



A Parent’s Perspective

TxP2P Quarterly Newsletter

TxP2P Update

Laura J. Warren, Executive Director, TxP2P

Not sure how it got to be October but here we are - time to start getting ready for the holidays. See page 3 for *Respite: Taking Time for Yourself*, page 4 for *Let’s Take Care of Ourselves*, and page 7 for *Dealing with Stress at Holiday Time* from our staff!

The Legislature will be starting in January and there are a lot of families and advocates preparing for this session. Parents are especially motivated after hearing about the findings about Special Education caps on eligibility for children to get Special Education services and the cuts on therapy through Medicaid. We have a lot to work on. See below for opportunities to get involved under *Advocacy Update*. We offer another way to get involved in our Medical Education Program on page 2.

Transition is another big topic for this newsletter—see page 2 for a new resource, *The Garrett Center* page 4 on *The Importance of a Vision*, and page 5 on *Learning to Let Go*.

Our last conference is in South Texas this weekend after three other very successful conferences. Next year, we will start again in Tyler on February 23.

It’s also time for our newly started tradition of an Open House followed by our annual Vine to Wine fundraiser and awards celebration—Thursday, November 29th. Hope some of you can join us! We’ll follow this with our End of Year Fundraising Campaign - if you are able to make a donation, it will be greatly appreciated. You can go to our Donate page (<https://www.txp2p.org/donate/donate>) and make a donation anytime. Have a great fall!

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Save the Date for TxP2P 2018 Open House & Vine to Wine

Better Business Bureau Building, 1805 Rutherford Lane, Austin 78754

TxP2P Office Open House 3:30 - 5:30 p.m.

TxP2P Awards Celebration 5:30 - 7:30 p.m.

You can purchase tickets for Vine to Wine at <https://www.txp2p.org/donate/donate/v2w-tickets> or call the office, 512-458-8600 or 866-896-6001. There is no cost for our Open House!

Advocacy Update

Linda Litzinger, TxP2P Staff

As we anticipate the upcoming January through May legislative session, please contact me if you wish to attend our mock bill hearing on November 15th (10:30 AM), if you’d like to visit your legislator’s office, or if you wish to file a bill. Your agenda is our agenda! Linda.Litzinger@txp2p.org or 512-922-3810.

Below are some efforts already in the works!

Education:

- Better-prepare general education teachers to meet the needs of all students.
- Better-prepare school administrators to meet the needs of a diverse population.
- Create a system of informed and transparent parent/student consent and accountability for SHARS.
- Ensure the digital privacy of students with disabilities
- Increase student access to mental health supports.
- Prevent educators’ use of harmful, aversive behavioral interventions.
- Elimination of undocumented daily suspensions.
- Simplify due process proceedings to promote equity and access for students and parents.
- Improve school safety by mandating third-party law enforcement investigation of alleged school employee assault or abuse of a child with disabilities.



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Long Term Services/Healthcare

- Restoration of therapists’ pay to stop the closure of ECI programs.
- Improve consumer outcomes and protections in Medicaid Managed care.
- Expand community services; increase diversion slots.
- Regarding medical cannabis, increase research and disability diagnoses.
- Regarding dental care for adults with disability, address inequities.
- Increase attendant workforce through better wages and less complex reporting.
- Improve compliance with new Home and Community Based Settings rules for day habilitation.
- Improve disaster planning and recovery

Also, there are efforts around employment, wages, and housing, should you wish to join us!

Spotlight on a TxP2P Program
Medical Education Program (MEd)

Sherry Santa, TxP2P

The TxP2P Medical Education Program (MEd) is a unique program that offers young healthcare professionals a glimpse into our lives as parents of children with disabilities or other special health care needs. We work with different Medical Schools and Pediatric & Family Practice Residency Programs across the state. Through this

volunteer program, parents train to become Family Faculty Members. Once a parent is accepted into the MEd program, they have the chance to interact with students and residents by sharing their child’s medical journey either in person or via video chat. MEd is a positive teaching program and



we believe that our first-hand knowledge of our child’s care can be used as teaching moments to help change the future of healthcare for our children. Contact Sherry Santa at Sherry.Santa@txp2p.org or call 512-458-8600 or 866-896-6001 if you are interested in helping with this program.

The Garrett Center, a Great New Transition Resource

Rosemary Alexander, TxP2P Staff

We welcome a new resource into the Texas world of transition—the Garrett Center, started in 2017 and located at Sam Houston State University. The purpose of the Garrett Center is “to provide information, professional development, training and resources to educators, students with disabilities, their families and the community. The Garrett Center facilitates multi-level and wraparound systems change to improve post-school results for people with disabilities. The Garrett Center provides tools and information on its website and conducts program evaluations of all facets of transition services including work-based learning and 18+ adult transition services. The Garrett Center staff

also provides services such as training and technical assistance for all stakeholder groups.” From <http://www.shsu.edu/centers/garrettcenter/>

The website has information for students in elementary, middle and high school, for families and for educators. For families, there is a list of nearly 20 parent tools; click on one and find a brief article or a chart with helpful information, such as accessing post-secondary education, promoting independence and self-determination for your child, planning guides for ARD meetings and how parents can help with student-led ARDs.

For example, the Self-Determination T-Chart (T is the

shape of the chart) is very simple but might really inspire you to get started on your child’s independence. There are 2 columns, one that asks you to answer, What am I doing for my child that he can do for him/herself?, and the second column, What does my child need to learn? What tools will I need? Just answering these questions will help you become more aware of how to promote independence. If you ask your child to help you fill it out, you might get his or her buy-in and involvement in the process.

Please take a look at this new website and stay tuned to what innovations this center will bring to Texas. (<http://www.shsu.edu/centers/garrettcenter/>)



Respite: Taking Time for Yourself

Sometimes, the best thing you can do for your child is take some time for yourself.

What is respite?

The word respite means “break” or “relief.” Respite services are designed to offer families a break from caring for their child with developmental delays or disabilities. Respite allows parents time to take part in activities that they find relaxing, entertaining or restful while a respite provider cares for their child.

A respite break can mean an hour to take a walk while a respite provider stays in your home to care for your child. It may be a weekend away while your child is cared for outside of your home. It can also mean time to take a nap or see a friend while the respite provider takes care of your child.

How is respite different from day care?

Day care and traditional child care are provided on a daily or regular basis so parents can go to work or school. Respite, on the other hand, is typically provided on an irregular or short-term basis to provide the parent with a break from caring for their child with developmental delays or disabilities.

How can respite help my family?

Parenting is a difficult job and every parent can benefit from a break. Caring for a child with developmental delays or disabilities presents additional challenges that go beyond the everyday stresses of parenting. As a result, you may need longer rest periods or more down time. In addition, it may also be more difficult to find a qualified person to care for your child. Respite services can provide you with the needed support.

There are several resources you can access to support your families’ respite needs. **The Take Time Texas website** (<https://www.dads.state.tx.us/taketimetexas/>) administered by the Texas Health and Human Services Commission services provides many tools and a searchable provider database to access help and support for families.

If you are a family receiving Early Childhood Intervention (ECI) services, your ECI program may have funds to help you pay for respite services. Ask your ECI service coordinator about:

- the availability of ECI respite funds,
- levels of funding based on level of care needed,
- process for prioritizing

requests,

- wait list policy,
- annual hourly limit, and
- annual total dollar limit.

Also, ask your ECI service coordinator to help you find providers in your circle of friends and family or in your community. Respite can help strengthen your whole family. It can help decrease stress and help increase your family’s health and well-being. In addition to giving you and other caregivers some rest, it may help free up time to spend with other members of your family.

Here are additional tips for finding a respite provider:

- Ask family members, friends, other parents or your child’s doctor, teacher or therapist for recommendations.
- Find providers in your community on the following website: www.taketimetexas.org.
- Call the 2-1-1 information and referral line.
- Search for child care providers through the state’s Child Care Licensing website: www.dfps.state.tx.us/child_care.
- Contact local college for students studying in fields such as child development, education, nursing, physical, occupational, or speech therapy.
- Contact your local children’s hospital.

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The Importance of a Vision (or if you don't know where you are going, you'll probably end up some place else!)

Linda Jones, Texas Network Connections program, TxP2P

One of the first things we do when starting a network is to have the family and the person at the center of the network create a vision for that person's future. This is a process that engages the mind as well as the heart. We encourage folks to dream big and to write down their vision of what an ideal future for their loved one would be – in as great detail as possible. What would it look like? What kind of living arrangements would their loved one have? Who would they be living with? What would a perfect day look like from

start to finish? What kinds of activities would they be doing?

And what about our loved one's financial security? How will they be supported? Who will be in charge of this aspect of your loved one's future? How will you ensure your wishes will be followed?

Often we are afraid to think about the future. It is too scary. But if we allow ourselves to be paralyzed by fear and use words like *can't*, *shouldn't*, *if only*, *doubt*, and *impossible*, then it's as if we are

being bullied. It is critical that we find the courage to confront our fears, for if we don't make known what we want, then the chances of a good outcome will be greatly reduced. On the other hand, every single time we talk about our vision and we share it with others, we are taking steps toward achieving that vision. So if only for a few minutes every day, dream the impossible dream!!



Let's Take Care of Ourselves!

Greta James Maxfield, TxP2P Staff

In all the preparations and accommodations of our busy school year, let's prioritize self-care as an essential component supporting a successful year. Do this because you have unique contributions that no one else can offer your family and community, and self-care enhances your ability to be that resource. Do it because ignoring this obligation to yourself and your family contributes to the conditions that specifically target and plague families already coping with disability and chronic health care needs and the daunting statistics on the harm they cause us. As the topic of self-care presented during our recent statewide conference highlighted, (<https://www.txp2p.org/Media/files/3070-Taking-Care-of-Myself.pdf>), the consequences of inattention to caregiver needs are real and deserving of our every effort to mitigate. Be sure to visit the links to worksheets on our website to help you organize your thoughts and discover avenues for implementing your own plans. <https://www.txp2p.org/Media/files/7040-Stress-Management.pdf>

There are so many avenues to find and implement care for ourselves: body, mind and spirit.

Let's all take the next few days or weeks and make it a priority to consider ways that we can adapt to the demands of the school year schedule and the upcoming holidays while including our own well-being as a goal that concurrently demands our attention. Call a friend and ask, "How will you include time to access the care you need?" Or "How will your unique needs for rest and relaxation and recreation be served best given the constraints of time, money, energy, transportation, etc.?" Or "What activity best serves your mental and physical health and well-being?"

Just starting that conversation in your family and community will model self-care as a priority and encourage your friends and family to prioritize personal care, too. Ideally those positive conversations create a mindful atmosphere that can help you find and support reliable allies as you explore ways to start, maintain and/or improve self-care activities. It may also help you to identify persons in your sphere who have a lack of appreciation for your needs as you care for yourself and your family. Even persons such as that will have a better

role model in you as you persist in your pursuit of what is good for you.

Regularly reviewing and being open to ways to be intentional about caring for ourselves as caregivers is a way of modeling self-care for the caregivers in our lives, too. Surrounding yourself with peers that value self-care will contribute to your own wellness. With creativity and an open mind your pursuit of the kind of activities that will become self-care initiatives offers a pleasant pass time. All of these activities will help you gain ideas and insight from responses of others you surround yourself with to augment your own ideas, and move from ideas to action.

Remember to give of yourself by volunteering for causes you care about; childrearing-related or other causes is an excellent way to support your social, emotional and intellectual connections and that has measurable effects on the well-being of those who volunteer. (<https://www.helpguide.org/articles/healthy-living/volunteering-and-its-surprising-benefits.htm>)

Alan was 5 when I learned about overnight summer camps for children with disabilities. The idea of letting him go sounded pretty much impossible back then. As time passed and he was getting closer to adulthood, I started thinking of those things that other kids his age do away from their parents. Many of them even live on their own already. Then I started thinking how unfair it was for him not to realize that he can have fun and do things away from us. I know that nobody will take care of him the same way I do, but my biggest fear was that he could get hurt away from me.

The first time we tried an overnight camp was 2 years ago when Alan was 17. Pretty much he didn't want to go and I didn't want to let him go, but he still went to CAMP Camp hoping for the best.

The whole family walked away with a huge sense of emptiness. His little sister even questioned if we were still a family because we left him behind while he cried his eyes out when we said bye. Everybody said, "don't worry and enjoy your time!" but I literally cried for 3 consecutive days. It was a huge relief when I went to pick him up and found him well.

I could tell he was extremely emotional and pleased to see his mama again. I know he got homesick, but he said, "I want to come back next year." Last year, he didn't just go back to Camp, we also booked a week at Camp Summit.

The first week, we cried again, but we both knew we had to let each other go. The second week, I decided to enjoy my time and have some mommy-daughter time with his sister on a 4-day trip to Mexico while Alan was gone. After those two weeks of camps, Alan affirmed again that he wanted to go to camp this year.

This summer, we scheduled 3 different camps: Ranch Camp, Camp Blessing and Camp Summit. So far, every time we have dropped him off, we still come back with that sense of emptiness. His dad told me that the house feels so big without him... indeed, it does.

As I write this, he has successfully attended 2 out of 3 camps this summer. We just went yesterday to pick him up from Camp Blessing and we could tell that finally he is enjoying his time away from us.

During this time, he has made decisions that he usually leaves up to us, like what he eats, what he does or where we go for fun. Probably, he realized he has to step up for himself when mom and dad are not around.

This morning he didn't need help to eat breakfast and he had the initiative to say out of the blue what he wanted to do over the weekend. Camp has taught me that he isn't only able to have fun away from us, but it's helping him to grow, get empowered and accomplish goals that we have worked on for a long time. I'm so proud of him!

Also I have learned that the way I take care of him is not the only one that works and *different* does not necessarily mean *wrong*.

Now that school is just about to start, I will look into new camps and mark my calendar to make sure I will visit their different websites in January or February to check on the dates that Alan will attend camp next summer. He's already looking forward to the next time and so I am. Camp is one of those things in life that you don't fully understand until you experience it.



Different, a Novel by Janet McLaughlin

About a Girl with Tourette syndrome

Review by Denise Thompson, Absolute Love Publishing

Absolute Love Publishing is excited to introduce our new middle grade read *Different* to the Texas Parent to Parent community. *Different* features 12-year-old Izzy who has Tourette syndrome. An authentic and empowering read, this novel shows kids that, despite our differences, we all deserve to be liked and accepted for who we are. It is an ideal read for any children who feel “different.”

Different has received exceptional endorsements and reviews and is based on author Janet McLaughlin’s personal family experiences. McLaughlin hopes this novel will create greater understanding in families, schools, and communities.

Lora Netherland, M.Ed. Special Education Teacher: “... As an educator for more than 30 years, it is wonderful to find a text that promotes an understanding of differences. I have had several students with Tourette syndrome, and the availability of literature to build awareness for class was limited. This book lends itself to class discussions about what it means to be ‘different.’

Brad Cohen, Brad Cohen Tourette Foundation President, featured in the Hallmark Hall of Fame Movie *Front of the Class*: “... Living with Tourette syndrome is never easy, but knowing others around you understand where you’re coming from sure makes life a lot easier to manage. *Different* reminds us all to embrace our challenges and celebrate the ways we are all ‘different.’”

Amanda Talty, Tourette Association of America President and CEO: “... I applaud *Different* for bringing light to this misunderstood neurological condition and personifying the challenges our community overcomes while educating and encouraging compassion. The author does a great job of showing that the term ‘different’ can be used in many ways, and not just as a negative connotation.”

Different
Twelve-year-old Izzy wants to be like everyone else, but she has a secret. She isn’t weird or angry, like some of the kids at school think. Izzy has Tourette syndrome. Hiding outbursts and tics from her classmates is hard

enough, but when a new girl arrives, Izzy’s fear of losing her best friend makes Izzy’s symptoms worse. And when she sees her crush act suspiciously, runaway thoughts take root inside of her. As the pressure builds and her world threatens to spin out of control, Izzy must face her fear and reveal her secret, whatever the costs. Authentic and perceptive, *Different* shines a light on the delicate line of a child’s hopes and fears and inspires us all to believe that perhaps we are not so different after all.

Different (<https://absolutelovepublishing.com/different/>) is an ideal story for middle-grade readers, as well as a thoughtful addition to classroom bookshelves, libraries, and parent resource groups.

Ready to read it? *Different* is available in print and digital formats from [Amazon](#), [Barnes & Noble](#), [Kobo](#), [iBooks](#), and [Absolute Love Publishing](#).

Would you like to invite author Janet McLaughlin to give an online or in-person presentation to your school or organization? Contact ambassador@absolutelovepublishing.com.



In Memoriam

One thing we learned a long time ago is that among children with disabilities and special health care needs, some leave us way too early. It’s a sad reality we all hope will not happen but some of us will grieve our child’s death. All of us here at Texas Parent to Parent are deeply saddened when we hear of a family’s loss and grieve with you.

We want to share our condolences to our TxP2P family who lost a child recently:

Madeline Gambrell, daughter of Erica & George Gambrell

With deepest sympathy, the Staff, Volunteers, & Board of Texas Parent to Parent

Dealing with Stress at Holiday Time

Rosemary Alexander, TxP2P Staff

As the holiday season draws near, families of children with disabilities and chronic illness may wonder how to add holiday preparation and stress on top of everything else they already cope with. We thought that you might appreciate hearing how different families cope with stress during the holidays or how they have learned to enjoy the holidays! Here is what some of the staff of TxP2P has to say on the subject. (And if you want to add your own tips or strategies, go to the TxP2P Facebook to share.)

From Rosemary: Holiday/family dinner days at my house have often been very stressful, and I finally figured out why. My stress grew out of expectations, expectations based on my childhood memories and how our society paints a warm, glowing, perfect picture of Thanksgiving and Christmas dinner! I learned to change my expectations and my stress certainly went down! Now we have lasagna or Chinese take-out instead of turkey and all the trimmings, we laugh when my son who has disabilities leaves the room instead of opening his gifts, and we build in walks, naps, and separate time for everyone. We focus on just being together in the most informal, casual way possible. It usually works like a charm, and I now look forward to these times together.

From Susan: Holidays are always a special time for our family. It is a time that all the family gets together, including my grown siblings. My daughter and I love to decorate, cook, and get presents for others. Even as I have grown older, the little girl in me still feels the excitement of holiday events. We didn't have much growing up but my mom always tried to make it special. My daughter loves any holiday whether Halloween, Thanksgiving or Christmas so I continue to make those as special as I can. They can be stressful, if we can't get everything done in time! But we try to remember how fun it is to get together with family and friends, share a meal and exchange gifts.

From Patty: Holidays have changed as my children have grown. We traveled home to family in other states when they were small. That was so

very stressful, with the prep and wear and tear on vehicles, children and relationships. Travel is hard on our daughter with disabilities so when we finally made the choice to begin spending our major holidays as our own small family unit at home, it was such a relief! We had many years of the relaxed Thanksgiving and Christmas days which I had longed for. Although it was never easy and entailed lots of work, but in the end, we made so many good memories. Now that the children are grown, it has been a joy to see them beginning their own celebrations which include many of the traditions we began. The intense decorating and fun at Halloween. Hiding eggs for each other which they find all year long. The annual Turkey Trot and relaxed dinner prep and meal for Thanksgiving. Way too many presents on Christmas morning, opened one at a time (decided on by rolling dice) which can last 1/2 the day filled with laughter, coffee and relaxation. Being able to continue to share some holidays together, adding a grandchild into the mix, yet accommodating our daughter's health has been a new challenge, so being flexible in the coming years will be a cornerstone of many holidays to come!

From Liz: I spent holidays all day with my extended family. This was too hard on the kids and in turn, on us. I accepted that we have to cut down on what we used to do, and do more of the things they can handle, like seeing Christmas lights.

From Katrine: First, I was thinking this was not relevant to my family situation and that I do not do many accommodations...but then again WE DO! When my daughter was diagnosed with Type 1 Diabetes, 5 years ago in September at age 11, I was terrified of our first holidays: Halloween, Thanksgiving and Christmas. So much food! And so much snacking. All routines out the window. And so much carbohydrate counting to keep track of. Her stocking was kind of low on candy those first years. I exchanged it with gift cards to iTunes, lip gloss, bubble bath, bath bombs and scratch off lottery tickets. Our advent calendar that used to be full of candy and treats was filled with more events, such as going to Zilker Park to see the Christ-

mas tree, a walk/drive around the neighborhood to see the lights, movie tickets, a planned game night with friends and so on. I tried to not add on a bunch of stuff cause the holidays are busy as it is, so I really just tried to write down things we were doing anyway, roll it up and tie it to the advent calendar (sometimes day of as plans changed). I also exchanged some of the candy for tiny surprises, and as a girly-girl, she was super excited to open up a new color of nail polish. And she really didn't care what she opened up. Part of the excitement was to open up something that had been our tradition her whole life.

We have had our mishaps, like when we showed up for Thanksgiving dinner over an hour away from home without any insulin! And we didn't noticed until when she was eating dessert! Insurance refused to refill it at the nearest pharmacy as we had just picked up our monthly supply. Doctors' offices were closed so we could not get an emergency vial filled. We ended up paying out of pocket for that one vial! Since then I have learned there are tons of Type 1 Diabetes Facebook groups where people would love to help each other out for emergencies like that, but it was our very first time and I freaked out and just bought a \$100 vial of insulin and told myself to Never Again forget the insulin! Which of course we have!

From Martha: On Thanksgiving and Christmas Days, we have no dress code, it's very informal, and everyone eats anywhere they want to sit down. The whole extended family gets together and we cook all day long, then eat at night. The kids can be anywhere with anyone or do their own thing. It's a great day!

From Cynda: For my daughter with autism, the unexpected is a disaster, so I try to have a plan ahead of time, a schedule in place, a structure that reduces her anxiety. We also try to have something the same each year—we are building our traditions!



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Conference Schedule

Date	Conference Title	Location	Registration Information
October 20, 2018	Txp2P South Texas Parent Conference	San Juan	www.txp2p.org
October 20, 2018	12th Annual AccessAbility Fest & AbilitySTRONG Parade	San Antonio	www.accessabilityfest.org
October 25-26, 2018	19th Annual Chronic Illness and Disability Conference—Transition from Pediatric to Adult-based Care	Houston	https://www.baylorcme.org/
February 10-12, 2018	2019 Inclusion Works Conference— "Rock the Boat"	Denton	www.thearcoftexas.org/ inclusion-works
February 20-22, 2019	2019 Texas Transition Conference	San Antonio	www.ttc.tamu.edu/texas- transition-conference