

A Parent's Perspective

TxP2P Quarterly Newsletter

TxP2P Update

Laura J. Warren, Executive Director, TxP2P

Hope you are healthy and have not been exposed to the flu and viruses going around. We've had staff, kids and parents out this year already and it's apparently just getting worse. So stay healthy!

Our first regional conference of the year is on Saturday, February 17th, in Tyler at the Tyler ISD Career & Technology Center. We had a great turnout last year for our first time in Tyler and we're hoping for even better this year. Then on April 14th, we'll be back at the First Baptist Church of Hurst for the Living with Disabilities 6th Annual Regional Conference. This will be followed by our statewide conference weekend, June 22-23rd, in San Marcos at the Embassy Suites & Convention Center. Our final conference for the year will be in South Texas, but we don't currently have a date. We will get this information out as soon as we have it; we'll be back in the Pharr-San Juan-Alamo ISD for another year.

We have added Sibshops to our list of activities at the regional conferences. This program is for the siblings of our children with disabilities, aged 8 through 12. They play games, do arts and crafts, and get to talk with other siblings. A trained Sibshop Facilitator leads the groups.

We were contacted by a professor/doctor from the University of Texas Southwestern Medical Center (Medical School) in Dallas to start training some of their medical students through our Medical Education Program (MEd), which thrilled us. However, we need to train several new Family Faculty in the Dallas/Fort Worth area, because there are 240 students to train. So, if you are interested in being trained as a Family Faculty for MEd, please contact our MEd Coordinator, Sherry Santa, at MEd@txp2p.org. We will also have MEd trainings in Austin/Round Rock, San Antonio and Amarillo this year, so if you are from those cities, give Sherry a call at 866-896-6001 or email her at Sherry.Santa@txp2p.org.

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Public Education - Your Opinion Needed!

Linda Litzinger, TxP2P Staff

Here are two opportunities to advocate for public education:

The first is a quick survey about methods of communication between school and family: https://www.surveymonkey.com/r/

<u>CWR9N6R</u>. Results will be compiled by the Arc of Texas and shared by various groups, including TxP2P.

The second opportunity regards the historical under-identification of students needing special education. A year ago, the United States Department of Education performed a series of onsite monitoring visits to review Texas' compliance with IDEA. USDE's final report was published January 10, 2018. The findings from

that report require the Texas Education Agency (TEA) to develop a plan to address four corrective actions. Here is the <u>TEA Proposed Initial Draft Plan</u> (PDF), to result in a final plan by April.

An integral part of the planning process will be the gathering of input from stakeholders. Parents, educators, and members of the community may comment on TEA's draft via this survey: <u>USDE Corrective Action Draft Plan Online Survey</u> or you may send an email to <u>TexasSPED@tea.texas.gov</u>.

In order for TEA to be able to access as many perspectives as possible, they are working to create a comprehensive list of stakeholder groups who work to improve services for students with disabilities. To have your group listed in their registry, please send an email including your group's name, target population, relevant funding sources, and mission to TexasSPED@TEA.texas.gov.

For assistance with any of this advocacy process, please contact:

<u>Linda.Litzinger@txp2p.org</u>.



WIC: Your Health & Resource Partner

Melanie Smith, WIC - HHSC

One out of every 10 children under the age of 14 has some type of special need. That means there are a lot of parents who need support and access to resources. WIC, the supplemental nutrition program for Women, Infants and Children, is a resource you may not know about.

WIC is a nutrition education program. Our team of nutritionists, registered dietitians and lactation consultants are equipped with the knowledge to help your child meet his or her unique nutritional needs.

For example:

• Our International Board Certified Lactation Consultants (IBCLCs) can help you get breastmilk to your premature infant.

- Our registered dietitians can help you ensure you're meeting the nutritional needs of your child with dietary restrictions.
- Our WIC staff can also guide you to other resources your family may need such as help with developmental delays, or even making sure the bills get paid.
- WIC provides nutritious food at no cost to you.

WIC staff track your child's growth and health to ensure your child is meeting his or her nutritional goals. If it's difficult to travel to the clinic with your child, WIC has special procedures allowing your child to stay at home, while you access the

information you need to help him thrive.

Pregnant women, post-partum women, and children under the age of five are eligible for the program. Parents, grandparents or guardians of children under the age of five can also get assistance.

WIC is your health and resource partner.

Call 1-800-942-3678 to make an appointment and get started today.

Nutritien Matters





Early Childhood Intervention

Summer Ideas - Infants and toddlers learn about the world around them by using all of their senses. Spring and summer are a great time for you to engage your child in activities that are suited for outdoor play. Here are a few fun ideas you can try that will support your child's development.

- Use a clean dry ice tray and place your child's favorite small snack into each of the containers (cheerios, gold fish or gummies); now have your child try to remove the snack using a fine pincer grasp (thumb and index finger).
- Use salad tongs to pick up ping pong balls and place into a reusable container. A great way to make this more fun is to decorate the container as an alligator or hippo and "feed the animals."
- Draw a rainbow and have your child place matching colored Fruit-Loops on the corresponding rainbow line. You can also use colored stickers or washable dot markers. Summer is a good time to use colored (washable) chalk on your sidewalk. Draw squares close to each other and have your toddler jump from square to square.
- Toss inflated balloons to your child while they use a pool noodle to try and hit it.
- Allow your child to copy simple figures in sand, shaving cream or pudding. Make sure they don't eat the sand or shaving cream! Practice scooping sand into a large bowl using a spoon.
- Blow bubbles and let your child try to pop them before they hit the ground. Encourage them to use both hands, and for older children, let them try to blow the bubbles themselves.
- On a hot day, try freezing colored water into various shapes and allow your child to enjoy the various sensations of touch and taste.
- Another fun summer activity for water-loving babies: fill a little pool with bubble bath and let him/ her revel in playing with bubbles! Throw in a few toys for your child to play detective and hunt around to find them! Use various containers to pour water, use cups and have a tea party! Make sure to always supervise your child when in or around water.
- Provide opportunities to climb, swing, and jump using age appropriate playground structures.

As with all activities, make sure your child is adequately supervised to ensure safety at all times. Early Childhood Intervention (ECI) is a statewide program with Texas Health and Human Services for families with children birth up to age 3, with developmental delays or disabilities.

For more information, please visit https://htm.texas.gov/eci

Going to Camp!

Early spring it the time to think about signing up your kid for summer camp, as many camps fill up during this time. So how do you take the leap, find the right camp, sign up and pay for it?

There are many benefits to your child going to camp, but here are 3:

- Your child will have new experiences, learn new skills, and meet new people.
- You will have a chance to spend 1-1 time with other family members and take a break.
- And it's a chance to practice the fine art of letting go. While away, your child will learn that he can be okay without you for a few days, and you can learn that your child can survive for a few days without you-- a big transition step for both of you!

Learning more about camp

Start by reading this very helpful article: https://www.navigatelifetexas.org/en/family-support/sending-your-child-to-camp. Here you will learn much more about the advantages, how to find the right camp, how to get ready for camp, and other ideas that are super helpful.

Finding a camp

Here are some options for the kind of camp you will look for: day camps and over-night camps, where your child might spend a weekend or up to 5 days out of town. And note that some camps are for children with special needs only, while others are for all children—in either case you will need to explore how a camp supports children with disabilities. You need to find a good match between your child's interests and needs and what supports a camp can provide.

At this link, you will find a way to search for camps: go to www.navigatelifetexas.org and type in summer camps in the search bar. Or to find camps in your area, go to www.navigate and click on Find lifetexas.org services-groups-events. Then at that page fill in summer camps, and you'll end up at a page where you can enter your location and get a list of camps in your area. Here is another website that helps you find a camp: http://find.aca camps.org/

There are several away camps in Texas that are for children and

Rosemary Alexander, TxP2P Staff

adults with disabilities from all over the state: Camp CAMP, Camp Summit and Texas Lions Camp. These camps provide genuine camping experiences with the supports needed by children (and adults) with all kinds of disabilities.

Paying for camp

Some camps have scholarships or a sliding-fee scale to help pay for the cost of summer camp. If your child is on a Medicaid Waiver like CLASS or HCS, your waiver budget can include funds for out-of-home respite for camp. Other possibilities are your Local Authority, your school district and local organizations. Please go to the www.navigatelifetexas.org article on sending your child to camp for details: https:// www.navigatelifetexas.org/en/ family-support/sending-your-child

<u>-to-camp</u>Take the plunge and find a way for your child to have fun while you

get some respite! Apply for camp



Texas Network Connections - Just do it!!

Linda Jones, Texas Network Connections - TxP2P

The start of a new year is often accompanied by New Year's resolutions - a time for new beginnings. you have been following discussions in this newsletter and elsewhere about Texas Parent to Parent's relatively new program -Texas Network Connections - then perhaps you are planning to start a personal support network for your son or daughter this year. We certainly hope so!!

Having a network is one way to ensure that our children have a community of caring individuals in their lives; even when you are no longer able to care for your child, there would be a support system in place with people who would how to maintain a good life for your family member. This is a good idea

no matter how you look at it.

Getting started is often the biggest Often we feel that challenge. everything must be in place, especially having a sizable group of people to join the network. Some of you may find it difficult to ask people to be part of something that is so important. However, we have found that more often than not, people are honored to be asked. And if you feel you don't know enough people well enough to ask them, start with whomever you have, even if it's only 2 or 3. A network is a dynamic entity that will necessarily change over time. People will go and new people will come. Such is the nature of life!

We can help!! We are now hosting monthly forum meetings where we

can answer your questions and help you take the first step in the process of starting a network. Starting on February 21, regular Forum meetings will be held on the third Wednesday of each month during February, March and April from noon to 1:00 p.m. at the Texas Parent to Parent offices at 1805 Rutherford Lane, in Suite 201. If you are not able to attend in person, no worries contact us at 866-896-6001 and we will arrange for you to be able to Skype or FaceTime into our

Regardless of these hesitations, the most important thing is to just get started - in other words - just do it!!

Spotlight on a TxP2P Program



Family Support: The Cornerstone in the Foundation of Texas Parent to Parent

Patty Geisinger, TxP2P Staff

No one is quite as alone as in that moment when a child receives a diagnosis. The ground shifts under your feet as you veer off onto a new path into the unknown with your child's future at stake. We have all been there and that is why the Family Support Team is so vital in helping parents when they are first embarking on this journey. Emotional support, information and resources for parents make up the cornerstone of our foundation at TxP2P and are always provided by parents of children with disabilities.

We answer the phone. This may seem a small thing to offer, but how many of us call and listen to endless instructions to get to a real person. We have been there. Waiting, waiting for someone to hear us, to answer questions, to bring us some help and hope. And we, like many, did not find that help we so desperately needed in a That is why the low moment. Family Support Team is determined to always answer the phone. One of our TxP2P core values says that even if we do not know the answer, we will find it and call you back!

We listen. This is the key for emotional support. The simple act of listening and hearing what a parent needs, asking guiding questions to figure out the whole

picture, and understanding what avenues they have already explored is so important. Although we may offer resource ideas and phone numbers. our Family Support Team's strength lies in sharing our own personal stories, how we found resources and what we have learned, instead of giving advice.

We grieve. Grief has come unbidden into our lives. According Dr. Ken Moses, "Parents generate core level dreams for their children even before the child Disability shatters those Grieving is the process dreams. whereby parents separate from those shattered dreams and begin creating new dreams. It is an unlearned, automatic feeling process, which must be shared with another. It may reoccur and is not an accepted state by society." We are here to share the good and bad, the highs and the lows. But our grief is not chronic sorrow. It may be cyclical in nature, but we recognize that if parents are given emotional support. resources and information, the listening and help they need, then the grief is lessened. We can move through the stages of adapting to our new life in an easier way if we have someone to turn to and share our grief.

We match. No one wants to have the only child with a certain diagnosis. No one should without their people. What makes Family Support so unique is that we train mentor parents to be matched with new parents. Finding another parent who has walked the same path, whose child is a bit older, opens doors into what the future holds. Sharing your own journey can bring such support to another family and be very healing in your own life!

We empower. Our goal is to empower families so that they can forge ahead on their own. assume every parent can become a strong advocate and we can assist by listening and allowing the space for parents to grieve and learn. We can match them with a more experienced parent. We offer trainings and conferences and so much more. Family support continues even as our children We need support as they through move school into adulthood. We need support as face surgeries and new diagnoses. We need each other. We are most empowered as advocates for our children when we support each other. We are the cornerstone of TxP2P—we are the Family Support Team!

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 families who have lost a child recently:

Angie Zecena, daughter of Maria Jaimes and Henry Zecena Emily Brown, daughter of Jon and Sharon Brown

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

Getting Ready for Spring ARDs

Liz Hong, TxP2P Staff

Spring brings beautiful flowers, warm breezes, and sunny days outside. But for many of us it can also bring ARD meetings and IEPs. Sometimes this means frustrating and overwhelming thoughts of what's ahead. To help prepare yourself for your child's next ARD meeting so that you can confidently stride in with a plan, start preparing for your ARD ahead of time. Using three basic steps, you can know where your child has been and where you would like to see him or her going!

Step one: Gather your data. Just as schools collect data on your child, you have been collecting data also. Look in files, emails, and wherever you keep your important papers. If you're like me, it will surely be in pile one, two or three. Look for communication notes, daily logs, doctor's notes, IEP goal updates, and last year's IEP. I also keep notes on behavioral incidents and doctor appointments. I try to communicate with the school in email, so I can find it all with a time and date stamp. Whatever you have, do your best to find it.

Step two: Review your documents. I am always surprised at how many details I have forgotten over the past year, so don't give in to the temptation to skip this step! It can show you how much your child has

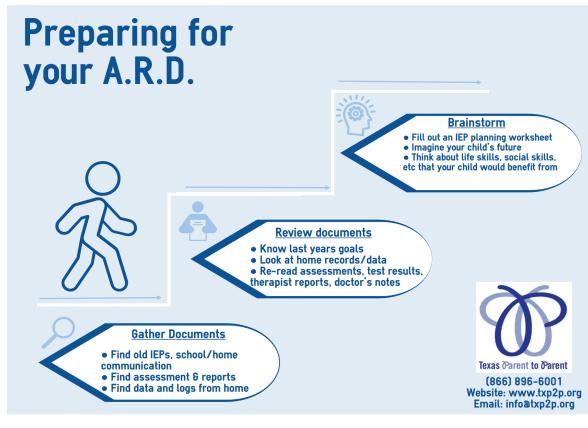
progressed over the past year and clue you in to where your child is struggling and a realistic idea of how far your child can progress in a year. Read through all of the updates to see if your child smoothly met this goal or if there were big bumps in growth. Knowing that your child suddenly made great gains on a goal can tell you to ask about this area so you can learn what tips and tools they used to make such great progress. Don't forget your own data or doctor's information. This information will show the school trends and needs for daily living and other important areas.

Step three: Plan. This is a great time to think about what you would like to see in your child's future. For younger children, you may be looking ahead to middle school or high school. For older children, you should start thinking about life after high school. IDEA tells us that an IEP is supposed to meet the unique needs of your child to prepare them further education, future employment, and independent living. It is important to think about all three of these areas when planning for an ARD meeting. As your child ages, it is a good idea to include them in the planning phase more and more to the maximum extent possible.

As I look through my data and gathered documents, I often find 2-3 is-

sues that have repeatedly come up. I like to take that information and write a parent report, which can help the school to get a good idea of what life is like at home. It is important to write this report in a neutral way and from a third person's perspective, taking the emotion out of the situation and giving the school a glimpse into what you are seeing at home. Statements like "he needs extra snacks at school" can be replaced with phrases like, "After school, when asked how his day went, Jack typically yells out answers until after he has eaten 3-4 high protein snacks and a glass of milk." This paints a picture of why you have come to the conclusion that Jack needs more snacks and presents information in a way that school staff can better accept.

Whether you expect smooth sailing or rough seas, planning ahead will boost your confidence and allow you to be a better advocate for your child. Reading through and thinking about where your child has been can help you offer input about your child's strengths and weaknesses and thoughts on how to help your child reach their future goals. So whether you have a little time or a lot, take the opportunity to get yourself ready for you next ARD.



Spanish Exchange Student with Visual Impairment Learns about Texas

Mariel Williams, Telegram Staff, Courtesy of Temple Daily Telegram

ROGERS - Like any other restless teenager, Valeria Blazquez Coca joined a student exchange program to try new things, meet new people and travel the world. Unlike other student travelers, she also hopes her experiences will also open doors for other disabled kids hoping to learn about another culture.

Valeria is from Spain, but she is also visually impaired. She has been a student at Rogers High School since August, where her hosts are Rogers Independent School District Superintendent Joe Craig and his wife Michele, who is a teacher for the visually impaired.

"I didn't want to study in Spain," Valeria said. "I just wanted to learn English exactly perfect ... and I wanted to have new experiences and know about culture, know a lot of new people — I just knew the Spanish kind of people, and I needed a change in my life."

Valeria said that the biggest difference between Spain and the United States has been how the culture here is more focused on home life. "In Spain, the people go a lot to the street — we almost live in the street," she said. "We don't stay at home. ... It's just a different mentality — we just go out and hang out with everyone."

School is also very different, Valeria said, and people react to disabilities differently. "In Spain, there's a lot of discrimination," Valeria said. "We have a long ways still for integration in Spain."

Having decided she wanted a cross-cultural experience, Valeria first looked into studying in Canada, but that did not work out. "My mother was very afraid at the beginning, like, oh, probably you should go to Canada because it's like ... a more European country," Valeria said. "The district (in Canada) didn't accept me. ... It's difficult for a family that doesn't have any contact with disabilities — it's a completely new experience."

Valeria came to the United States through Share!, an exchange program of the nonprofit Educational Resource Development Trust, and a Spanish organization called Students in USA. Share! began reaching out to teachers who work with disabled students in order to find house parents who feel able to host a student like Valeria, which is how the Craigs got involved.

The Craigs have never hosted an exchange student, but their older son, Zach, is about to go to college next semester, so this seemed like a good time to start. Craig said the family has enjoyed having Valeria stay with them. "If it's good for (your) family, it is a wonderful experience," he said. "We have a lot of fun together... Her and my eighth-grader (Jaxon), they're normal — they're siblings, they have fun together and they give each other a hard time." Having an exchange student on campus, Craig said, has been a good experience for Rogers students. "They get to learn something about people that they didn't know before," he said. "She's done great — she's made some great friends."

Valeria is scheduled to return to Spain at the end of the spring semester. "But I actually don't want to go back," she said. "I would like to go to (college) here, but college here is very expensive — in Spain it's almost free."

Valeria said she would encourage other students with disabilities to consider joining an exchange program. Finding ways to make things work — such as adding Braille stickers to a washing machine — is not as hard as it might seem, she said. "The families sometimes don't want these kinds of students because they don't know how to treat them," Valeria said. "(But) if I can do it, everybody can do it. I'm not special." When she goes home, Valeria expects she will miss the Craig family, and American culture. "I'm here for almost a year, and I feel like I was American forever," she said. "I will miss, I think, everything."



Helping Your Child Run the Show: Introducing Myself

Amy Litzinger, TxP2P Staff

This will be part of a three part series on helping your child learn and practice self-determination skills. It's not so much how to, but rather my thoughts and experiences on how this worked and didn't work for me as a self-advocate.

As a little kid: I didn't have much trouble introducing myself. I'd introduce everyone to each other all the time, without shame. It didn't occur to me not to tell everyone about my disability. I had no trouble telling everybody what I wanted. I like using pictures and props, but I didn't need them. I liked introducing my parents to my friends, and vice versa.

Older kid: Eventually, we came up with different ways of introducing myself depending on the age of the person, and what they needed to know, especially doctors. I kept my introductions short and simple. My parents knew all my friends, but not because I was trying. They just did.

High school: I was friends with everybody. I also learned how to downplay my differences. This did not always work to my advantage, but I also learned that I preferred smaller groups of friends as an introvert. My parents knew my

friends, because I was excited I had friends, and they were still driving my van. But the key is I was choosing my friends, and adults didn't make the introduction. I was starting to use big sheets of paper to explain what I needed from new teachers. I was also beginning to learn how to introduce myself to attendants (as I began services) and how to introduce them to my friends. Interviews and the first few weeks with new employees are still hard for me.

College: I started formalizing my introduction sheet, officially called "A Little about Me", for professors. It explained a few things about my diagnosis, what that meant for me, things I would and wouldn't need from them for their class. I also explained my procedure in the rare event I was absent, or if I got stuck somewhere. 1 added that sometimes my friends drove my van off campus . I included my extracurricular activities and gave this to sponsors. Also, Facebook! Not everyone I introduced myself became mγ friend. introduction adapted. My parents did not always know my friends.

Graduate school: I had full-fledged conversations with my professors about specifics, after the

introduction. The piece of paper felt less necessary, and I learned not to send it to peer TA's. I would update the page every semester and sometimes re-send it to the same professors. They liked this as a reminder. I started making different sheets for attendants specific to their job expectations. I have learned not to introduce myself assuming that this is a perfect job for everyone, or to give them too much information that might be overwhelming, especially if they are new to physical disability. My parents know almost none of my friends.

Employment: I started tailoring my sheet to ideas specific to the job I was starting, similar to how one might tailor a resume to the job posting or description. This works well for me. My parents know most of my friends, because all my friends work in advocacy too.

Up next: "Helping Your Child Run the Show: Making Choices"



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
Sunday, Feb. 4— Tuesday, Feb. 6	2018 Inclusion Works!	San Antonio	https://www.thearcoftexas.org/ events/inclusion-works/
Feb. 17, 2018	2nd Annual East Texas Parent Conference	Tyler	www.txp2p.org
Feb. 21-23, 2018	Texas Transition Conference	Houston	www.ttc.tamu.edu/
Feb. 27-28, 2018	Central Texas African American Family Support Conference	Austin	ttps://ctaafsc.com
April 14, 2018	6th Annual Living with Disability Information & Resource Conference	Hurst	www.txp2p.org