



TxP2P Update


Laura J. Warren, Executive Director, TxP2P

Spring rains bring wild flowers. **And floods!** But not your typical flood! Once again, we had a flood on the 2nd floor of our building for the 2nd time of having an office as TxP2P. For those of you who remember our first flood (frozen then broken pipe in the attic at the AGE Building), this is not a fun experience. However, we are now all dried out, the wall is repaired and the latest rain did not bring anymore floods!

Our 14th Annual **TxP2P Statewide Parent Conference** in San Marcos is Friday & Saturday, June 22nd & 23rd. We are very excited to announce that Zach Anner, award-winning comedian, show host, and public speaker, will be our Keynote Speaker on Friday. Zach has been a guest star, and is now a full-time writer on, ABC’s hit family sitcom, *Speechless*. He also has a memoir called *If at Birth You Don’t Succeed: My Adventure with Disaster and Destiny* and will present on *Life Gives You a Wheelchair, Make Lemonade*. Registration is still open but child care, parent scholarships, and hotel rooms will soon be gone. You can find the registration on the sidebar of our home page of our website, www.txp2p.org.

We have a date! Our **South Texas Parent Conference** in the Rio Grande Valley will again be in San Juan at the PSJA Early College High School and will be on Saturday, October 20th. Call for speakers is now open - If you want to do a presentation for us, please contact Cynda at Cydna.Green@txp2p.org or go to the home page sidebar (www.txp2p.org) for more information. We are accepting Speaker Proposals until August 24th.

I hope you all have a great summer! I know that you are probably preparing for your summer activities but don’t forget that we still have the threat of hurricanes and tornadoes for the next 6 or 7 months. One of the articles in this newsletter is on Emergency Preparedness – **please read it**. Although I grew up on the Galveston Bay, it never occurred to me until Hurricane Katrina that you could go away for a weekend and your house might not be there when you get back. What would you do? Where would you start? It’s best to be prepared!

Volume 18, Issue 1
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Inside this Issue:
♥ TxP2P Update—pg. 1
♥ Cyber Bullying—pg. 1 & 2
♥ Emergency Preparedness—Pg.3
♥ Health Care in Transition—Pg. 4
♥ Texas Network Connections—Pg. 4
♥ Spotlight on TxP2P —Pg. 5
♥ Travel the World —Pg. 5
♥ Chutes & Laughter —Pg. 6
♥ In Memoriam—Pg. 6
♥ Helping Your Child Run the Show —Pg. 7
♥ Conference Schedule—Pg. 8


Cyber Bullying at School

Linda and Amy Litzinger, TxP2P Staff

David's Law passed during the last legislative session, intending to prevent cyber-bullying, possible student suicides, and/or student retaliation against schools. The law makes cyber-bullying a punishable offense, and adds responsibilities to schools.

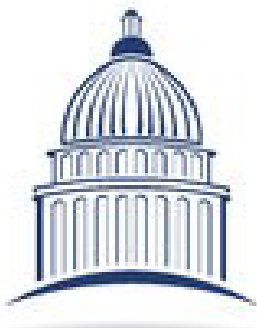
The bill which took effect on 9/1/2017 was named after a young man named David who took his life after being bullied. It adds the definition of bullying to Texas Education Code, and thoroughly

describes cyberbullying, which has lately become prevalent. The bill makes it clear that the law applies to bullying initiated on campus property, and even outside of school if it disrupts school function or a student’s educational opportunities. Schools are given numerous new responsibilities regarding bullying, including notifying parents if their child is bullied.

In addition to allowing for restraining orders, it requires a parent of the perpetrator to take action to

curb the bullying. Finally, the bill adds language regarding fines, expulsion and jail time.

Continued on page 2



Cyber Bullying at School

Continued from Page 1

Attorney Benson Varghese from Fort Worth writes a great description in *The Jurist* of the new law, which is titled "[Nine Things You Need to Know about Texas' New Cyberbullying Law.](http://www.jurist.org/hotline/2017/08/benson-varghese-cyberbully-texas.php)" (<http://www.jurist.org/hotline/2017/08/benson-varghese-cyberbully-texas.php>)

Mr. Benson's included this definition of cyberbullying, "Cyberbullying is basically the electronic version of bullying. It occurs when an individual engages in bullying through the use of any electronic communication device, including a phone, computer, camera, e-mail, instant message, text message, social media, or website. Some examples of cyberbullying could include:

- Sending viscous text messages, emails or instant messages about a student,
- Spreading rumors or gossip by posting it to social networking sites,
- Taking and sending embarrassing pictures or videos without permission,
- Creating a fake profile and pretending to be another student."

Mr. Benson has also summarized a school's responsibility under the new law, "The law requires school districts to include cyberbullying in their district policies and to adopt districtwide policies and procedures that:

- prohibit bullying of a student;
- prohibit retaliation against anyone who provides information about a bullying incident;
- establish a procedure for notifying parents and guardians about bullying incidents;
- establish actions students should take to obtain assistance and intervention in response to bullying;
- set out available counseling options for victims, perpetrators, and witnesses of bullying;
- establish a way for students to anonymously report bullying; establish procedures for investigating and verifying reported incidents of bullying;
- prohibit disciplinary measures on a student who is a victim of bullying and used reasonable self-defense in response to the bullying;
- ensures that discipline for bullying a student with disabilities complies with federal law, including the Individual with Disabilities Education Act."

Recently, in a Texas House of Representatives Public Education hearing, we learned that Texas Education Agency has created a website on [cyber-bullying](https://tea.texas.gov/Academics/Learning_Support_and_Programs/Technology_Resources/Internet_Safety_Cyberbullying/) (https://tea.texas.gov/Academics/Learning_Support_and_Programs/Technology_Resources/Internet_Safety_Cyberbullying/), yet currently there is no mandatory training of teachers, students or parents. Families can ask their school for training.

STOP
cyberbullying



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Emergency Preparedness

Since Texas is prone to natural disasters and extreme weather, making a plan and taking steps to be prepared for such events can reduce the impact an emergency or natural disaster has on your family. And it can be a lifesaver for children with disabilities and special healthcare needs.

Planning for an Emergency

To plan for an emergency, families of children with disabilities and special healthcare needs should consider the following:

- Create a page of simple emergency instructions for your home – with information about exits, fire extinguishers, and power shut-offs. Put them where you can easily see them. Do emergency drills.
- Decide where you would find shelter in case of an emergency. This may be in your home, local hospital, school, and church or a nearby city. If possible, take your child to visit any location away from your home so that they become familiar with it before an emergency happens. Take a picture of the location to help during drills.
- Make a list of family, friends, teachers, neighbors, and other caretakers, including their contact information; these individuals might help you in an emergency or natural disaster.
- Remember your pets and service animals. Include their food, paperwork, licenses, and care in your plans.

Complete a short [emergency information form](http://www.texasprepares.org/English/RoN_plan-cards.pdf) (http://www.texasprepares.org/English/RoN_plan-cards.pdf) to keep in your child's backpack, at school, and at other places your child might be. Try to keep an electronic copy that's easy to get to if you need to evacuate. You can use an online storage system or email it to someone you trust who does not live in your community. Be sure that every one of your child's caregivers knows where to find these forms.

If your child uses a machine that needs electricity, such as a ventilator, oxygen, or feeding pump, call your local power company and talk to them about your child's needs. You can find their number on your monthly utility bill, and you can ask them what you need to do to get a higher priority placed on your home in case of a power outage. Also, keep a portable generator and fuel. Medicaid [Waivers](https://www.navigatelifetexas.org/en/insurance-financial-help/texas-medicaid-waiver-programs-for-children-with-disabilities) (<https://www.navigatelifetexas.org/en/insurance-financial-help/texas-medicaid-waiver-programs-for-children-with-disabilities>), [insurance plans](https://www.navigatelifetexas.org/en/insurance-financial-help) (<https://www.navigatelifetexas.org/en/insurance-financial-help>), or [special grants](https://www.navigatelifetexas.org/en/insurance-financial-help/funding-grants-for-children-with-disabilities) (<https://www.navigatelifetexas.org/en/insurance-financial-help/funding-grants-for-children-with-disabilities>) might pay for one.

You might want to let your local fire department and 9-1-1 team get to know your child and their needs. See our [Working with Emergency Responders](https://www.navigatelifetexas.org/blog/article/working-with-emergency-responders) article (<https://www.navigatelifetexas.org/blog/article/working-with-emergency-responders>) for ideas on how to do this.

After you have an emergency plan for your own home, make plans for other places your child spends time. This could include your child's school, therapy centers, grandparent's house, or summer camps.

The "GO Kit"

A GO kit has all the things your child or family needs if you are in an emergency situation. It should include a weeklong supply of the things your child needs to live and thrive. Remember, some supplies and medications might be hard to get during a natural disaster or emergency.

Your GO kit might include:

- Water, ready-to-eat food, batteries, flashlights, and cell-phone chargers.
- Personal hygiene supplies (including wet wipes, small towels, and antibacterial foam).
- A copy of your child's emergency plan and care notebook. See our [Organizing Medical Records](https://www.navigatelifetexas.org/en/diagnosis-healthcare/care-notebook) (<https://www.navigatelifetexas.org/en/diagnosis-healthcare/care-notebook>) page to learn more about care notebooks.
- Medications, medical supplies, and equipment.
- Favorite toys or stuffed animals, headphones, sleep masks, or other comfort items.
- Copies of important documents like a birth certificate, Social Security card, guardianship paperwork, and powers of attorney. Keep these documents in a waterproof container.
- A credit card and cash.
- One or two changes of clothing. People are likely to donate clothes to your family in an emergency.

Set a schedule for updating your GO kit. Check expiration dates and see if everything is still useable. Here are a few more [GO kit suggestions](http://www.dshs.state.tx.us/preparedness/e-prep_public.shtm) (http://www.dshs.state.tx.us/preparedness/e-prep_public.shtm).

To read and learn more about emergency preparedness, visit the [Navigate Life Texas](https://www.navigatelifetexas.org/en/family-support/emergency-preparedness-for-families-of-children-with-disabilities) (<https://www.navigatelifetexas.org/en/family-support/emergency-preparedness-for-families-of-children-with-disabilities>) website. There you will find a very informative [emergency preparedness video](https://www.navigatelifetexas.org/en/videos/video/emergency-preparedness) (<https://www.navigatelifetexas.org/en/videos/video/emergency-preparedness>), a host of additional suggestions, and resource links that can assist you in case you encounter an emergency.

[Navigate Life Texas](http://www.navigatelifetexas.org/en) (www.navigatelifetexas.org/en) contains a wealth of resources for families of children with disabilities and special healthcare needs and provides information about many different topics.

Health Care in Transition: It is Never Too Early or Too Late!

Ivy Goldstein, TX DSHS

“If you don't know where you are going, any road will get you there.”
~Lewis Carroll~

Truer words were never spoken, especially when it comes to transition planning. A good plan with clear direction is more likely to lead to the desired destination. Surprisingly, essential information about one area of transition is often overlooked in the planning process - health.

All of us need our health in check to be successful pursuing a vocation, higher education, employment, and even having fun with friends. The road to the adult health care system is bumpier when a student has a special health care need, but schools can help smooth the path. Making sure the change from pediatric to adult health care is addressed by the ARD Committee and related goals are included in student IEPs will promote better transition outcomes.

Here are some things to consider:

For students heading to college - does the youth/young adult know how to explain their medical condi-

tion to others? This will become important as they will need to self-identify to access disability services. Have they identified health care providers near campus and do they understand how alcohol interacts with their prescription medications? What IEP goals can support their learning and development in a college setting?

For students with higher support needs that may be in a Life Skills class - does the youth/young adult understand how to make healthy food choices or the importance of daily exercise? Is there an opportunity to role-play in class? Can the parent follow up the classroom instruction with a home exercise to call in a prescription refill to the pharmacy? Call a doctor's office and make an appointment? Again, what IEP goals can support learning and skill development?

For students with medical complexity (i.e. dependent on technology) - are parents having conversations with providers to find out how long their son or daughter can continue being seen in the practice after age 18? Are they connecting with other parents and finding out

who the adult providers are with the knowledge and experience to provide care in adulthood? Planning for the transition to the adult health care system includes students with significant support needs, too.

Through the advances of modern medicine, the overwhelming number of children and youth with special health care needs will celebrate their 21st birthday. There are many tools to support the successful transition from pediatric to adult health care. Here are two:

Got Transition? -- The national technical assistance center focused on improving transition from pediatric to adult health care. See their Readiness Assessment for Youth, Readiness Assessment for Parents/Caregivers and many more valuable resources at <http://www.gottransition.org/>.

Navigate Life Texas- a website created for parents, by parents, that is beneficial to all, including educators. Lots of resources on transition to adulthood, including medical transition, are featured. <https://www.navigatelifetexas.org/en>.

A Big Hug of Support

Linda Jones, Texas Network Connections - TxP2P

Ivy first heard Rosemary Alexander talk about networks over a decade ago. Years later a friend told her, “You have to do this for Sophie!” Yet another 5 years passed. Then when her daughter turned twenty, a major breakthrough occurred. Ivy's concern for Sophie's well-being outweighed her fear of asking people to be part of a network. She shared, “My biggest fear was asking people who were not family or close friends. I just couldn't bring myself to do it.”

About that time, Texas Network Connections was birthed by Rosemary and Denise Sonleitner as a program of Texas Parent to

Parent. Though she has always been a “do-it-yourselfer,” Ivy realized that she didn't have to start a network alone. She decided to tap into the expertise that existed. Denise helped her craft a letter of invitation. Once she had the tool with the words to ask, she floated it by an old friend. Her overwhelmingly positive response was significant and gave Ivy the courage to keep moving forward with the formation of a network.

Almost 4 years later, “Snapshots”, Sophie's 18 member network, is well established. Reflecting back, Ivy says the first two years were spent with the network members getting to know each other. Since then, they share each other's

birthday celebrations, they helped plan Sophie's transition from the school system into community life, and generally, they help Ivy be more strategic in planning the future. Ivy shares that she is most surprised and delighted in the feeling that she doesn't have to shoulder everything by herself. “Having the network is like a big hug of support!”



Spotlight on a TxP2P Program

PATHWAYS TO ADULTHOOD TRANSITION PROGRAM

Cynda Green, TxP2P Staff

Do you wonder what your child with a disability will do after graduation? Are you worried about where your child will work, live and what they will do all day? If so, the Pathways to Adulthood program is here to help support you and your family through the process of your child's transition to their life after graduation. We at TxP2P know that families may feel overwhelmed and anxious as they face transition issues, and we will help you gain the information, ideas, tools, and support needed to plan for the future. The following are ways we help.

We provide information on:

- Funding sources
- Legal issues: guardianship and alternatives, such as power of

attorney and Supported Decision Making

- School transition services and maximizing remaining school years
- Medical Transition
- Opportunities for work
- Ideas for establishing a positive, family-run home
- Building networks of support
- Emotional obstacles parents face in planning

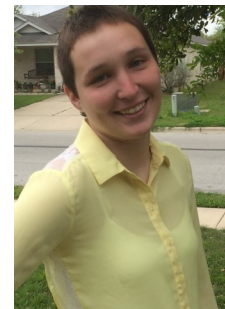
Here are ways we can help:

- Parent Transition Volunteers to provide one-on-one emotional support
- Workshops across the state regarding transitioning to adulthood (see the [TxP2P homepage \(https://www.txp2p.org\)](https://www.txp2p.org) for current schedule of workshops)
- TxP2P transition listserv that

provides a way to share ideas and information

- Two full days of transition planning sessions at our annual statewide conference and sessions at each of our 3 regional conferences
- Transition staff in the office to take phone calls on transition questions

For more information, please call or email the Transition Coordinator, Cynda Green, at 737-484-9045 or email her at:



Travel the World and Bring it All Home

Greta James Maxfield, TxP2P Staff

"The fact is, with every friendship you make, and every bond of trust you establish, you are shaping the image of America projected to the rest of the world. That is so important. So when you study abroad, you're actually helping to make America stronger." – Former First Lady, Michelle Obama

Each year, many international students enter private homes, schools, and communities worldwide to participate in this cooperative mission. Most of those students are high functioning with no known health concerns.

However, study abroad may have particular benefits for persons who have disabilities because of the opportunity it affords to enhance autonomy, confidence, self-acceptance as well as executive functioning skills. Through the expansion of social networks and

social/emotional learning opportunities, sending students abroad may also help our communities build and maintain more bonds, in more places, with the benefit of improving the lives of persons with disabilities and their families anywhere they may happen to live.

Recently, the Texas Parent to Parent newsletter shared an interview with a young Spanish student in the midst of an adventure: literally making her way blindly to Texas where she is enjoying every minute as an international high school exchange student. She has the good fortune of unwavering support from a delighted host family, and she is making the most of the opportunities that this journey offers. She is making real her vision of herself as an independent individual, enjoying the pursuits of a self-determined person and building international

bonds of friendship and exchange that impact all of us in positive ways.

That story emphasizes a world of possibilities life has to offer including for those with disabilities. Educational travel may be one of the best ways that we can reach beyond borders, literal or figurative, beyond comfort zones and safe spaces to influence others, attract them to our causes, and interact with the world more fully, representing ourselves and our families as we are. Some helpful websites:

[Disability-Focused International Exchanges | Mobility International USA](https://www.miusa.org/exchanges)
www.miusa.org/exchanges
[Disability Travel: International Programs - Transitions Abroad](https://www.transitionsabroad.com/listings/travel/disability/internationalprograms.shtml)
www.transitionsabroad.com/listings/travel/disability/internationalprograms.shtml

Chutes & Laughter

Carla Scruggs, TxP2P Volunteer

Jonathan Scruggs has goals. One of those goals is to own a business offering games (mostly parachute games) to families for birthday parties or just plain fun.

Jonathan was homeschooled after third grade, when it became apparent he couldn't learn in an environment that bothered his sensory system so much, and in a school that didn't offer a specialized reading comprehension program.

Jonathan loved homeschooling. First, everything could be slowed down. He could go on a field trip and take all the time he needed to learn about an exhibit in a museum or how a goat dairy operates. He could go to speech and occupational therapy when other kids were in school, so he wasn't trying to learn those things after a long school day. He also got to spend more time with his little sister.

Homeschooling worked well for Jonathan, so he continued all the way through high school. He had always done several jobs around the house, so during high school he started pet sitting, watering gardens, and mowing for neighbors. He also learned to drive and it was a proud day when he received his driver's license.

When Jonathan graduated from high school he attended the STEPS (Skills, Training and Education for Personal Success) program at Austin Community College. He learned more about using the computer and personal finance, and passed the para-educator institute training.

One month before graduation, Jonathan went to work for a woman who qualified for household help. He has been working for her since April 2016, helping keep her house clean and organized, and sometimes picking up prescriptions and groceries. He also picks up recycling weekly for the Backpack Coalition through his church.

Jonathan enjoys being active and is a member of the Dangerous Athletes Adaptive Rowing Team. He also loves kayaking and paddle boarding, cycling, and running with friends in the Turkey Trot and the Austin Half-Marathon.

Jonathan has been leading parachute games since May 14, 2012, starting with a homeschool co-op field day, then large homeschool group field days, park days, and Longhorn Best Buddies Field Day. It is one of his favorite things! Jonathan and his parents were part of an entrepreneurship class led by Picasso Einstein, a company that teaches people with developmental disabilities (and their families) how to create self-employment for meaningful employment.

Now, Jonathan and his parents are working toward developing a small business so Jonathan can do the thing he loves and be paid for it. He will still volunteer to run games at parks periodically, so let us know if you'd like to be notified when he comes to a park next! His email is ChutesAndLaughter@gmail.com



In Memoriam

It is with great sorrow that we announce the passing of one of the founding members of Texas Parent to Parent. **Madeline Sutherland** made a tremendous impact on the families of Texas as the founding director of the Infant Parent Program for children 0-3 in Austin. As a tireless advocate for parents and children with disabilities, she was a tremendous source of support and encouragement as we began TxP2P.

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

Helping Your Child Run the Show: Making Choices

Amy Litzinger, TxP2P Staff

This is part two of a three part series on helping your child learn and practice self-determination skills.

As a little kid: I made a lot of little choices, like what color clothes to wear or what to drink for meals. Most of the time people knew what I was going to choose anyway, but I liked having the options. It helped me learn that it mattered what I said. I could change things. All of the options were equally weighted, and wouldn't make much material difference if chosen.

Older kid: I started making choices about my activities. This was exciting for me, especially when I got to pick the order of when I would do things. I also started picking activities based on my own interests and developing friendships. I decided about planning a small outing, which after school or summer activity to participate in, and picking my own snacks or lunch.

Middle school: Choosing my friends and my activities became even more of a highlight. I really liked choosing my own electives, and choosing my group often went hand-in-hand. I made some less than wise choices about what order to do things and where to put my homework. How to spend unstructured time became very important socially. I still don't like when others try adding unexpected items. I also didn't like when adults that were required to be around me would take away my friends' choices without cause, because it reflected on me. Good days were when adults listened to my choices, especially around natural supports.

High school: Now there were even bigger consequences, especially those of not giving me choices. This became a problem at school because my peers were being faced with choices I was never even exposed to because of the presence of an adult. Often choices were taken away from me unnecessarily, simply because I had a disability. Also, choices and responsibilities given to me at home were not matched at school because my paraprofessional was a school employee, rather than my hired attendant. My peers were driving, choosing where to go, even choosing first jobs. I didn't get this preparation. I discovered I love Person Centered Thinking!



College: This is the land of too many choices. I appreciated that my parents were still around to catch me or help me make decisions, but I liked being the one with the final say. Professors gave me choices, including how and when to disclose my disability. Before, I readily talked about my clearly visible difference, but I liked this, especially choosing how to meet my needs and what to try next. Medical decisions also became big in this era. Some of these were scary. I wish I'd had more guidance.

Grad school: I ended up having fewer choices socially because most of the time I wasn't living on campus, and most of my friends had family responsibilities, but I had more choices professionally and in my home life. I enjoy making choices about research and tailoring my own assignments.

Employment: Making career choices is a growth process, but there are a lot of state and federal disability systems that don't allow much choice, based on financial rules, despite promoting person centered planning. However, I enjoy areas where I can make choices about where to grow, what projects to start, and how to prioritize tasks. I love making checklists, so that I can watch how much I'm accomplishing. Making choices about where I can help, or who to work with, always seems to make the task easier or more enjoyable.

LISTSERV NOTICE: Our newest listservs are **Tyler & Vicinity, Midland/Odessa & Vicinity and Creative Housing.** Contact Susan.Prior@txp2p.org if you want to join them. If you want to moderate a local listserv for your area, we'd love to set up more local groups. Contact Laura at Laura@txp2p.org to discuss moderating one for us.

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Conference Schedule

Date	Conference Title	Location	Registration Information
June 22-23, 2018	TxP2P 14th Annual Statewide Conference	San Marcos	www.txp2p.org
July 12-15, 2018	National Down Syndrome Congress Convention	Dallas	www.ndsccenter.org/annual-convention
August 2-3, 2018	26th Annual Autism Conference	San Marcos	www.txautism.esc2.net
August 3-5, 2018	Abilities Expo	Houston	www.abilities.com
August 11, 2018	A Look Ahead Conference	Arlington	www.alookaheadseries.com/schedule