



PANDEMIC EDITION



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Down Syndrome Association
of Central Texas

2020 Impact Report





DSACT Mission

Our mission is to provide education, support, and resources to individuals with Down syndrome, their families, and professionals and the community while building public awareness and acceptance of the abilities of individuals with Down syndrome.



2020 Impact Report

Dear Friend of DSACT,

What a historic year - around the world and here at home! As I reflected on 2020, I flipped through my work journal where I scribble my To Do Lists, notes, and leadership thoughts about DSACT. The COVID-19 pandemic first showed up in February and has never left. I re-read my early notes - the different definitions of outbreak, epidemic, pandemic. Underlining terms like social distancing measures. For 3 days (3/17-3/19) I tracked infection numbers, trying to get a sense of scale and speed. On 3/17 there were 5,702 US cases and 106 Texas cases. Forty-eight hours later the sobering numbers were 13,159 across the US and 260 in Texas. Now we know that was just the beginning. A page later, I wrote down a new statistic showing Americans giving to charity had dropped to all all-time low (73%). When I wrote that, we had just canceled our spring Cocktail Bash fundraiser and member-wide 3/21 World Down Syndrome Day potluck. The early days of 2020 were filled with steadily constricting impacts to DSACT, our members, to all of us.

So what did DSACT do? We took a clear-eyed view of our budget and programs, surveyed our members, proofed it all against our mission statement - and we found *determination and resilience*. Wherever we could, DSACT moved recreational programs online, moved social gatherings to Zoom, transformed parent conferences into webinars. We filled our newsletters with resources and sent them weekly. We brought in nationally recognized medical and educational experts to conduct presentations at no cost to our members. We greatly ramped up our information and referral activities, answering concerns as parents struggled with everything from “my child won’t wear a mask” to the challenges of meeting the distance learning needs for a child with Down syndrome.

DSACT did this while trimming our budgets and watching every penny. Fiscal management was constant. In keeping a mission-based focus on our members’ economic concerns, we made a key decision to make our services free. To our donors, we made the value proposition that we were no longer in the “transactional” fundraising model of selling event tickets - but the deeper altruistic value of donating because DSACT has proved worthy of support by demonstrating our “mission in action.”

They responded in generosity and we are so grateful to them.

2020 dealt a harsh blow. The DSACT community faced it bravely, rallying together to support one another, to stay healthy mentally and physically, and to find joy where we could. And our membership grew! DSACT added over 1,300 new members in 2020 and expanded 18% to over 8,600 members around the globe. Here in Central Texas, we directly serve a community of 815 families.

We're proud to share this "Pandemic Edition" demonstrating DSACT's determination, resilience, and impact in 2020.



A handwritten signature in black ink that reads "Jennifer".

Jennifer A. Edwards
Executive Director

DSACT Vision

Our vision is a world in which all members, including those with Down syndrome, are accepted, valued for their uniqueness, respected for their abilities and contributions, and assured the opportunity and choice to create their own path to fulfillment and success.



Our DSACT community couldn't be together, but we still celebrated!

3/21 DSACT Day/World Down Syndrome Day

We had to cancel our potluck picnic party, but that didn't stop Central Texas from honoring us! 3/21 was declared "DSACT Day" by proclamation throughout Central Texas including Travis County, Austin, Round Rock, Leander, Pflugerville, and Dripping Springs.



Buddy Walk Your Block Weekend October 17-18, 2020

Our members made our Buddy Walk joyous by walking their neighborhoods, proudly displaying yard signs, sharing their pet photos, sending us their talent videos and photos, and generally having good fun! Throughout October, DSACT provided lots of free activities including classes, social gatherings, and DJ Mel's Living Room Dance Party. Check out our [member slideshow](#) and our [calendar of events](#).



Holiday Party December 13, 2020

Zoom Santa! Yes, even in a pandemic, DSACT was able to invite Santa Claus to host a fun holiday party of singing, storytelling, and the latest news from the North Pole. Members had chances to win Nutcracker ballet passes and we offered vouchers for the Trail of Lights drive-thru.



A New Partnership Helps Train UT Dell Medical School Pediatric Residents

Two major pieces of the DSACT mission are providing educational support to the Central Texas professional medical community and building awareness of the abilities of individuals with Down syndrome. DSACT took a major step forward in this area with an official partnership with the UT Dell Medical School.

In this project, DSACT families help first year pediatric residents learn about life with Down syndrome through interviews and conversations conducted via Zoom. In 2020, eight future pediatricians received information and tips from families, and all residents offered positive feedback and encouragement to continue the partnership, expressing how much they learn from each family about living with an individual with Down syndrome and the medical, educational, and social needs of individuals with Down syndrome from birth to middle age.

“The beginning (diagnosis) is so important. It’s very important to provide the diagnosis without apology, but also with certainty. I’ll also be mindful that there is a whole world beyond what we see in the clinic. For example, what can I do to help families think ahead to the adult years when individuals are out of school - how are they preparing for what to do during the day? What about transportation to work?”

— Dr. Amanda Stevens,
2020 UT Dell Medical School resident



“This is such a unique experience, so helpful for those of us who have thus far had little experience learning from families affected by Down syndrome. Learning about holding high expectations for individuals with Down syndrome has been helpful and eye-opening.”

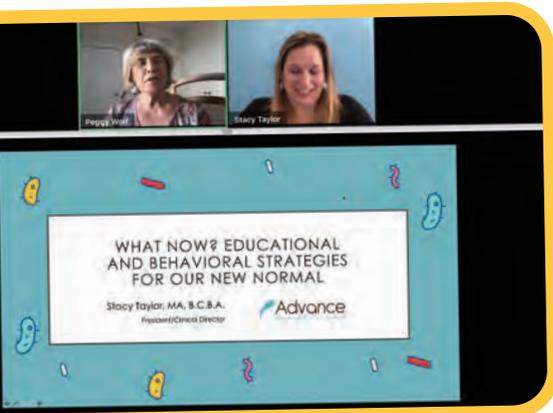
— Dr. Tiffany Robles,
2020 UT Dell Medical School resident

DSACT Supports New Adult Healthcare Guidelines

Other big medical news in 2020 included the release of the [first evidence-based medical care guidelines](#) for adults with Down syndrome. A project that had been in the works for several years, DSACT was proud to be a financial sponsor for the research and publishing of this important resource and we were excited to share it with the Central Texas professional medical community and DSACT members of all ages.

The Year of Webinars: for Training, Education, and Connection

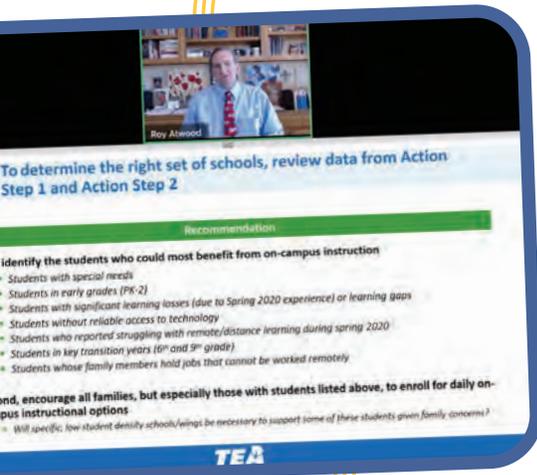
DSACT offered nine webinars to families and the professional community in 2020. Early in the year, we focused on helping families with practical questions about how to make the best of virtual therapy sessions. As the pandemic progressed and we realized how extensive and long-term our isolation would be, we focused on mental and physical health. And when we reached the fall and were still unable to gather in person, we had nationally-recognized experts join the DSACT community virtually.



Speech Empowerment: Shelley Bernis, licensed Speech and Language Pathologist and founder of Empower Telespeech shared her expertise with providing telehealth speech services to individuals with intellectual and developmental disabilities (IDD) as they prepare for and attend post-secondary education programs.

Making the Most of Teletherapy: Our friends from the physical and occupational therapy programs at University of St. Augustine answered questions about how to get the most out of the teletherapy experience, and shared exercises for babies and toddlers.

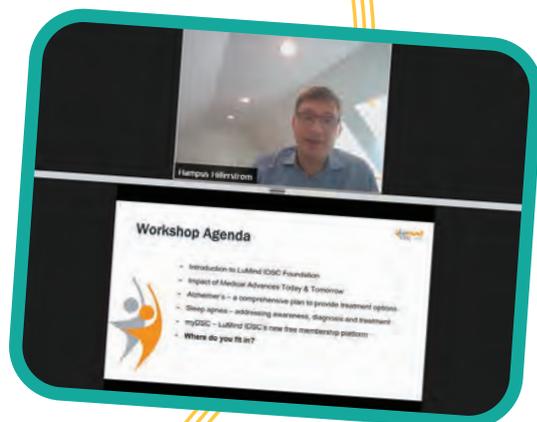
Teletherapy Guide and At-Home Activities for Babies and Toddlers: Therapy 2000's Macey Ciment and Ashley Jones showed us how to make the most of virtual occupational and speech therapy time for babies and toddlers, including new activity ideas to make therapy fun and engaging.



Homeschool/Remote Learning Family Discussion: DSACT organized a discussion and networking opportunity for families across the nation who are homeschooling, curious about homeschooling, or searching for tips about at-home learning for students with Down syndrome.

Down Syndrome, Health, and Isolation: Amerigroup community health worker Rogelio DeLeon and registered nurse Monique Gonzales focused on isolation and its effects on the health of individuals with Down syndrome. They reviewed general health considerations and expertise to improve health outcomes for individuals with Down syndrome.

LuMind's Community Engaged Approach to Tackling Alzheimer's Disease and Sleep Apnea in Down syndrome: LuMind IDSC Foundation CEO Hampus Hillerstrom shared how the LuMind team works tirelessly on advancing awareness, treatments, and diagnostics for these conditions that significantly affect our children and adults with Down syndrome. This webinar was generously provided in loving memory of DSACT member Kathy Kirkpatrick by her family.



What Now? Educational and Behavioral Strategies: Behavior expert Stacy Taylor shared tips and skills to effectively engage children to improve their online educational experience.

David Egan: More Alike than Different: Self-advocate David Egan discussed his current and past advocacy work and his new book, *More Alike Than Different: My Life with Down Syndrome*.

Legal Questions about Special Education? Get Answers! Attorney Roy Atwood provided expertise to parents struggling with at-home learning. He helped parents to understand compensatory education, legal education rights, contingency plans, and at-home supports.

DSACT made educational support during the pandemic a top priority

Workshops for Educators:

DSACT trained 134 professionals in Austin, Leander, and Pflugerville school districts and Lone Star School of Music. We provided expertise to the Leander ISD Superintendent and his team to improve communication with parents and to develop more inclusive opportunities for students with Down syndrome.

Parent support, consultations, & best practice guidance:

DSACT focused strongly on supporting parents and students with the sudden shift in daily routines and rapidly changing approaches to delivering education. Suddenly, children were home all day with very limited options for the interactions and routines they had known. Parents told us they needed support to keep their children from regressing academically and behaviorally.

DSACT responded by immediately offering individual and group consultations to share expertise and problem solve. We shared weekly newsletters to parents with helpful articles on a variety of topics: creating schedules, routines, using visuals, behavior, academic resources, emotional health, and ways to foster independence.

DSACT's Lori Tullos Barta Awards for Educator and Education Team of the Year

In 2020 we were delighted to celebrate the dedication of outstanding educational professionals who went above and beyond!

Educator of the Year: **Susan Thompson**, Hendrickson High School, Pflugerville ISD, was nominated by DSACT parent **Erica Licon** for the amazing support of daughter **Ari**. Ms. Thompson set high expectations and promoted inclusion within the school and the community. She encouraged the parents to also expect the most of Ari. School Principal Garcia stated: "I think that more than anything, Mrs. Thompson understands her role as an advocate for her students."



Education Team of the Year was awarded to **Kelly Looman**, **Lauren Meeks**, **Carolyn Bryant**, and **Lindsay Gumtow** of Parkside Elementary School in Georgetown ISD. They were nominated by DSACT parent **Rupali Ghudji** on behalf of her daughter **Ishika**. The team fully embraced inclusion to create an atmosphere in which Ishika could thrive. Principal Lauren Meeks said, "At Parkside, we wholeheartedly believe that every student should enter our building and feel a genuine sense of belonging. This award stands for the culture of inclusivity that Parkside has worked so hard to create for each and every one of our students."



New Parents and Speech Therapy

DSACT welcomed 25 new babies to our community

Welcoming new parents to our Central Texas Down syndrome community is one of DSACT's most important and loved traditions. With the help of our New Parent Coordinators, new parents are embraced and introduced to the world of DSACT's Baby Talk group. DSACT sends a new parent welcome package to new families to further the congratulations - books for parents and babies, stuffed animals and rattle, a resource guide, and more. DSACT appreciates the dedication and commitment of our New Parent Coordinators: Sara Dodd, Marne Litton, Brisa Salcido, and Norma Urbina.



"Your wonderful program helped us grow and understand Down syndrome better. Thanks for everything y'all do!"

— Jessica Hipolito, parent

Zoom saves DSACT's PEAK Speech Therapy Program

Like many DSACT programs in 2020, our signature speech therapy program - Parents Enhancing Articulation in Kids (PEAK) - experienced a significant creative makeover. For a program based on an in-person group model, we had to make quick changes in late February that extended through the year. Our eleven participants persevered through monthly individual Zoom therapy sessions with our speech therapy partners at Speak Freely.



"I think River's overall intelligibility has improved. Better enunciation and less consonant deletion. When we do not understand something he says, he will work very hard to be understood when he repeats it. He seems to have the tools and is using them."

— Bridget Henderson, parent

"Some news I wanted to share - we were recently with (but still mostly social distanced from) many family and friends we don't see often and had not seen at all since quarantine began. EVERYONE was commenting on, praising, and excited about Breda's speech progress. She is saying more words and you can understand more of the words she says. Thank you for making the PEAK program possible."

— Connolly Lees, parent

Maintaining connections and staying positive during the pandemic

DSACT worked hard to ensure our members could maintain their friendships and have some fun during the months of isolation. For health and safety reasons, our monthly in-person socials took a hiatus in 2020. But we got creative and as a result, our DSACT's teen and adult groups continued to meet online. We were happy to see engagement increase as the groups welcomed some new participants who hadn't been able to make it to the traditional Central Austin meetings.



DSACT recreational programs also moved online and were offered free of charge to our members. Virtual book club, social dance, and fitness bootcamp sessions kept members active and healthy at home. As a member of our national Down Syndrome Affiliates in Action group, we were able to offer our programs to Down syndrome associations across the country and share other groups' virtual program opportunities with DSACT members.

Donors & Supporters

From parents to large corporations, generous donors make DSACT programs and services possible. Without the help of these supporters, DSACT would not be able to serve our growing membership. Thank you to everyone who contributed their time and talent and to those who joined DSACT at our events and programs this year - we couldn't do this great work without you and we look forward to seeing you in 2021! If you'd like to join this group of supporters, please contact us at (512) 323-0808 or donate online at www.dsact.org/donate.



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Marne Litton
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Texas Pearls
Deborah Trejo
Norma Urbina



Join us in our great mission to support our community of over 800 families!

Donations are gratefully accepted and much needed. If you are interested in discussing a gift to DSACT, including us in your workplace giving campaign, holding a fundraiser, or including DSACT in your estate plan, please contact Jennifer A. Edwards, Executive Director at jennifer.edwards@dsact.org

The Down Syndrome Association of Central Texas is a 501(c)3 nonprofit organization serving the Down syndrome community for over 29 years. Our tax ID/EIN is 74-2577312. All donations are tax deductible, as allowed by law.

Down Syndrome Association of Central Texas

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