

Down Syndrome News

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SECOND QUARTER 2020

NEWSLETTER OF THE



NATIONAL
DOWN SYNDROME
CONGRESS

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The Benefits of Busy

I have the privilege of talking at conferences and consultations across the country about problem behavior, a major concern for parents and professionals alike. Problem behaviors can be tiresome, but they are often part of our lives, whether we have a child or student with Down syndrome or not.

Stacy Taylor, MA, BCBA, Owner, Advance Behavior & Learning, daughter with DS, Maitland, FL

When I talk about behavior, I often discuss the importance of identifying the "function" of behavior which describes why a behavior may occur. Understanding why a behavior occurs helps better understand how to arrange the environment to prevent it and to help reduce it in the future. Behaviors may occur for; attention, escape, to get something you want or for sensory reasons.

No matter why a behavior occurs, I am here to tell you that there is hope! Things can improve and the answer may lie, in part, with being (and staying) busy. We know the positive impact that learning has on problem behaviors, but so often we focus on how to stop bad things from happening, instead of focusing on how to get good stuff happening.

Being busy can be distracting and if I am busy, then I may simply have less time to engage in problem behaviors. There is nothing wrong with a little distraction. It is important though that we are prepared with a variety of alternative activities to help

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Letter From the President

Dear Families,

Let me start by saying I hope that you are all doing well. Who would have ever thought that in late May I would be writing this letter to our members, but not making plans to see you in New Orleans in June? I am still saddened that we had to make the decision to cancel the 48th Annual NDSC Convention, and although it was heartbreaking for so many, I know that it was the right thing to do. I know that the past few weeks have been trying for many, in so many different ways. We have all worried about our health and the health of our loved ones, about finances, and about what the future will look like. One thing that did not burden our thoughts, though, was whether the NDSC would remain dedicated to an improved world for individuals with Down syndrome and if it would be here to support our families. In fact, it has been quite the contrary. During this time of uncertainty, my fellow Board members and the staff have truly made lemonade from lemons.

Although the staff has been working from their homes, they have still been manning the telephones, answering our questions, and advocating in Washington, D.C., for the rights of those with disabilities. They have gone above and beyond to provide webinars and other resources on everything from preparing your family and home for online learning, services to students with disabilities during coronavirus related school closures, and how families can advocate for their loved one with Down syndrome if they are hospitalized. As well, members of our Board of Directors and staff played key roles in a collaborative Q&A on COVID-19 and Down Syndrome that was published in both extended and abbreviated versions in both English and Spanish. And yes, they planned and are executing an NDSC

Convention like no other.

We hope that you, like thousands of others, have been "on the couch" for the NDSC virtual convention. Nothing will ever replace being together in person, but we are proud to have reached out farther and provided an opportunity for more people to attend our Convention via the first-ever Convention From Your Couch than ever before!

As a final note, thank you for allowing me the honor of serving as your Board President for the past three years. It has been a tremendous privilege and nothing short of an amazing experience. It has been a great joy to meet so many families and to share my family with so many of you. I appreciate the support and encouragement that I have received over the past three years, but my term as President will officially come to an end at the general membership meeting on June 27. I am grateful that I will still serve on the Board in the role of Immediate Past President, so please continue to reach out.

I look forward to seeing you all in Phoenix in 2021; until then, stay safe and stay well.

Gratefully,



The NDSC Convention Isn't the Only Thing Going Digital This Year

The *Down Syndrome News* is also going digital. You may remember that last January the Board of Directors made the decision to eliminate NDSC membership fees. One benefit of each paid membership was receiving the *Down Syndrome News* in your mailbox. With the elimination of member fees, we also eliminated the delivery of hardcopy publications. Instead, members will receive the *Down Syndrome News* in their inboxes. Members who paid fees in 2019 will still receive the hardcopy publication for the duration of their current membership, but by January of 2021, all issues of *Down Syndrome News* will be delivered to your inbox.

If you would like to continue to receive a hard copy of the *Down Syndrome News* delivered to your home or business, you may purchase a \$25 subscription. To purchase your subscription please visit our website at ndscenter.org – click the News & Events tab – then click Down Syndrome News in the dropdown. Scroll to the bottom of the Down Syndrome News page to complete the Subscription Request Form.



The Benefits of Busy (continued from page 1)

block and redirect behavior. This is tricky as it takes planning. I have met with so many well-meaning, intelligent people (parents and professionals) that just don't plan effectively. Ask yourself what this person needs to be successful today, tomorrow, and in the future and begin to set them up for success right now. While learning and maturation occurs, it is up to us to be thoughtful and help plan their success. If a student is an early finisher then a teacher can be prepared with activities to do next so that student does not get "bored" in class and begin to misbehave. If a child is going to a doctor's appointment, parents can be prepared with options if the child needs them. Planning ahead to help keep your loved one with DS busy is essential.

I recall doing a conference recently and a parent brought their teenager who happened to have DS with them (which I always welcome although I know it can be difficult for families to pay attention whilst parenting!). What made the situation more difficult was that the mother brought nothing for this teenager to do during the full day, 6-hour conference. Nothing. I do not know a neurotypical teenage child that would sit through a conference, even one that they were interested in (and I know I am not that interesting, LOL!). As you may expect, this young woman became disruptive early into the conference and the mother became more and more frustrated as the conference continued. She approached me on break and asked what to do when her daughter behaves like this and I asked her the simple question of "what do you expect her to do instead right now?". This was a light bulb moment for this parent. She realized that she literally had given her child the choice to do nothing and set an unreasonable expectation which was creating the problem behaviors. We discussed some sensory items she could have, a cute purse she could carry them in and how to teach her to wear headphones so she could even listen to music in situations like these. As a single mom she had no choice but to bring her everywhere and she loved to be with her...wouldn't have it any other way, but her child wasn't feeling the same joy all the time. I get it (and her mom was cool so it wasn't that!). She just did not know how to be engaged in the same way or perhaps for the same time as the other attendees. Teaching her daughter how to be busy in this situation and in others could help block most, if not all, of these problem behaviors. It would just take some planning and some teaching.

Not only does being busy serve as a great distracter, it is also a great repertoire builder. Problem behaviors are always a problem of weak repertoires. If you can teach skills from a variety of areas (leisure, communication, social, independence, etc.) problem behaviors become irrelevant. For some individuals this may mean taking the time to teach specific leisure skills to help them get busy. For others it may mean teaching them organization and planning skills to help them stay busy.

There are great benefits to being busy and focusing on learning to help prevent and reduce problem behaviors. Just remember to keep teaching and have fun!!

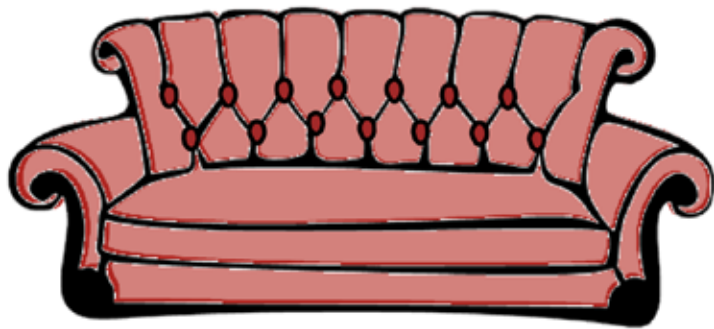


Here are some tips to help get you started:

- Teach those who value attention how to get it appropriately. This may be by calling a name, tapping an arm, or raising a hand.
- Teach those who may need help along the way how to ask for it using words, signs, pictures, or technology.
- Activity schedules can provide a visual sequence of what to do next or what options are available to help keep busy.
- Learning to do chores at home or help around the classroom is a great way to stay busy and it also helps others.
- When teaching play and leisure skills, make sure your child learns a variety of play types.
- Use visual and auditory cues to help teach. A picture may be used to help encourage different block designs or how to draw. A timer can be used to help increase the length of time an activity occurs.
- Teach independent activities too as being busy cannot always involve others as you may be busy yourself!
- Include quiet, calm activities to ensure that there is not a fatigue-factor and potential problem behaviors that may result from being tired.
- Restrict or rotate access to activities (depending on your child's age) to help make them more interesting and fun.

C • O • N • V • E • N • T • I • O • N

FROM YOUR COUCH



S2020: E1: The One Where We All Practiced Social Distancing

NATIONAL DOWN SYNDROME CONGRESS



NDSC Advocacy Training Boot Camp From Your Couch!

Saturday, June 27 • 1:00 PM–3:00 PM ET

We will begin the final day of our virtual event with the NDSC Advocacy Training Boot Camp. This intensive session is aimed at beginner advocates and is a great opportunity to get the advocacy training you have been wanting but didn't have time to squeeze in during the NDSC Convention. This year you can attend from the comfort of your own home, and the virtual NDSC Advocacy Training Boot Camp is free with your NDSC Convention From Your Couch registration. This session features information from effective self-advocates, parent advocates, and the expert NDSC Policy Team. Learn what advocacy is, basics of the legislative process, how to engage and build relationships with elected officials, how to utilize social media in your advocacy efforts and other important resources and tips. Advocacy Training Boot Camp is designed to be an Advocacy 101 mini-course with a focus on legislative advocacy, but even the most experienced advocate will walk away with something new and re-energized after joining the open discussion on how to effectively engage with legislators.

Awards Ceremony

Saturday, June 27 • 4:00 PM–5:00 PM ET

Join us as we recognize and celebrate organizations and individuals who have made extraordinary contributions to research, advocacy, and awareness of the Down syndrome community.

Saturday, June 27 Schedule

All times are Eastern

1:00–3:00 PM	Advocacy Bootcamp
3:00–4:00 PM	Break
4:00–5:00 PM	Awards Ceremony
5:00–6:00 PM	Break
6:00–6:30 PM	General Membership Meeting
6:30–7:00 PM	Break
7:00–8:30 PM	Plenary with keynote speaker Zach Gottsagen and interview with <i>The Peanut Butter Falcon</i> producers and director
8:30–9:00 PM	Break
9:00–10:00 PM	321 Zoom Dance Party

General Membership Meeting

Saturday, June 27 • 6:00 PM–6:30 PM ET

All NDSC Members are invited to attend the 2020 General Membership Meeting to be held at 6:00 PM ET on June 27. This is an opportunity for members to hear updates from:

- NDSC Treasurer and NDSC Foundation Trustees will update members on the financial standings of the organization
- NDSC Executive Director David Tolleson will provide an overview of organization activities
- The Nominating Committee will present the slate of nominees for election to the Board of Directors
- New Board member elections
- Other business will be conducted as warranted



Plenary with Zach Gottsagen

**Saturday, June 27
7:00 PM–8:30 PM ET**

Zach Gottsagen and the producers and director of *The Peanut Butter Falcon*.



Meredith Martin

Small Town Girl With Big Ambition

Meredith Martin has lived her entire life with her parents Jerry and Janet in Neligh, Nebraska, a town so small it does not even have a stoplight. Although she comes from a small town, her mother knew at a young age that Meredith was destined to do big things, and she is living up to those expectations every day.

Soon after Meredith was born, the news of her diagnosis of Down syndrome reached one of her father's classmates who sent Meredith's parents a copy of the NDSC Newsletter. This turned out to be a useful source of information as resources were not readily available in Neligh and the NDSC became the family's support since they were somewhat distanced from support groups. One of the first resources that she sent Meredith's parents was a copy of an NDSC Newsletter. And so, at the age of two, Meredith's journey with the NDSC began.

The guidance provided early in Meredith's life lead to early intervention in the home.

Meredith attended special education preschool and attended a private preschool. Her elementary and high school years were a combination of special and regular education, where she made many friends. She has a few high school friends that have moved to other communities that she still keeps in touch with.

Meredith works several part-time jobs. She works in the office and medical center at the hospital in Neligh. To fill up the rest of her week, Meredith also works at an assisted living facility and a local grocery store. Meredith enjoys working because it keeps her healthy and active and shows others in her community that people with Down syndrome can be productive citizens who contribute to their communities.

Although Meredith has a busy schedule, she still finds time to stay active by doing Zumba and kickboxing. She also loves to get out and ride her bike or walk. Meredith is also an author. In 2014, her first book, "My ABC Building Blocks for Growing UP with Down Syndrome," was published.

When Meredith turned 15, she began attending Youth & Adult sessions at the NDSC Convention. With the support

of friends, Meredith's confidence grew, and opportunities opened for her. Meredith and her family have attended NDSC Conventions since 1995, and in 2001, Meredith even presented the Welcome at the 2001 convention Opening Plenary. She has served on the NDSC Board of Directors and is now a member of the Self-Advocate Council, where she participates in the SAC Book Project. However, her favorite part of the NDSC is the friends that she has made while attending the NDSC Conventions. She says that the friendships that she has made are amazing. Meredith is part of a group of eight self-advocates that get together each year with for a long weekends throughout the year other than convention and she considers them some of her BEST friends.

Meredith loves her small town. She also loves big adventures and big goals. She is a woman with a busy work life, an active social life, and a life filled with lots of family and friends. Meredith is an inspiration to all who know her and is proof that when you set a goal, and you work toward that goal, anything is possible!



Become an NDSC FRIENDraiser!

If you find value in the information and resources that NDSC provides year-round, please join us for our first-ever peer-to-peer fundraising campaign.

3 ways to become an NDSC FRIENDraiser:

1. Donate by texting the word CONVENTION to 44321
2. Create your personal fundraising page – It's easy -text the word CONVENTION to 44321
3. Email NDSC Development Director, Christine Milano, at Christine@NDSCcenter.org for assistance setting up your page.

When you create a fundraising page of your own you can ask friends and family to help you fundraise. It's easy, it's fun, and the TOP fundraiser will be acknowledged at the Zoom 321 Dance Party on June 27. Your efforts will help NDSC continue to enhance our services and programs, extend our outreach to rural and urban communities, and continue to support the families who need us the most. **Let the FUNdraising and FRIENDraising begin!**

National Down Syndrome Organizations Combine Efforts to Publish Q&A on Covid-19 and Down Syndrome

An Important Resource for Families During Unprecedented and Uncertain Times

The NDSC worked as part of a group of national organizations to publish an important Q&A on COVID-19 and Down syndrome. The consortium consisted of the Down Syndrome Medical Interest Group-USA (DSMIG-USA), Global Down Syndrome Foundation (Global), LuMind IDSC Foundation (LuMind IDSC), National Down Syndrome Congress (NDSC), National Down Syndrome Society (NDSS), and National Task Group on Intellectual Disabilities and Dementia Practices (NTG).

The Q&A on COVID-19 and Down syndrome was reviewed by numerous clinicians, advocacy organizations and family members of individuals with Down syndrome, and includes answers to the following general questions:

- How can I help prevent the spread of the virus?
- What common symptoms should I look for?
- What should I consider when it comes to decisions made by, or on behalf of my loved one with Down syndrome?

One key takeaway from the Q&A addresses the question of people with Down syndrome being considered “high risk.” Based on the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH), people categorized as “high risk” include those with “underlying medical conditions” that people with Down syndrome are more likely to have. Some examples are lung disease and respiratory difficulties (e.g. asthma, sleep apnea), ongoing heart disease or heart failure, obesity, diabetes, or having lower immune function (e.g. people undergoing cancer treatment or taking drugs for rheumatoid arthritis or lupus that lower immune function).

This Q&A is informational only and not intended to provide medical advice or related advice. This Q&A should NOT be considered a substitute for the advice of medical professionals or other professionals. Consult with your doctor or other healthcare professional(s) for medical advice.

To access the resource, in both English and Spanish, and in its abbreviated and extended versions, families, friends, and professionals should visit the NDSC website under the Programs & Resources tab – COVID-19 Resources.



NDSC member, Kim Knight of Marietta, GA, shares “As a parent of a young child with Down syndrome I am wondering if he is higher risk and what that even means. We are glad this resource will give us some advice specific to Down syndrome.”

“I have a child who is forty and I’m not sure how to explain why we aren’t following his routine anymore, what the new routine should be, or if he should see his cousin across town,” said Jacqueline Olimpio from Olney Maryland. “I am grateful for any advice that can help me navigate this difficult time.”



Q&A on COVID-19 and Down Syndrome

Abbreviated Version • Revised April 27, 2020

ORGANIZERS:



SUPPORTING ORGANIZATIONS:

Down Syndrome Affiliates in Action, Exceptional Parenting Magazine, GiGi's Playhouse, International Mosaic Down Syndrome Association, Jerome Lejeune Foundation, Matthew Foundation, T21 Research Society



2021 CONVENTION

**The JW Marriot Phoenix Desert Ridge Resort & Spa
Will be the Home of the NDSC 49th
Annual Convention, July 8-11, 2021**

We are excited to announce that the 2021 NDSC Annual Convention will be held at the beautiful JW Marriott Phoenix Desert Ridge Resort & Spa, in Phoenix, Arizona! Although we are proud to have been able to provide a top-notch virtual conference this year, we miss seeing everyone, learning together, and dancing together, and can't wait to all be together next summer!

The one of a kind "Giant Family Reunion" that we call the NDSC Convention will not be the only priceless experience that you receive in 2021 in Phoenix, Arizona. You may want to plan to extend your stay because the JW Marriot Phoenix Desert Ridge Resort & Spa is the perfect location for a family vacation. The family-friendly resort offers a multitude of amenities for all ages, including five pools, and the best lazy river west of the Mississippi, incredible dining options, an on-site spa, and a championship golf at Wildfire Golf Club.

Outdoor Pools and the Lazy River: The pools and lazy river are a great get-away. It is also a great place to gather with friends for an evening swim when we are not dancing the night away. The resort features five outdoor pools, two jacuzzis, a winding water-slide, and a kids' splash pad, but the feature that we all enjoy the most is the lazy river! Cabana cottages, pool suites, daybeds, and chaise lounge chairs can be reserved so that you are sure to have your spot to relax poolside.

Spa and Fitness: The hotel is equipped with a modern fitness center that offers daily classes, outdoor activities, and the Revive Spa. These amenities are perfect for those who want an early morning workout or who want to relax after a long day of workshops at the convention.

Championship Golf at Wildfire Golf Club: The Wildfire Golf Club is home to two courses on the resort. These world-class courses designed by golf legends Arnold Palmer and Nick Faldo feature all the beauty of Arizona and a challenge for even the most avid golfers. In addition to the two championship courses, the club offers rentals and lessons, as well as a driving range and putting greens.



Promoting Healthy Habits Early to Make a Lasting Impact: Understanding Obesity in Children with Down Syndrome

Angela R. Caldwell and Emily E. Haus

Children with Down syndrome are more likely to become obese than both typically developing peers and peers with other developmental disabilities. In fact, approximately half of all children with Down syndrome between the ages of two and eighteen are considered obese. Because being overweight as a child increases the risk of serious health problems (such as cardiovascular disease, type 2 diabetes, and obstructive sleep apnea syndrome) in adulthood, it is important that clinicians and families partner together to help young children develop healthy habits early in life.

We know that all children need healthy nutrition, plenty of physical activity, and a sufficient amount of sleep to mitigate the risk of obesity during childhood. Recent research suggests that children with Down syndrome demonstrate less nutritious dietary patterns, participate in less vigorous physical activity, and report more sleep problems than peers. While it is unclear when and why these less healthy behavior patterns emerge, there is data to support that children with Down syndrome experience rapid weight gain between the ages of two and six years. In order to prevent this rapid weight gain from occurring, it is crucial that we prioritize building a foundation of healthy habits within the first three years of life.

Low muscle tone most certainly contributes to a child's ability to engage in healthy habits during early childhood. For example, feeding problems due to low tone in the oral cavity may make it more difficult for children to eat and build preferences for healthy foods like fresh fruits and vegetables, as these foods often require mature and sustained chewing patterns. Delays in gross motor development related to low muscle tone may limit a child's ability to participate in vigorous physical activity early in life. A lack of physical activity could affect a child's ability to sleep well, and poor sleep quality may affect physical activity the following day due to low energy levels. Likewise, inadequate nutrition could also impact energy levels and, consequently, physical activity throughout the day. These risk factors are firmly interconnected and unhealthy behavior in any one area could contribute to less healthy patterns in another. While the high risk of obesity among children with Down syndrome is well-documented, prevention efforts have been largely neglected.



Pediatric occupational therapists (OTs) are experts at promoting healthy behaviors by working with families to create routines that provide opportunities for exploration and play within the natural environment. For example, an OT may provide strategies to make mealtimes and exploring novel foods more fun for your child. Similarly, an OT can help you build a calming bedtime routine to make the transition from awake to sleep easier for you and your child. OTs are also known to be creative problem solvers and can help you identify activities to get your child moving more throughout the day that are within your child's physical capacity. If you are interested in learning about innovative solutions to overcome barriers to healthy routines, reach out to a pediatric occupational therapist within your early intervention team or local community.

Families of children with Down syndrome are often vigilant about language and motor development during the first three years of life. This is a call to action to be equally as vigilant about the formation of healthy habits during this critical period of development. Adults with Down syndrome demonstrate high rates of cardiovascular disease, diabetes, and obstructive sleep apnea. Preventing excess weight gain during childhood could help reduce this gap of observed health disparities. Although there are many complex genetic, environmental, and behavioral factors that contribute to the obesity epidemic, it is important to recognize that obesity is largely preventable if action is taken early in life.

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PrO-PEAR

Preventing Obesity through Parent Empowerment and Activation of Routines University of Pittsburgh: PRO19100089

Would this study be a good fit for you?

- **Do you have a child with Down syndrome aged 12-36 months?**
- **Is your child walking independently?**
- **Are you willing to participate in an interview and data collection from your home?**

What would happen if you took part in the study?

If you and your child decide to take part in this study, you would be asked to participate in 2 interviews from your home. During these interviews, we will ask about your daily family routines and your ability to build a foundation of healthy habits for your child. Additionally, we will ask that your child wear a device on their wrist and/or their thigh that both measure activity and sleep behavior over a two-week period, and that you video-record four of your child's meals. Finally, we will ask that you answer questions about your child's nutrition, physical activity, and sleep. This information will be used to design an obesity prevention intervention specifically designed to meet the needs of families of young children with Down syndrome.

For more information, please contact Angela Caldwell, PhD, OTR/L at (412) 383 -7231 or ARL78@pitt.edu. Dr. Caldwell is an assistant professor within the Occupational Therapy Department at the University of Pittsburgh.

Eligible families who take part will be compensated to thank them for their time.

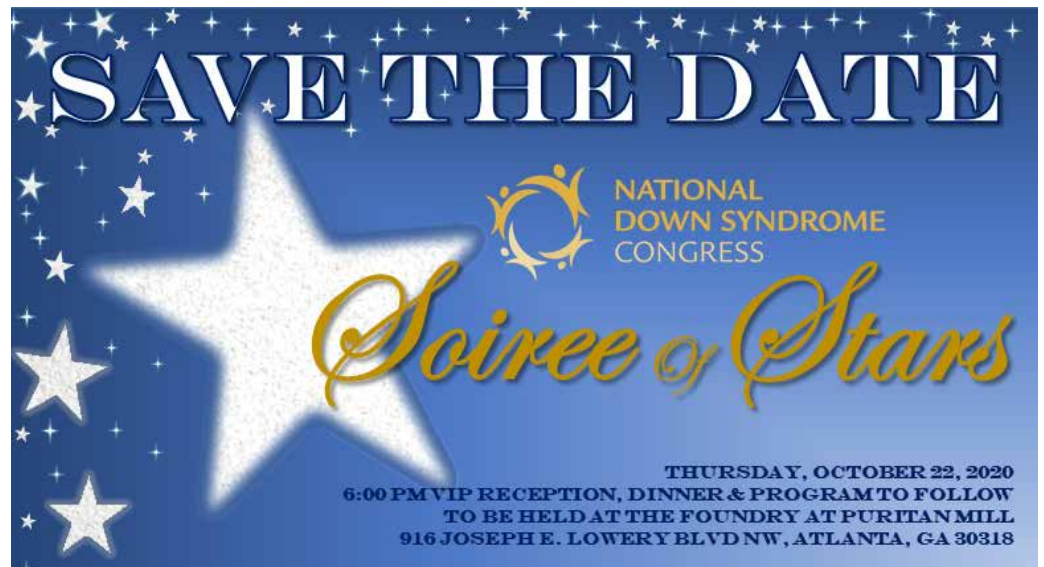


NDSC to Host Inaugural Gala

On October 22, 2020, the National Down Syndrome Congress will host its inaugural Soiree of Stars Gala at The Foundry at Puritan Mill in Atlanta, GA. The event will shine a light on individuals, organizations, and businesses that have made an impact in the Down syndrome community.

The event honorees include:

- **Meria Carstarphen for her work in the community**
- **#everydayheroes - Honoring self-advocates performing essential jobs in our community**
- **Down Country for their outreach work**
- **Kennesaw State University for their inclusive postsecondary education program**



Revenue raised from this event will support the work of NDSC, allowing us to continue to foster our Affiliate Program, a network of local and regional groups across the globe that provide support and resources to those with, or serving those with, Down syndrome. Funds raised will help continue to build programs and provide resources such as one-day summits and captioned webinars, in both English and Spanish, through our Center for Outreach & Education, whose purpose is to reach individuals, families, and professionals where they are. The efforts of this event will support the NDSC National Call Center; the production of printed materials; in English, Spanish, Icelandic, and other languages as requested; and our annual convention, the largest single gathering of people with Down syndrome, their families, and the medical and education professionals who serve them, in the world.

Start Now to Plan for Students Transitioning Back to School

Ghere, G. (2020). *Start now to plan for students transitioning back to school (Distance Learning Series #9)*. Minneapolis, MN: University of Minnesota, TIES Center.

As the saying goes, the country is truly building the distance learning plane as we fly it. The change to distance learning has been very challenging for many students, families, and instructional teams. 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 plan for successfully transitioning students with significant cognitive disabilities back into school. States are discussing what returning to school might look like and the possible timeframes. We don't know exactly when that will be or what form it will take, but there are steps that we can take now to plan for that time so 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. Relationships between students and teachers, students and peers, and teachers and parents/families are foundational for effectively implementing distance learning and for having discussions about transitioning back into school. During distance learning, a team's communication with their students and families should let them know that they matter and that their voices are heard. It shows that teachers care about them, how they are doing, and how they are weathering this dramatic change in their lives.

All of the efforts during distance learning to build and sustain relationships with students and families by sending emails, dropping off materials, creating short videos, and using online platforms create the on-ramp for having important discussions about transitioning back to school. Staying connected is the basis for the mutual trust that will support communication and problem solving about how to re-engage the student with classes, friends, teachers, schedules, and rituals and routines.

Communication, communication, communication

The stronger the communication web during distance learning, the stronger the available connections for planning a student's transition back to school. 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 something is changing...again...and that it will mean changes in how school looks for all students. This is particularly important for students who have receptive and expressive communication challenges. Provide students with information about the forthcoming changes through multiple means of representation. For example, teachers can write social stories that can be read to students. Educators and families can also add new vocabulary for emotions (e.g., excited, worried, happy, nervous) and for actions (e.g, social distancing, washing



hands, wearing a mask) to low-tech or high-tech AAC devices to facilitate a means for them to express themselves. Provide them with the opportunity and appropriate support to express their questions and concerns. Assist them to work through any excitement or anxiety that emerges. Be particularly cognizant of students expressing their emotions about the change through new or expanded behaviors and collaborate with the families to support the children to use other ways to express themselves.

When the time is near for the change to being back in buildings to occur, 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.

Similar to the importance of parent/family voice in navigating and individualizing distance learning, including the student's 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:

- To what extent does the overall initial transition plan for all students work for individual students?
- Where does the plan need to be further individualized?
- What was learned during distance learning that helps to facilitate 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 from this transition provides insights should a temporary change in how education is provided happen again in the future.

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 regarding academics, behavior/social-emotional, communication skills, functional skills for each student before distance learning started? Review each student’s progress notes, progress monitoring data and work samples from the beginning of the school year until in-person school ended to create a picture of what were the gains and the rate of change that each student made during that period. This becomes the baseline for forward planning.
- Data during distance learning: We know that data collection is challenging for many teachers and families, that the data will have gaps, and that it will be less systemized than previously. However, use what you have to make your best-informed determination of what each student is learning during distance learning. Be sure to capture information from the families about the skills that each student is learning and/or generalizing 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, and
 - data teachers collect during all contacts with a student

So What? What do 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 that 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 convey 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 the transition period to prepare the student for returning to school, during the transition period as new/old routines are re-established and moving on after the routines are re-established?
- How will you continue to blend what was learned during distance learning about integrating technology to enhance student learning, connections with parents/families, and generalization of skills between school and home to accelerate student learning?

The plans for reopening school, whether fully, gradually, or with modified schedules, will look different across the states. Teachers will need to take their state and district plans and translate them into supporting individual students. Regardless of the specifics, the key components of the relationships, communication, and data will be foundational for all planning.

Looking for more resources on how to plan and collaborate during COVID?

Distance learning can be challenging for students with significant cognitive disabilities, their families, and their teachers. Students and their families may be frustrated by the technology and the demands created by distance learning. Similarly, teachers may need to utilize technologies they may still be learning while figuring out how to effectively engage students. To address current needs during the COVID-19 crisis, TIES Center launched a distance-learning series. To access the complete distance-learning series visit the TIES Center website at www.TIESCenter.org.

The information in this Brief is not an endorsement of any identified products. Products identified in this Brief are shared solely as examples to help communicate information about ways to reach the desired goals for students.

TIES Center is supported through a cooperative agreement between the University of Minnesota and the Research to Practice Division, Office of Special Education Programs, U.S. Department of Education (# H326Y170004). The Center is affiliated with the National Center on Educational Outcomes (NCEO) which is affiliated with the Institute on Community Integration (ICI) at the College of Education and Human Development, University of Minnesota. The contents of this report were developed under the Cooperative Agreement from the U.S. Department of Education, but do not necessarily represent the policy or opinions of the U.S. Department of Education or Offices within it. Readers should not assume endorsement by the federal government. Project Officer: Susan Weigert

The National Center on Educational Outcomes (NCEO) leads the TIES Center partnership. Collaborating partners are: Arizona Department of Education, CAST, University of Cincinnati, University of Kentucky, University of North-Carolina–Charlotte, and the University of North Carolina–Greensboro.

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El beneficio de estar “Ocupado”

He tenido el privilegio de hablar en conferencias y debates en todo el país acerca del problema de comportamiento y este tema es de gran preocupación tanto para padres como para profesionales. Los problemas de comportamiento pueden ser agotadores, pero generalmente forman parte de nuestras vidas así tengamos o no un niño o estudiante con síndrome de Down.

Escrita por Stacy Taylor, Stacy Taylor, MA, B.C.B.A., Presidenta Academia de Comportamiento y Aprendizaje Avanzado y Academia de Aprendizaje Avanzado en Maitland, FL. Traducido por Nora Bahamonde.

Cuando hablo acerca del comportamiento, yo siempre expongo la importancia de identificar la “función” del comportamiento que describe el por qué esta conducta puede ocurrir. El entender el motivo del comportamiento nos ayuda trabajar con el entorno para prevenir y ayudar a controlarlo en el futuro. Los problemas de conducta pueden ocurrir por llamar la atención, escapar, o por obtener algo que se desea o por motivos sensoriales.

No importa el por qué la conducta ocurre, yo estoy aquí para decirte que hay esperanza. Las cosas pueden mejorar y la respuesta puede depender en parte, en estar (y permanecer) ocupado. Sabemos el impacto positivo que el aprender tiene en el problema de conducta. Pero nosotros usualmente nos enfocamos en evitar que las malas cosas sucedan en vez de enfocarnos en que las cosas buenas ocurran.

Estar ocupados puede distraernos y si estamos ocupados podemos simplemente tener menos tiempo para involucrarnos en problemas de comportamiento. No hay nada malo con distraerse un poco. De todas maneras, es importante que estemos preparados con una variedad de actividades alternas para bloquear y desviar la conducta. Esto es complicado y necesita planeamiento. He conocido a mucha gente bien intencionada e inteligente (padres y profesionales) que no planean de manera efectiva. Pregúntate a ti mismo (a) qué es lo que esta persona necesita para triunfar ahora, mañana, y en el futuro y empieza a prepararte para lograrlo ya en este momento. Mientras el aprendizaje y la crianza ocurren, es nuestra responsabilidad el ser consientes y ayudar a planear esta meta. Si el estudiante es de aquellos que terminar las tareas pronto, entonces la profesora debe estar preparada con las siguientes actividades de manera que el estudiante no se “aburra” en clase y empiece a comportarse mal. Si el niño está yendo a una cita médica, los padres pueden prepararse con diferentes opciones por si el niño las necesitara. Planear por adelantado es esencial para poder mantener ocupado a tu ser amado con síndrome de Down.

Recuerdo, en una conferencia recientemente, una madre trajo a su hija adolescente con síndrome de Down (así me me place que vengan, aunque se lo difícil que es para el familiar poner atención mientras cuida de su hijo (a)). Lo que hizo la situación más difícil era que la madre no trajo nada para entretener a su hija durante las 6 horas de duración de la conferencia. Nada. No he conocido a un adolescente neurotípico que pueda permanecer quieto durante una conferencia, así sea interesante para él o ella (¡y sé que yo no soy tan entretenida, ¡ja...ja!). Como era de esperarlo, esta joven adolescente empezó



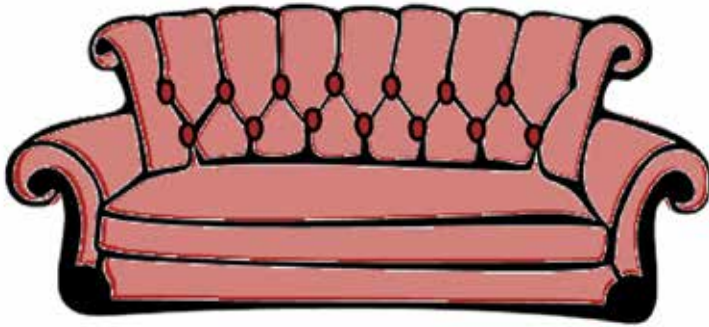
a molestar muy temprano en la conferencia y la madre se frustraba cada vez más a medida que la conferencia se llevaba a cabo. Al momento del receso, la madre se acercó a mí y me preguntó qué es lo que ella podía hacer cuando su hija se comporta de esa manera y yo le respondí con esta simple pregunta: “¿Qué es lo que esperas que ella pueda hacer este momento?” Este fue un momento de luz para esta madre. Se dio cuenta que literalmente ella le dio la oportunidad a su hija de hacer nada y estableció una expectativa irracional, lo que dio lugar al problema de comportamiento. Discutimos acerca de cosas sensoriales que ella podía haber traído; por ejemplo, una bonita cartera con unos audífonos de manera que ella pueda escuchar música en situaciones como esta. Como madre soltera, ella no tiene otra opción que llevar a su hija a todas partes y ella adora estar con ella...no podía ser de otra manera, pero la muchacha no disfruta todo el tiempo. Lo entiendo (¡y su mamá era chévere, pero esto no lo era!). Ella no sabía como participar de la misma manera, o por lo menos el mismo tiempo que otros asistentes. El enseñar a su hija cómo estar ocupada en estas situaciones y en otras, podría bloquear parte o quizá todo el problema de comportamiento. Esto podría solamente tomar un poco de planeamiento o enseñanza.

No solamente el estar ocupado sirve como gran distracción, es una técnica constructiva. Los problemas de comportamiento son siempre problemas de falta de opciones. Si puedes enseñar habilidades en diferentes áreas (placer, comunicación, social, independencia, etc.) los problemas de comportamiento se vuelven irrelevantes. Para algunas personas esto puede significar tomar tiempo para enseñar entretenimientos específicos para ayudarles a estar ocupados. Para otros esto puede significar el enseñarles habilidades de organización y planeamiento para ayudarles a estar ocupados.

continúa en la página 15...

C.O.N.V.E.N.C.I.O.N

DESDE TU SOFÁ



NATIONAL DOWN SYNDROME CONGRESS



Campo de Entrenamiento de Activismo de NDSC, desde tu sofá!

27 de junio • 1:00 PM–3:00 PM ET

Empezamos el día entero de Campo de Entrenamiento de Activismo de NDSC. Esta sesión intensiva está dirigida para los activistas principiantes. Es una excelente oportunidad para asistir al entrenamiento que querías, pero no habías tenido tiempo de encajarlo durante una Convención de NDSC. Desde la comodidad de tu casa, el Campo de Entrenamiento de Activismo (Bootcamp) será gratis después de registrarse gratis a la Convención desde tu sofá de NDSC. La sesión presentará información impartida por auto activistas, padres activistas, y expertos del equipo de políticas del NDSC. Aprende que es Activismo, bases del proceso legislativo, como participar y construir relaciones con funcionarios elegidos, como usar redes sociales para tus propósitos de activismo y otros importantes recursos y sugerencias. El Campo de Entrenamiento de Activismo está diseñado para ser un Advocacy 101 mini-course con énfasis en activismo legislativo; inclusive un experimentado activista aprenderá algo nuevo y se revitalizará después de unirse a la discusión abierta acerca de como entablar diálogos con los legisladores.

Ceremonia de Premiación

27 de junio • 4:00 PM–5:00 PM ET

Únete a nosotros para celebrar y reconocer organizaciones y personas quienes han aportado extraordinariamente a la investigación, activismo, y a generar conciencia sobre la comunidad de síndrome de Down.

Sabado, Junio 27 Horario

Todas son horas del Este

Toda la programación se presentará en inglés

1:00–3:00 PM	"Campo de entrenamiento" de Activismo
3:00–4:00 PM	Receso
4:00–5:00 PM	Ceremonia de Premiación
5:00–6:00 PM	Receso
6:00–6:30 PM	Reunión General de Miembros
6:30–7:00 PM	Receso
7:00–8:30 PM	Reunión general con el orador principal Zach Gottsagen
8:30–9:00 PM	Receso
9:00–10:00 PM	321 Zoom Fiesta Bailable

Reunión General de Miembros

27 de junio • 6:00 PM–6:30 PM ET

Todos los miembros de NDSC están invitados a asistir a la Reunión General de Miembros del 2020 a llevarse a cabo el 27 de junio a la 6:00 PM ET. Esta es una oportunidad para los miembros de ponerse al día de los siguientes temas:

- El Tesorero y los Administradores de los fondos de NDSC informarán a los miembros sobre la situación financiera actual de la organización.
- El Director Ejecutivo de NDSC, David Tolleson, presentará una descripción general de las actividades de la organización.
- El Comité de Nominaciones presentará la lista de candidatos para elegir a los directores de la Junta.
- Elecciones de los nuevos miembros de la Junta
- Otros asuntos serán tratados si el tiempo lo permite.



Plenario con Zach Gottsagen

27 de junio

7:00 PM–8:30 PM ET

Zach Gottsagen y los productores y directores de *The Peanut Butter Falcon*.
[El Alcón de Crema de Maní]



Las organizaciones del síndrome de down combinan esfuerzos para publicar una lista de preguntas y respuestas relacionadas a la enfermedad del coronavirus (covid 19) y el syndrome de down

Importante recurso para las familias durante estos tiempos inciertos y sin precedentes

Las Preguntas y Respuestas [Q&A] acerca del COVID-19 y síndrome de Down fue revisada por numerosos clínicos, organizaciones activistas, y familiares de personas con síndrome de Down e incluye respuestas a las siguientes preguntas en general:

- ¿Cómo puedo ayudar a prevenir la propagación del virus?
- ¿Cuáles son los síntomas comunes de los que debo estar atento?
- ¿Qué debo considerar cuando debo tomar decisiones por y en nombre mi ser querido con síndrome de Down?

El punto importante que las preguntas y respuestas (Q&A) tratan es si las personas con síndrome de Down son consideradas de "alto riesgo." Basados en la información de los Centros para el Control y la prevención de Enfermedades (CDC por sus siglas en inglés) y el Instituto Nacional de la Salud (NHI por sus siglas en inglés), las personas consideradas de "alto riesgo" incluyen a aquellos con "subyacentes enfermedades," las cuales las personas con síndrome de Down tienden a padecerlas. Algunas a mencionar son enfermedad pulmonares y dificultad para respirar (por ejemplo, asma, apnea del sueño,) enfermedades del corazón recurrentes o afección cardíaca, obesidad, diabetes, o tener un sistema inmunológico bajo (por ejemplo, personas con tratamiento de cáncer o que estén tomando medicamentos para artritis reumatoides o lupus que provocan bajas en el sistema inmunológico).

Estas preguntas y respuestas son informales y no proveen opinión médica o servicios relacionados. Estas preguntas y respuestas NO DEBEN ser consideradas como reemplazo de la opinión de profesionales médicos u otros profesionales. Consulte con su médico u otros profesionales de salud para obtener concejos médicos.

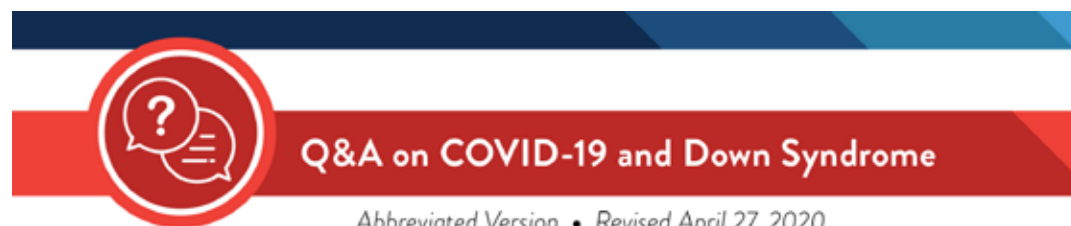
Las preguntas y respuestas tienen el soporte adicional de las siguientes organizaciones nacionales e internacionales: Down Syndrome Affiliates in Action, Gigi's Playhouse, International Mosaic Down Syndrome Association, Jerome Lejeune Foundation, and T21RS.

Para poder ingresar a la fuente de información, en inglés y español, y a su corta y amplia versión, las familias, amigos, y profesionales deben visitar el sitio web de NDSC bajo la pestaña ["tab"] de – COVID-19 Resources.



Kim Knight de Marietta GA y miembro de NDSC, comparte: "Como madre de un pequeño con síndrome de Down me pregunto si el esta dentro del grupo de alto riesgo y qué esto significa. Estoy contenta de que este recurso nos proveerá de específica información en lo que respecta a la relación de síndrome de Down y COVID 19."

"Yo tengo un muchacho que tiene 40 años y no estoy segura de cómo explicarle que no puede seguir su rutina regular, cuál su nueva rutina debe ser o si el podrá ver a su primo que vive al otro lado de la ciudad," dijo Jacqueline Olimpio de Olney, Maryland. "Agradezco por cualquier información que pueda ayudarme a navegar por este momento difícil."



ORGANIZERS:

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Down Syndrome Medical Interest Group-USA

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SUPPORTING ORGANIZATIONS:

Down Syndrome Affiliates in Action, Exceptional Parenting Magazine, Gigi's Playhouse, International Mosaic Down Syndrome Association, Jerome Lejeune Foundation, Matthew Foundation, T21 Research Society

Aquí tienes algunos puntos que te pueden ayudar a iniciar esto:

- Enséñale como llamar la atención de una manera apropiada. Esto puede ser llamando por el nombre, tocando el brazo, o levantando la mano.
- Enséñale como puede pedir ayuda usando palabras, señas, gráficos, o tecnología.
- Los horarios de actividades pueden proveer una secuencia visual de qué hacer después o qué opciones están disponibles para mantenerse ocupado.
- Aprender a hacer quehaceres de la casa o ayudar en la clase es una excelente manera de mantenerse ocupado y ayuda también a mantener ocupados a otros.
- Cuando estas enseñándoles juegos o destrezas de entretenimiento, asegúrate que tu hijo (a) aprenda diferentes tipos de juegos.
- Usando señales visuales y auditivas pueden ayudar a la enseñanza. Un gráfico puede ser usado para ayudar a diseñar bloques o como dibujarlos. Un reloj de alarma puede ser usado para incrementar el lapso durante una actividad.
- Enseña también actividades para poderlas realizar solos ya que estar ocupados no siempre envuelve el estar con otros, tu puedes estar ocupado y solo.
- Incluye actividades suaves y calmadas para asegurarte que no haya el factor de cansancio y por lo tanto riesgo de problemas de comportamiento que pueden ser el resultado de cansancio.
- Alterna el acceso a las actividades (dependiendo de la edad de tu hijo) para ayudarle a que ponga más interés y se divierta más.

Hay grandes beneficios al estar ocupados y enfocados en aprender a prevenir y reducir problemas de comportamiento. ¡Solo recuerda mantener enseñando y disfrutando!

¡Convierte en un compañero de NDSC!

Si tu valoras la información y recursos que NDSC comparte durante todo el año, por favor únete a nuestra primera y nueva campaña de recaudación de fondos compañero a compañero.

Tres maneras de convertirte en un compañero de NDSC

1. Haz tu donación enviando vía texto la palabra CONVENTION al numero 44321
2. Crea tu propia página de recaudación de fondos en línea— Es fácil, envía por texto la palabra CONVENCION al número 44321.
3. Envía un correo electrónico a la Directora de Desarrollo, Christine Milano, a Christine@NDSCcenter.org para recibir asistencia al momento de crear tu página en línea.

Cuando tu tengas tu página de recaudación de fondos en línea, puedes pedir a amigos y familiares ayuda para recaudar. Es fácil y divertido, y las personas que recuden más fondos serán reconocidas por su esfuerzo en la Fiesta Bailable Zoom 321 el día 27 de junio. Tus esfuerzos ayudarán a NDSC a continuar mejorando nuestros servicios y programas, extender nuestros servicios a comunidades rurales y urbanas, y continuar ayudando a familias que necesitan más. **¡Empecemos a recaudar fondos y amigos!**

Down Syndrome News

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Mission

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

Vision

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

Statement of Policy and Disclaimer:

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

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

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To update your contact information, call 800-232-6372 or email info@ndsccenter.org.

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



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