A Parent’s Perspective  

TxP2P Update - Paying It Forward

Laura J. Warren, TxP2P

Paying it Forward Call for Stories! TxP2P is all about family support and connecting parents to the support they need. Our listservs, conference, and matching program are the key ways we connect families to each other. However, we know that parents meet each other in many other ways: waiting rooms in doctor’s offices, hospitals, or therapy centers, family meetings or trainings at your school district or local disability group, rallies for legislative issues and sometimes across your back yard. So in an effort to celebrate all successes in family support, we have created a contest for families to tell us where they received support from another parent or family member or from a professional who works with your child and/or your family. Nominate that person for a Paying it Forward Award by writing up the story about their support for you and your family (500 words or less), send us a photo or two of your child, and you’re entered. We will then put the nominated stories up on our website for you all to vote for your favorite story. The winning nomination and the person who submitted it will receive 2 free conference registrations to our next Annual Parent Conference, July 26-27th in San Marcos. You can mail to 3710 Cedar St., Box 12, Austin, 78705 or email jdimare@txp2p.org the story or go to www.txp2p.org and submit it there. We are busy selecting speakers and planning for our conference this July – watch for the registration flyer in April!

*See page 8 for Conference Registration update.

Trainings

Our Pathways to Adulthood Program is taking their transition training to Ft. Worth in April and Amarillo & Lubbock in May. Check our website for details.

Our Supporting Parent Volunteer training goes to Denton in March, Edinburg in April, Houston in May and Round Rock in June.

New Staff

We would like introduce you to our two new Family Support Team members.

Monica Castillo comes to us from the Valley. Monica has 2 sons. One son has Asperger’s syndrome and the other has ADHD. Sherry has triplet girls who were born premature and adopted 3 siblings who have Fetal Alcohol Affect, 1q21.1 deletion, and Post Traumatic Stress Disorder. She likes to say she does things in threes! Welcome to our new staff!

Legislative Update: Be a Leader!

My daughter Amy and I are participating in our sixth legislative session; in Texas these are held every two years from January through May. Of the past five sessions, we have seen two sessions result in children & adults receiving additional funding for the Medicaid Waiver slots, and three sessions that have resulted in no additional funding for the “interest” lists. So you can see why the lists have grown to over 100,000 people.

At Texas Parent to Parent, Amy and I teach legislative advocacy to any family member or other interested parties on absolutely any cause that they may wish to advocate for – that’s our job! However, we worry that the younger families can’t participate because they are so busy struggling with basics of learning about a disability, building a medical team, or learning to navigate the school system.

If you are a leader of a disability group in your locale, please help younger families to learn some basic facts:

• the Legislature funds services offered by ECI, DARS, and DADS and that this process is going on right now,

Continued on page 2
Legislative Update: Be a Leader!

- your legislator is elected and paid to represent you and your wishes,
- TxP2P teaches families how to be a resource on disability and what families need for your legislator, how to create a bill, and how to call, write, visit, and testify in bill hearings and that we make it easier for families to engage in the process.

So, we ask you to spread the word that we can help you participate, that we can handle some of the logistics for you, and that we have funding from the Texas Council on Disability for your travel expenses in this learning process. Consider spending a day with us in the Capitol visiting the committee or legislator of your choice or spending part of a day with your legislator and staff back home. Here is how to contact us: linda.litzinger@txp2p.org or cell/text 512-922-3810.

Catherine Avril Morris, Parent

The Things They Said

When my son August died unexpectedly at birth, people said, “God needed another little angel in heaven.” Which, since I am not religious, did not comfort me. They said, “Everything happens for a reason.” Which made no sense, because what could possibly be the reason for an innocent baby to die? They said, “You’re so strong. If anyone can get through this, it’s you.” That one hurt me the most.

I thought, Are you kidding me? I did not feel strong. I felt broken, chopped down at the knees. For months postpartum, my body and my spirit felt loose, chaotic and raw, as if I had been stabbed, over and over. As if August had been ripped away from me. Strong? I felt torn apart. Irreparably and irrevocably shattered.

Besides, I wondered, what was the real message? Did other people get to keep their babies because they were just too weak to endure what my husband and I were going through? Was this one of those “whatever doesn’t kill you makes you stronger” experiences—was there some lesson I was supposed to learn from our tragedy? If so, wasn’t there a way I could have learned it that wasn’t so devastating?

Twenty months later, our daughter Pearl was born at home, late at night, in a mad, bright, dizzying rush of sound and energy. Her birth was a painful and exhilarating experience, and I basked in its miraculous glow: We did it! We brought a healthy, living child into the world. Pearl was here, safe and sound.

Thirty seconds after she was born, I looked into her face and exclaimed, “She has Down syndrome!” Our midwife said, “No, she’s just a little swollen.” But a week later, our pediatrician gave us the official diagnosis—Trisomy 21—confirming what we already knew.

At first, I wallowed in devastation. How could this have happened? How could we have one child who had died and another who had a chromosomal abnormality? It felt like losing another child all over again, and in a sense, I had: I believed I had lost the child I’d expected, the baby I had hoped for so fervently.

When our friends and family heard the news, they said, “Pearl has found the perfect family. If anyone can do this, you two can. It was meant to be.”

Again, I thought, Are you kidding me? You see, I heard this in a grim, duty-bound sort of way—as in, the road ahead would be tough, but we would do a good job caring for Pearl because we had to. Because my husband, a Special Ed teacher, already knows American Sign Language. Because we’re blessed with lots of love and support from our family and friends. Because we have access to resources that can help Pearl become who she is meant to be. Because we are the kind of people who will do the best we can, no matter the obstacles.

All of the above are facts, and I can’t argue with any of them; we’re undoubtedly in a better position than many to care for a child with special health care needs. But does that mean we were meant to do so? The concept smacked of bad karma, of being chained to a predestination that made my soul shudder.

Besides, since August’s death, I hadn’t been much for thinking in terms of “meant to be.” Our baby died and my entire worldview turned inside out. His death seemed to confirm one of two things: Either we were being punished by the universe for some unknown crime, or life was harsh, random, with no order or meaning at all. For a long time, I couldn’t determine which was true. I tried my best to believe life was random, despite my superstitious mind continually cycling back around to believing we were cosmically screwed. Discovering that Pearl had Down syndrome only added to my confusion— at first. But now, months into our life with her, my worldview has changed again. I do think Pearl was meant to be ours. I think we
The Things They Said

fumbled blundered toward her blindly as she claimed us with a true and certain aim. She’s the daughter we called into being amidst heartbeat and hope. We are the family she decided, with great purpose, to join.

And I am inexpressibly glad she’s here. At first I thought of her having Down syndrome as a bad thing, and as something separate from Pearl, herself. Now, she and her extra twenty-first chromosome are one and the same. Down syndrome no longer seems like something negative to me, any more than her being a girl or having two arms and two legs: it is part of who she is, and she is so much more miraculous than I can adequately express in words.

When a child dies—a real, flesh-and-blood child like August, not a fantasy, hoped-for child like the one I envisioned when I became pregnant again—there is nothing anyone can say to make it better, except, perhaps, “I am so sorry.” But here is what I wish someone had said to me during those first three weeks of Pearl’s life when I was once again so very, very sad:

You are going to fall utterly, madly, obsessively in love with this child. Not in several months or years, but in a matter of days.

This baby girl is going to delight you down to your toes. She will bring you more joy than you thought possible. She has already begun doing so.

This little one is going to make the pain of losing your son all the keener, because she will show you exactly how much you lost when you lost him.

This is the child you have been yearning and hoping for. She is the child you begged the universe to send you. She is here. Your longed-for life has begun.

I wish someone had said these things to me back when I was very, very sad. But if they had, I wouldn’t have believed them. These were things I had to learn on my own. And now I send out enormous gratitude to the universe, and to Pearl, for the fact that figuring them out for myself hardly took long at all. And I send out the hugest love to August. After losing a child, something like Down syndrome just doesn’t seem like that big of a deal.

Local and online resources:

• Down Syndrome Association of Central Texas
• My Healing Place — Grief support for people of all ages
• Pregnancy and Infant Loss Group at Round Rock Medical Center — Call (512) 341-6493

Children’s Policy Council

The Children’s Policy Council (CPC) will be soliciting for new parent members in the near future. The Children’s Policy Council (Council) works to assist the state in improving Texas’ systems of supports and services for children with disabilities and their families by offering recommendations to improve access to appropriate services, improve the quality of services, and maximize cost efficiencies. The primary goal of these recommendations is to promote healthy families and ensure that children with disabilities have the opportunity to grow up in safe and nurturing families.

The Council, statutorily authorized by HB 1478 (77th Legislature, 2001), is charged with assisting the Texas Health and Human Services Commission (HHSC) in developing, implementing, and monitoring programs for long-term supports and services providing support to children with disabilities and their families. The purpose is to present the Council’s priority recommendations for consideration by the Executive Commissioner of HHSC and the Texas Legislature.

Over the past year the CPC has created and made presentations to HHSC/DADS on Long Term Services and Supports Reform and Acute Care Medicaid Reform, produced 2 white papers for HHSC on Managed Care Dental and Pharmacy, participates in a DME (Durable Medical Equipment) Advisory Panel with HHSC, prepared and presented a Legislative Recommendation Report and is monitoring Legislation that affects children with disabilities and Managed Care/waiver reform and its impact on children with disabilities is a priority interest for the CPC. This is a parent driven Council and 51% of its members are parents or relatives of children with disabilities. The CPC will be posting its notice for member applications on the HHSC website in the near future. If you are interested in applying for this Council, please contact Laura Warren at Laura@txp2p.org or 866-896-6001 ext. 101.

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Texas Children’s Health Plan
Texas Children’s Hospital
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Work: Making a Contribution

A common fear for parents as their child with disabilities grows up is that he or she will sit at home all day after graduation and do nothing. They wonder, how do I assist my child to have a full, meaningful day? A primary answer for these concerns is WORK!

From A Good Life, by Al Etmanski, comes the idea that everyone must work, no matter the disability. Work in this book is defined as making a contribution, and everyone deserves the opportunity to make a contribution to his or her community, to use his talents and follow her passion. Work has many benefits as well: work gives meaning to our lives, provides a routine, a schedule, a reason to get up and get going every day, connects us with people, makes us feel useful, and possibly earns money!

These beliefs about work mean that we must consider our children's gifts and then find a place where they can use those gifts. This perspective leads to a new way of thinking about our children: instead of seeing disabilities, we must now look for abilities. Focusing on their abilities and interests will be the first step in building work opportunities for our children.

Another important key is expanding our view of work. We usually think of work as the 8-5 job we've been doing for years, but that model may not work for your child. We will expand the concept of work to include volunteering, working part-time, and entrepreneurship or self-employment; a person's work might be 40 hours a week or 1 hour a week, or somewhere in between. Remember, our definition of work is making a contribution, and all of these forms of work fit that definition.

I hope that so far, I've convinced you to consider work as an important part of your child's life as he or she grows up. But how do you get started? What can help your child learn about work and find the right path? To get started we must give them work experience and call on all our resources, at home and school, to create work opportunities.

**Encourage your child to gain work experience at home and in the neighborhood.**

Look for tasks around the house and neighborhood your child might be able to do and encourage him or her to do them regularly, tasks such as yard work, pet care, picking up mail and papers while the neighbors are out of town, watering plants, babysitting, running errands, anything that promotes your child's sense that work is important and gives him work experience. It's important to keep a log—see what your child can do, what help is needed, what makes him or her happy and engaged.

What services can your child provide that are in demand? Look around at your elderly neighbors—they may need someone to watch TV with or teach them how to use their electronic gadgets, run errands or cook some meals for them. Likewise your busiest neighbors may be eager to pay someone to walk the dog, water the plants, run to the grocery store, and so on.

**Use school to gain work skills and experience.**

Push your child's school to help with the "everyone can work" project. Some of the ways that school can help your child gain work skills and experience are:

- Classes to develop work skills, resume writing, good work habits, etc.
- Internships to gain work experience (usually un-paid), first on campus and then off campus (Community-Based Vocational Instruction or CBVI)
- Off-campus paid work in the last year or so of school. A school VAC (Vocational Adjustment Counselor) or a supported employment coach can help your child find a job and provide job coaching as your child learns to do a job.

**Ask school staff to sit down with you and your child (not at an ARD!) to brain-storm about work options for your child. Some of the ideas might be translated into IEP goals. Here are some questions to ask at a brainstorming meeting:**

- What are your child's talents, strengths and abilities?
- What does she love to do? What are his likes and dislikes? What motivates her? What does he get excited about?
- Does your child like quiet or noise, inside or outside? Consider what kind of environment will work best for your child.
- What supports does she need to work?
- What work opportunities are available near home or on a bus line? Remember, you may be providing the transportation later!

**Find a supportive work environment.**

- Look for a place that is already diverse. Notice the grocery stores, hardware stores, pharmacies where people with disabilities already work. Their presence shows a willingness to hire and to adapt the work-place to suit the person. Sometimes, instead of a small caring place, you might find opportunities at a state agency or a big company that has a hiring requirement or policy to promote work for people with disabilities.
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- Consider self-employment. Self-employment can be more flexible and creative and truly promote work geared to your child's energy level, interests and abilities.

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Rosemary Alexander, Ph.D., TxP2P
During my pregnancy, we found out we were going to have a baby. We had just joined a new Church. I was so excited, thinking this would be "the" gel that bonded us all together. During my pregnancy, we found out that Daniel was going to be born with some challenges. I was pregnant during Lent and it was the first time for me to hear the Holden Evening Prayers – it was beautiful! Then during one of the hymn sings, we sang "Here I am Lord" – as we sang the words "Is it I Lord?" and "I will go Lord if you lead me", Don and I just looked at each other and tears started streaming down my face.

During that time, we went through multiple ultrasounds – one of the first few, we were actually told they thought Daniel had a syndrome that would actually kill him before he was born and we were told of our "options." I told them to never mention it again – we had seen our baby and we were having him! Spunky? Or Faith?

I finally started calling different medical professionals asked us "what would you like for us to do?" We told them to just make him as comfortable as possible, if I had had him naturally, he might not have survived. He came out pink and then turned blue – they resuscitated him and immediately put him on a ventilator to find out what was going on – another "God thing" – if they had known ahead of time what his actual diagnosis was, they may have "encouraged" not trying to resuscitate him (we were actually told that quite some time later). After making a diagnosis of Osteogenesis Imperfecta Type II and telling us that his prognosis was not good and survival rate was 2 months at the most, the medical professionals asked us "what would you like for us to do?" We told them to just make him as comfortable as possible, if that meant staying on the ventilator that was fine with us. During those first few days, our pastor came up to the hospital and performed Daniel’s baptism. I remember going home without...
my baby – I remember the emptiness – I also remember trying to hold myself together for everyone else – especially our other kids and my Dad. When I was still in the hospital and had been given Daniel’s diagnosis – I remember laying there, with my Mom by my bedside and thinking about planning a funeral, instead of a baby homecoming. At that moment I was also thinking about my Dad – he had heart problems but was always strong in my eyes. He had retired as a School Superintendent, but still substituted because he loved school and children so much – and he was working part-time, of all places at a Funeral Home in Rockdale. I remember asking my Mom if she thought Daddy could go through a funeral for his grandson.

I remember coming to Church the first time – again, without my baby, and being in the pew and standing for the prayers and hearing Daniel’s name lifted up in prayer – each Sunday - that turned into 14 months of Sundays (that’s 56 Sunday’s! I had to calculate that one!) Remember we were told he wouldn’t be coming home? Well, he did come home at 14 months of age (yes, he spent his first birthday in the Neonatal Intensive Care Unit, but I still made him a birthday cake to share with the nurses, doctors and staff).

I think it was approximately 6 weeks after Daniel came home that we did have that “public affirmation” of Daniel’s baptism. Daniel was still on the ventilator and we sat in the back of the Church so the noise of his many machines wouldn’t be “too” distracting. We watched the video of the service not too long ago – a very precious memory – and heard our pastor share a story in front of the Congregation – he said he had kept asking us to do a public affirmation of Daniel’s baptism because he felt he needed to talk to Don because I kept talking about when Daniel was coming home, and he knew what Daniel’s diagnosis and prognosis were - and that I might not be dealing with reality. We all kind of laughed about it, but I knew, I had that feeling that Daniel was coming home – Spunky? Or Faith?

Fast forward to 2013 – I still have 4 children and now 4 beautiful grandchildren! I bring them up, because I never want them to be “left behind” – I’ve made that part of my goal ever since Daniel was born. I never “expected” Daniel’s siblings to “have” to watch him, take care of him or be responsible for him – they still needed to be kids/teenagers themselves. They each had their own way of communicating and being with Daniel - I think they are typical siblings in a lot of ways, and Daniel has taught them a lot about life.

Have these past 20 years been easy? Absolutely not – that may be a shock to some of you, others may know a little of what our lives are like, but I don’t like to dwell on the negative – I can’t – Spunky or Faith? I know at some of the hardest times in my life – it has to be Faith. I have also learned to be “Spunky” when it comes to getting services for Daniel – and I can get pretty Spunky! I also know that at some of the hardest times in my life, I am that person in the poem “Footprints in the Sand”, because I can’t even walk, much less crawl, but I am carried.

I’d like to mention something that I feel very strongly about – People First Language! People First Language is just that – putting the person first – it says what a person has, NOT what a person is. Daniel is a young man who happens to have a disability.

People with disabilities are just that – people – they are Mothers, Fathers, children, friends, neighbors, relatives. We all have our different abilities – let’s look for those, our gifts and not how we are different. Romans 15, verse 7 says: “Accept one another, then, just as Christ accepted you, in order to bring praise to God.”

**Tips for Parents in Preparing for ARD’s from a Transition**

**Coordinator’s Lens**

Denise Geiger, Transition Coordinator, Leander, TX

**E**very ARD has the name of someone very precious on the paperwork, your child’s. As you prepare for the ARD’s this spring, it has always been my experience that the ARD’s go much better when the child is in attendance, even as early as 3 years old. The use of a plan for how they are included is recommended. Start slowly at elementary level and then grow them into the person negotiating in the room and problem-solving effectively in High School.

The ARD Committees are there to make decisions that impact the child and help the child to make progress toward their goals in life. Coming from a Transition Coordinator’s viewpoint, **it has been my experience that student involvement in the ARD is to the benefit of everyone involved and is the best tip that I have.** By including the student’s in their ARD, the entire team is helping the student to have a true voice in their life and to learn and appreciate their Strengths, Preferences, Interests and Needs (SPIN).

The student’s involvement has been shown to help everyone to focus on what is important within the construct of the IEP process. Students can share a poster, a power point, read from a simple ARD agenda prepared ahead of time, video themselves as they go through the key points within the ARD or simply learn the fine art of coming to the meeting to introduce everyone, state the purpose and to tell the team their dreams in life.

**Another valuable tip** is for the student to have some sort of Transition Assessment done with them in a collaborative manner. Even from the age of 3, the child

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Tips for Parents in Preparing for ARD’s

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has areas from which good informal transition assessments can give valuable guidance for the ARD committee to look at and support as the child grows. Transition Assessments are often thought to just be for students at the Secondary Level, but the best time to start transition planning is at the age of 3.

By looking at these informal assessments, your ARD committee is looking at the areas of IDEIA-2004 which says that the team should be growing the areas of Social/Recreation/Leisure, Adult Living skills, Lifelong Learning and Employment skills with Community Integration being a focus within all of the 4 life domains. Some examples of Transition Assessments are as follows: Student Independence in the Classroom, Transition Decision-Making Matrix, Self-Advocacy Checklist, Social Skills Rating Checklist and High School Graduation Readiness Profile. Ask your district what transition assessment they use and advocate for them as early as possible.

By requesting one or more of these informal assessments, the parent is beginning the process of growing those skills that will support the child in sustaining a meaningful life upon outcome. Some of the skills that I am referring to are as follows: organization, time management, self-initiation skills, passing of time, quality of work, self-advocacy skills, self-determination skills, problem-solving skills, goal setting skills, relaying accurate messages between home and school skill and so many other skills that are imbedded within the educational environment, but sometimes have to be deliberately focused on in order to make steady progress over the many years within the school system.

A compliance tip that helps in preparing for ARD’s is for everyone to understand the impact of the statewide testing and how this impacts the post-secondary options. When a child is able to handle the general education curriculum at the standard set for all students, then that child is aimed at general education standard in High School at one of the following standards: Distinquished, Recommended or Minimum Program rigor. If a student is modified in their curriculum even at 3rd grade, then it is so important for everyone to understand that this child will be headed to a Minimum Plan in High School and can access services from the public school system through the age of 21, if needed. So understanding the graduation options for your child even while in Elementary is important as the ARD committee plans for the current year. This information is found in the Texas Commissioner’s Rules 89.1070 b (1) (2) (3) and (4).

My last tip is that every ARD committee actually sketch out an actual old-fashioned TIMELINE of how long each child could access services. I use this kind of timeline of the years from when the meeting is held to how long the child is eligible for services. Sometimes this very simple tool will allow the team to look gently and with true preparation to the time that is available and use the years with purpose.

The most powerful of all meetings is when the student’s voice is heard and when the team uses transition planning as the compass. The courage that it takes to plan forward will be much easier when the focus is on the child. Supporting self-advocacy skills and self-determination skills within the ARD process from the time the child is 3 years old will propel the child forward to achieve possibilities that allow them to soar and achieve lives with meaning upon exiting the public school system.

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 are grief with you. We want to share our condolences to our TxP2P families who have lost a child recently:

- Jasmine Villapando, daughter of Judy Fabian

We have some resources available for bereavement and there are groups in many areas which we are always willing to find for you. You may continue to receive the newsletter for as long as you like. We do have trained volunteers whose children have passed away and are willing to be matched as needed.

With deepest sympathy,
TxP2P Staff, Volunteers,
Texas Parent to Parent is committed to improving the lives of Texas children who have disabilities, chronic conditions, and/or special health care needs. We accomplish this by empowering families to be strong advocates through parent to parent support, resource referral and education, and by educating professionals about the unique needs of our children.

CONFERENCE REGISTRATION UPDATE

For the past 8 years, we have mailed a hard copy of our Conference Registration Packet to everyone on our mailing list. That’s now over 5,000 people! In order to save some trees and money, we have decided to handle registration a little differently this year. Once registration opens, we will send a flyer to everyone announcing registration is available on our website. The whole registration packet along with the registration form itself will be available for you to view and/or print on-line. If you want us to mail you a registration packet or you cannot register on-line, you can call or email our office and we can mail you a packet or help you register over the phone. We feel that not only will this be a cost savings but will also streamline the process of registration. Please feel free to contact Susan Prior or Jeanine Pinner at 866-896-6001 or susan.prior@txp2p.org or jeanine@txp2p.org if you have any questions.

Conference Schedule

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<th>Registration Information</th>
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<tr>
<td>Sunday, March 3 to Tuesday, March 5, 2013</td>
<td>2013 Statewide Independent Living Conference</td>
<td>Austin</td>
<td>For more information, go to: <a href="http://www.txsilc.org/conference/">http://www.txsilc.org/conference/</a></td>
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<tr>
<td>Thursday, March 21 to Saturday, March 23, 2013</td>
<td>Texas Association for Education &amp; Rehabilitation of Blind &amp; Visual Impaired (TAER) Annual Conference</td>
<td>Dallas</td>
<td>For more information, go to: <a href="http://www.txaer.org/conferences.html">http://www.txaer.org/conferences.html</a></td>
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<td>Wednesday, April 3, 2013</td>
<td>Young Minds Matter: Transition Age Youth Hogg Foundation</td>
<td>Houston</td>
<td>For more information: <a href="http://www.hogg.utexas.edu/detail/247/">http://www.hogg.utexas.edu/detail/247/</a></td>
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<tr>
<td>Tuesday, June 11 to Thursday, June 13, 2013</td>
<td>Texas Assistive Technology Network Conference</td>
<td>Houston</td>
<td>For more information: <a href="http://www.texasat.net">http://www.texasat.net</a></td>
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