NATIONAL DOWN SYNDROME CONGRESS

DOWN SYNDROME NEWS

Volume 45, Number 2
Third Quarter 2022

In this Issue

Images by Jay Silverman.

BEHIND THE PICTURES

at the NDSC 50th Annual Convention

The 50th NDSC Annual Convention, "Lagniappe in the Big Easy", closed out the month of June - and what an incredible event it was. Thank you to all those who joined us in New Orleans to learn, educate, experience and have a blast! This year, being our 50th convention and our first in-person event since 2019, we knew it was going to be extra special and it truly was the reunion of a lifetime for community with more than 2500 people attending, presenting, exhibiting, and volunteering from 46 states and eight countries over four days.

The weekend kicked off with GLOBAL's Research & Medical Care Roundtable, followed by in-depth Deep Dive sessions, spanning topics on health all the way to inclusion and self-advocacy, then First-Time attendee orientations in English and Spanish. The fun activities began Thursday evening with our Connections Reception, where first timers, 50th timers and everyone in between got the chance to share their convention experiences, meet up with people they've gotten to know online, and more.

Friday was action packed full of more Deep Dives, kickoff parties for Youth & Adults (Y&A) and Siblings Conferences, and the first General Conference workshop cycle. The 4th Annual College fair provided information on incredible post-secondary opportunities. All the while, the exhibit hall was open, so everyone had the chance to learn something new, find a new book, or practice their dancing with our great exhibitors and sponsors. At the General Membership Meeting, the new board slate was ratified and afterwards the board elected new officers (see back cover for a listing).

At the plenary session we heard incredible presentations by keynote speakers Debbie Antonelli and Jake Pratt,

but it quickly transformed into a dance party as we paraded into the 321 Dance! where everyone danced the night away to their favorite jams.

Saturday began with more informative and unique sessions, including the NDAC Town Hall meeting and OSEP Listening Sessions, where families interacted with the U.S. Department of Education Office of Special Education Programs (OSEP) Director and former NDSC Board Member, Valerie C. Williams, and other Senior OSEP staff. Throughout the day professionals in their fields spoke on their expertise while General Conference attendees had the option to pick which sessions they would most benefit from out of fourteen in each of their three cycles. Simultaneously, the Y&A and Sibs had their own set of exciting workshops and sessions. As the day turned to night we put on our party attire for a fun evening, starting with the banquet, followed by the masquerade ball with a live band.

Our final day at convention went fast, but it was still full of so much learning at the remaining workshop cycles and Advocacy Training Boot Camp. During these sessions our Y&A conference concluded with their annual Talent Show featuring many awesome acts and fun performances, while the Siblings off-site trip toured Mardi Gras World.

We cannot wait to do it all again next year at the 51st NDSC Annual Convention in Orlando, Florida from July 20th-23rd, 2023. We hope to see you all there!

Letter From the NEW President

Hello,

I'm Kate Dougherty, the President of the National Down Syndrome Congress. I want to thank all the host committee members, sponsors, vendors, exhibitors, volunteers, presenters and, most of all, self-advocates and families who attended the 50th Annual NDSC Convention in New Orleans. Convention is the best time of year for me and my family as it's the one time we feel the world is the way it needs to be. We are already looking forward to the 51st in Orlando, Florida, at the JW Marriott/Ritz Carlton Orlando Grand Lakes, July 20-23, 2023. In the meantime, I'm grateful that the NDSC hosts events year-round all over the country. I personally can't wait to attend the Big Game Ball on September 1st in Atlanta -- I hope to see you there.

Being elected president in New Orleans is a privilege and honor. I never imagined this possibility 14 years ago in 2008, as my husband and I sat in a NICU holding our beautiful baby boy in our arms and our family joined the ranks of the "lucky few." With Elliot's birth we got lucky, not once but twice! We got lucky the first time because when we asked the question, "What is Down syndrome?" our doctor's response was this: "Down syndrome is simply an extra chromosome. Anything you or I may or may not have an individual with Down syndrome may or may not have. We simply know there are higher propensities for different medical conditions than others. So here's what we are going to do: We are going to fix that hole in his heart. Then you are going to take home your beautiful baby boy and you are going to love him big time. If you can't do that, then I am."

After meeting literally thousands of families, we know not everyone gets as lucky to have such a progressive and positive delivery diagnosis—something the NDSC, along with Dr. Kishore Vellody and others, is working overtime to change. While this is an overly simplistic explanation of that extra chromosome and the impact it may or may not have, our doctor's delivery of Elliot's diagnosis and positive response was vitally important in those first moments.

Then we got lucky a second time because, as our NICU nurse began printing off information from the web (Siri didn't exist), and as we waded through a wealth of outdated misinformation, we found an article featuring self-advocate Austin Davenport, who was working, living independently, and recently engaged to his future wife, Christie Hockel.

It was through Austin that we knew the dreams of our heart for our son were possible. It was also through Austin and Christie that we found the National Down Syndrome Congress. In a rural area, resources and services look different. For almost three years, before attending our first convention in San Antonio, Texas, in 2011, we used the website and phone line at the National Down Syndrome Congress to make sure we were getting our son the latest and best medical, behavioral, therapeutic, and educational interventions. I would stay up late at night and read the stories of the NDSC's self-advocate speaker bureau. My knowledge grew about what was potentially possible for someone living with an extra chromosome.

Because of the NDSC, when Elliot was six months old, and I was faced with a situation of lack of knowledge when a member of our rural community asked me (while I held my beautiful baby boy in my arms) if I thought Elliot would be able to live in a group home or if I would have to institutionalize him, my reply was, "I was thinking college!" College was and remains one the Dougherty family's goals for Elliot. He will

proudly tell you he plans to go to university and play football (well, his mom's not sure about that last part).

This is just one of the many reasons I'm excited about the NDSC's Big Game Ball, September 1, 2022, at the College Football Hall of Fame in Atlanta. The Big Game Ball honorees exemplify the priorities of the NDSC to:

- increase access to inclusive postsecondary opportunities for students with Down syndrome and other intellectual disabilities,
- develop high-quality inclusive postsecondary programs,
- provide Model Program Accreditation Standards for postsecondary education programs, and
- advocate for educators who will continue to forge the path of inclusive education at all levels.

All of this leads to meaningful employment, independent living, and improved quality of life for people with Down syndrome.

I would personally like to invite you to join me September 1st at the Big Game Ball. If you cannot attend, please TEXT NDSC to 269-89 to donate to and vote for the team of your choice while showing your love for the possibilities these post-secondary programs and other programs like them bring to our self-advocates.

As president of the National Down Syndrome Congress, I am thrilled to serve our amazing self-advocates, families, friends, communities, and organizations who love those who rock that extra chromosome. I have promised the Board to visit groups and organizations who are working to improve the access and quality of life for individuals with Down syndrome. If you are interested in having me visit your group or organization, or if you have ideas, concerns or questions, you are welcome to call or text me personally at 217-617-3568 or email me at info@upatdowncountry.com.

I thank you for the love and belief in all our self-advocates. We are all more alike than different.

Kate Dougherty,
President, NDSC

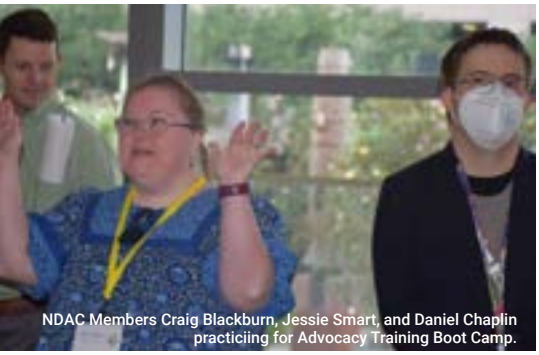
Policy & Advocacy in Action

NDAC
National Down Syndrome Advocacy Coalition

Become an NDAC Member and Help Advance NDSC's Policy Agenda!

The NDSC Policy & Advocacy Team, based in Washington, D.C, advocates for the rights and improved opportunities for people with Down syndrome and their families throughout the lifespan. NDSC's Legislative Priorities focus areas include education (pre-K-12), postsecondary education, health care, employment, Medicaid long term services and supports, financial empowerment and community inclusion. Under the leadership of the NDSC Policy Team, NDSC also develops Policy Positions for each new Congress (every two years) with guidance from the NDSC Policy and Advocacy Council, consisting of national experts and NDSC board members.

The NDSC Policy Team is a small but mighty team of seasoned professionals that works on a bipartisan basis. To advance these legislative priorities, the NDSC Policy Team engages National Down Syndrome Advocacy Coalition (NDAC) members. NDAC is the Grassroots Advocacy Program for the National Down Syndrome Congress.


NDAC Members Craig Blackburn, Jessie Smart, and Daniel Chaplin practiciing for Advocacy Training Boot Camp.

Launched in 2017, NDAC is a member service of the NDSC and is designed to educate individuals with Down syndrome, their family members, and other allies about policy issues and provide the advocacy tools and techniques they need to engage with their elected officials to effectively advocate for change. With this program, we bring together advocates of all abilities and levels of experience from across the country who have a passion for the Down syndrome community. Through NDAC's education, training opportunities, and engagement on social media, we have cultivated a broad coalition of advocates who will effectively engage with lawmakers, agencies, and other key decision-makers to promote policy change.

One recent success is the ABLE Age Adjustment Act, which was included in a federal retirement tax package brought before the Senate Finance Committee. NDSC was able to quickly mobilize NDAC members to reach out to Senators on the Finance Committee and ask them to vote yes to moving the bill out of committee. These efforts were successful, and the bill passed out of committee unanimously. The bill's lead sponsors, Senator Bob Casey (D-PA) and Senator Jerry Moran (R-KS) thanked and applauded NDSC's ability to engage advocates so quickly.

Additionally, NDAC members are involved in local and state advocacy efforts. The quarterly NDAC calls provide an opportunity for state advocates to share strategies. Many NDAC members play a key role at the Advocacy Training Boot Camp at the NDSC Convention. NDAC member presentations are included in the Training Resources below.

Currently, there are 636 individual NDAC members representing 48 states. For more information, check out NDAC FAQ. Joining NDAC is free and easy just by completing an online application. NDAC Advocates of all levels and abilities are welcome, needed, and valued. NDAC also has a closed Facebook group for those who join.

Training Resources for Advocates

The NDSC Advocacy Training Boot Camp at the 2022 NDSC Convention was launched five years ago to provide beginner advocates with the tools and resources needed to advocate for policies that are good for people with Down syndrome and other intellectual disabilities. It is also an opportunity for networking. The following materials and presentations that were shared at Boot Camp are accessible year-round on the NDSC website:

- The Advocacy Journey Begins with YOU by Heather Sachs and Jawanda Mast
- Keynote: How Families and Self-Advocates Saved IDEA by Stephanie Smith Lee
- Win with Your One-Pager by Jessie Smart
- Voices of Parent Advocates Panel: Successful State and Local Advocacy by Tony Zanfordino, Liz Gary, Denise Gehringer
- Action Plan, Website, Resources, NDAC, Questions and Answers by Jawanda Mast
- Training Resources including:
  - Self-Advocate One-Pager Examples
  - One-Pager Template
  - Resource List
  - Action Plan Template and Example
  - The NDSC Advocacy Tool Kit for Self-Advocates

Impact of Physical Health Conditions

Every thorough mental health assessment should include an assessment of physical health to ensure that physical health problems are not affecting mental well-being in any way. This is true whether or not the adult with Down syndrome is suspected of having any kind of mental illness. Discovering physical health problems early in their course may prevent them from causing mental health problems.

We sometimes find that a physical problem is the direct cause of a mental health problem and sometimes it is a contributing factor. However, in either case, as time goes by, the problem often develops other "layers," and treatment of the physical problem alone is often not adequate. It is necessary to address the problem from all aspects: physical, psychological, and social.

Below is a list of physical health conditions, their possible impact on mental health, and tests or procedures that can be done to assess for the conditions. The list is not comprehensive. In our experience, these conditions have most often contributed to mental health problems in adolescents and adults with Down syndrome. Based on the history, physical, and findings of the tests or procedures, referral to a specialist may also be indicated.

Dr. Brian Chicoine

Dr. Brian Chicoine has provided medical care to individuals with Down syndrome for over 30 years. He graduated from Loyola University of Chicago Stritch School of Medicine and completed his Family Medicine residency at Lutheran General Hospital.

PAIN
Possible impact: Depression, behavior change, aggression, and anxiety
Test or procedure: Interview the adult with Down syndrome and their family/caregiver; thorough physical exam; additional procedures as indicated based on history and physical exam

HEARING IMPAIRMENT
Possible impact: Anxiety, apparent loss of cognitive skills, depression, agitation, aggression
Test or procedure: Hearing test from an audiologist at least every 2 years, or more frequently if indicated by possible change in hearing

VISION IMPAIRMENT
Possible impact: Anxiety, depression, apparent loss of cognitive skills, agitation
Test or procedure: Complete vision exam at least every 2 years or more frequently if indicated by possible change in vision

SEIZURES
Possible impact: Aggression, depression, apparent loss of cognitive skills
Test or procedure: EEG and imaging of the brain (CT scan or MRI)

CERVICAL SUBLUXATION
Possible impact: Loss of skills (particularly decreased ambulation skills, loss of muscle function, incontinence), anxiety, agitation, depression, loss of interest in activities
Test or procedure: Thorough neurological exam (as part of physical exam); lateral cervical spine x-rays in flexion, extension, and neutral; CT scan and/or MRI of cervical spine

URINARY TRACT PROBLEMS*
**Includes urinary tract infections and difficulty/inability to empty the urinary bladder*
Possible impact: Development of incontinence, urinary frequency, agitation, anxiety
Test or procedure: Urinalysis (urine test) and possibly urine culture; ultrasound of the bladder and kidney (a pre- and post-void ultrasound or a bladder scan is helpful to assess for problems with emptying the bladder)

ARTHRITIS
Possible impact: Agitation, depression, apparent loss of skills
Test or procedure: Physical exam; x-rays

DIABETES
Possible impact: Apparent loss of skills, urinary incontinence, increased urinary frequency and/or drinking of fluids, agitation, depression
Test or procedure: Blood sugar; consider Hemoglobin A1C (further testing indicated if blood sugar suggests diabetes)

DENTAL CONCERNS
Possible impact: Agitation, poor eating, depression, aggressive behavior
Test or procedure: Thorough dental exam; dental exams as indicated

HYPOTHYROIDISM
Possible impact: Depression, loss of cognitive skills, appetite change
Test or procedure: Blood test for TSH and free T4

HYPERTHYROIDISM
Possible impact: Anxiety, hyperactivity, depression, loss of cognitive skills
Test or procedure: Blood test for TSH and free T4 (and possibly free T3)

SLEEP APNEA & OTHER SLEEP DIFFICULTIES
Possible impact: Depression, loss of cognitive skills, agitation, psychoses
Test or procedure: Observe sleep and keep a sleep log (although it is easy to miss sleep apnea with observation alone); formal sleep study in a sleep lab or at home

GASTROINTESTINAL PROBLEMS
Possible impact: Loss of appetite, depression, agitation, anxiety
Test or procedure: Stool test for blood; blood tests for anemia (CBC), celiac disease, liver disease, and gall bladder disease; x-rays, ultrasounds, CT scans, and endoscopy as indicated by history, physical, and other tests

MEDICATION SIDE EFFECTS
Possible impact: Can contribute to essentially any behavioral or psychological change
Test or procedure: Careful history to look for potential link to medication; possible trial off the medication

Additional mental health resources in our Resource Library can be found here.

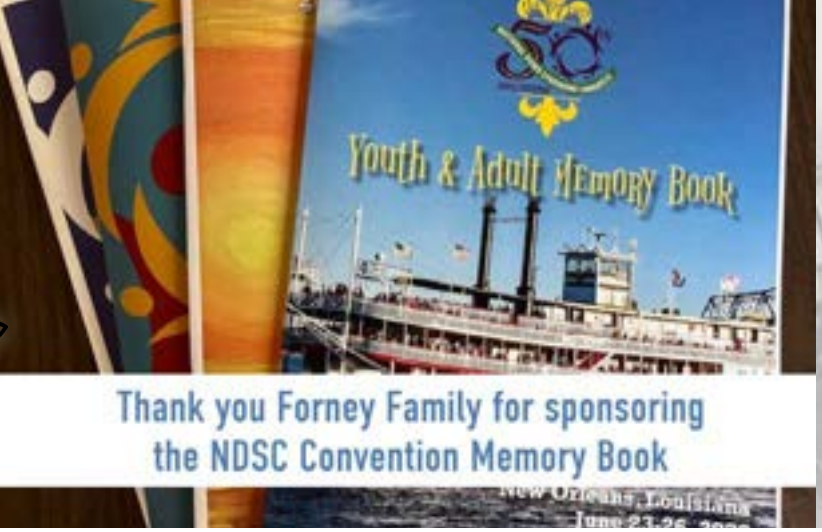
Chicoine, B. (2022, June). Impact of physical health conditions on Mental Health. Advocate Medical Group Adult Down Syndrome Center. From https://adscresources.advocatehealth.com/impact-of-physical-health-conditions-on-mental-health.

Melissa Silverman

Melissa was born on June 25th, 1982, and was thrilled to celebrate her 40th birthday during the NDSC 50th Annual Convention in New Orleans. Born and raised in Maryland, Melissa and her family have been involved with NDSC since she was born, attending their first NDSC convention when Melissa was just four months old. When Melissa turned 15, she was thrilled to participate in her very first Youth and Adults conference and has not missed a single convention or her chance to participate in the Talent Show since. Her incredible participation in our community led to her being elected to the NDSC Board of Directors in 2006. Melissa later became a member of the Self-Advocate Council (SAC) and loves advocating for herself and her fellow self-advocates.

Not only is Melissa very involved with NDSC, but she also maintains a career in childcare. In 2001, Melissa graduated high school as the first person with Down syndrome to earn an academic diploma in Baltimore County. Melissa then began the Single Step program at the Community College of Baltimore County and earned her 90-hour childcare certificate. Since 2005 Melissa has been working in childcare as a teacher assistant. She began as an assistant in a preschool for four years and later switched to work at a public elementary school in their before- and after-school programs.

When Melissa isn't working, she is living and loving her life, practicing her favorite hobbies and spending time with her friends, some of whom she has known since birth. Some of her top favorite ways to spend her time are public speaking, going to country music concerts, seeing Broadway musicals, practicing professional magic, and, most importantly, cooking. Melissa loves to cook and even offered several cooking workshops over Zoom during the pandemic. Check out Melissa's self-published book *Just a Girl in Love with Cooking*, available on Amazon, to find out her trade secrets in the kitchen.



BIG GAME Ball

Silent Auction

BIDDING STARTS AUG 29

Even if you can't make it to the College Football Hall of Fame on September 1, you can get in on the fun when you bid on items in the silent auction.

To view items and start bidding click below beginning Monday, August 29.

View Auction

Planning for Students Transitioning Back to School - Three Important Components

Returning to in-person instruction? Pause and think!

What has been working during distance learning? What do we need to remember and expand upon now that students are returning to the school building?

Students have returned to school, with continued variability across the nation. While schools and families did not have much notice, if any, to plan for distance learning, instructional teams have the opportunity and the responsibility to continue to plan for successfully transitioning students with significant cognitive disabilities back into school or remaining online, if that is the case, due to medical needs. We don't know exactly what form learning will take ongoing throughout the year, but there are steps that we can take now to assure it goes as smoothly as possible for as many students as possible.

RELATIONSHIPS, RELATIONSHIPS, RELATIONSHIPS

The relationships with students from before and during distance learning are the foundation for transitioning students back into school after a break, period of distance, or hybrid learning. Relationships between students and teachers, students and peers, and teachers and parents/families were foundational for effectively implementing distance learning. These relationships are equally important for having discussions about transitioning back into school. During distance learning, a team's communication by sending emails, dropping off materials, creating short videos, and using online platforms with their students and families, let them know that teachers cared about them, they mattered, and that their voices were heard. Communication such as that needs to remain consistent and thoughtful now.

Staying connected and continuing the mutual trust that was developed will support relationships and problem solving so that students can successfully re-engage with classes, friends, teachers, schedules, and rituals and routines.

COMMUNICATION, COMMUNICATION, COMMUNICATION

The stronger the communication web was during distance learning, the stronger the available connections for planning a student's transition back to school will be. The communication web includes communicating with:

- students to help them understand the changes that are forthcoming;
- families about their concerns, desires, and updates on student needs, as well as to understand what the students are communicating to their families about the change, and;
- instructional team members to assure that everyone is connected and collaborating as planning moves forward.

Presuming competence is foundational for all planning. Move forward by presuming that students understand that things are changing...again...and that it will mean changes in how school looks for all students, not just them. This is particularly important for students who have receptive and expressive communication challenges and students who depend on routines for support.

Include family and student input

Ask families what they learned about how to support their child's learning during distance learning. In areas of the country that returned to in-person instruction last spring, some parents have shared that no one from their school team reached out to them to ask what worked best for their child even though the parent had the most direct knowledge about how the student learned during this period.

Similar to the importance of parent/family voice in navigating and individualizing distance learning, including student voice will be critical for smoothly transitioning back to school. Incorporate students in making meaningful choices about what their day will look like. Depending on the individual student's needs, there will also be specific questions and concerns to problem-solve:

- How well does the school-wide transition plan work for individual students?
- Where does the plan need to be further individualized?
- What was learned during distance learning that helps to support the transition back to school?
- What can be learned from transitioning back to school after previous summer and winter breaks that can help guide this transition?

Also, consider that everything learned during this transition provides insights for possible future changes in how education is provided.

Use multiple communication strategies

Provide information to students about the changes through multiple means of representation. For example, teachers can provide pre-teaching with visuals and text that can be read to, and viewed, by students. During this time of transition, re-engage with previously used visuals to talk about taking a bus again, school schedules, new teachers, a different locker, their peers, and activities. Add new visuals and teach about following safe procedures at school, such as washing hands, social distancing, changes to schedules, etc.

Provide students with the opportunity and appropriate support to express their questions and concerns. Add new vocabulary for emotions that may need to be expressed right now (for example, excited, worried, happy, nervous) and for actions (for example, social distancing, washing hands, wearing a mask). These changes can be made in both low-tech or high-tech AAC devices to help students express themselves. Assist them to work through any excitement or anxiety that emerges. Remember, behavior is communication. Some students might express their feelings about change through new or expanded behaviors. Collaborate with the families to support the children to use socially acceptable ways to express themselves.

DATA, DATA, DATA

A series of reflective questions "What? So What? Now What?" provides a way for framing the available data and using them to guide transition planning and decision making.

What?

What are the facts? What do we know about student learning?

Data from before distance learning commenced: What are the data that you have about individual students' academics, behavior/social-emotional skills, communication skills, and essential skills from before distance learning started? Review each student's progress notes, progress monitoring data, and, if available, work samples from the past two years. Use them to create a picture of student gains and the rate of change during that period. This provides some background information for forward planning.

Data during distance learning: We know that data collection was challenging for many teachers and families, that the data will have gaps, and that they will be less systemized than they were previously. However, use what you have to make your best-informed understanding of what each student learned during distance learning. Be sure to capture information from the families about the skills that each student learned and/or generalized across environments during this period. Possible sources of data during distance learning include:

- student work samples;
- online apps and platforms (such as IXL math completed, audiobooks or reading platforms, educational games, BrainPop or BitsBoard Pro activities);
- family data logs and updates;
- data teachers collect during contacts with a student, and;
- students telling you what worked and did not work last school year.

Continued on page 15...

Why is it important to seek an evaluation and formal diagnosis of autism in Down syndrome?

When my son Nick was in elementary school, I started avoiding functions sponsored by our local Down syndrome group. Nick would sit off to the side, tapping a toy or random object while his peers interacted in group play. His verbal communication difficulties and self-stimulatory (known as stimming) behaviors were prominent. There were other behaviors like eloping, incontinence, aggression and meltdowns that were becoming serious. We felt very alone and isolated during that time.

We decided to seek an evaluation for autism, because our gut feeling was this was more than Down syndrome. Getting the secondary diagnosis of Down Syndrome-Autism Spectrum Disorder (DS-ASD) helped us to better understand our son and get more support to guide him. Nick is now 28 years old and I have a better understanding of how to navigate this journey both as a parent and DS-ASD consultant.

So, why is it important to seek an evaluation and formal diagnosis of autism in Down syndrome? Here are seven reasons why the secondary diagnosis is important:

- It helps families, the IEP team, and others understand how to better support the child.
- It provides access to services, strategies, and therapies aimed at the complex challenges associated with DS-ASD.
- It opens a gateway to map out the needs. Three main areas of focus are behavior management, communication and sensory needs.
- It allows the family to qualify for federal and state funding. Many states offer waiver that provide in-home family support.
- It assists education and health providers in understanding what issues to consider when doing evaluations, and treatment plans, along with educational strategies, supports, and goals.
- It steers families to support groups that understand the additional complexities associated with the secondary diagnosis. Many families express the feeling of isolation and not fitting into Down syndrome or autism support groups. Nationally recognized groups like the Down Syndrome-Autism Connection offer expertise, resources and a safe space for DS-ASD families to freely share (www.ds-asd-connection.org).
- It validates and legitimizes a family's concerns about their child's development and explanation for the challenging behaviors, language deficits, and sensory needs.

The secondary formal diagnosis of autism enabled our family to access professionals to address the autism piece. First, the Board-Certified Behavior Analyst (BCBA) observed and recorded data, and then the IEP team came together to create a behavior support plan (BSP).

The second piece of mapping a plan was addressing communication. If a child is non-verbal, they will often get frustrated and act out through their behaviors. Many undesired behaviors are an attempt to express an unmet need or struggle. A speech evaluation can determine an appropriate mode of communication such as a Picture Exchange Communication System (knowns as PECS) or a higher tech speech generating device. This gives the child a voice to express their feelings, wants and needs. Once the behavior and communication needs are assessed, accommodations can be put into place. Some examples are visual schedules, social stories, timers, and token boards.

The third piece was getting an occupational therapist on board to assess and implement a sensory diet and breaks when my son felt over- or under-stimulated.

Implementing strategies and interventions in these three areas made a positive impact both at school, home and in the community for Nick. In addition, we applied for the state Medicaid waiver which provides funds for in-home family support including respite care and behavior management. Having outside help with respite care relieves the burden of stress on the family and enables parents to continue to enjoy personal interests and get a break from caregiving.

The latest research indicates that 16-18% of individuals with Down syndrome have a secondary diagnosis of autism. If you think your child is showing symptoms of autism, discuss these concerns with your pediatrician or primary care physician. It's important to screen for medical issues first. Once medical reasons are ruled out, the physician can submit a referral for a formal evaluation. An autism evaluation and diagnosis can be made by a professional specializing in autism, a developmental pediatrician, neurologist, psychologist and/or psychiatrist.

Getting a formal evaluation for a dual diagnosis of DS-ASD was a gamechanger. The interventions and strategies we implemented helped Nick reach many goals that we couldn't have accomplished alone. It also led us to connect with families on this same journey so we no longer felt alone.

Teresa Unnerstall, DS-ASD Consultant
Teresa Unnerstall is a DS-ASD consultant, speaker, blogger at www.nickspecialneeds.com and author of A New Course: A Mother's Journey Navigating Down Syndrome and Autism.

Melissa Silverman

Melissa nació el 25 de junio de 1982 y estaba encantada de celebrar su cumpleaños número 40 durante la 50ª Convención Anual de la NDSC en Nueva Orleans. Nacida y criada en Maryland, Melissa y su familia han estado involucrados con NDSC desde que ella nació, asistiendo a su primera convención de NDSC cuando Melissa tenía solo cuatro meses. Cuando Melissa cumplió 15 años, estaba emocionada de participar en su primera conferencia de Jóvenes y Adultos y desde entonces no se ha perdido una sola convención o su oportunidad de participar en el Show de Talentos. Su increíble participación en nuestra comunidad la llevó a ser elegida miembro de la Junta Directiva de NDSC en 2006. Más tarde, Melissa se convirtió en miembro del Consejo de Autodefensores (SAC por sus siglas en inglés) y le encanta abogar por sí misma y por sus compañeros autogestores.

Melissa no solo está muy involucrada con NDSC, sino que también mantiene una carrera en el cuidado de niños. En 2001, Melissa se graduó de la escuela secundaria como la primera persona con síndrome de Down en obtener un diploma académico en el condado de Baltimore. Melissa luego comenzó el programa 'Single Step' en el Community College of Baltimore County y obtuvo su certificado de cuidado infantil de 90 horas. Desde 2005, Melissa ha estado trabajando en el cuidado de niños como asistente de maestra. Comenzó como asistente en un preescolar durante cuatro años, y luego pasó a trabajar en una escuela primaria pública en sus programas para antes y después de la escuela.

Cuando Melissa no está trabajando, vive y disfruta de su vida, practica sus actividades favoritas y pasa tiempo con sus amigos, algunos de los cuales conoce desde que nació. Algunas de sus formas favoritas de pasar el tiempo son hablar en público, ir a conciertos de música country, ver musicales de Broadway, practicar magia profesional y, lo más importante, cocinar. A Melissa le encanta cocinar e incluso ofreció varios talleres de cocina por zoom durante la pandemia. Consulte el libro autoeditado de Melissa "Just a Girl in Love with Cooking", disponible en Amazon, para descubrir los secretos que tiene para compartir en la cocina.

Continued from page 11...

So What?

What does the data tell us?

- What do all of the data convey about what, where, and how student learning occurred during the school year?
- Are there data that convey where skills were gained during the period of distance learning? (In addition to academics, consider the generalization of skills, level of independence, and the use of technology.)
- Are there any data that show a loss of skills during this period?
- What do the data convey about gaps in learning that persist or maybe are now evident?
- How did different ways of teaching impact student learning? What worked? What did not work?
- What questions cannot be answered and need more data once school starts?

Now What?

What are the next steps?

From the array of data, what areas do you feel need to be prioritized:

- before school starts to prepare the student for returning to school?
- during the transition period as new/old routines are re-established?
- moving on after the routines are re-established?

How will you continue to use information gained during distance learning about:

- integrating technology to enhance student learning?
- connecting with parents/families?
- generalizing skills between school and home to improve student learning?

The plans for reopening schools will look different across the states. Teachers will need to take their state and district plans and translate them to supporting individual students. Regardless of the specifics, the key components of relationships, communication, and data will be foundational for all planning.

Ghere, G. (2021). PI #1: Planning for Students Transitioning Back to School - Three Important Components. Minneapolis, MN: University of Minnesota, TIES Center.

Gail Ghere, Ph.D.

Gail is a Research Associate with the TIES Center. She provides technical assistance and develops resources on effective inclusive education systems, Multi-tiered Systems of Support (MTSS) that are inclusive of students with significant cognitive disabilities and application of research-based practices that lead to positive outcomes for students with disabilities.

¿Por qué es importante buscar una evaluación y un diagnóstico formal de autismo en el síndrome de Down?

Cuando mi hijo Nick estaba en la escuela primaria, comencé a evitar las funciones patrocinadas por nuestro grupo local de síndrome de Down. Nick se sentaba a un lado, golpeando un juguete u objeto al azar mientras sus compañeros interactuaban en el juego grupal. Sus dificultades de comunicación verbal y conductas de auto estimulación (conocidas como "stimming") eran prominentes. Había otros comportamientos como fugarse, incontinencia, agresión y crisis nerviosas que se estaban volviendo serios. Nos sentimos muy solos y aislados durante ese tiempo.

Decidimos buscar una evaluación para el autismo, porque nuestra intuición era que esto era más que el síndrome de Down. Obtener el diagnóstico secundario de Síndrome de Down-Trastorno del Espectro Autista (SD-TEA) nos ayudó a comprender mejor a nuestro hijo y obtener más apoyo para guiarlo. Nick ahora tiene 28 años y tengo una mejor comprensión de cómo navegar este viaje como madre y como consultora de SD-TEA.

Entonces, ¿por qué es importante buscar una evaluación y un diagnóstico formal de autismo en el síndrome de Down? Aquí hay siete razones por las que el diagnóstico secundario es importante:

- Ayuda a las familias, al equipo del PEI y a otros a comprender cómo apoyar mejor al niño.
- Proporciona acceso a servicios, estrategias y terapias dirigidas a los complejos desafíos asociados con SD-TEA.
- Abre una puerta para mapear las necesidades. Tres áreas principales de enfoque son el manejo del comportamiento, la comunicación y las necesidades sensoriales.
- Permite que la familia califique para fondos federales y estatales. Muchos estados ofrecen exenciones que brindan apoyo familiar en el hogar.
- Ayuda a los proveedores de educación y salud a comprender qué problemas considerar al realizar evaluaciones y planes de tratamiento, junto con estrategias educativas, apoyos y objetivos.
- Dirige a las familias a grupos de apoyo que entienden las complejidades adicionales asociadas con el diagnóstico secundario. Muchas familias expresan la sensación de aislamiento y de no encajar en los grupos de apoyo para el síndrome de Down o el autismo. Grupos reconocidos a nivel nacional como Down Syndrome-Autism Connection ofrecen experiencia, recursos y un espacio seguro para que las familias DS-ASD compartan libremente (www.ds-asd-connection.org).
- Valida y legitima las preocupaciones de una familia sobre el desarrollo de su hijo y la explicación de los comportamientos desafiantes, las deficiencias del lenguaje y las necesidades sensoriales.
- El diagnóstico formal secundario de autismo permitió a nuestra familia acceder a profesionales para abordar la pieza de autismo. Primero, el analista de comportamiento certificado por la junta (BCBA por sus siglas en inglés) observó y registró los datos, y luego el equipo del PEI se reunió para crear un plan de apoyo del comportamiento (BSP por sus siglas en inglés).

La segunda parte del mapeo de un plan fue abordar la comunicación. Si un niño no es verbal, a menudo se frustrará y actuará a través de sus comportamientos. Muchos comportamientos no deseados son un intento de expresar una necesidad o lucha no satisfecha. Una evaluación del habla puede determinar un modo de comunicación apropiado, como un sistema de comunicación de intercambio de imágenes (conocido como PECS por sus siglas en inglés) o un dispositivo de generación de voz de alta tecnología. Esto le da al niño una voz para expresar sus sentimientos, deseos y necesidades. Una vez que se evalúan las necesidades de comportamiento y comunicación, se pueden realizar adaptaciones. Algunos ejemplos son los horarios

visuales, las historias sociales, los cronómetros y los tableros de fichas.

La tercera pieza fue contratar a un terapeuta ocupacional para que evaluara e implementara una dieta sensorial y descansos cuando mi hijo se sintiera sobre o poco estimulado.

La implementación de estrategias e intervenciones en estas tres áreas tuvo un impacto positivo en la escuela, el hogar y la comunidad para Nick. Además, solicitamos la exención estatal de Medicaid que proporciona fondos para el apoyo familiar en el hogar, incluido el cuidado de relevo y la gestión del comportamiento. Tener ayuda externa con el cuidado de relevo alivia la carga de estrés de la familia y permite a los padres continuar disfrutando de sus intereses personales y tener un descanso del cuidado.

Las últimas investigaciones indican que entre el 16 y el 18 % de las personas con síndrome de Down tienen un diagnóstico secundario de autismo. Si cree que su hijo muestra síntomas de autismo, discuta estas inquietudes con su pediatra o médico de atención primaria. Es importante evaluar primero los problemas médicos. Una vez que se descartan las razones médicas, el médico puede enviar una referencia para una evaluación formal. La evaluación y el diagnóstico del autismo pueden ser realizados por un profesional especializado en autismo, un pediatra del desarrollo, un neurólogo, un psicólogo y/o un psiquiatra.

Obtener una evaluación formal para un diagnóstico dual de SD-TEA fue un cambio total. Las intervenciones y estrategias que implementamos ayudaron a Nick a alcanzar muchas metas que no podríamos haber logrado solos. También nos llevó a conectarnos con familias en este mismo viaje para que ya no nos sintiéramos solos.

Teresa Unnerstall, Consultora SD-TEA
Teresa Unnerstall es consultora de SD-TEA, oradora, bloguera en www.nickspecialneeds.com y autora de "A New Course: A Mother's Journey Navigating Down Syndrome and Autism".

Planeación para estudiantes en la transición de regreso a la escuela: Tres componentes

¿Volver a la instrucción en persona? ¡Haz una pausa y analiza!

¿Qué ha estado funcionando durante el aprendizaje a distancia? ¿Qué debemos recordar y ampliar ahora que los estudiantes regresan a las escuelas?

Los estudiantes han regresado a la escuela con una variabilidad continua en todo el país. Si bien las escuelas y las familias no tuvieron mucho aviso, si es que hubo alguno, para planificar el aprendizaje a distancia, los grupos de instrucción tienen la oportunidad y la responsabilidad de continuar planificando la transición exitosa de los estudiantes con discapacidades cognitivas significativas de regreso a la escuela o permanecer en línea, si ese es el caso, debido a necesidades médicas. No sabemos exactamente qué forma tomará el aprendizaje a lo largo del año, pero hay pasos que podemos tomar ahora para asegurarnos de que se desarrolle de la mejor manera posible para la mayor cantidad de estudiantes posible.

RELACIONES, RELACIONES, RELACIONES

Las relaciones con los estudiantes antes y durante el aprendizaje a distancia son la base para la transición de los estudiantes de regreso a la escuela después de un receso, un período de aprendizaje a distancia o híbrido. Las relaciones entre estudiantes y maestros, estudiantes y compañeros, y maestros y padres/familias fueron fundamentales para implementar efectivamente el aprendizaje a distancia. Estas relaciones son igualmente importantes para tener conversaciones sobre la transición de regreso a la escuela. Durante el aprendizaje a distancia, la comunicación del equipo mediante el envío de correos electrónicos, la entrega de materiales, la creación de videos cortos y el uso de plataformas en línea con sus estudiantes y familias, les hizo saber que los maestros se preocupaban por ellos, que eran importantes y que sus voces eran escuchadas. Una comunicación como esa debe permanecer consistente y reflexiva ahora.

Mantenerse conectado y continuar con la confianza mutua que se desarrolló apoyará las relaciones y la resolución de problemas para que los estudiantes puedan volver a participar con éxito en clases, reintegrarse con sus amigos, maestros, horarios, rituales y rutinas.

COMUNICACIÓN, COMUNICACIÓN, COMUNICACIÓN

Entre más fuerte fue la red de comunicación durante el aprendizaje a distancia, más fuertes serán las conexiones disponibles para planificar la transición de un estudiante de regreso a la escuela. La web de comunicación incluye comunicarse con:

- estudiantes para ayudarlos a comprender los cambios que se avecinan;
- familias sobre sus inquietudes, deseos y actualizaciones sobre las necesidades de los estudiantes, así como para comprender lo que los estudiantes están comunicando a sus familias sobre el cambio, y;
- miembros del equipo de instrucción para asegurar que todos estén conectados y colaborando a medida que avanza la planificación.

Presumir competencia es fundamental para toda planeación. Avance suponiendo que los estudiantes entienden que las cosas están cambiando... otra vez... y que eso significará cambios en la apariencia de la escuela para todos los estudiantes, no solo para ellos. Esto es particularmente importante para los estudiantes que tienen problemas de comunicación receptiva y expresiva, también para los estudiantes que dependen de las rutinas para recibir apoyo.

Incluya la opinión de la familia y del estudiante

Pregunte a las familias qué aprendieron sobre cómo apoyar el aprendizaje de sus hijos durante el aprendizaje a distancia. En áreas del país que regresaron a la instrucción en persona la primavera pasada, algunos padres han compartido que nadie del equipo de la escuela se acercó a ellos para preguntarles qué funcionó mejor para su hijo, a pesar de que el padre tenía el conocimiento más directo sobre cómo

el estudiante aprendió durante este período.

Similar a la importancia de la voz de los padres/familia en la navegación e individualización del aprendizaje a distancia, incluir la voz de los estudiantes será fundamental para una transición sin problemas de regreso a la escuela. Incluya a los estudiantes para que tomen decisiones significativas sobre cómo será su día. Dependiendo de las necesidades individuales del estudiante, también habrá preguntas e inquietudes específicas para resolver problemas:

- ¿Qué tan bien funciona el plan de transición de toda la escuela para estudiantes individuales?
- ¿Dónde debe individualizarse aún más el plan?
- ¿Qué se aprendió durante el aprendizaje a distancia que ayuda a apoyar la transición de regreso a la escuela?
- ¿Qué se puede aprender de la transición de regreso a la escuela después de las vacaciones de verano e invierno anteriores que puede ayudar a guiar esta transición?

Además, considere que todo lo aprendido durante esta transición brinda información para posibles cambios futuros en la forma en que se brinda la educación.

Use múltiples estrategias de comunicación

Proporcione información a los estudiantes sobre los cambios a través de múltiples medios de representación. Por ejemplo, los maestros pueden proporcionar enseñanza previa con imágenes y texto que los estudiantes pueden leer y ver. Durante este tiempo de transición, vuelva a interactuar con las imágenes utilizadas anteriormente para hablar sobre tomar un autobús nuevamente, los horarios escolares, los nuevos maestros, un casillero diferente, sus compañeros y actividades. Agregue nuevas imágenes y enseñe cómo seguir procedimientos seguros en la escuela, como lavarse las manos, distanciamiento social, cambios de horarios, etc.

Proporcione a los estudiantes la oportunidad y el apoyo adecuado para expresar sus preguntas e inquietudes. Agregue nuevo vocabulario para las emociones que pueden necesitar expresarse en este momento (por ejemplo, emocionado, preocupado, feliz, nervioso) y para acciones (por ejemplo, distanciamiento social, lavarse las manos, usar una mascarilla). Estos cambios se pueden realizar en dispositivos de Comunicación Aumentativa y Alternativa (CAA) de baja o alta tecnología para ayudar a los estudiantes a expresarse. Ayúdelos a superar cualquier emoción o ansiedad que surja. Recuerde, el comportamiento es comunicación. Algunos estudiantes pueden expresar sus sentimientos sobre el cambio a través de comportamientos nuevos o ampliados. Colaborar con las familias para ayudar a los niños a usar formas socialmente aceptables de expresarse.

DATOS, DATOS, DATOS

Una serie de preguntas reflexivas "¿Qué? ¿Para qué? ¿Ahora qué?" proporcionan una manera de enmarcar los datos disponibles y usarlos para guiar la planificación de la transición y la toma de decisiones.

¿Qué?

¿Cuáles son las circunstancias? ¿Qué sabemos sobre el aprendizaje de los estudiantes?

Datos de antes de que comenzara el aprendizaje a distancia: ¿Cuáles son los datos que tiene sobre las habilidades académicas, conductuales/socioemocionales, habilidades de comunicación y habilidades

Continúa en la página 21...

DOWN SYNDROME WORLD™
GLOBAL DOWN SYNDROME FOUNDATION

BECOME A GLOBAL MEMBER

You can help GLOBAL Lengthen & Improve Lives!

JOIN TODAY!
Stop By our Table at the Exhibit Hall or visit: DownSyndromeWorld.org

DID YOU KNOW THAT...

- The National Institutes for Health Down syndrome research budget has quadrupled in the last 4 years thanks to GLOBAL advocacy?
- GLOBAL published the first ever Medical Care Guideline for Adults with Down Syndrome and is now adding topics?
- Over 2,000 patients from 33 states and 10 countries have been served at the the Sie Center for Down Syndrome at Children's Hospital Colorado?
- Clinical trials are underway for drugs to treat alopecia, psoriatic arthritis, Alzheimer's disease, and more?

Make Change Happen by Becoming a GLOBAL Member Today!

BENEFITS INCLUDE:

- Quarterly issues of the award-winning Down Syndrome World™ magazine
- Digital access to all current and past issues of Down Syndrome World™
- "I ♥ Someone with Down Syndrome" bumper sticker
- Support GLOBAL's life-changing research and medical care

Members gain FREE access to our popular quarterly educational webinars, both current and archived!

RECENT WEBINARS INCLUDE:

- Eye Research & Eye Care for Individuals with Down Syndrome Across the Lifespan
- Executive Function Skills in Everyday Life: From Research to Intervention
- Alzheimer's Disease in Down Syndrome: Understanding the Connection

Memberships are also available for Down syndrome organizations!

Children's Hospital New Orleans
LCMC Health

Ochsner®
Hospital For Children

DS GNO
Down Syndrome Association of Greater New Orleans

PREMIUM DIAPERS, TRAINING PANTS & YOUTH PANTS

www.mycomfees.com

Viene de la página 19...

esenciales de los estudiantes individuales antes de que comenzara el aprendizaje a distancia? Revise las notas de progreso de cada estudiante, los datos de seguimiento del progreso y, si están disponibles, las muestras de trabajo de los últimos dos años. Úselos para crear una imagen de los logros de los estudiantes y la tasa de cambio durante ese período. Esto proporciona información básica para la planificación anticipada.

Datos durante el aprendizaje a distancia: sabemos que la recopilación de datos fue un desafío para muchos maestros y familias, que los datos tendrán diferencias o brechas, y que estarán menos sistematizados que antes. Sin embargo, use lo que tiene para comprender mejor lo que cada estudiante aprendió durante el aprendizaje a distancia. Asegúrese de capturar información de las familias sobre las habilidades que cada estudiante aprendió y/o generalizó en todos los entornos durante este período. Las posibles fuentes de datos durante el aprendizaje a distancia incluyen:

- muestras de trabajo de los estudiantes;
- aplicaciones y plataformas en línea (como matemáticas IXL completadas, audiolibros o plataformas de lectura, juegos educativos, actividades BrainPop o BitsBoard Pro);
- registros y actualizaciones de datos familiares;
- datos que los maestros recopilan durante los contactos con el estudiante, y;
- estudiantes diciéndole lo que funcionó y lo que no funcionó el año escolar pasado.

¿Para qué?

¿Qué nos dicen los datos?

- ¿Qué transmiten todos los datos sobre qué, dónde y cómo ocurrió el aprendizaje de los estudiantes durante el año escolar?
- ¿Hay datos que transmitan dónde se adquirieron las habilidades durante el período de aprendizaje a distancia? (Además de lo académico, considere la generalización de habilidades, el nivel de independencia y el uso de la tecnología).
- ¿Hay datos que muestren una pérdida de habilidades durante este período?
- ¿Qué transmiten los datos sobre las brechas en el aprendizaje que persisten o que tal vez ahora son evidentes?
- ¿Cómo impactaron las diferentes formas de enseñar en el aprendizaje de los estudiantes? ¿Qué funcionó? ¿Que no funcionó?
- ¿Qué preguntas no se pueden responder y necesitan más datos una vez que comience la escuela?

¿Ahora qué?

¿Cuáles son los siguientes pasos?

De la matriz de datos, ¿qué áreas cree que deben priorizarse?

- ¿antes de que comience la escuela para preparar al estudiante para regresar a la escuela?
- ¿durante el período de transición a medida que se restablecen rutinas nuevas/antiguas?
- ¿seguir adelante después de que se restablecen las rutinas?

¿Cómo continuará utilizando la información obtenida durante el aprendizaje a distancia acerca de:

- la integración de la tecnología para mejorar el aprendizaje de los estudiantes
- La conexión con los padres/familias
- La generalización de habilidades entre la escuela y el hogar para mejorar el aprendizaje de los estudiantes

Los planes para reabrir las escuelas serán diferentes en los estados. Los maestros deberán tomar sus planes estatales y distritales y traducirlos para apoyar a estudiantes individuales. Independientemente de los detalles, los componentes clave de las relaciones, la comunicación y los datos serán fundamentales para toda la planificación.

Ghere, G. (2021). PI #1: Planificación para estudiantes que hacen la transición de regreso a la escuela: Tres componentes importantes. Minneapolis, MN: Universidad de Minnesota, Centro TIES.

Gail Ghere, Ph.D.

Gail es investigadora asociada del Centro TIES. Brinda asistencia técnica y desarrolla recursos sobre sistemas educativos inclusivos efectivos, Sistemas de Apoyo de Múltiples Niveles (MTSS, por sus siglas en inglés) que incluyen a estudiantes con discapacidades cognitivas significativas y la aplicación de prácticas basadas en investigaciones que conducen a resultados positivos.for students with disabilities.

Carta de la NUEVA Presidenta

Hola,

Mi nombre es Kate Dougherty, la presidenta de National Down Syndrome Congress. Quiero agradecer a todos los miembros del comité anfitrión, patrocinadores, proveedores, expositores, voluntarios, presentadores y, sobre todo, auto-defensores y familias que asistieron a la 50ª Convención Anual de la NDSC en Nueva Orleans. La convención es la mejor época del año para mí y mi familia, ya que es la única vez que sentimos que el mundo es como debe ser. Ya esperamos con ansias la 51° en Orlando, Florida, en el JW Marriott/Ritz Carlton Orlando Grand Lakes, del 20 al 23 de julio de 2023. Mientras tanto, estoy agradecida de que el NDSC organice eventos durante todo el año por todo el país. Personalmente, no veo la hora de asistir al Big Game Ball el 1 de septiembre en Atlanta. Espero verlos allí.

Ser elegida presidente en Nueva Orleans es un privilegio y un honor. Nunca imaginé esta posibilidad hace 14 años, en 2008, cuando mi esposo y yo estábamos sentados en una UCIN con nuestro hermoso bebé en brazos y nuestra familia se unió a las filas de los "pocos afortunados". Con el nacimiento de Elliot tuvimos suerte, ¡no una sino dos veces! Tuvimos suerte la primera vez porque cuando hicimos la pregunta, "¿Qué es el síndrome de Down?" la respuesta de nuestro médico fue esta: "El síndrome de Down es simplemente un cromosoma extra. Cualquier cosa que usted o yo podamos o no tener una persona con síndrome de Down puede o no tenerla. Simplemente sabemos que son más propensos a diferentes condiciones médicas que otras personas. Así que esto es lo que vamos a hacer: vamos a arreglar ese agujero en su corazón. Luego, te llevarás a casa a tu hermoso bebé y lo amarás incondicionalmente. Si no puedes hacer eso, entonces yo lo haré".

Después de conocer literalmente a miles de familias, sabemos que no todos tienen la suerte de tener un diagnóstico de parto tan progresivo y positivo, algo en lo que NDSC, junto con el Dr. Kishore Vellody, entre otros, están trabajando incansablemente para cambiar. Si bien esta es una explicación demasiado simplista de ese cromosoma adicional y el impacto que puede tener o no, la entrega de nuestro médico del diagnóstico de Elliot y la respuesta positiva fue de vital importancia en esos primeros momentos.

Luego tuvimos suerte por segunda vez porque, cuando nuestra enfermera de la UCIN comenzó a imprimir información de la web (Siri no existía), y mientras examinamos una gran cantidad de información errónea obsoleta, encontramos un artículo que presentaba al auto-defensor Austin Davenport, quien trabajaba, vivía de forma independiente y recientemente se había comprometido con su futura esposa, Christie Hockel.

Fue a través de Austin que supimos que lo que todo lo que soñábamos de corazón para nuestro hijo era posible. También fue a través de Austin y Christie que encontramos al National Down Syndrome Congress. En un área rural, los recursos y servicios se ven diferentes. Durante casi tres años, antes de asistir a nuestra primera convención en San Antonio, Texas, en 2011, usamos el sitio web y la línea telefónica del NDSC para asegurarnos de que le brindábamos a nuestro hijo los mejores y más recientes servicios médicos, comportamentales, terapéuticos, e intervenciones educativas. Me quedaba despierta hasta altas horas de la noche leyendo las historias que los auto-defensores compartían en la oficina de NDSC. Mi conocimiento sobre lo que era potencialmente posible para alguien que vivía con un cromosoma adicional aumentó gracias a esto.

Cuando Elliot tenía seis meses de edad me enfrenté a una situación de falta de conocimiento, y gracias a la NDSC supe manejar, cuando un miembro de nuestra comunidad rural me preguntó (mientras sostenía a mi hermoso bebé en mis brazos) si pensaba que Elliot sería capaz de vivir en un hogar grupal o si tuviera que institucionalizarlo, mi respuesta fue: "¡Estaba pensando en la universidad!" La universidad fue y sigue siendo uno de los objetivos de la familia Dougherty para Elliot. Él te dirá con orgullo que planea ir a la universidad y jugar al fútbol (bueno, su mamá no está segura de esa última parte).

Esta es solo una de las muchas razones por las que estoy muy emocionada con el Big Game Ball de NDSC, el 1 de septiembre de 2022, en el Salón de la Fama del Fútbol Americano Universitario en Atlanta. Los homenajeados de Big Game Ball ejemplifican

las prioridades del NDSC para:

- aumentar el acceso a oportunidades postsecundarias inclusivas para estudiantes con síndrome de Down y otras discapacidades intelectuales,
- desarrollar programas postsecundarios inclusivos de alta calidad,
- proporcionar estándares de acreditación de programas modelo para programas de educación postsecundaria, y
- abogar por educadores que continuarán forjando el camino de la educación inclusiva en todos los niveles.

Todo esto conduce a un empleo significativo, una vida independiente y una mejor calidad de vida para las personas con síndrome de Down.

Personalmente, me gustaría invitarlos a acompañarme el 1 de septiembre en el Big Game Ball. Si no puede asistir, envíe un mensaje de texto a NDSC al 269-89 para donar y votar por el equipo de su elección mientras muestra su amor por las posibilidades que estos programas postsecundarios y otros programas similares brindan a nuestros autogestores.

Como presidenta del NDSC, estoy encantada de servir a nuestros increíbles auto-defensores, familias, amigos, comunidades y organizaciones que aman a aquellos que lucen ese cromosoma adicional. He prometido a la Junta visitar grupos y organizaciones que están trabajando para mejorar el acceso y la calidad de vida de las personas con síndrome de Down. Si está interesado en que visite su grupo u organización, o si tiene ideas, inquietudes o preguntas, puede llamarme o enviarme un mensaje de texto personalmente al 217-617-3568 o enviarme un correo electrónico a info@upatdowncountry.com.
Les agradezco el amor y la fe en todos nuestros autogestores. Todos somos más parecidos que diferentes.

Kate Dougherty,
President, NDSC

Down Syndrome News

ISSN0161-0716
Publisher: National Down Syndrome Congress

Executive Director: Jordan Kough

Editor: Emily Artner

General Correspondence and Memberships:
National Down Syndrome Congress
30 Mansell Court, Suite 108 Roswell, GA 30076

phone: 800.233.NDSC | 770.604.9500
fax: 770.604.9898
email: info@ndsccenter.org

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

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

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

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

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, the 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.