

TxP2P Update

Laura J. Warren, TxP2P Staff

I hope everyone had a wonderful holiday break and things are going well for you and yours. We are all about conferences for the next several months.

Our first regional conference of the year is on Saturday, February 25th, in Tyler at the Tyler ISD Career & Technology Center. It's our first conference in this area so we hope to have a good turnout. Then on April 22nd, we'll be back at the First Baptist Church of Hurst for the Living with Disabilities 5th Annual Regional Conference. This will be followed by our statewide conference weekend, June 16-17th, 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 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 have also added several new staff recently and would like to welcome Martha Aguilar, Liz Hong, Katrine Nordstrom and DeAnna Medart to our Family Support Team and Elisabeth Hunter and Adriana Valadez to our Pathways to Adulthood Team.

We also had two unexpected retirements that I have not acknowledged even though they happened this summer and fall – Debbie Wiederhold was with us for over 12 years, being the 4th staff member to join TxP2P. After the conference and a long vacation, Debbie decided not to come back on contract as planned but to retire. She helped us build TxP2P and was an integral part of the organization.

Jan DiMare joined us as a staff member in 2010 but was really with us from the beginning – we had our first Board of Directors meeting at her dining room table and she and her husband, Charlie, were both on our Board for years. Jan set her own schedule so wasn't here on a regular basis, but I still find myself wondering when she'll be in. We miss both Jan and Debbie very much but wish them well in their further endeavors.

Happy 15th Birthday, TxP2P!

Laura J. Warren, TxP2P Executive Director

It's very hard to believe that we started Texas Parent to Parent 15 years ago. Our first Board meeting was around one of our member's dining room table. At that meeting, we decided who wanted to be a staff member and who wanted to be a Board member. Sue Regimbal, Tammy Mann, and I all agreed to be staff. Patty Geisinger agreed to be a permanent volunteer staff. Little did we know where we would be 15 years later.

A grant writer fell out of the sky, by way of Vermont and Waxahachie, Texas, shortly before our first Board meeting. Nancy Post taught Sue and me how to write grants, while Patty and Tammy figured out how to serve the parents and professionals who called us. We were very fortunate to have additional help in getting our nonprofit status with the IRS and our

first grant.

The grant came through the Texas Council for Developmental Disabilities (TCDD) to train pediatric and family practice residents – other statewide parent to parent programs helped us with the training piece and Dr. Chris Johnson and Elaine Hime helped us make it Texas specific and write the grant. It allowed us to rent an office and get a phone – we did the parent support piece as volunteer work. By the end of 2002, we had 200 parents registered with us.

It took 3 more years to start receiving funding to cover family support through state and federal grants. We lost Tammy to the UT School of Social Work after a couple of years but have added 21 talented and passionate staff and contract staff. We have grown and added programs, including over 30 listservs, 4 conferences, a Facebook

presence, advocacy, transition services, transition action groups, and now our Texas Network Connections. For the first time ever, we have a full Board of Directors who are helping us, thanks to Denise Sonleitner's recruiting efforts and leadership.

There are over 7,500 families and 1,400 professionals on our mailing list now. We continue to grow and dream up bigger and better activities and programs. I'm looking at retirement in the next 2-3 years but I no longer worry about where TxP2P is going. The staff and Board have it covered.



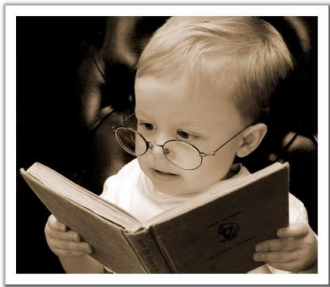
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Employment First

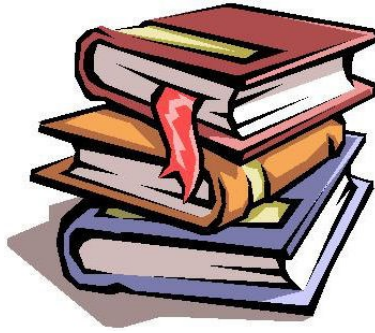
Linda Litzinger, Staff

If you wish to assist with Legislative Reform regarding employment options for persons with disabilities, please read on.

A recent study shows that people with disabilities who have achieved fully-integrated employment in their community find themselves to be healthier, safer and happier. They form relationships with co-workers, have fewer health issues, find an increased sense of well-being, and increase their feelings of competence and self-worth. Texas is thus developing a program called Employment First.



Employment First places an emphasis on becoming fully integrated in a job or volunteer position of your choosing. Using supported employment professionals, you experience full immersion in the workplace of your choice, as an alternative to the existing model where a group home transports everyone to the same segregated worksite.



In July, our federal government published rules for the “Workforce Innovation and Opportunity Act” or WIOA, and coincidentally Disability Rights–Texas authored a paper titled “Living on a Dime and Left Behind.” This paper reveals that 10,000 Texans are employed at less than minimum wage in sheltered workshops, where 58% earn less than 50c/hour, and 25% have their employer as their representative payee.

WIOA is designed to strengthen and improve our nation’s public workforce system, preparing and placing Americans with significant barriers to employment, including significant disabilities, into high-quality jobs and careers. Career preparation shall begin early (age 10 for blindness; age 14 for the remaining population with disability), in order to prevent placing graduating students in sub-minimum-wage sheltered workshops. At least 15% of the Vocational Rehabilitation allotment must be spent on pre-employment transition services.

WIOA calls for a unified state plan, with coordination and reporting requirements among educators, vocational rehabilitation and the Health and Human Services Commission (HHSC). It strengthens federal guidelines for states, school districts, and employers to fully integrate people with disabilities in the workplace, offering additional supports.

Legislators are thus writing bills for the upcoming session to be better aligned with new federal requirements, to gradually phase out sheltered workshops, to ensure that existing day habilitation centers register and be regulated, and to add more options and supports to help people to prepare for integrated employment. If you wish to help address this policy reform, from any viewpoint, please do not hesitate to contact Linda Litzinger at linda.litzinger@txp2p.org or 512-922-3810.



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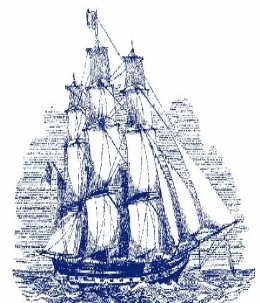
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Charting Your Course to Financial Security

When my daughter first got asthma, I could tell the doctor when she needed her inhaler, which ones she used and exactly what days she had woken up coughing. But time passed, and asthma become more normal and I quickly let that fall behind to more important concerns like who had OT and when everyone needed a ride.

So that day in January when the doctor asked me a billion questions that I couldn't answer, I felt the sting of Mommy Guilt. What kind of mom doesn't know how many times her daughter woke up from coughing? So, as I drove home chastising myself, I came to a new resolve - this year I was taking it back. I would cast off the days of looking confused, frazzled, and disorganized and embrace the new super organized, on-top-of-it Me.

We have four kids. And in their own way they all have lots of needs, asthma, extra worries, glasses, hockey practice, teenage-ism to name a few.

But my boys' needs had trumped everyone else's, and it had finally reached the point where I could no longer keep track of my daughter's asthma, and my teen who could adeptly work the chaos of our house to his advantage. And I was tired of feeling inept, incapable, and like I wasn't giving enough, and so "I'm taking it back in 2016" became my rallying cry.

It is one thing to make a New Year's Resolution, and quite another to actually achieve it. Where on Earth would I begin?

As I look back, I think the very first thing I did was lay my cards on the table at all 3 schools. I had so much guilt that someone's form wasn't signed, or I didn't check a backpack, and I was trying to get every project done and have the perfect IEP. I was trying to be Super Mom, and these things couldn't slip!

So, I told them about my children. You see, my kids are the sweet ones that teachers love during the day and they couldn't possibly imagine the chaos we swam through at home. I explained that there was more than one child who was high needs, and that explosive outbursts were the norm and that I was struggling to stay on top of it all, and I couldn't do the homework part anymore.

I called my teen's school and spoke with the counselor and told her I couldn't keep up with his grades and missing assignments and told all his teachers that our home was one battling crisis after another on a regular basis. I told them all, then I gave myself permission

to fail.

The schools knew I couldn't do it all anymore, and they knew they would have to seek me out if there was a problem. The relief I felt from this one tiny step lit the fire of change.

Next, I knew our home needed some changes. At our busiest, we had 6 standing appointments every week and three specialists we needed to see every three months plus check-ups and glasses.

Between that and cleaning up after 4 wildebeests who left oceans of toys and dishes in their wake, it was just too much!! I was struggling to get everything done, and I'm pretty sure we had a re-dirtying machine because no matter how hard I cleaned, the house remained messy. So, I prescribed myself one big task a day. I could clean. Or I could do appointments. But I would NOT do both.

It was hard to adjust. And I wonder if my husband thought I didn't do anything all day. But honestly, it looked just about as messy as before.

Suddenly, I wasn't quite so anxious and tired and grumpy, and felt a little more okay with the real status of things. I liked these rules. They seemed to be working.

The next few phases were harder. I didn't quite know where to go. My parent support match had suggested the need to take care of myself, but I couldn't remember who I had been or what I needed. I had spent so much of the last 5 years managing the needs of the rest of my household, that I had forgotten.

Then one day, my son's therapist suggested I might benefit from some therapy myself. I'm sure she thought I was just plain crazy. I would pack 3 hungry, grumpy kids in the car, drive their dad to work 30 minutes early, and rush to therapy and not once did I ever actually have enough time to get there. Getting those kids to therapy at 8:00 in the morning was like trying to move a mountain, I just didn't know it. So of course it made sense that I came in frazzled, anxious, stressed, and probably looking a tad crazy.

So, I tried not to be offended. Thankfully, my parent support match had told me that I was living in unusual circumstances, and that many families raising children with complex issues benefit from having therapy to help them get through this time. And so, nervously, I gave the therapist a call.

The changes became more rapid after I started therapy. She validated my

feelings, and taught me how to help my children, and soon I began feeling stronger, and more capable, and less anxious. We took baby steps.

But soon this change became evident in my posture, my clothes, and my whole being. I began to feel confident again. I began to feel less crazy. I was living in unusual circumstances. My kids were high needs. And it was okay that I couldn't be the Super Mom I had always wanted to be. I was getting the most important things done.

Then my husband got hurt and ended up at home every day. As I rushed the children out the door one morning, I realized he didn't know which medications were given when, which doctor handled what, or when the kids had appointments.

I kept our house running, but I was running it alone and he had no idea what was going on. It left me feeling overworked and him feeling out of the loop and unneeded. He started taking on jobs, getting meds ready, making the calendar, making kids lunches.

Then one day I sat in my therapist's office saying he's doing the dishes wrong. My therapist looked at me said, "At least he is doing it." For a few minutes, I still grumbled under my breath, and then I realized nothing fell apart when he did it, it was just different. So I tried to let it go. I tried not to check on it, or at least not too often.

Begrudgingly handing over these tasks freed up time to do little things, like finish a warm cup of coffee. It may not seem like much but I hadn't had a warm cup in years and wow, it tasted so much better.

Soon, my husband began attending therapy, too. Don't ask me how that happened. It was hard to convince him, but the stars aligned, or fate intervened, or he fell and got hurt and ended up bored on disability. Either way, he too began seeing her.

Eventually, we began going together. We started small. The therapist recommended the simple step of not answering the kids' basic questions until saying, "let me talk to your dad/mom." We began consulting each other for things like snack, TV, or park time. And while we are still working on it, I began to feel less like having another person who needed my attention, and more like having a partner on my side. It's hard sharing the responsibility of raising little humans.

Continued on page 4

Taking it Back in 2016

Continued from page 3

So, I was surprised how one little change slowly affected our parenting dynamic. Perhaps the most difficult step of my journey was letting go. I didn't leave the children for more than a couple of hours and I always worried about what I would come home to.

My son has separation anxiety and has always been glued to his Mommy. I told myself he needed me, and so I put his needs first and began to put away my needs, like haircuts, peaceful child-free trips to Target, and coffee dates with friends. It wasn't worth the tears, crying, and chaos that followed the separation.

And then he began Kindergarten and things fell apart. And I began to wonder if maybe I had done him a disservice. It was easier to stay there and make sure everything was the all right.

But now I couldn't. I needed to get a job, and he needed to go to school, and he had never learned how to be away from me. So I left. I left them with their dad, or their grandparents and began to go to work, or the store alone. And soon, the crying stopped. The chaos became smaller and smaller.

And I was working again and doing things I enjoyed. Little by little, I began to remember me. Who I was. What I needed. What I wanted out of life. Soon, I was a Me again.

In the very first conversation I had with my parent support match she

recommended I "prioritize myself, my marriage, my children, and the child we had added to our family, in that order." I thought she was crazy. I had been doing it completely the opposite. Our lives revolved around this hurt little soul and my son's anxiety. I had nothing left for myself or my husband, we were the grown-ups.

When I began crying out "I'm taking it back in 2016," I had only one goal: to not feel so stressed, frazzled, and disorganized. But once I started acknowledging and validating my needs, I began to have the empathy and energy to help my husband with his. And as we began to work together, soon I felt comfortable letting go of the responsibility, the knowledge, and the decision making and eventually we were able to better help the kids and give them what they need.

As I sit here on the close of 2016, taking it all in, I realize that somehow through the chaos and turmoil, my support parent's idea had naturally come to fruition. We had begun to prioritize ourselves and our marriage before the kids. I am still stressed and way too disorganized. Except now I am okay with it.

The pull of being Super Mom has faded and morphed to where I define success

as when everyone is getting most of their needs met.

I'm still embarrassed when people pop over and see the tornado of a house I live in, but I have my permission to do the minimum. And though I did not set out this year intending to shift my priorities, I realize I did.

Slowly we shifted everything and I can now say that I am a recovering Super Mom living a much more peaceful life. I still go to my daughter's appointments and have no idea what day she coughed herself awake. But she is healthy and we spend time together where we play and have fun together, and I realized that is worth so much more to me.



DARS Programs and Services have Transferred

As of September 1, 2016, programs and services previously administered or delivered by the former Texas Department of Assistive and Rehabilitative Services (DARS) have been transferred to the Texas Workforce Commission (TWC) or Texas Health and Human Services Commission (HHSC). Listed below are programs and services and which agency they have been transferred to.

Texas Workforce Commission (TWC)	Health & Human Services Commission (HHSC)
Vocational Rehabilitation Services	Autism Program
Blind & Visually Impaired Services	Blind Children's Vocational Discovery & Development Program
Criss Cole Rehabilitation Center	Blindness Education, Screening & Treatment Program
Independent Living Services for Older Individuals Who are Blind	Comprehensive Rehabilitation Services
Business Services – Vocational Rehabilitation	Deaf & Hard of Hearing Services
Providers' Resources – Vocational Rehabilitation	Disability Determination
Business Enterprises of Texas	Early Childhood Intervention Program
Rehabilitation Council of Texas	Independent Living Services
Service Animal Information	

If you need help with TWC services call 1-800-628-5115 or visit their website at <http://www.twc.state.tx.us/>.
If you need help with HHSC services call 1-877-787-8999 or visit their website at <https://hhs.texas.gov/hhs-services>.

Effective September 1, 2016, the Department of Assistive and Rehabilitative Services (DARS) Early Childhood Intervention (ECI) program became a part of the Texas Health and Human Services Commission (HHSC). ECI programs statewide are still providing the same services for families with children birth to 36 months with developmental delays or disabilities. To find the number of the ECI program in your area, or for questions or complaints, call the Health and Human Services (HHS) Office of the Ombudsman at **1-877-787-8999** or visit our new web site: www.hhs.texas.gov/eci



Supported Decision Making in Real Life!

Caroline Nelson, TxP2P Parent

When I remember my son at 16 and 17, many things come to mind: his love of politics and travel, his curiosity about different world cultures and diversity within our own country, civil rights, marriage equality, sports – the games themselves and issues of ethics within the NCAA, doping and the behavior of professional athletes within intimate relationships. The list of his interests and curiosities – then and now – goes on and on.

I also remember having to coax him out of the house due to mental health issues, to bargain with him about one mandatory outing per weekend, learning to use hair clippers myself so our one mandatory outing wasn't wasted on a haircut. I remember struggling with well-meaning educators, some of whom knew exactly how to reach and teach him on his true ability level and others who expressed doubt that he would ever be able to independently handle a community money transaction because he shut down every time they attempted to count coins. And it was all true: he understood supply and demand, but he couldn't count change.

As his 18th birthday approached, a number of people asked me, as if it were a given, if I was working on his guardianship. I said no. I recognized his need for support in handling adult-level financial and medical decisions, and I certainly worried about his level of independence which was so hampered by his mental health and illness. But I also saw my bright, engaged boy who was excited to vote, who was afraid of girls (because, ultimately, he had an interest in them) and who was thoughtful and open to suggestions as long as we presented them in a non-bossy way that felt respectful of his growing autonomy.

I resisted the idea of a guardianship

because I felt I couldn't take his adult decision-making rights away. Although I worried about his ability to predict or handle "real world" consequences of potentially faulty decision-making or the potential for being taken advantage of in a bad mental health moment, I felt that I could support his understanding of his options and remain present or near his decision-making opportunities.

I could help protect him to the extent I needed to while shifting the ultimate responsibility for the final decision to him. In the end, I felt it was better for his mental health for us to express the confidence in leaving him with his rights than it would be to choose the possibly safer option of a guardianship.

I knew we could set up powers of attorney to accomplish a lot of what we needed. But as a lazy non-practicing attorney, I opted instead to draw up a private contract – an agreement between our son and his parents that invited us in to assist with decision-making but that clearly left him in the driver's seat when it came to the final word.

At the time, just two and a half years ago, this was unorthodox. The school honored our agreement, though it was not something they were accustomed to seeing. We crossed our fingers that we wouldn't run into a snag at the bank or in a hospital. It felt right and risky at the same time.

In the meantime, unbeknownst to us, the Texas legislature was working on legislation that would codify the legitimacy of an agreement like ours, and in the winter my son turned 19, the Arc of Texas came out with a model Supported Decision-Making Agreement (SDMA). The SDMA accomplished everything I was originally looking for. While any SDMA is customizable to the individual and the situation, the Arc's model

covered every contingency that was important in our case.

In the SDMA, our son and we (his parents) agree to the roles we will all play in his adult decision-making. The SDMA clearly states that our now-20-year-old has complete and final decision-making authority, including the right to nullify the agreement or "fire" us as his supporters.

It clearly gives his permission to third parties for us to help him understand the decisions in front of him, to communicate his wants and needs and to interact with professionals. Our son has given us a blanket FERPA release and HIPPA release so we can have access to his records and information. And – the Arc's model form contains language citing to the new statute, so a doubting educator, banker, medical professional or anyone doing business with our son knows they are relying on a legitimate legal mechanism.

We all three – my son, his Dad and myself – carry a paper copy in our wallets, and we have used it on the spot with third parties who don't know us in addition to giving it to all of our son's providers and educators to have on file. It has proven to be the mechanism we need to both ensure his autonomy *and* our ability to help.

And...it satisfies the lazy non-practicing lawyer in me – who understands the legal ramifications but hasn't gotten to the Power of Attorney part of the to-do list yet.

For more information, go to:
<https://www.thearcoftexas.org/wp-content/uploads/2016/06/Supported-Decision-Making-For-Families-UPDATED-Jan-2016.pdf>

Building on Strengths

Rosemary Alexander, TxP2P Staff

Thanks to Jennifer Neffendorf for this idea, provided on the transition listserv when I asked for newsletter article ideas

Parents of children with disabilities spend a lot of time describing and explaining our children – to doctors, school staff, therapists, family members, even to the public. The natural impulse is to talk about our children’s disabilities — that’s what needs fixing, that’s what needs explaining, that’s what reveals how to fix their deficits. It’s our job!



But what happens when we shift the perspective to our children’s strengths, talents, gifts?

I had the joy of attending a 5-day seminar in Vancouver 12 years ago hosted by PLAN, a parent organization started in the 1980’s. This seminar truly changed the way I talked about—even felt about—my son Will.

At the seminar, we were never asked to state our children’s disabilities or describe them in negative terms; rather we talked about them positively.

Up to then, I always talked about what Will needed and what was wrong with him. After it, I started to think much harder about his gifts and how to always talk about what he gives to us. And from there I began to think less about fixing Will and more about regarding him as a complete, unique human being with all the strengths and foibles that we all have.

I didn’t stop therapies and advocacy, but I made a conscious effort to start every conversation with what he’s good at. That perspective changed my focus and

eventually even my interactions with Will.



In preparing for life after graduation, you can start to make this shift from “how do I fix this person?” to “who is this person and how can we build a life based on his or her strengths and talents, interests and passions?” This shift in perspective can start at school.

I have discovered a wealth of ideas by googling “IEP goals based on strengths.” For example, in answering the question, why are students often left out of IEP meetings, the writer says, “because these meetings, much like the IEPs themselves, are deficit-focused.

In the first 5 minutes, someone will share a “Strengths and Weaknesses” narrative which leads to several smiles and sighs at the “strengths” noted. Check the box, we are done with strengths. No one wants the student to stay and hear all about their disabilities and deficits. The model is to build IEP goals “that focus on growing signature strengths.” (<http://www.viacharacter.org/blog/using-strengths-to-set-goals-on-ieps/>)

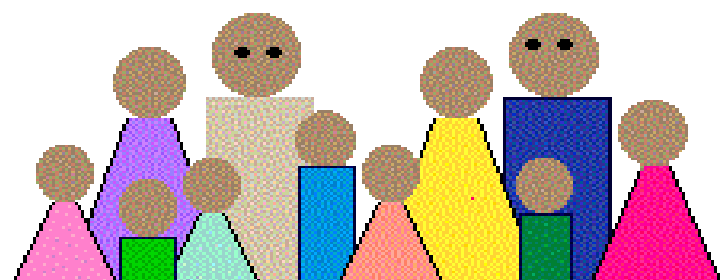
Under IDEA **Transition services** means “a coordinated set of activities for a child with a disability that... is based on the individual child’s needs, taking into account the child’s strengths, preferences, and interests” (<http://www.parentcenterhub.org/repository/transitionadult/>), so the law actually encourages this perspective.

Your job as a parent is to ask school staff to learn about your child’s strengths, preferences and interests, through student interest assessments, parent and student interviews, and looking for trends in the data schools have accumulated about your child. Have a planning session with school staff focused on exploring your child’s strengths, preferences, and interests and then write IEP goals that begin here, with the positive.

Beyond school, you’ll need a way to continue working for a life for your child based on his or her strengths, preferences, and interests.

The key for our planning for Will’s adulthood has been to build environments where he could use his strengths and interests. We have tried to find people to work with him that honor and respect his ways of communicating and activities that use his talents. Instead of trying to change him, we have tried to structure environments where he can be himself.

This approach doesn’t mean we quit—we still continue to encourage learning new skills and developing new interests, but it does mean being aware of imposing MY ideas on what avenues to pursue and look instead at what he has taught us about the essential Will, the place to start!



We Work Together

Mental Health Awareness Day Flight Freedom TX

May 2017



We are reaching out to various communities throughout the State of Texas. To participate or for questions, please contact Jameson Cardenas at jlcardenas@austin.utexas.edu or Kay Barkin at Kay.Barkin@mhmrtc.org.

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:

Natalie Schulze, granddaughter of Jewell Walters

Cate George, daughter of Emily & Jon George

Samantha Hall, daughter of Belinda & Scott Hall

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

LISTSERV NOTICE: Yahoo Groups will no longer allow us to “add” people to our listservs - we can only invite you to join. Unfortunately, many of our invitations go into spam and you never see them. Another way to join the listservs is to send an email to the moderator and ask to subscribe. Contact Susan.Prior@txp2p.org if you want to join the any of the following: Advocacy, ADD/ADHD, Autism, Bipolar, Cerebral Palsy, Dad’s, Dyslexia, ECI, Homeschoolers, Medical Home, Medicaid Waiver, Mental Health, NICU, Rare & Undiagnosed, Spanish, Texas Network Connections, Transition, Traumatic Brain Injury, or local area Listservs (Amarillo, Austin, Bryan/College Station, Coastal Bend/Corpus Christi, Dallas/Ft. Worth, El Paso, Houston, San Antonio, San Marcos, Rio Grande Valley, & Waco/Temple). 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
Feb. 8-9, 2017	17th Annual Central Texas African American Family Support Conference	Austin, Texas	https://ctaafsc.wordpress.com/
Feb. 12-Feb. 14, 2017	Inclusion Works Conference	Houston, Texas	https://www.thearcoftexas.org/iw-2017/
Feb. 22-24, 2017	Texas Transition Conference	Houston , TX	http://ttc.tamu.edu/
Feb. 25, 2017	1st Annual East Texas Parent Conference	Tyler, Texas	www.txp2p.org
March 1-2, 2017	Accessible Transportation Summit	Austin, Texas	https://www.eiseverywhere.com/ehome/214352/480926/