Down Syndrome News

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NEWSLETTER OF THE



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Dating and People with Down Syndrome -FAQs by Terri Couwenhoven, MS



Terri Couwenhoven, M.S., is a certified sexuality educator specializing in developing programs and resources for people with intellectual/ developmental disabilities, their families, and the professionals who support them. Terri has combined her expertise with her interest and passion for supporting people with intellectual disabilities and ensuring they have accessible information about sexuality. In addition, she is an author, the Clinic Coordinator for the Down Syndrome Clinic at Children's Hospital of Wisconsin, and a parent of an adult with Down syndrome.

Terri has written four books on sexuality. Her book, "Boyfriends & Girlfriends: A Guide to Dating for People with Disabilities," was written for teens and adults with intellectual disabilities to help them understand the dating process. "Teaching Children with Down Syndrome about Their Bodies, Boundaries, and Sexuality" was written for parents, providing facts and practical ideas for teaching their sons and daughters with Down syndrome about their bodies, healthy dating relationships, marriage, and sexuality.

Terri speaks to parents, professionals, and people with intellectual disabilities all over the country, and her workshops were some of the most sought after presentations this summer during the NDSC's Convention From Your Couch. Below she has compiled a list of the most common frequently asked questions by parents of teens and adults with Down syndrome and other intellectual disabilities.



My daughter is immature, but I hope she can date someday. As a parent, what can I do to prepare her for dating?

Just because she is immature now does not mean she will be forever. Often people with limited experiences can be immature. Hopefully, with life experiences, including opportunities to date- she will mature. Life experience is a great teacher. In the meantime:

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Letter From the President

Dear NDSC Families,

It is with much honor that I write my first letter to you as the president of this organization I love so dearly. I beam with pride and am deeply humbled when I think about the people whom I am surrounded by and the work that we do. To see our team of staff and volunteer board members in action, making an immediate about-face, after coming to the hard decision to cancel the 2020 in-person convention, and go to a completely digital convention was extraordinary. Although we missed out on being together, we did not miss the mark on bringing you the information and resources that are the purpose of the annual gathering.

Since June, we have been working diligently to ensure that the rights of people with Down syndrome are protected during the COVID-19 pandemic. We have addressed concerns regarding discriminatory

medical treatment rationing and created a resource for caregivers should a loved one be hospitalized during the COVID-19 pandemic. We have created libraries to help our member families sort through the avalanche of information regarding COVID-19 and Down syndrome, race relations, and to help self-advocates navigate the upcoming election.

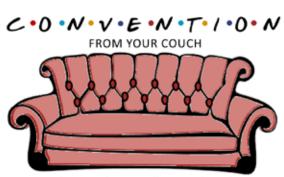
The NDSC staff and Convention Planning Committee are already at work planning and preparing for our 49th Annual NDSC Convention to be held July 8-11, 2021, at the beautiful JW Marriott Phoenix Desert Ridge Resort & Spa, in Phoenix, Arizona. We are counting down the days until we get to bring everyone together again. Although we are known for our "Giant Family Reunion" and all those four days together brings, please remember that we are here for you 365 days a year to provide resources and support.



In late March, the NDSC Board of Directors and staff made the difficult decision to cancel our annual in-person convention. Our team pivoted and created the first ever **NDSC Convention From Your Couch.** Rather than our traditional 4-day event, we were able to provide **47 days of programming and social opportunities** providing resources and much needed social time for our member families.

The General Conference offered **22 workshops** accounting for **4,256 attendees** viewing live or clicking to watch recorded sessions.





S2020: E1: The One Where We All Practiced Social Distancing NATIONAL DOWN SYNDROME CONGRESS

Experts joined us to provide **5 three-hour Deep Dive sessions** with **413 families** taking advantage of the opportunity to have this focused time on a single topic.

The Youth & Adults Conference hosted 13 opportunities to participate in workshops and showcase talents in the Open Mic night and the Talent Show Extravaganza. The more than 740 clicks to join friends to learn, share, and socialize allowed us to continue to bring the heart and soul of any NDSC gathering, our self-advocates, together.

It would not be an NDSC event without a dance! This year we brought together **95 attendees** who danced the night away at the **NDSC 321 Zoom Dance Party** to close out the event.

2020 Awards—And the Winner is...

The NDSC 2020 National Media Award,

honors outstanding national media efforts, which create better understanding of Down syndrome and people with Down syndrome. The award recognizes programs on television, documentaries, feature films, national publications, serials, syndicated columns, and social media. The National Media Award presented for the media efforts broadcast or published in 2019-2020 went to "The Peanut Butter Falcon."



The NDSC Education Award recognizes outstanding performance on behalf of students with DS. Nominees were judged by their demonstrated leadership and innovation in creating or advancing best educational practices for students with Down syndrome with **The TIES Center** taking the award.



The Outstanding Affiliate Award

recognizes an affiliate parent group of the NDSC, which has performed outstanding service on behalf of people with Down syndrome and their families.

Groups are judged on advocacy services, relationship to the NDSC, support to families, fundraising activities, and local and regional programs and services. The 2020 winner of this award is **Down Syndrome Association of Middle Tennessee** (**DSAMT**).



The Sig Pueschel NDSC Service Award

recognizes an individual or organization for outstanding contributions to the NDSC. This year's winner keeps the NDSC online and digital. Without them

the Convention From Your Couch would have not been possible. Thank you and congratulations to **NTI Networks**, this year's award winner.



The Pueschel/Tjossem Memorial Research Award recognizes research, which has contributed to greater knowledge and understanding of Down syndrome and has improved the lives of people with Down syndrome or their families. This year the award went to the Global Down Syndrome Foundation Work Group for their work producing the "GLOBAL Medical Care Guidelines for Adults with Down Syndrome."



Christian Pueschel Memorial Citizen Award recognizes an individual with Down syndrome whose achievements, service and contributions have enhanced the value and dignity of people with Down syndrome and their families. This year the award was presented to Bradley Carlisle of Georgia.

The Exceptional Meritorious Service Award recognizes an individual whose service and contributions to people with DS and their families have had local, state, and national significance. The 2020 award goes to Terri Couwenhoven.





The NDSC President's Award was a particularly heart-felt award, presented as Dr. Kishore Vellody's last act as president before turning over the reins. This year's award

was given to **the Down Syndrome Diagnosis Network (DSDN)** for their work educating physicians on the importance of a positive delivery of a diagnosis and the opportunities that the organization provides for parents to connect, providing both education and support to families in the Down Syndrome community.

Dr. Vellody also presented **Board Service Awards** to **Marilyn Tolbert, Sarah Mulligan, and Jazzy Holman,** recognizing their time and service to the NDSC.

New Board members were elected at the General Membership meeting held on Saturday, June 27, 2020. Congratulations to our newest Board members Lora Olson and Barb Helm.

GLOBAL Research & Medical Care Roundtable

Thank you to GLOBAL Down Syndrome Foundation for bringing the GLOBAL Research & Medical Care Roundtable to Convention From Your Couch. The roundtable hosted 120 attendees during the live session.

Advocacy Training Boot Camp



The third annual Advocacy Training Boot Camp was held on June 27, with over **350 advocates** attending from across the country in our first ever virtual conference.

The Advocacy Training Boot Camp provided an Advocacy 101 mini-course with a focus on legislative advocacy, but even the most experienced advocate walked away with something new. This training was geared towards parents, professionals, and of course, self-advocates. It was organized and run by the NDSC Policy & Advocacy Team along with Grassroots Advocacy Consultant Jawanda Mast.

The program featured information from effective self-advocates, parent advocates, and the expert NDSC Policy & Advocacy Team. Sessions included presentations on the legislative process, engaging with elected officials, how to advocate locally, state coalition-building, and tips from self-advocates. Rachel Mast, one of the presenters, said, "I love helping at the Advocacy Training Boot Camp! It made me proud." One participant stated, "This was very informative for me as a beginner advocate - I feel much more prepared to start my advocacy journey."

All session handouts, presentations, and more advocacy resources can be found on the NDSC website under the Policy & Advocacy tab/Policy Trainings dropdown. These are free resources, which include the Advocacy Toolkit for Self-Advocates developed by the NDSC Self-Advocate Council along with the NDSC Policy Team.

Look Out Phoenix, Here We Come in 2021

The NDSC staff and Convention Planning Committee are busy working on plans for the 2021 Convention at the JW Marriot Phoenix Desert Ridge Resort & Spa, July 8-11, 2021.







#GIWINGTUESDAY Giving Tuesday is December 1

Giving Tuesday is a global generosity movement unleashing the power of people and organizations to transform their communities and the world.

Save the Date and join us as we come together on December 1, 2020, to celebrate the impact NDSC has had on the Down syndrome community in 2020. Be on the lookout for more information and plan to join us for a Zoom Dance Party to celebrate.



2021 NDSC Awards Nominations are Open!

Each year awards are presented at the convention to recognize individuals and organizations for outstanding achievement and contribution within the Down syndrome community.

Nominations are now being accepted for all award categories. If you know of an individual or organization that you feel is deserving of consideration for one of the 2020 NDSC awards, please nominate them through our online nomination form.

Nominations may be submitted by any person or organization wishing to direct the attention of the NDSC Board of Directors to outstanding achievement. In its selection, the Board of Directors will not necessarily be restricted to those programs or individuals, but may consider reports of outstanding achievement from other sources and may, on its own initiative, select award recipients.

Nomination forms and supporting materials should be submitted by mail, e-mail or fax to the NDSC Center by January 15, 2021. Selections are made in the Spring. All awards will be presented at the NDSC Annual Convention.

Award Categories

Exceptional Meritorious Service Award

This award recognizes an individual whose service and contributions to people with Down syndrome and their families have had local, state and national significance.

Employer of the Year Award

This award recognizes an employer for efforts in creating employment opportunities for people with Down syndrome.

Christian Pueschel Memorial Citizen Award

This award recognizes an individual with Down syndrome whose achievements, service and contributions have enhanced the value and dignity of people with Down syndrome and their families.

Sig Pueschel NDSC Service Award

This award recognizes an individual or organization for outstanding contributions to the NDSC.

National Parent Group Award

This award recognizes an affiliate parent group of the NDSC, which has performed outstanding service on behalf of people with Down syndrome and their families. Parent groups will be judged on advocacy services, relationship to the NDSC, support to families, fundraising activities and local and regional programs and services.

Pueschel/Tjossem Memorial Research Award

This award recognizes research, which has contributed to greater knowledge and understanding of Down syndrome and has improved the lives of people with Down syndrome or their families.

AWARD GUIDELINES

- Does the program, publication, or individual promote a positive image of people with Down syndrome?
- Does it accentuate abilities, not disability?
- Does it focus on people, not on the condition of Down syndrome?
- Does it celebrate diversity?
- Does it use people-first language?
- Does it enhance the dignity of people with Down syndrome?
- · Does it avoid stereotyping?
- · Does it present accurate information?
- Does it recognize the value of the person with Down syndrome?

National Media Award

This award honors outstanding national media efforts, which create better understanding of Down syndrome and people with Down syndrome. The award recognizes programs on television, documentaries, feature films, national publications, serials, syndicated columns and social media. National Media Awards may be presented for the categories of film, print and online. The media efforts must have been broadcast or published within the last calendar year.

Education Award

This award recognizes outstanding performance on behalf of students with Down syndrome. Nominees will be judged by their demonstrated leadership and innovation in creating or advancing best educational practices for students with Down syndrome.

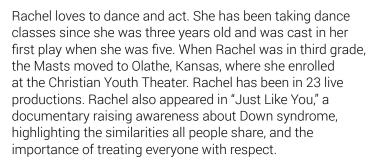
SELF-ADVOCATE SPOTLIGHT

Rachel Mast

Rachel Mast REALLY LOVES her life and lives it to the fullest.

If you have the opportunity to spend time with Rachel, you can't help but love life too. Outgoing, energetic, fun-loving, and determined are some of the words that may be used to describe Rachel. She is also a driven young woman with many accomplishments.

Rachel was born in Memphis, Tennessee, in 1999. She is an only child with a big supportive family. She loves to spend time with her parents, grandparents, and other relatives and says that she especially enjoys taking trips to New York City and going on Disney Cruises with her parents.



Rachel was an active student at Olathe South High School. She came into high school with a bang, winning a dance-off on the first day of her freshman year. She was elected to Student Council and served all four years, was an Olathe South Thespian, was elected to the Winter Court freshman year, was Prom Princess her junior year, and went to four proms her senior year! The role that Rachel loved the most in high school was serving as the manager for the girls' volleyball team. She also learned in her general education English and theatre class that she loved Shakespeare. A highlight of her time in high school was being cast as Strato in her school's production of Julius Caesar her junior year. She loved her active social life but didn't let the fun interfere with her studies as she made the honor roll and was inducted in the National Honor Society.

As long as she can remember, Rachel has dreamed of going to college. She visited several colleges and thought that she would be a Razorback like her parents, but ultimately made the decision to attend Missouri State. She was accepted as one of eight students to the first Bear POWER class. She lived on campus in a dorm suite with roommates who are not enrolled in the Bear POWER program.

Due to COVID Rachel has taken this year off from college and is participating in Johnson County Project SEARCH, an internship employment and education program for individuals with intellectual and developmental disabilities over the age of 18, who are interested in community



employment. Rachel also works as a hostess at Olive Garden and says that she loves seeing people that she knows in her community. She also spends much of her time with her friends. Rachel's best friends are from her church and school. She says that some of her friends have Down Syndrome, and some do not. She met many of her friends at the NDSC Youth & Adults Conference.

Rachel attended her first NDSC Convention when she was young. When she was old enough, she began attending the Youth & Adults Conference. She says that her favorite part was meeting new friends and learning. Her time with the NDSC inspired her to become a strong self-advocate, advocating from an early age for people with Down syndrome. Rachel began going to Washington DC to advocate at the age of 12. Over the course of the next eight years, she visited Washington, D.C. five times and was a well-known name with Kansas leaders. With each trip, Rachel shared her love for life, her hopes, and her dreams. She advocated on every level and shared her dream of going to college and that she wanted a job, possibly as an actress on Broadway. She spoke of her desire to live on her own and to one day get married. But her dream to live in a pink house was what caught the attention of Senator Jerry Moran (R-KS) during their first meeting. Rachel also explained that if Senator Moran did his part by cosponsoring the ABLE Act, she would do her part and work hard.

Rachel's advocacy efforts played a pivotal role in the passage of The Achieving a Better Life Experience (ABLE) Act in Congress. She traveled to Washington, D.C. multiple times to speak with her congressmen and senators. In January of 2015, Rachel testified on behalf of the ABLE Act, speaking about the importance of ABLE to her future. Once passed, Rachel was the first person in Kansas to open an ABLE account. The Kansas ABLE Act allows people with disabilities to create tax-free savings accounts for costs associated with disabilities. Rachel considers her work in helping to pass this act as her most significant accomplishment.

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Advocacy in Action

NDSC's Policy Work During COVID-19

NDSC advocacy efforts are strictly non-partisan. We work and advocate with both Republicans and Democrats and evaluate policies and policy priorities based on how those policies will impact individuals with Down syndrome and their families, and those with other disabilities.



Since the COVID-19 pandemic began, NDSC has been advocating to protect the rights of individuals with disabilities and to obtain funding and resources to support them across many areas. All NDSC funding requests for the COVID-19 relief bills would have a significant impact on individuals with Down syndrome, their families, and caregivers who support them.

During COVID-19, NDSC has been advocating to:

- Increase funding and resources for Medicaid Home and Communitybased Services (HCBS) providers who are faltering and collapsing due to COVID-related closures. HCBS are vital to individuals with disabilities to help them maintain their independence and access the community.
- Secure resources for Direct Support Professionals (DSPs) and provider agencies, and designate DSPs as essential workers so they have access to personal protective equipment when assisting people with disabilities. DSPs work directly with people with disabilities with the aim of assisting the individual to become integrated into the community.
- Increase funding for implementation of the Individuals with Disabilities Education Act (IDEA) in schools to support students with disabilities during virtual learning and protect their IDEA rights.
- Prevent COVID-related medical rationing schemes that discriminate against people with disabilities. See our website under Parent Webinars for a webinar on this subject.
- Changed hospital visitation policies so that people with disabilities can have a support person with them.
- Expand paid leave to caregivers of people with disabilities who need to stay home due to COVID;
- Expand payment of COVID stimulus checks (dependent credit of \$500) to taxpayers who claim dependents over age 18 with disabilities.
- Expand Supplemental Nutrition Assistance Program (SNAP) benefits (upon which many people with disabilities rely) to enable people to use benefits for online delivery and takeout to minimize COVID risk.
- Expand unemployment benefits to include part-time workers with disabilities who have been laid off due to COVID.

How can you get involved as an advocate?

Getting involved with advocacy is so important for self-advocates, parents, family members, and professionals as it provides a way to stay informed about the policy issues that affect you and advocate for change. Policy and legislation directly impact your everyday life and the NDSC Policy Team is here to help you navigate the advocacy landscape. There are many ways to get involved:

- Join the National Down Syndrome Advocacy Coalition. It is free to become a member of our nationwide grassroots advocacy networkattend our quarterly policy calls, join our NDAC group on Facebook and more.
- Download your copy of the NDSC Advocacy Toolkit for Self-Advocates from the NDSC website.
- Sign up for our Action Alerts. Receive timely and targeted asks and talking points for specific policy topics and contact you legislators in seconds! We make it easy for you to advocate.
- Sign up to receive our monthly Newsline.
 The Policy Team highlights key policy issues and gives you brief explanations of different relevant topics.
- Like our Facebook page (National Down Syndrome Congress Policy & Advocacy) or follow us on Twitter, @NDSCpolicy.

Self-Advocate Spotlight Continued

In 2019, Rachel accepted the Laura Lee Self-Advocate Leadership Award at the State of the Art (SOTA) Conference on Inclusive Postsecondary Education and Individuals with Intellectual Disabilities. She also gave the keynote speech talking about her advocacy for Down syndrome and her goals in life. Rachel said receiving the award was very emotional for her.

When asked about her keys to being a strong self-advocate, she has these words of advice: "You have to keep respect in your heart — be kind and treat other people like you want to be treated." "Step up for yourself and don't take no for an answer." But the one thing that Rachel shares with nearly everyone is her love for life. When you meet her, she will most likely introduce herself by saying, "Hi, I am Rachel. I have Down syndrome, but I am not called Down syndrome. I really love my life."

Q&A on COVID-19 and Down Syndrome

We are proud to work with other Down syndrome organizations to provide useful information surrounding COVID-19. By now, you have likely heard about the Q&A on COVID-19 and Down Syndrome document. This Q&A an important resource for individuals with Down syndrome and their families. Our most recent update to the document was released 07/30/20. We will continue to work with other national organizations and will provide updates these documents as they are available.

The abbreviated and extended versions of the document may be accessed in both English and Spanish from the NDSC website at ndsccenter.org. Below are a few examples of questions and answers provided in the documents.

Q2. Are individuals with Down syndrome at "high risk" for COVID-19?

A. The CDC, the NIH, public health professionals and infectious disease experts have highlighted people who are more "at risk" or "high risk" for COVID-19. High risk means a person could be more likely to get the disease. They could also be more likely to have a severe illness. Experts say that people over age 65 and people with medical problems are at higher risk for getting severe COVID-19.

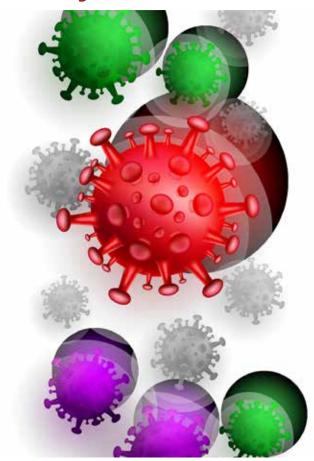
We do not know if people with Down syndrome are more likely to get sick with COVID-19. In general, people with Down syndrome are more likely to get infections. Also, many people with Down syndrome have other medical problems that could make them more at risk for severe illness from COVID-19. In addition, the CDC has recently classified people with disabilities as "people who need to take extra precaution." For these reasons, it is very important to follow the recommended precautions to prevent COVID-19 in people with Down syndrome.

Q3. What are the medical problems that people with Down syndrome may have that put them at high risk?

A. Children and adults with Down syndrome often have more than one health problem. If these problems are untreated or active, that person may be at higher risk for COVID-19. These can include:

- · Certain heart problems.
- · Chronic respiratory problems.
- History of severe respiratory infections.
- · Asthma.
- · Obstructive sleep apnea.
- People who may have lower immune function, such as:
 - · People with diabetes.
 - People receiving chemotherapy or undergoing active treatment for cancer.
 - People on certain medications that lower the function of the immune system (such as for treatment of rheumatoid arthritis, lupus, or psoriasis).

More detailed information about Down syndrome and the underlying medical conditions considered high risk for COVID-19 is available in the Expanded Version of this Q&A on the NDSC website at ndsccenter.org.



Q6. How can I help a person with Down syndrome understand COVID-19 and how to stay healthy?

A. People with Down syndrome tend to be very sensitive to other people's feelings. Most people with Down syndrome will pick up that "something is going on." Try to avoid too much exposure to the news. We suggest you share information and answer questions about COVID-19. Be calm and give facts. Use simple words and pictures. Try to follow the same daily schedule as much as possible. Many strategies can help:

- Practice handwashing using the chorus of a favorite song or the "ABCs" or "Happy Birthday." Handwashing should be for about 20 seconds.
- When in public spaces, wear a face covering or mask that covers your mouth and nose.
- Use social stories, words like "staying in your bubble," and visual supports to show what keeping a safe distance looks like.
- Explain that smiling, waving, and socialization from a distance is fine, but avoid hugging, handshaking, and touching others.

Additional resources and links are available in the Expanded Version of this Q&A on the NDSC website at ndsccenter.org.

Health Care Transition Toolkit

Health care transition, or HCT, is the process of moving from a child/familycentered model of health care to an adult/ patient-centered model of health care, with or without transferring to a new clinician. It involves planning, transfer, and integration into adult-centered health care.



Got Transition and its National Family

Health Care Transition Advisory Group have developed a new toolkit for families to use, to guide their youth's transition from pediatric to adult health care, as they assume more independence in taking care of their own health and using health services. NDSC's Programs & Partnerships Director, Tamara Pursley, serves in the Advisory Group and has been contributing to this important resource over the last year and a half.

The toolkit includes a set of easy-to-use resources, including a transition timeline, questions to ask your doctor, turning 18 and what it means, and more. This new Family Toolkit is intended for families who have youth with and without special health

Download the toolkit and other tools, take parent and selfadvocate assessments and find additional resources on Got Transition's website-www.gottransition.org.

Book Release!

Did you happen to catch sessions by Terry Katz or Lina Patel during **Convention From** Your Couch? If you did, you heard mention of a new book coming out this fall and it is now available.

Whether you're just getting started potty training your child with Down syndrome or have been at it for months or years, "Potty Time for

Kids with Down Syndrome: Lose the Diapers, Not Your Patience" offers the specialized guidance needed for you and your child to be successful!

Drawing on their years of experience working with and toilet training children with Down syndrome, authors Terry Katz, Ph.D., and Lina Patel, Psy.D have created a customizable developmentalbehavioral model based on a thorough understanding of how the behaviors of children with Down syndrome are affected by their neurodevelopment. For instance, the low muscle tone common in children with Down syndrome can affect bladder and bowel control. Or a child may be motivated to continue using a diaper because he enjoys the interaction while being changed. The book's empathetic and encouraging tone coupled with its positive behavior-based strategies geared specifically to children with Down syndrome will help parents avoid typical challenges.

This title (and many others) are on sale now, at www.woodbinehouse.org





"The vote is the most powerful nonviolent change agent you have in a democratic society. You must use it because it is not guaranteed. You can lose it."

-John Lewis, late U.S. Congressman

Every four years Americans go to the polls to elect our nation's president and other local, state, and federal officials. Tuesday, November 3, 2020 is election day. On this day, voters will not only choose the President and Vice-President but will elect local, cities and state officials. This federal election also includes electing 1/3 of the Senate, and all House of Representatives. State and local races may also include elections for such positions as school and city council boards, county commissioners, and other public service officials.

To help you navigate the voting process and understand the importance of voting, we have launched the NDSC Your Voice, Your Vote campaign, sharing information such as state deadlines, tips, and tools to make the voting process easy and clear for self-advocates and their families. We are sharing information on our social media pages and have created a Your Voice, Your Vote Resource Library on our website where you can find resources, guides, and more.

To register to vote you must be a United States citizen, be at least 18 years old, and fit residency requirements. Guardianship may complicate your eligibility. In some states, people with guardians are not able to vote.

Due to the risks that COVID-19 poses to many people, voting may look a little different than in previous years. Many people may choose to vote early when possible, and many states are making it easier for citizens to vote by mail-in absentee ballots this year due to coronavirus. Every state's election rules are different, deadlines for mail-in absentee submission and early voting dates may be different from state to state, so check your states guidelines at voter.org.

Information provided by NDSC is strictly non-partisan. We will not support either the Republican or the Democratic party but will provide information as to the voting process.

















Dating and People with Down Syndrome continued from cover

Share information in concrete ways- There are usually plenty of opportunities to share information about dating well before your daughter is old enough to actually date. Look for teachable moments to share basic information about dating. For example, if an older sib has a partner, you can explain how they met, how they plan dates, and reasons people date. You could explain the purpose of dating by saying something like .. "your brother and _____ spend time dating to see if they are a good match for each other." If there is a break-up, "not all dating relationships work out the first time. It takes time to find the right person." Or, "this relationship didn't work out because your sister was going away to college, and she knew that keeping a relationship going with ____ at a distance would be too hard." Or, "they got divorced because the

relationship was unhealthy." Educating your daughter while she is able to observe others go through the process can help her acquire information in a concrete way and counteract the fantasy-like thinking that can happen with inexperience. Also, there are real, sequential steps and skills in the dating process that most people I work with are unaware of. For example, knowing how to find someone to date and then assessing for mutual interest are precursors to going on a date, but often these steps are skipped.

Check Yourself- With each step of maturity, as parents, we need to take time to examine our feelings, biases, and values. Dating is certainly one of those milestones. Some questions you can think about: What are my biggest hopes regarding dating? What are my biggest fears? What skills and information does my child need that would support success in the dating world? Are my standards for my daughter with Down syndrome similar or different than her other siblings? Same aged peers? Why? Why not? Being clear about your biases and values can help you shape parental messages that are unique to your family.

My son, a young adult, really would like to date but can't seem to find anyone who interests him. I would love for him to experience this rite of passage. What can I do?

The first step in the dating process is finding someone who interests you and this is often the most challenging and complex task for people with developmental disabilities. Your job as a parent is not to find someone for your son, but instead:

- Ensure your son has an active social life. It's hard to find someone if you are not out there meeting and connecting with others. Your son should have friends in both worlds- the world of typical people and the world of people with disabilities. He will, however, have a better chance at finding a dating partner if he is regularly interacting with other people with disabilities.
- Identify skill or social deficits that might be preventing your son from connecting with others. Do some quiet observing at social functions. Is he off to the side too nervous or anxious



to start up a conversation? Does he struggle with initiating, conversing, or ending a conversation? Or does he demand all of the attention and have a hard time sharing the limelight with another person? Figuring out what work is needed is a good first step.

• Pay attention to relationships that are working. For all of us, we tend to connect with people who have common interests and abilities. When he clicks with another person, facilitate additional opportunities for him to be with the person. Build on common interests to keep the relationships going if it's working!

My daughter is only interested in dating people who do NOT have a disability (her typical peers). How do I handle that?

This is a common scenario, particularly among a generation of young adults who have grown up fully integrated in school and in the community. The difficulty here is that in order for a dating relationship to develop, there must be mutuality of feelings between two people. I have not yet seen a dating relationship develop between a person with Down syndrome and a nondisabled peer (that doesn't mean it can't happen, but it is uncommon). More often than not, when one person has a disability and the other does not, the sexual feelings are typically one-sided and based on mutual friendship rather than a mutual sexual attraction. Successful partnering is more likely to happen when people have similar interests, abilities, and skills. When a person with Down syndrome labels a friend as a "boyfriend/girlfriend," they are more often misinterpreting the relationship based on sexual attraction they are experiencing.

The bigger question becomes why your daughter feels or perceives that people with disabilities are not potential dating partners? Is she uncomfortable around other people like them? Why is that? Is she aware she has a disability? How does she feel about that? Does she understand how her disability affects her uniquely? Teens and adults with Down syndrome that insist on dating people without disabilities may need counseling

to deal with a range of potential issues. For some individuals, this is a complex and difficult process. We know, for example, that people with visible disabilities experience prejudices, ridicule, and teasing more often that those who do not have disabilities. These experiences impact their perceptions of self. For others, self-advocacy training can help them learn about the disability movement, embrace their unique gifts and help them with self- acceptance as they enter the world of dating (self-advocacy training is typically introduced at the high school level). An important foundation for healthy sexuality and healthy relationships is embracing all aspects of who you are and feeling okay about what makes you...you.

I am so worried about my daughter being hurt or exploited. How do I prevent that from happening in dating relationships?

Chaperoning is an excellent way for inexperienced newbies to practice the rituals of dating in the context of supervision. I advise chaperoning if a person has had minimal experience with dating, has little information about the dating partner, has few skills, or will likely need some assistance with handling money, communication, etc. Chaperoning should be viewed as an opportunity to identify skills that are needed and then teach and allow them to practice those skills while they are being supported. As your daughter gains skills and becomes more confident and competent, her need for chaperoning (and your need to be there) should fade over time.

Also, group dating is a common way many of us learned to be around others safely before moving to couples dating. Same- aged, typical peers are often engaged in group dating in late middle school or early high school. These experiences are "practice sessions" for learning and understanding the social complexities of dating.

My son was in a healthy dating relationship for a few years. When things got serious, however, his partner's parents cut it off. He is still mourning the loss of this relationship. How do I help him?

Unfortunately, I hear this story often. People with Down syndrome and other intellectual disabilities do encounter a unique set of barriers/obstacles as they move from dating into a serious, long term relationship. For example, for most individuals who are interested in dating, some level of support is needed. Assistance with planning the date, coordinating transportation, and figuring out how chaperoning might happen is all work that needs to be done. Some families/support providers are up to the challenge; some are not. The couples I know who have been in dating relationships often have supportive staff or parents who understand this is a necessary and supportive role they play. In addition, for individuals who are living in the community, support providers are recognizing that clients desire to engage in dating relationships is normal and healthy, but we still have work to do to ensure proactive policies and procedures that support healthy sexuality for individuals in these settings. The challenge for paid support providers and parents often comes down to ensuring there is a balance between "safety" and "individual rights" and this is not always easy. In other situations, I find a paralyzing fear of sex and consequences of sexual activity interrupts the natural progression of how a relationship could develop and mature over time.

Reminder—The Down Syndrome News is Going Digital in 2021

This means that there is just one more edition that will be mailed to you. 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.

No matter the reason, break- ups are hard, and the feelings of loss are real. Explore options for counseling if you feel like he needs extra help in moving forward. Also, encourage and beef up socialization with friends, family, and others in his social network. It will take time to heal, but the more people who can support him during this process, the better.

Is it normal for someone to have no interest whatsoever in dating?

It is normal for there to be a range of interests in dating. For some people with Down syndrome, an interest in dating spikes in adolescence. For others, a desire to date comes much later. Some individuals may not think about dating until they meet a compatible partner whose mutual interest is obvious. And others may not be interested in dating or finding a partner but instead prefer an active social life with friends. All of these are normal.

I think my son is gay? How can I support them as they enter the world of dating?

Adolescence is a time when awareness of identity and sexual orientation sharpens. My experience (and the literature validates my experience) is that people who have intellectual disabilities who are gay experience much more oppression, marginalization, and many more layers of discrimination than gay people without disabilities. Families have also shared with me that organizations that support and welcome gay individuals are not necessarily disability friendly. Similarly, groups or organizations that support people with disabilities, do not necessarily embrace sexual diversity. And, those organizations that tout support for people with disabilities who are LGBTQ+ are often focused on people with a physical disability rather than intellectual disability. So, your son will likely need MORE support than someone without a disability. I strongly recommend counseling so he can understand this aspect of who he is as well as learn how to advocate for himself.

Rainbow Support Groups are popping up around the county and are designed specifically for people with intellectual and developmental disabilities who need support in a safe, comfortable environment. Their goal is to help people with I/DD talk about their issues and feelings, decide when they are ready to come out, and how to come out to other people.



Terri Couwenhoven, M.S. es un educadora sexual certificada que se especializa en desarrollar programas y recursos para personas con discapacidades intelectuales/desarrollo, sus familias y los profesionales que las apoyan. Terri ha combinado su experiencia con su interés y pasión por apoyar a las personas con discapacidades intelectuales y asegurar que tengan información accesible sobre la sexualidad. Además, es autora, coordinadora de la Clínica de Síndrome de Down del Hospital Infantil de Wisconsin y madre de un adulto con síndrome de Down.

Terri habla con padres, profesionales y personas con discapacidades intelectuales en todo Estados Unidos y sus talleres fueron unas de las presentaciones más solicitadas este verano durante la Convención de NDSC "Desde tu sofá". A continuación, ella ha compilado una lista de las preguntas más frecuentes de los padres de adolescentes y adultos con síndrome de Down y otras discapacidades intelectuales.

Citas y Personas con síndrome de Down —Preguntas Frecuentes Por Terri Couwenhoven MS

Mi hija es inmadura, pero espero que pueda salir con alguien algún día. Como padre, ¿qué puedo hacer para prepararla para citas futuras?

El hecho de que sea inmadura ahora, no significa que lo sea para siempre. A menudo las personas con experiencias limitadas pueden ser inmaduras. Esperemos que con las experiencias de la vida, incluyendo las oportunidades de salir con alguien, ella madure. La experiencia de vida es un gran maestro. Mientras tanto:

Compartir información de manera concreta-

Normalmente hay muchas oportunidades para compartir información sobre citas mucho antes de que su hija tenga la edad suficiente para salir con alguien. Busca momentos de enseñanza

para compartir información básica sobre citas. Por ejemplo, si un hermano mayor tiene una pareja, puedes explicar cómo se conocieron, cómo planifican las fechas y las razones por las que la gente tiene citas. Podrías explicar el propósito de las citas diciendo algo como.. "tu hermano y _____ pasan el tiempo saliendo para ver si son una buena pareja para el otro." Si hay una ruptura, "no todas las relaciones de citas funcionan la primera vez. Lleva tiempo encontrar a la persona adecuada". O, "Esta relación no funcionó porque tu hermana se iba a la universidad y sabía que mantener una relación con a distancia sería muy difícil". O, "se divorciaron porque la relación no era saludable". Educar a su hija mientras es capaz de observar a otros pasar por el proceso puede ayudarla a adquirir información de manera concreta y contrarrestar el pensamiento fantasioso que puede ocurrir con la inexperiencia. Además, hay pasos y habilidades reales y secuenciales en el proceso de citas que la mayoría de las personas con las que trabajo no conocen. Por ejemplo, saber cómo encontrar a alguien con quien salir y luego evaluar por interés mutuo son precursores para tener una cita, pero a menudo estos pasos se saltan.

Auto-Reflexiona- Con cada paso de la madurez, como padres necesitamos tomarnos un tiempo para examinar nuestros sentimientos, prejuicios y valores. Las citas son ciertamente



uno de esos hitos. Algunas preguntas en las que puedes pensar: ¿Cuáles son mis mayores esperanzas en cuanto a las citas? ¿Cuáles son mis mayores temores? ¿Qué habilidades e información necesita mi hijo para tener éxito en el mundo de las citas? ¿Son mis estándares para mi hija con síndrome de Down similares o diferentes a los de sus otros hermanos? ¿Son los mismos compañeros de edad? ¿Por qué? ¿Por qué no? Ser claro en cuanto a sus prejuicios y valores puede ayudarle a dar forma a los mensajes de los padres que son únicos para su familia.

A mi hijo, un joven adulto, le gustaría salir con alguien pero no encuentra a nadie que le interese. Me encantaría que él experimentara este rito de paso. ¿Qué puedo hacer?

El primer paso en el proceso de salir con alguien es encontrar a alguien que le interese y esto es a menudo la tarea más desafiante y compleja para las personas con discapacidades de desarrollo. Tu trabajo como padre no es encontrar a alguien para tu hijo, sino más bien:

 Asegúrate de que tu hijo tenga una vida social activa. Es difícil encontrar a alguien si no estás fuera conociendo y conectando con otros. Su hijo debería tener amigos

















en ambos mundos, el de las personas típicas y el de las personas con discapacidades. Sin embargo, tendrá una mejor oportunidad de encontrar una pareja para salir si interactúa regularmente con otras personas con discapacidades.

- Identifique las deficiencias de habilidades o sociales que podrían impedir que su hijo se conecte con otros. Haga una observación silenciosa en las funciones sociales. ¿Está demasiado nervioso o ansioso para iniciar una conversación? ¿Tiene dificultades para iniciar, conversar o terminar una conversación? ¿O exige toda la atención y le cuesta compartir el protagonismo con otra persona? Averiguar qué trabajo se necesita es un buen primer paso.
- Presta atención a las relaciones que funcionan. Para todos nosotros, tendemos a conectar con personas que tienen intereses y habilidades comunes. Cuando se conecta con otra persona, facilita oportunidades adicionales para que esté con la persona. Construir sobre intereses comunes para mantener las relaciones si está funcionando.

Mi hija sólo está interesada en salir con gente que NO tienen una discapacidad (sus compañeros típicos). ¿Cómo puedo manejar eso?

Este es un escenario común, en particular entre una generación de jóvenes adultos que han crecido completamente integrados en la escuela y en la comunidad. La dificultad aquí es que para que se desarrolle una relación amorosa, debe haber una reciprocidad de sentimientos entre dos personas. Aún no he visto que se desarrolle una relación amorosa entre una persona con síndrome de Down y un compañero no discapacitado (eso no significa que no pueda suceder, pero es poco común). En la mayoría de los casos, cuando una persona tiene una discapacidad y la otra no, los sentimientos sexuales son típicamente unilaterales y se basan en la amistad mutua más que en la atracción sexual mutua. El éxito de la asociación es más probable que ocurra cuando las personas tienen intereses, habilidades y destrezas similares. Cuando una persona con síndrome de Down etiqueta a un amigo como "novio/novia", con mayor frecuencia está malinterpretando la relación en base a la atracción sexual que están pasando.

La pregunta más importante es por qué tu hija siente o percibe que las personas con discapacidad no son parejas potenciales. ¿Se siente incómoda con otras personas como ella? ¿Por qué? ¿Es consciente de que tiene una discapacidad? ¿Cómo se siente ella al respecto? ¿Comprende cómo le afecta su discapacidad de manera única? Los adolescentes y adultos con síndrome de Down que insisten en salir con personas sin discapacidades pueden necesitar asesoramiento para tratar una serie de problemas potenciales. Para algunos individuos, este es un proceso complejo y difícil. Sabemos, por ejemplo, que las personas con discapacidades visibles viven prejuicios,

son ridiculizados y les hacen burla más a menudo que las que no tienen discapacidades. Estas experiencias afectan sus percepción de sí mismos. Para otros, el entrenamiento de auto-abogacía puede ayudarles a aprender sobre el movimiento de la discapacidad, abrazar sus dones únicos y ayudarles con la auto-aceptación al entrar en el mundo de las citas (el entrenamiento de auto-abogacía es típicamente introducido en el nivel de la escuela secundaria). Una base importante para sexualidad y relaciones sanas es abarcar todos los aspectos de quién eres y sentirse bien con lo que te hace... tú.

Me preocupa que mi hija sea lastimada o explotada. ¿Cómo evito que eso suceda en las relaciones de pareja?

Tener un chaperón para que los novatos sin experiencia practiquen los rituales de las citas en el contexto de supervisión. Aconsejo un chaperón si la persona no ha tenido mucha experiencia en tener citas, tiene poca información sobre la pareja, tiene pocas habilidades o probablemente necesite ayuda con el manejo del dinero, la comunicación, etc. Tener un chaperón debe verse como una oportunidad para identificar las habilidades que se necesitan y luego enseñarlas y permitir que practiquen esas habilidades mientras se les apoya. A medida que su hija adquiere habilidades y se vuelve más segura y competente, su necesidad de ser acompañante (y la suya de estar allí) debería desaparecer con el tiempo.

Además, las citas en grupo son una forma común en que muchos de nosotros aprendimos a estar cerca de los demás de forma segura antes de pasar a las citas en pareja. Los compañeros típicos de la misma edad suelen tener citas grupales a finales de la escuela secundaria o principios de la secundaria. Estas experiencias son "sesiones de práctica" para aprender y comprender las complejidades sociales de las citas.

Mi hijo estuvo en una relación saludable de citas durante unos años. Sin embargo, cuando la relación ser convirtió mas seria, los padres de su pareja lo cortaron. Todavía está de luto por la pérdida de esa relación. ¿Cómo puedo ayudarlo?

Desafortunadamente, escucho esta historia a menudo. Las personas con síndrome de Down y otras discapacidades intelectuales se encuentran con un conjunto único de barreras/obstáculos al pasar de una cita a una relación seria y duradera. Por ejemplo, para la mayoría de los individuos que están interesados en salir con alguien, se necesita algún nivel de apoyo. La ayuda para planificar la fecha, coordinar el transporte y averiguar cómo se puede acompañar es todo el trabajo que hay que hacer. Algunas familias/proveedores de apoyo están a la altura del desafío; otras no. Las parejas que conozco que han tenido relaciones de pareja a menudo tienen

P&R sobra COVID-19 y síndrome de Down

El objetivo de la información incluida en este documento de P&R es el de ayudarlo a cuidar a su ser querido con síndrome de Down durante la pandemia de coronavirus (COVID-19). Puedes compartir libremente esta información.

Hemos intentado responder a las preguntas que son importantes:

- Qué puede ser lo peculiar de este virus en personas con síndrome de Down
- · Cómo ayudar a impedir la extensión del virus
- Oué considerar al momento de tomar decisiones

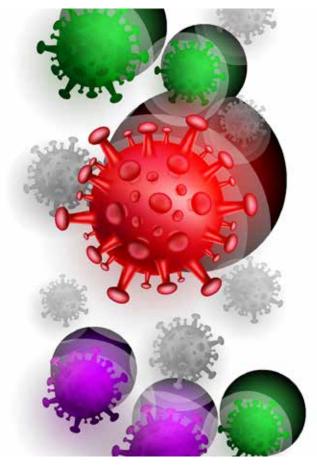
Muchos expertos han trabajado en conjunto para ofrecer esta información. Conforme se conozca más sobre este virus, se irá actualizando la información. Este documento no debe sustituir a la opinión y consejos de su médico. Debe consultar a su médico y demás profesionales sanitarios para conocer su opinión.

Si le parece que usted, su ser querido o cualquier otra persona bajo su cuidado puede tener COVID-19, llame inmediatamente a su médico u otro profesional sanitario. Llamar en primer lugar es importante: si va a una consulta o a un hospital, aumenta más el riesgo de contagiarse con el virus o de expandirlo. Si primero llama, la consulta o el hospital estarán preparados para recibirle.

En caso de urgencia, sírvanse llamar al 911*. En otros países, averigüe el número de emergencia local. Es importante que se cuide. Si enferma o se cansa demasiado, no podrá atender a los demás.

¡Manténgase sano! Hay otros que dependen de usted. Cuando pueda, contáctese con su familia y sus amigos. Pueden tener problemas con esta epidemia y se servirán de su ayuda.

Para acceder al documento completo, visite el sitio web de NDSC.



Mensaje del Presidente

Queridas familias del NDSC,

Me da mucho orgullo escribir esta primera carta como presidente de esta organización que amo tanto. Me enorgullezco y me siento muy abrumada cuando pienso en la gente que me rodea y en el trabajo que hacemos. Ver a nuestro equipo de empleados y voluntarios de la mesa directiva en acción, haciendo un giro de 180 grados después de tomar la difícil decisión de cancelar la convención en persona y moverla a una convención digital fue realmente extraordinario. Aunque estamos tristes de que no pudimos convivir juntos en persona, no fallamos en traerles la información y recursos que son el propósito de nuestro convivio anual.

Desde Junio hemos trabajado diligentemente en asegurarnos de que los derechos de gente con síndrome de Down sean protegidos durante la pandemia COVID-19. Hemos abordado las preocupaciones sobre el racionamiento discriminatorio de los tratamientos médicos y creado un recurso para los cuidadores en caso

de que un ser querido sea hospitalizado durante la pandemia COVID-19. Hemos creado bibliotecas para ayudar a las familias de los miembros a clasificar la avalancha de información sobre COVID-19 y el síndrome de Down, las relaciones raciales, y para ayudar a los autogestores a navegar las próximas elecciones.

El equipo del NDSC y el comité de planificación de la convención ya está trabajando en la planificación y preparación de nuestra 49ª edición anual de la convención del NDSC que se llevara acabo el 8 a 11 de julio del 2021, en el hermoso JW Marriott Phoenix Desert Ridge Resort & Spa en Phoenix, Arizona. Estamos contando los días hasta que nos reunamos todos de nuevo. Aunque somos famosos por nuestra "Reunion Familiar Gigante" y todo lo que trae esos cuatro días, por favor recuerden que estamos aquí los 365 días del año para proveer recursos y apoyo.



Shauntel Neal-Howe

personal de apoyo o padres que entienden que es un papel necesario y de apoyo que desempeñan. Además, en el caso de las personas que viven en la comunidad, los proveedores de apoyo reconocen que el deseo de los clientes de entablar relaciones de pareja es normal y saludable, pero aún queda trabajo por hacer para garantizar políticas y procedimientos proactivos que apoyen una sexualidad saludable para las personas en estos entornos. El reto para los proveedores de apoyo remunerado y para los padres suele consistir en garantizar que haya un equilibrio entre la "seguridad" y los "derechos individuales", y esto no siempre es fácil. En otras situaciones, encuentro que un miedo paralizante al sexo y a las consecuencias de la actividad sexual interrumpe la progresión natural de cómo una relación podría desarrollarse y madurar con el tiempo.

No importa la razón, las rupturas son duras, y los sentimientos de pérdida son reales. Explora las opciones de asesoramiento si sientes que necesita ayuda extra para seguir adelante. Además, aliente y refuerce la socialización con los amigos, la familia y otras personas de su red social. Llevará tiempo sanar, pero entre más personas puedan apoyarlo durante este proceso, mejor.

¿Es normal que alguien no tenga ningún interés en salir con alguien?

Es normal que haya una variedad de intereses en las citas. Para algunas personas con síndrome de Down, el interés por las citas aumenta en la adolescencia. Para otros, el deseo de salir con alguien viene mucho más tarde. Algunos individuos no piensan en salir con alguien hasta que encuentran una pareja compatible cuyo interés mutuo es obvio. Y otros pueden no estar interesados en salir o en encontrar una pareja,

sino que prefieren una vida social activa con amigos. Todo esto es normal.

¿Creo que mi hijo es gay? ¿Cómo puedo apoyarlo mientras entran al mundo de las citas?

La adolescencia es una época en la que se agudiza la conciencia de la identidad y la orientación sexual. Mi experiencia (y la literatura valida mi experiencia) es que las personas con discapacidad intelectual que son gays experimentan mucha más opresión, marginación y muchas más capas de discriminación que los gays sin discapacidades. Las familias también han compartido conmigo que las organizaciones que apoyan y dan la bienvenida a los gays no son necesariamente amigas de las discapacidades. Del mismo modo, los grupos u organizaciones que apoyan a las personas con discapacidad, no necesariamente abrazan la diversidad sexual. Además, las organizaciones que ofrecen apoyo a las personas con discapacidad que son LGBTQ+ suelen centrarse en las personas con una discapacidad física en lugar de una discapacidad intelectual. Por lo tanto, es probable que su hijo necesite MÁS apoyo que alguien sin una discapacidad. Recomiendo encarecidamente el asesoramiento para que pueda entender este aspecto de quién es y también para que aprenda a abogar por sí mismo.

Los grupos de apoyo Rainbow están apareciendo por todo el condado y están diseñados específicamente para personas con discapacidades intelectuales y de desarrollo que necesitan apoyo en un entorno seguro y cómodo. Su objetivo es ayudar a las personas con I/DD a hablar de sus problemas y sentimientos, a decidir cuándo están listos para salir del armario y cómo salir del armario con otras personas.

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.

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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.

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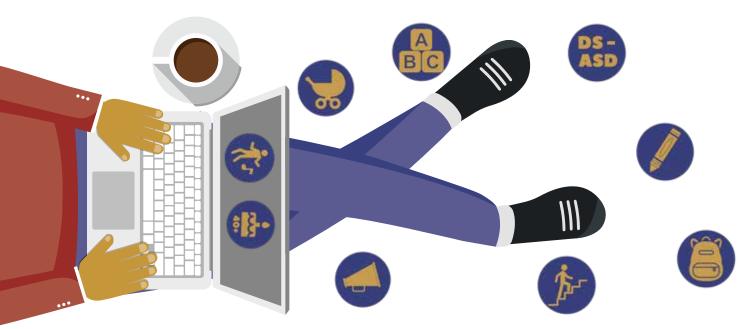
When we **empower** individuals and families from all demographic backgrounds, we **reshape** the way people understand and experience Down syndrome.



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Down Syndrome News

A newsletter published quarterly by the National Down Syndrome Congress



Ages & Stages is Coming Soon

As we found success with *Convention From Your Couch*, we have also learned that families are hungry for more virtual learning and sharing options. This fall we will launch a **new learning series titled Ages & Stages**. This program will include webinars, resources, and sharing session opportunities for individuals and their families covering all ages and stages of the lifespan. The series will include both free and premium options. **For more information and details coming soon, follow our social media pages and subscribe to receive our emails and monthly E-News.**