**A Parent’s Perspective**

**TxP2P Quarterly Newsletter**

**A Parent’s Perspective**

**TxP2P UPDATE**

Laura J. Warren, TxP2P

Did you get the registration packet? Registration for the 8th Annual TxP2P Parent Conference is OPEN! Come join us for over 60 sessions on topics such as special education, transition, advocacy, behavior, autism, legal issues, medical/therapies, etc. The Teen Transition Summit is also back along with the one-day SibShop. New this year is a 3-hour Sibling Group for teens who have mild disabilities that have siblings with more significant disabilities. We’ll have Joe McDermott join us for a birthday celebration (TxP2P is 10 years old this year!) at the Family Gathering on Friday night. And we’ll have entertainment for the kids in childcare, including a petting zoo.

If you haven’t received your registration packet yet, call the office at 800-896-6001 or email Susan.Prior@txp2p.org. Hope to see you there!

**TxP2P Paying It Forward Awards:** Would you like to win a free conference registration for yourself and a friend? Please join us and participate in our first ever Paying It Forward Awards contest for family support. TxP2P always needs family stories about family support for our grants, reports, and legislators. We invite you to write and submit a one-page story about someone who has supported you and/or your family. There are 2 categories: 1) support you have received from another parent or family member, or 2) support you have received from a professional, service provider, or anyone else. Finalists will be selected by a committee and winners will be chosen by public on-line voting through our TxP2P Facebook page. The winners (parent who submitted story and person who they wrote about) for each category will receive a free registration to the conference. Please check out our webpage for more details: www.txp2p.org/contest

**Legislative Update – 2 Important Issues for Medicaid Waivers for All Receiving Services and Those Waiting!**

Linda Litzinger, TxP2P

Proposed changes to Medicaid Waivers around parental income: The Lieutenant Governor released the interim changes that are to be considered related to Health and Human Services. Included in these potential changes is “Financial eligibility determinations to ensure parental income and resources are considered when the client is a minor.” While the hope is that parental income will not be used to determine eligibility but just to assess a fee associated with the services, no one knows exactly what this will mean for all the children receiving services and those on the interest list waiting for services. The Senate will start discussions on this in March and the House will start work in May.

“Electronic Visit Verification” or EVV is in the pilot phase of being rolled out across Texas for all consumers using CDS (Consumer Directed Services) for their Medicaid Waivers and DADS (Texas Department of Aging and Disabilities Services) contractors providing certain services. It will only be used for “in-home” services. The service provider must use a telephone or computer to verify when the service begins and ends. DADS hopes to contain costs using this system.

Most consumers and providers are in the dark about the implications of what an EVV system means. It has been piloted in many areas of the state already and those that have piloted it are concerned over the time it takes to make corrections to the time sheets because of the complications the EVV creates. If a service provider forgets to call before or after the service starts, the time sheet must be corrected via a computer. For more information, read this White Paper: http://www.dads.state.tx.us/evv/WhitePaper.pdf Additional information can be found: http://www.dads.state.tx.us/evv/index.html

So the question is, what can you do about these changes? If you would like to be involved in voicing your opinion on these changes, please contact Linda Litzinger with the TxP2P Advocacy Network at Linda.Litzinger@txp2p.org
**Miscellaneous Texas Services**

**Case Management for Children & Pregnant Women**

**Are you on Medicaid and need help finding health-related services?**

Families receiving Medicaid are eligible for free case management services for children with disabilities, who have ongoing health conditions or health risks that other children the same age do not normally have; and to women with high risk pregnancies. Case managers can assist families in getting help with:

- Accessing needed medical services or dental care, including setting up visits with specialists,
- Assisting with family or behavioral problems,
- Ensuring your child’s school is meeting their needs and attending school meetings,
- Financial or housing problems,
- Finding other help near where they live, and
- Helping to get medical supplies or equipment.

Services are provided to children with a health risk from birth through 20 years of age and will help families gain access to medical, social and other health-related services. If you are eligible for Medicaid and would like help in getting services to keep health problems from getting worse, contact the Texas Health Steps Outreach and Informing Hotline at 1-877-THSTEPS or 1-877-847-8377.

If you think you may be eligible for Medicaid but do not currently receive services, contact 2-1-1 to find out about services in your area. You may also apply for services at your local HHSC benefits office or online at [www.yourtexasbenefits.com](http://www.yourtexasbenefits.com).

**Medicaid Buy-In for Children**

Need help paying for medical bills but make too much money for traditional Medicaid?

The Medicaid Buy-In for Children program can help pay medical bills for children with disabilities. The program is designed for families who need health insurance, but make too much money to get traditional Medicaid. Families are able to “buy in” to Medicaid by making a monthly payment.

To be in this program a child must:

- be age 18 or younger,
- meet the same rules for a disability that are used to get Supplemental Security Income (SSI),
- live in Texas; be a U.S. citizen or legal resident, and
- not be married.

The Medicaid Buy-In for Children program pays for health-care services such as doctor, dental or hospital visits; emergency care; medicine; glasses; mental health care; care in the home or other place of care; speech therapy; occupational therapy; physical therapy; regular checkups and help with Medicaid services (case management).

For more information, call 2-1-1 or 1-877-541-7905.

**TSA (Transportation Security Administration) Creates Helpline for Travelers with Disabilities**

TSA has launched TSA Cares, a toll-free helpline to provide information and assistance to passengers with disabilities and medical conditions and their families before they fly. Travelers may call TSA Cares toll free at 855-787-2227 prior to traveling with questions about screening policies, procedures and what to expect at the security checkpoint. Travelers who are deaf or hard of hearing can use a relay service to contact TSA Cares or can e-mail TSA-ContactCenter@dhs.gov. The hours of operation for the TSA Cares helpline are Monday through Friday 9 a.m. – 9 p.m. EST, excluding federal holidays. After hours, travelers can find information about traveling with disabilities and medical needs on TSA’s website at: [http://www.tsa.gov/travelers/airtravel/disabilityandmedicalneeds/](http://www.tsa.gov/travelers/airtravel/disabilityandmedicalneeds/)

When a passenger with a disability or medical condition calls TSA Cares, a representative will provide assistance, either with information about screening that is relevant to the passenger’s specific disability or medical condition, or the passenger may be referred to disability experts at TSA. TSA recommends that passengers call approximately 72 hours ahead of travel so that TSA Cares has the opportunity to coordinate checkpoint support with a TSA Customer Service Manager located at the airport when necessary.

**Identify Communication Difficulties on Your Texas Drivers License or State ID**

Texas Drivers License and State ID cards allow for the addition information about any medical condition that may impede communication with a peace officer on the back of the card, provided that a signed physician’s statement (Form DL-101) verifies the condition.

FOR NEW APPLICANTS: Bring in your paperwork and all forms, including DL-101, to your local DPS office and request that the medical condition be included on the back of the card.

For information on applying for a State ID card: [http://www.txdps.state.tx.us/DriverLicense/applyforID.htm](http://www.txdps.state.tx.us/DriverLicense/applyforID.htm)
The irreversibility of it was what bothered me the most. I’d never be able to fix Meredith. She was as stuck with this unfortunate diagnosis as much as I was.

I spent my first year searching for answers and schlepping Meredith to therapy appointments, doctor’s appointments and play groups with typical babies and mothers that had no idea what to say to me. Meredith was my first baby as well, so I was doubly clueless.

One time I was at the grocery store with Meredith long before she could walk and an older woman noticed I was carrying her. “You are spoiling her,” she said. “She can walk.”

“She can’t walk,” I told her. And of course my thought bubble said: Did you really just give me unsolicited advice on one of the hardest goals of my daughter’s life while deciding between the Honeycrisp and Golden Delicious?

What a weird planet we live on, parents like us.

Comments like that really ruined my day, but I had plenty of positive karma from support groups and the therapists from Early Childhood Intervention, the statewide program to help families get therapy and other services for their child with disabilities. I’ve been lucky that the vast majority of teachers and therapists in Meredith’s life have been caring, helpful and driven.

Meredith has an unusual diagnosis called Agenesis of the Corpus Callosum meaning the fibers of her brain creating a bridge between the two hemispheres did not form and she has a small cerebellum also due to a Dandy Walker variant. I found a few people to talk to early on who had the same diagnosis for their child, but it’s really hard to see into the future until you’ve walked it.

Everyone warned me about middle school, however, and, man, were they right. It has been an epic struggle to find the social support let alone the best curriculum for Meredith in middle school. I’m not sure where the disconnect was between Meredith’s hugely inclusive experience in elementary school and her sudden relocation to an island with few friends and very little exploration off the island unless it was the entire group of Life Skills castaways. She seemed to lose her rights and her social status as an individual.

I guess I turned into the mother from hell when I began writing about all that in the Austin American-Statesman, but I felt the need to open it up. I suppose the biggest lesson I learned is Meredith’s education is only as good as the scheduling, which is deeply dependent on how many aides are in the classroom.

I recently help start a vegetable garden to be shared by kids in Life Skills castaways. She seemed unless it was the entire group of school and her sudden relocation to an island with few friends and very little exploration off the island unless it was the entire group of Life Skills castaways. She seemed to lose her rights and her social status as an individual.

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How I got HIPP (Health Insurance Premium Payment Program)
By Cynda Green, TxP2P Staff

What is HIPP? It is a Texas Health Insurance Premium Payment program that helps families pay for private health insurance. Your family can get HIPP if you have a child or young adult in your family that gets Medicaid and someone in your family has private health insurance through their employer. If your family gets HIPP, Medicaid will pay your insurance premium.

Your private insurance must cover the person who is receiving Medicaid and pay at least 60% of the costs when you go to the doctor, buy medicine, get out patient care, have lab test, X-rays or are in the hospital.

How do they decide if you qualify for HIPP? You must provide documents of your insurance plans and rates sheets. Once all the required documents are received your case goes to the insurance review committee.

The insurance review committee will then see what Medicaid estimates as an annual cost of your child receiving Medicaid and if the private group insurance is less than the estimated cost from Medicaid then you qualify for the HIPP program.

Once you qualify you will be required to send in proof of monthly insurance premium payment and then HIPP will process your reimbursement. Your case will be reviewed every 11 months to make sure it continues to be cost effective.

After going through the process when my daughter started receiving Medicaid, what I found out the hard way was the HIPP department is very slow in responding to applications and if there are any missing documents they will not notify you, they will wait for you to call. Don’t wait for someone from the HIPP program to contact you regarding your case, be proactive and call them.

You must contact HIPP with any changes of insurance, address, phone number, etc. as soon as possible. Keeping your HIPP records up to date helps them send premium payment to you on in a timely fashion.

You can find addition information online at www.GetHIPPtexas.org or by calling 1-800-409-1188.

Transition to Adulthood: Person-Centered Planning & Personal Networks (a 2-part series)

PART 1. PERSON-CENTERED PLANNING

When my son Will was 20 years old, I panicked! It really hit hard that he only had 2 years left in school and then he’d be “out on the street,” with nowhere to be each day and none of the services and opportunities of public school programs. At that point, I called in the troops to do person-centered planning.

Person-Centered Planning (PCP) is a process that brings together a group of concerned friends and family to explore opportunities with the focus person. Developed in the late 70’s to early 90’s in Canada, the US and the UK, the term “person-centered” emphasizes that plans are based on the focus person’s dreams and goals, as opposed to “service-centered,” which promotes the convenience and needs of service agencies and providers.

You can start this process for your child at any age, but this planning process is often used as a person approaches adulthood...so that’s why I grabbed the idea for Will at age 20. We were lucky that our school district had staff trained to facilitate PCP, so I requested a meeting. We had it in our home - I thought home was best for planning a life after school supports were gone - and we invited school staff, care providers, Will’s brother, and a family friend who had known Will for years.

I was scared that we’d throw a party and no one would come - but they did come! We had a light supper and a meeting led by 2 facilitators. They brought large tablet paper and markers and a list of questions to ask the group, so we got started planning what Will’s life would look like after graduation.

In most PCP meetings, the facilitator addresses questions to the focus person first and then opens it up to the group, but because Will does not use words to express himself, we all spoke for him. We put ourselves in his shoes, and judging from his behavior and responses in various situations, imagined what he would say. We talked about where he spends his time and with whom, what he likes and dislikes, what he’s really good at, what he fears (and some parental fears came out at that point) and what his dreams and goals are. Then we chose one goal and created a list of steps to accomplish that goal, including who would do what by when.

The first goal we chose to work on for Will was to have a day full of things he wanted to do routinely after graduation. We talked about jobs and what his school job coach (present at the meeting) was pursuing to develop work for him; recreation and social opportunities; transportation; and people to assist him through his day. We divided up the tasks and set a date for a follow-up meeting.

What I learned that night was so important to me and our family:• there were people out there willing to contribute to Will’s quality of life, once we scraped up the courage to ask them• anxiety goes down when you start to plan, and• talking with others about a shared vision for the future gives you hope.

I soon became a PCP facilitator myself and have facilitated many plans for people of various ages over the last 10 years; I’ve had the pleasure of seeing how this process can work in a variety of circumstances. One thing I’ve observed is that you never know Continued on Page 5
what the focus person will say; things that sometimes really surprise parents! "I want to lose 20 pounds." "I want a girlfriend/boyfriend." "I want to be a jet pilot." "I want to move out." "I want to live with my parents forever." "I want to not be bullied at school anymore." "I want a driver's license." The trick is for the facilitator to take whatever is said and use it as an opening door to the future.

Want to be a jet pilot? I would ask, what do you like about the idea? The answer might be: I like airports, I want to wear a uniform, I like to tell people what to do! Now you have the first step along a career path! Want to not be bullied at school anymore? The steps generated by the group might be: let's build a small group of school supporters and friends, talk to the principal and staff, assure the person that it's a good thing to report being bullied, and work on the skills to know when and how to report bullying. Now you have the first steps for working on social groups and safety. Want to lose 20 pounds? The facilitator might ask for input from the group on how they have lost weight and then plan for the focus person to join a gym or find an exercise buddy. Want a driver's license? That wish starts exploring what it takes to get a license and what alternatives are available when someone doesn't have a license - a door opens to discuss transportation. The process is positive and exploratory; it gives the focus person a chance to practice self-determination; it provides the group with a direction to proceed in looking at options for the person's future. The process often leads to a discussion of the fundamental questions, where will this person work, play and live in the future? And then how will this person be safe and supported? Another thing I have learned through my PCP experience is that any process that focuses on the future is useful - it doesn't have to be Person-Centered Planning. The fundamental idea is to initiate a discussion with a small group of people who know the focus person, can brain-storm with him or her to generate ideas for carrying out a goal, and can give a little time to support them, even if it's just for a few months.

You are probably asking, great, but how do I get started? Where can I find a facilitator? First, see if someone in your public school special ed. department or your Regional Education Service Center might be up on PCP training or some other planning tool for transition. If not, try other sources: PATH is a similar process and The Arc of Texas has facilitators trained to lead a PATH (www.thearcoftexas.org - then look for the Texas Microboard Collaboration through the Arc). There are several excellent websites that could help you get started: http://www.pacer.org/tatra/resources/personal.asp http://www.ncset.org/publications/viewdesc.asp?id=1431 www.capacitythinking.org.uk/PersonCrtPlShort.pdf

Using one of these guides, perhaps you and another parent could trade off facilitating a planning process for each other.

What is Texas Project FIRST?

H as your child recently been diagnosed with a disability or been referred for special education services? Maybe your child has been receiving special education services and it’s time to figure out the next steps. Wherever you are in the process, the Texas Project FIRST website provides accurate and consistent information to help you navigate the special education maze and become a more effective participant in your child’s educational programming.

Launched in September 2006, the Texas Project FIRST website is a project of Family to Family Network under a grant from the Texas Education Agency and Region 9 Education Service Center. Texas Project FIRST stands for “Families, Information, Resources, Support and Training.” The website contains a wealth of information on special education, written in a way that’s easy for parents to understand.

On the home page you will find a list of age ranges (0-3, 3-5, 5-11, etc.). By clicking on the age range of your child, you will pull up an

Continued from Page 4

Continued from Page 6

Finally, I have learned another truth about PCP, a hard truth: most families need a supporting group to carry out a plan. I have seen far too many lovely plans end up on a shelf, with no action and no outcomes. Families often are too overwhelmed with day-to-day parenting to have the energy and resources for working on the steps that a group might generate. Not only do we need PCP facilitators, we also need personal networks to help carry out a plan. And that is another great topic. (Tune into the next TxP2P newsletter for more on networks!)
What is Texas Project FIRST?

index of topics relevant to that age group. All age range pages list some common topics at the top of the page, including links to:

- Education Service Centers
- Family to Family Network
- trainings and articles about the Special Education Process (Portfolios, ARD Agenda, Special Ed 101, etc.)
- Community Services (Medicaid Waiver Programs, Social Security, DADS, DARS, HHSC, etc.)

After Community Services, you will find information on a variety of topics, in alphabetical order. Most of these topics provide “links” that will take you to more information on that specific topic. Some examples of topics you will find there are:

- Accommodations
- Autism
- Autism Supplement
- Diagnosis vs. Disability – Defining Eligibility
- Dispute Resolution Process
- Planning for the Future (i.e., Self Advocacy, Self Determination, Transition, and Alternatives to Guardianship)
- Individualized Education Plan Development
- Graduation
- Statewide Assessments

Each of the age range pages also includes items that are relevant to that age group. For example, in the 0-3 and 3-5 areas, we have information on:

- Preparing to Transition to Preschool
- Preschool Options
- Preschool Curriculum

In the 11-16, 17-21 and Post Graduate age ranges, we have information on:

- Employment
- Independent Living
- Post Secondary Options

On the left-hand side of every page, you will find links to:

- Texas Education Agency (TEA) – here you will find information on Curriculum (TAKS), Statewide Assessment (TAKS/STAAR), State Guidance documents, and Data Reports (region and district)
- Federal and State Laws
- Texas Statewide Parent Training and Information Center
- A Listing of Statewide Conferences
- Glossary and Acronyms - these were removed from TEA’s Guide to The ARD Process in the most recent update
- Other Parent Training Resources

The Other Parent Training Resources page allows parents to access FREE online trainings on a variety of issues; as well as find out what training is available at their local Education Service Center. The Other Parent Training Resources page also has a link to the Directory of Community Resources where parent can enter their zip code to find local organizations that may provide support or training.

Many of the Texas Project FIRST articles are also available in Spanish – click on “en espanol” at the top of the page. There is a place on the website for you to register for updates so that we can send you quarterly e-mails to notify you of any additions or updates to the site. If you cannot find what you are looking for, there is a Search box, as well as a place to “Contact Us” with specific questions.

Whatever stage of the education process your child is experiencing, we encourage you to spend time on the Texas Project FIRST website. If you don’t have internet service or a computer in your home, many public libraries and community centers have computers that you can use and someone there who can help you log on. With knowledge of the ARD process, you as a parent can be more involved and better prepared to take an active role in your child’s education.

Texas Project FIRST is an activity of the Texas Continuing Improvement Process (TCIP) under the auspices of the Texas Education Agency (TEA) and Region 9 Education Service Center, and is focused on helping to fulfill the goals of TEA and the Parent Training Committee. Texasprojectfirst.org is a project of Family to Family Network, dedicated to providing accurate and consistent information on the special education process.

Sunshine Foundation: Answering the dreams of our children . . .

By Susan Prior, TxP2P Staff

The Sunshine Foundation is the original wish granting organization founded to fulfill the dreams of seriously or chronically ill, physically challenged and abused children ages 3-18 whose families cannot fulfill their requests due to the financial strain that the child’s illness may cause.

The foundation was founded by a former police officer, Bill Sample, in 1976. His vision began while on protective duty at an area hospital in Pennsylvania where he saw the frustrations families experienced in providing for their children. The Sunshine Foundation has answered over 36,000 dreams since then.

Dream requests have ranged anywhere from a trip to a theme park in Florida, a request for a computer, meeting a celebrity or sports star, attending a ball game to getting new bedroom furniture. The dream is as individual as the child.

Most of the foundation’s funding comes from individuals and corporations. It is also supported by volunteer chapters that help raise money and refer children.

The criteria to receive a dream for your child are:
Assistive Technology, Apps for Kids, Center for Early Literacy Learning, & Head Start Center for Inclusion

EI understands that families and professionals are increasingly using the internet and technology to access information. Technology is a powerful tool that can help children be more independent, participate in games and other activities with peers, and communicate preferences.

WHAT IS ASSISTIVE TECHNOLOGY (AT)?

Assistive Technology (AT) allows people with disabilities to perform tasks and participate in everyday activities in different ways. It is any item, piece of equipment, or product system that helps a person do something that his or her age appropriate peers can do without assistance. Examples: A wheelchair used for mobility, a communication device to speak, digitized books or Braille to read, hearing aides to hear, or an oversized switch to activate a toy.

Here are resources that provide tips, tools, demonstrations and valuable information on how assistive technology can be used at home and in the classroom.

SNAApps4Kids

SNAApps4Kids is a volunteer community of parents, therapists, doctors, and teachers who share information on how they are using the iPad, iPhone, iPod Touch and Android devices with children who have special needs. They have found these mobile devices to provide accessibility for children who may have been previously disengaged from the world because of challenging language, motor, or other developmental delays. Given the rising number of apps on the market and the diverse skills of children with special needs, parents have found each other to be one of the best resources for choosing apps to enhance everyday life for their children. While this group is primarily parent-driven, their efforts are naturally collaborative with the people who help their children develop particular skills — therapists and educators. Visit http://www.snaapps4kids.com/about/ for more information on creative and useful ways to incorporate technology into learning and development.

CENTER FOR EARLY LITERACY LEARNING

The goal of the Center for Early Literacy Learning (CELL) is to promote the adoption and sustained use of evidence-based early literacy learning practices. This site has resources for early childhood intervention practitioners, parents, and other caregivers of children, birth to five years of age, with identified disabilities, developmental delays, and those at risk for poor outcomes. The CELL is a major initiative of the Center for Evidence-Based Practices at the Orelena Hawks Puckett Institute.

The CELL has published 15 new CELL practice guides with adaptations for infants, toddlers and preschoolers, which show how to adapt early literacy activities so that young children with disabilities can participate. The guides can be used by practitioners or parents, or by parents in collaboration with practitioners. They describe everyday home, community, and childcare learning opportunities that encourage early literacy learning. All are available online at http://www.earlyliteracylearning.org/pg_tier2.php.

HEAD START CENTER FOR INCLUSION

The success of inclusion depends on everyone realizing that it involves more than children “just being there.” Inclusion refers to the full and active participation of young children with disabilities in programs with typically developing children. For thirty years, research findings and public policies have promoted preschool inclusion as an important element in producing positive outcomes for young children with disabilities and their families (Guralnick, 2001; Smith & Rapport, 2001; Strain, McGee & Kohler, 2001).

The Head Start Center for Inclusion systematically addresses existing barriers to effective inclusion and increases the competence, confidence and effectiveness of personnel in Head Start programs to include children with disabilities.

In particular, the Head Start Center for Inclusion has a website page designed just for families. It contains a wealth of information on supporting and including children with special needs in the classroom and home. The Head Start Center for Inclusion has key pieces of information to get families started. Please browse this page for all things related to families of children with special needs. Take a look at the other areas of the site for even more information on inclusion. http://depts.washington.edu/hscenter/families.
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.

Finally we have rain!

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<tr>
<th>DATE</th>
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<th>CITY</th>
<th>REGISTRATION INFORMATION</th>
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<tr>
<td>Sunday, April 22, to</td>
<td>2012 Texas Statewide Independent Living Conference</td>
<td>Dallas</td>
<td>For more information: <a href="http://www.txsil.org/conference/">http://www.txsil.org/conference/</a></td>
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<td>Tuesday, April 24, 2012</td>
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<td>Tuesday, May 15 to Thursday, May 16, 2012</td>
<td>Spiritual Crossroads: Faith, Mental Health and the African American Community Hogg Foundation</td>
<td>Fort Worth</td>
<td>For more information: <a href="http://www.hogg.utexas.edu/detail/247.html">http://www.hogg.utexas.edu/detail/247.html</a></td>
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<td>Tuesday, June 12 to Thursday, June 14, 2012</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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<td>Friday, June 29 to Saturday, June 30, 2012</td>
<td>Texas Parent to Parent Annual Parent Conference</td>
<td>Austin</td>
<td>For more information: <a href="http://www.txp2p.org/training/conference.html">http://www.txp2p.org/training/conference.html</a></td>
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