people. You are helpful and caring. You are generous.	A woman explains she gets great pleasure from being nice to people any time she can.
	Social Intelligence	You are closely aware of your feelings and the feelings of others. You seem to say the right thing in many situations.	A man noticed a sad expression on his co-worker's face and asked her how she was doing.
Justice	Teamwork	You value being a team player. You are loyal to your group. You always fulfill your duty on teams and in groups.	A young woman decides to give back to her community by volunteering.
	Fairness	You believe strongly in equality for everyone. You treat people the way you want to be treated.	A woman demands justice to her supervisor when she sees a co-worker being mistreated.
	Leadership	You are good at organizing groups of people. You would much rather be the leader than a follower in a group.	A man explains he enjoys being an advocate for people who do not have "a voice."

Continued on page 6

Building a Strengths Mindset

continued from page 5

.....

VIRTUE CATEGORY	CHARACTER STRENGTH	DESCRIPTION	EXAMPLE
Temperance	Forgiveness	You often give people a second chance after they have harmed you. You are good at letting things go.	In response to being teased, a man decides to simply walk away and "let it go."
	Humility	You are a modest person. You do not brag about yourself. You place the attention on other people.	A musician shares how he is happy to perform on stage but to let others get the attention.
	Prudence	You are cautious to not take too many risks. You are good at planning. You are responsible and usually on time.	An adult is described by friends as very organized and committed to his goals.
	Self-Regulation	You are disciplined. You are good at handling stress. You control your bad habits (e.g., eating, drinking).	A woman announces to her family that she has decided to quit smoking.
Transcendence	Appreciation of beauty & excellence	You often observe beauty around you. You are filled with wonder. You want what you & others do to be "just right."	A man walks into a museum and marvels at the beauty and precision of the artwork.
	Gratitude	You often feel grateful for your life and for the good things that happen. You almost always tell people "thank you."	A couple expresses their appreciation for having connected with a new friend.
	Hope	You are optimistic. You are positive. You often look to the future and see good things.	A young woman describes the forward-thinking optimism of her roommate: "She looks forward, and only forward."
	Humor	You love to make people smile and laugh. You are playful with people. You turn gloomy situations into fun ones.	A man is playful & mischievous with his group; he makes others smile and laugh with each joke.
	Spirituality	You are filled with a sense of life purpose and meaning. You practice a particular faith or set of beliefs.	A young boy enjoys praying and reciting sacred phrases from religious texts.



Empire State Building Lights Up for World Down Syndrome Day

One of the most famous landmarks in the world, the Empire State Building, is lighting up blue and yellow in honor of World Down Syndrome Day! The lighting will be a stunning reminder to honor and celebrate people with Down syndrome on March 21st.

NDSC's national partners for WDSD 2015, Down Syndrome Affiliates in Action, Global Down Syndrome Foundation, International Down Syndrome Coalition, International Mosaic Down Syndrome Association, LuMind Research Down Syndrome Foundation and National Down Syndrome Society, are all thrilled to see the New York skyline light up in blue and yellow on March 21st!

Accepting Nominations to Serve on NDSC's Board of Directors

The National Down Syndrome Congress is looking for people who have an interest in serving the Down syndrome community as a member of the NDSC Board of Directors. Board members have the opportunity to shape policy, lead initiatives and make a difference through rewarding work as a team.

Board members are elected at the NDSC's annual meeting, which will be held Saturday, June 27, 2015, during the NDSC Convention in Phoenix, Arizona.

Any NDSC member in good standing is eligible for nomination to the Board of Directors. Self-nominations are welcomed, as well as nominations by third parties. The Nominating Committee is chaired by Immediate Past President James Faber, with representation from the general membership. Members can express interest in learning more about board service without making a commitment to complete and submit an application for this year, by sending an email to jimfaber@q.com.

The NDSC seeks wide representation in its board membership and considers factors such as areas of expertise, prior experience on not-for-profit boards, geographical representation, age of person or family member with Down syndrome, parent/professional status and ethnic representation. The Nominating Committee is particularly interested in adding persons of color to the board, as well as those with backgrounds in accounting, finance, higher education, fundraising and conference program planning.

A Nominee Information Form as well as an overview and description of the board selection process is available on the NDSC website, www.ndsccenter.org, or by calling the Center at 1-800-232-6372. To submit a name for the Nominating Committee to consider, please send a completed form by mail or email to: James Faber, 18760 Autumn Way, Monument, CO 80132; jimfaber@q.com

Deadline for nominations is Friday, April 24, 2015.

Ana Cruz Joins NDSC Staff

Ana Cruz has joined our staff in Atlanta, as Communication Specialist, working with our Spanish communication in print, web and social media.

Ana is originally from Costa Rica with degrees and experience in Spanish,

Communication, Public Relations and Journalism.

Ana will be working primarily on translation and editing, in order to provide greater support for Spanish-speaking families. Ana and her husband are the parents of three daughters. Ana had a cousin with Down syndrome, who was her inspiration to work at our organization. "Arturo improved my outlook in life by teaching me the value of unconditional love." We welcome Ana to the NDSC team!



Welcome Ricki Sabia as Senior Education Policy Advisor

We are pleased to welcome Ricki Sabia as our Senior Education Policy Advisor, working closely with NDSC's Governmental Affairs Director Susan Goodman, in Washington, D.C.



Ricki has long been known as an expert in the field of education policy for students with disabilities, and is noted for her advocacy in the area of universal design for learning. Many of our members will know Ricki from her work at the NDSS Policy Center for more than ten years. Right off the bat, Ricki is working on the re-authorization of the Elementary and Secondary Education Act, and will work on other education policy issues as they arise.

Ricki and her husband are the parents of two sons, including Steve, who is 22 and has Down syndrome.

Where in the World will the NDSC Convention Meet Next?

Just how does the NDSC choose a particular city to host the world's largest meeting for the Down syndrome community each year? When will the convention come to my town? These are questions we answer quite often...and the answer? It's complicated!

The NDSC is gearing up for its 43rd annual national convention in Phoenix, Arizona. How did we choose Arizona for 2015? Some people are scratching their heads about the decision to take NDSC's giant family reunion to one of the hottest cities in America in June! We can assure you the families in Arizona are not. It has been 18 years since our last convention in Arizona, and they are really happy to have us return.

The convention host city is determined by a variety of factors, including geographic rotation, venue availability, affiliate support, sleeping room rates and more.

Keep in mind, people with Down syndrome live all over the country, not just destination markets like Boston, Washington, DC and Southern California. As a service organization, the NDSC takes pride in rotating the "Super Bowl" of conventions geographically around the country. This allows families of all backgrounds better access to the world's leading experts on Down syndrome, sometimes in their own backyards. Sure, many attendees build their summer vacation around our convention each year—but attendance is really driven by families who live in the region of the country where we hold the event.

Once a region is identified, venues are solicited. For the past 20 years or so, the NDSC has hosted the convention during the summer, when children are typically out of school. That window gets smaller each year, as school districts in some parts of the country don't break until mid-June, while other school districts start their new year in early August. The week of July 4th isn't particularly good timing for conventions either, so we have to remove that week from the mix, too.



The ideal convention venue is a single hotel, with more than 1,000 sleeping rooms and 100,000 square feet of meeting space. When we have to use a convention center or multiple hotels it drives up the cost and makes it more difficult for families to navigate. Our convention is essentially four conferences taking place simultaneously.

- The General Convention requires a ballroom which will fit 2,000 people theater-style, an exhibit area large enough for 120 table top exhibitors, and 18 breakout rooms that can hold a minimum of 100 chairs theater-style.
- The Youth & Adults Conference requires a large ballroom that can be divided into two halves and can hold 225 people at banquet-style tables in each room. We also need at least six breakout rooms for Y&A, ideally on the same floor as the ballroom. This space must also be close to restrooms, but preferably away from exit doors, elevators and stairwells. Safety is the NDSC's number one priority when planning the Youth & Adults Conference space.
- The Brothers & Sisters Conference and Kids' Camp require an additional 10 breakout rooms with their own unique specifications.

- Additionally, we partner with the medical professionals who comprise DSMIG-USA, the Down Syndrome Medical Interest Group, who like to meet in conjunction with our convention.

After venues are considered, we reach out to the local NDSC affiliate parent organization. No brainer— right? Wrong! Many local affiliates struggle with meeting their everyday goals and initiatives, so when the NDSC calls and asks how they feel about recruiting 450 volunteers and raising \$15,000...they aren't always able to commit. Thankfully, most affiliates are up for the challenge and are willing to accept the Host Committee roles and responsibilities.

Why so many volunteers, you ask? Again, it's complicated! Volunteers are the key to pulling off a successful convention weekend for the more than 3,500 participants. Key roles like manning the registration table, stuffing tote bags, checking in volunteers, hosting workshop rooms, and collecting evaluations are just a few areas of need. The largest number of volunteers are needed to support the Youth & Adults Conference and Kids' Camp, which require more than 100 people daily. Both of these run much more smoothly when volunteers have experience working with people with Down syndrome and are able to volunteer for multiple days. (The NDSC volunteer coordinator works side-by-side with the local volunteer committee to ensure all volunteers are recruited, confirmed and trained in time for the convention.)

Raising \$15,000 is another tall order for many local affiliates, which is why the NDSC does not make this a requirement for our hosts. It is a suggested amount to contribute to help offset the cost of purchasing attendee tote bags, volunteer t-shirts, and speaker gift bags. (These items are printed with the local affiliate's logo

and any extras are given back to the affiliate to use at their discretion after the convention.)

- ✓ Geography – Check
- ✓ Venue – Check
- ✓ Affiliate support – Check

Next on the list is negotiating a sleeping room rate, with a goal of staying under \$150. This isn't an easy task. Most large hotels are only able to meet this request in their off-season or non-peak months (hence Phoenix in June). The JW Marriot Desert Ridge's rack sleeping room rate is \$349. Our convention rate is more than 50% less than that. When you couple that savings with

ideal meeting space, that venue gets a high rating on our list.

We also consider the ease and availability of transportation options, proximity to the airport, and local amenities, like restaurants, shopping and attractions. It's also nice to have free or low-cost parking, affordable Wi-Fi connections and refrigerators in sleeping rooms. Downtown vs. suburbs, number of non-stop flights, affordable food

and beverage options, area attractions...oh my! No stone is left unturned when selecting the site of the NDSC Convention. That's not to say that we are able to find a host city and venue that meets every criteria on our list! The Convention Planning Committee and then ultimately, NDSC's Board of Directors selects the city and venue that they feel will offer the best convention experience possible.

This year is Phoenix, last year was Indianapolis, the year before Denver. Where in the world will the NDSC convention be next? Join us this summer in Phoenix to find out! If you'd like the convention planning committee to consider your city for an NDSC convention, send an email to info@ndsccenter.org.



DS (Daily Smiles) Can Change Everyone's Day

John T. Farley is completing his final semester at the University of Memphis TigerLIFE Program.

As part of his college experience, John T's parents felt it would be beneficial to connect him with University Athletics. After making several inquiries, the strongest recommendation was to pursue involvement in the baseball program.

The Farleys were overwhelmed when head baseball coach, Daron Schoenrock (known to all Tiger Fans as Coach Rock) actually called the Farley home in the fall of 2013. He invited John T to come to the baseball complex (FedEx Park) for a general interview and get-acquainted session. Imagine their surprise when he was introduced to the team **THAT DAY** on the pitcher's mound as the newest addition to the team!

From day one, John T has been accepted and included as part of the Memphis Tigers team. What was originally scheduled to be a Wednesday and Friday afternoon experience has evolved to be four to five days a week, for several hours at a time. John T wants nothing more than to be with his team. Just like the rest of the Tigers, baseball is where their friends are, where they have fun, and where they learn about belonging and working together.

Coach Al Woods, Head of Baseball Operations said, "John T assists our Baseball Managers with day to day functions at practice and games and everyone on the team enjoys his company. John T has a smile on his face every day, and I think that's the key ingredient for our players, because baseball is a tough game. Even great players fail daily in baseball, and John T helps our players from being upset and puts a smile back on their faces. Whether John T is leading the pre-game cheers with the players or serving as a batboy, he works extremely hard to do the best job he can for the team. John T loves life and the University of Memphis. He shares that love with our team. I find myself becoming more upbeat when John T is around. His positive attitude gives off a vibrant energy. He can turn a bad day around with just a few words. John T has helped me understand that a team is made up of a lot of different people and personalities, and you do not have to be a good athlete to be a great teammate."

Head Coach Daron Schoenrock sums up John T's role on the team by saying, "The University of Memphis Tigers Baseball program is extremely blessed to have John T Farley as part of our baseball family. We look forward, every day, to



seeing his smiling face come through the gates to help us with practice, equipment and mainly keep our competitive world of college athletics in perspective. His positive attitude, service and pride he takes in doing little things for our baseball program is impactful far beyond words. John T is teaching our guys, on a daily basis, that Down syndrome is something that is real, but doesn't affect the heart. John T has a wonderful heart, inspires our guys to enjoy every day and get to know the heart of people they deal with every day. Our Tiger program is blessed to have John T with us and we look forward to a long and lasting relationship with him. He is a wonderful person and loves his baseball Tigers!"

Sophomore Pitcher Trevor Sutton shares his thoughts about John T: “JT is a huge part of our Tiger family and he has been putting smiles on our faces since the day he walked in. Having the privilege to get to know JT the last two years has been one of the greatest experiences I could ever ask for. The first thing I noticed about JT was how he brought a smile and laughter to the field each day. No matter what, I always saw him smiling and rooting for the Tigers. One memory I have that shows how much JT cares about this team is when we were getting ready to play a game on a Saturday afternoon. Our team had been struggling over the last few weeks and we were searching for a spark of life. JT stepped in front of the team and gave a pep talk, giving us the spark we needed to get a win that day!”

“I believe that I have learned more from JT than I could ever teach him. JT has showed me that no matter what I have going on in life, a simple smile can brighten someone else’s day. Each day when we show up to the field we look forward to seeing JT because he is part of our family. We love his enthusiasm and his love for Tiger baseball. I’m extremely thankful and blessed to have had the opportunity to get to know JT over the last two years. I am blessed to be able to call him a friend of mine.”

Senior Manager, Brandon Porter says, “For the last two years, John T has graced the University of Memphis baseball team with his

presence, and everyone in this facility is better for it. Even though he does not make it to every practice or event, when he does attend there is a palpable increase of energy that greatly uplifts our team. He even leads our team in pre-game prayers and speeches, which have become primetime events in our dugout. Overall, JT’s greatest accomplishment is his innate ability to make everyone happier.”

“He rarely is not smiling, and he is always happy to talk to anyone. He has made such an impact in my life that our relationship has not been confined to the baseball field. We have gone to dinner, hung out off the field, and even have gone to an NBA basketball game together. John has touched all of our lives in varying degrees, and we are blessed to know him. I believe that you can learn from much more from others than they can learn from you. This is true in regards to my relationship with John, for I have learned much more from him than he has from me. And I will firmly believe that I am better for it.”

Brenda Farley explains, “As a family we have always had John T in the mainstream in church, classrooms, sports, and employment. His involvement with the Tiger Baseball Team has been the MOST INCLUSIVE and embracing opportunity that John T has experienced in his lifetime. From



these tributes, you can see that his excitement, attitude, and DAILY SMILES has a huge impact on others, and the acceptance and peer inclusion has been amazing for his self-esteem and personal satisfaction. Coach Rock and the entire University of Memphis Baseball program is #1 and the ENTIRE program ROCKS!!! GO TIGERS.”

John T. Farley is a member of the board of directors of the National Down Syndrome Congress, serving the final year of his three year term.

(TigerLIFE is a post-secondary program for individuals with intellectual disabilities, providing a 2-year certificate with individualized programs of study. TigerLIFE is administered by the University of Memphis Institute on Disability (UMID), whose purpose is to assist people with physical and developmental disabilities in finding meaningful and lasting employment.)

INTELIGIBILIDAD DEL HABLA:

Cómo ayudar a niños y a adultos a desarrollar y a mantener un habla comprensible (Parte 3 de 3)

Dra. Libby Kumin, CCC-SLP

PROCESOS FONOLÓGICOS

Cuando los niños comienzan a desarrollar el lenguaje, la mayoría lo hace a través de los llamados «procesos fonológicos». Éstas son simplificaciones de sonido o sustitución de patrones que descubren los niños normalmente por ellos mismos y que hacen la producción del lenguaje más fácil. Les permite producir una diversa variedad de sonidos, aún cuando ellos no sean capaces. Es un paso para aprender sonidos y patrones de sonidos de su lengua (donde van los sonidos, qué sonidos pueden ser combinados, etc.)

Por ejemplo, un niño puede decir «dratón» en vez de «ratón» porque todavía no puede producir sonidos palatales. O quizás no puede pronunciar todas las consonantes finales, decir «ga» para «gato» y «gafa». Al mismo tiempo, puede decir «to» para el «topo» y «fa» para la «fanta», dando muestra de que es capaz de pronunciar las sílabas finales de gato y gafa. Algunas veces el problema es que no sabe cuándo usar estos sonidos, no que no pueda decirlos.

¿Qué puede hacerse en casa?

El proceso fonológico más común entre los niños con síndrome de Down, es la supresión de la consonante final—no producir el sonido de la consonante final de las palabras. Tú puedes ayudar a hacer necesario el uso de estos sonidos finales a propósito. Crea un juego de tarjetas, cuyo fin sea hacer parejas con ellas, o utilízalas para crear un juego mnemotécnico de emparejar, donde haya que buscar las parejas. Las imágenes o las fotos que elijas, deben ser de palabras que sólo se diferencien en el sonido final de la palabra, como «sol y son». Si tu hijo sabe leer, escribe la palabra bajo la imagen y haz el sonido final de las letras que previamente has puesto en negrito. Los jugadores tienen turnos en los que preguntan, « ¿Tienes un _____? » Si tu hijo dice el sol,

hazle creer que no sabes qué tarjeta quiere. Entonces enséñale la pronunciación correcta. « ¿Quieres el son o el sol? »

VOZ

La calidad de la voz de tu hijo, el volumen, y el tono que utiliza cuando habla, también pueden afectar la inteligibilidad. En niños con síndrome de Down, la calidad de la voz se describe a menudo como ronca, áspera, o entrecortada. Para los problemas de voz, es necesario el examen de un otorrinolaringólogo antes de comenzar cualquier tratamiento. Puede haber razones médicas para el problema, como alergias o diferencias anatómicas en la laringe (caja de la voz), que pueden requerir tratamiento médico. La calidad de la voz también puede estar relacionada con el tono muscular bajo.

Tono

El tono se refiere a cuán alto o bajo se reproduce el sonido de la voz. Generalmente, la gama de tonos que son capaces de alcanzar los niños y los adultos con síndrome de Down, es similar a la que alcanzan las personas que no lo tienen.

El volumen

Para que sea inteligible, tu hijo tiene que hablar suficientemente alto para que el oyente lo escuche, y adecuarse a la situación. A menudo, las dificultades no se deben a problemas respiratorios o de producción de la voz, sino que se relacionan con la falta de conocimiento del volumen por parte del niño. Por eso lo que el niño realmente necesita aprender es cuándo hablar alto y cuándo hablar bajo. Como mejor se enseña



DRA. LIBBY KUMIN

ésto es en casa (o en la comunidad), en situaciones de la vida real. En casa puedes hacer saber a tu hijo que no lo estás escuchando bien, y que por lo tanto necesita hablar más alto. Puedes hacerle saber que cuando hablas por teléfono, él tiene que hablar más bajo. Incluso puedes hablar y practicar diferentes situaciones. La práctica puede ser todo lo que se necesite para incrementar o disminuir el volumen.

Actividades en casa

- Habla de voces altas y bajas. Etiqueta las voces como voces «internas» y «externas».
- Practica en voz alta en un túnel; así puede oír el eco.
- Hazle una demostración al usar una voz suave, como la de un susurro o la voz baja.
- Observa los ruidos fuertes y suaves del entorno. Por ejemplo, cuando oigas al león en el zoológico, comenta el fuerte rugido. Escucha los sonidos suaves del entorno, como el goteo del agua o los pájaros que gorjean, y habla sobre ellos.
- Habla de lugares en los se requiere hablar bajo, por ejemplo en la escuela o en la iglesia, y de lugares donde puedes (y debes) hablar en voz alta, por ejemplo en un partido de fútbol o en una montaña rusa.
- Lee libros sobre susurrar y sobre sonidos altos y bajos. Algunos libros recomendados para tratar el volumen del habla son (Títulos en inglés):
 - *Sr. Brown Can Moo, Can You?* del Dr. Seuss,
 - *Noisy Nora* de Rosemary Wells,
 - *SHHH!* de Suzy Kline
 - *Noisemakers* de Judith Caseley,
 - *Helen and the Great Quiet* de Rick Fitzgerald,
 - *The Quiet Noisy Book* de Margaret Brown, y
 - *The Very Quiet Cricket* de Eric Carle
- Juega a juegos en los que tu hijo tenga que hablar alto, bajo o susurrar. El teléfono es un buen ejemplo, pero recuerda usar mensajes cortos. Muchos niños hacen fila. El primero susurra un mensaje en el oído del siguiente niño de la fila y así sucesivamente. El último niño tiene que repetir el mensaje que ha oído y compararlo con el que envió el primer niño.

- Cuando tu hijo haya aprendido a controlar el volumen y no recuerde cómo hacerlo, usa una señal o pista como recordatorio.

RESONANCIA (EQUILIBRIO ORAL/NASAL)

La resonancia se refiere a cuán llena y vibrante suena una voz—el tono de la voz. Cuando alguien suena como si estuviera congestionado o «gangoso», nos damos cuenta de la calidad de la resonancia vocal. Muchos niños con síndrome de Down tienen problemas de resonancia, basados en condiciones médicas. Si tu hijo tiene alergia o tiene las amígdalas hipertrofiadas y adenoideas, puede que sólo respire por la boca. Consecuentemente, los sonidos nunca pueden resonar en la cavidad nasal. Sonará constipado, como si tuviera un eterno resfriado. Ésto se conoce como hiponasalidad. Un otorrinolaringólogo o un alergólogo, pueden tratar el problema. Si tu hijo tiene el velo del paladar corto (paladar blando), una cavidad palatal alta, o insuficiencia velo-faríngea, (problemas al usar el paladar blando y los músculos de la garganta para aislar la cavidad nasal y guardar el aire/sonidos fuera de la nariz, y expulsar el aire por la boca), esto se conoce como hipernasalidad. La hipernasalidad hace que el habla de tu hijo suene gangosa. El patólogo del habla y lenguaje puede proporcionar ejercicios para fortalecer el músculo de tu hijo, y así ayudarlo a mejorar el cierre velofaríngeo. Si la hipernasalidad es grave y afecta a la inteligibilidad, sería necesario pedir un tratamiento a un equipo maxilofacial. Estos equipos suelen estar compuestos por especialistas clínicos del habla y por dentistas y se les puede encontrar en los hospitales. Puede ser que le prescriban un aparato para el habla, similar a un puente dental que haría el cierre velofaríngeo más fácil. O que le recomienden la cirugía faríngea, que también ayudaría al cierre.

VELOCIDAD

La velocidad del habla, o lo rápido que hablamos, es un factor importante por el que se nos puede entender fácilmente o no. Los niños con síndrome de Down pueden presentar un índice rápido, lento o irregular y

Continúa en la página 14

Inteligibilidad del habla

Continúa de la página 13

.....

que cambia la velocidad del habla. Los patrones de velocidad no se han registrado en la bibliografía. En mi experiencia como patóloga del habla y lenguaje, he advertido que los niños con síndrome de Down suelen hablar rápido o en arranques. Suelen comenzar a una velocidad asequible para el oyente, pero aceleran a menudo conforme avanza la conversación. Cuando se presenta una velocidad rápida o a borbotones, suele haber una mala articulación o incomprensibilidad, porque no hay pausas entre las palabras, y estas tienden a toparse unas con otras. Si tu hijo presenta problemas para hablar a una velocidad apropiada, hay varias actividades que puedes probar en casa.

Actividades en casa

- Usa una tabla dinámica para ayudar al niño a desarrollar un patrón rítmico más regular. Si tu hijo suele usar cinco palabras, la tabla dinámica debería tener cinco círculos o cinco etiquetas. El niño deberá poner el dedo en el primer círculo cuando diga la primera palabra, en el segundo círculo cuando diga la segunda palabra, y así sucesivamente. Esto actúa como recordatorio visual para hablar de forma más rítmica.
- Golpea ligeramente un tambor cuando tu hijo habla y de este modo intenta que iguale la velocidad del habla con la del tambor. Por ejemplo, haz que tu hijo practique diciendo frases como *¡Hola! ¿Cómo estás? Estoy bien, ¡Hasta luego!* al ritmo del redoble. También puedes usar un metrónomo para este tipo de práctica.
- Ten conversaciones con tu hijo en las que cada uno cante las palabras con ritmo musical. Utiliza una canción que tu hijo ya sepa, o compón una canción diferente. Utiliza canciones lentas y rápidas. También puedes cantar a una velocidad y ritmo determinados usando un metrónomo y una melodía concreta.
- Habla del habla lenta y rápida, y demuéstrole el habla lenta y rápida. Juega un juego en el que diga oraciones o lea una historia mientras que tu niño mueve un coche a lo largo de un camino de juguete. Cuando hable despacio el niño tiene que mover el coche

despacio. Cuando aumente la velocidad, él debe hacer que el coche acelere. Cuando el niño se familiarice con la actividad, haz que repita las frases después que tú lo hagas, y que mueva el coche según la velocidad del discurso. Esta actividad se puede hacer también con un caballo de juguete en un camino o un barco del juguete en un río.

- Lee la historia de *la tortuga y la liebre*, y habla sobre la lentitud y la rapidez. Puedes usar ritmo o cantar una canción muy rápido y muy lento.



FLUIDEZ

.....

La fluidez se refiere a la suavidad del discurso—cómo un sonido fluye fácilmente en el siguiente sonido, una sílaba fluye en la sílaba siguiente, y una palabra fluye en la palabra siguiente. Al hablar de problemas de fluidez, nos solemos referir al tartamudeo. Los niños que tartamudean suelen hacer repeticiones o bloques (los períodos de silencio en los que parece que luchan para emitir un sonido).

El tartamudeo o falta de fluidez es más frecuente en personas con síndrome de Down. Actualmente, las mejores estimaciones calculan que entre el 45% y el 53% de las personas que tienen síndrome de Down, tartamudean. Los problemas de fluidez, a veces aparecen junto con dificultades en el ritmo del habla. Si tu hijo tiene problemas de fluidez, es importante que no centres tu atención en ellos. Mantén el contacto visual, sé muy paciente y escucha lo que tu hijo diga. No

completes las palabras que le resulten difíciles y no le obligues a disminuir el ritmo. Hazle saber que seguirás escuchándolo hasta que acabe.

Los problemas de fluidez son complejos y necesitan ser tratados por un patólogo del habla y del lenguaje. Él o ella le sugerirán actividades para hacer en casa apropiadas al tipo de problema de fluidez que tu hijo tenga.

PROSODIA

Prosodia es el término general para hablar del ritmo del discurso. La prosodia engloba el uso del tono y la entonación para expresar el significado. Por ejemplo, en inglés, la voz asciende gradualmente al final de la oración en oraciones interrogativas, y desciende en oraciones enunciativas. He observado clínicamente, que la prosodia suele ser problemática para los niños con síndrome de Down, especialmente cuando empiezan a usar frases más largas. Suelen enfatizar la palabra equivocada en una oración o hablar monótonamente de algo.

Actividades en casa

- Ayuda a tu hijo a aprender más sobre la musicalidad del lenguaje jugando a cantar palabras, como si estuvieras en la ópera. Como por ejemplo, canta «Buenos días. ¿Cómo estás?» Esto enfatiza la entonación y el ritmo.
- Juega a un juego en el que finges ser un robot o un alien que habla de forma monótona en un tono (o usa un títere). El trabajo de tu hijo es enseñarle a hablar como un humano. Por ejemplo, tú dices, « ¿Tengo la pelota?» En un tono robótico. Tu hijo repite, « ¿tengo la pelota?» ascendiendo el tono al final. Él no te dará la pelota hasta que imites su modelo correctamente.
- Usa las mismas palabras con diferentes entonaciones. Por ejemplo, pregunta, «¿helado?» Si tu hijo tiene que responder, «helado», con la entonación de afirmación, sí lo quiere. Si lo articula como una pregunta (imitándote), dices, «bueno, ¿quieres helado?» Entonces cambia los papeles. Tu niño pregunta, «¿béisbol?» y tú dices, «béisbol», y enciendes la televisión para comenzar a ver el partido.

Llegados a este punto, nos hemos centrado en el discurso de la persona que habla. Pero ser capaz de comprender qué dice el hablante, abarca más que el discurso. La comprensión también implica lenguaje pragmático y factores no verbales de la lengua, cuán complejo es el mensaje, las diferencias en los oyentes, y los factores en el ambiente.

FACTORES PRAGMÁTICOS DEL LENGUAJE

La pragmática se refiere al lenguaje social y al lenguaje diario. ¿Cómo afectan las habilidades interpersonales del lenguaje de tu hijo para que el oyente pueda entenderlo? ¿Es más difícil entender a tu hijo cuando se aleja del tema? Puedes enseñar a un niño, guiones sociales, al usar juegos de roles y practicarlos. Por ejemplo, descarga fotos de gente famosa, entre ellos los cantantes favoritos de tu hijo, o sus ídolos deportivos. A continuación, practica una habilidad concreta, como fingir saludar a cada uno. La terapia puede ayudar a tu hijo a aprender y a mejorar su capacidad para contar que ocurrió, contar una historia, cómo pedir ayuda, y cómo reconocer cuándo alguien no entiende lo que ha dicho. En la adolescencia, los grupos sociales de habilidades pueden ayudar.

FACTORES DE HABLA NO VERBAL

¿Cómo afectan las habilidades comunicativas no verbales de tu hijo (como el contacto visual) a lo que el oyente entiende? Normalmente solamente se necesita llamar la atención de habilidades como el contacto visual, y después practicarlas para ayudar a tu hijo a aprenderlas.

*Para continuar leyendo el artículo: “**Inteligibilidad del habla: Cómo ayudar a niños y a adultos a desarrollar y a mantener un habla comprensible**” ingrese al blog del NDSC en español: <http://blogenespanol.ndsccenter.org/> Este es el último de una serie de tres artículos que debatirán los factores que pueden afectar a la inteligibilidad del habla en los niños y adultos con síndrome de Down, con el objetivo de ayudar a las familias y a los terapeutas de lenguaje a identificar y trabajar los factores específicos que afectan a la falta de comprensión del habla de su hijo.*

Down Syndrome News is a benefit of your annual membership in the National Down Syndrome Congress. To renew or join today, visit ndsccenter.org or call 1-800-232-NDSC (6372).



30 MANSELL COURT, SUITE 108
ROSWELL, GA 30076
NDSCCENTER.ORG

NON-PROFIT ORG.
U.S. POSTAGE
PAID
SACRAMENTO, CA
PERMIT NO. 1491

DOWN SYNDROME *News*

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

A large poster for the 43rd Annual NDSC Convention. The background is a photograph of a desert landscape with a prominent rock formation. Overlaid on the image is a large, stylized letter 'D' in the shape of the state of Arizona. Inside the 'D', the text "43rd Annual NDSC Convention" is at the top. Below it, the words "BEYOND ALL LIMITS" are written in large, bold, white letters, each on a different colored rectangular background (dark blue, teal, and gold). At the bottom of the 'D', the dates "June 25-28, 2015" are written in white on a dark red background.

43rd Annual NDSC Convention

BEYOND ALL LIMITS

June 25-28, 2015

A poster for the "321 dance" event. The background is a solid light purple color. At the top, the text "321 dance" is written in a large, stylized font, with "321" in purple and "dance" in white. To the right of "321" is a small logo for the National Down Syndrome Congress. Below the title, the date "June 27, 2015" and the fundraising goal "Fundraising Goal: \$25,000" are written in white. In the center, there is a silhouette of a group of people dancing. At the bottom, the text "Register Today:" is followed by the website "www.ndsc.donordrive.com/" and the offer "Free T-Shirt for everyone who raises \$100 or more!" in white.

321 dance

June 27, 2015
Fundraising Goal: \$25,000

A silhouette of a group of people in various dance poses.

Register Today:
www.ndsc.donordrive.com/
Free T-Shirt for everyone
who raises \$100 or more!