



A Parent's Perspective

TxP2P Quarterly Newsletter

TxP2P Update

Laura J. Warren, TxP2P Staff

Our 9th Annual Parent Conference in San Marcos on Friday & Saturday, July 26th & 27th is almost here! Registration is open and we have some funding for family registrations for the Central Texas area thanks to Region 13 Education Service Center. We will be back at the Embassy Suites in San Marcos. Registration ends on July 12; the last day to get a hotel room for the lower price under the TxP2P room block is June 25 unless they run out of the rooms earlier – they did run out last year!

All your favorites are back – 2 complete tracks on transition issues so you have lots of sessions (14) to choose from as well as sessions on behavior, genetic issues, autism, blind & visual impairments, resources including Medicaid Waivers, special education, parenting, siblings, and much more; Teen Summit - youth and young adults 2-day conference within a conference; child care with a petting zoo, City of San Marcos police cars, fire engines, etc. for the kids to explore, and Tom's famous games. A few of the additional highlights are:

♥ We are offering a pre-conference session on Thursday evening with Dr. Bruce Cohen who will discuss Mitochondrial Disease and what families should know about it. Dr. Cohen is one of the leading physicians in this field.

♥ Our keynote at the Friday Opening session will be **Kathy O'Connell**, a self-advocate with Cerebral Palsy. Kathy will present ways to empower your child with a healthy sense of self. She will intertwine stories from her own childhood to assist you in helping a child develop an awareness of self, create healthy boundaries, and show ways to actively join your child in the recognition of his or her potential.

♥ **Dr. Angelo Giardino & Dr. Carl Tapia** from Baylor College of Medicine/Texas Children's Health Plan will present at Friday lunch on the national perspective on developing medical homes, how to work with your child's physician to create a medical home for your child, and how health care reform will influence the medical care future for all of us.

♥ **Joe McDermott** will be back on Friday night to entertain parents and kids alike at our Family Gathering. Hope to see many of you at the conference!

Paying It Forward Awards – it's not too late to vote for your favorite parent/family support story. Visit our website (www.txp2p.org) and follow the link to the voting for the awards which will be announced at the conference. Your vote determines the winners, who will receive free conference registrations! Voting ends 6-9-13!

Volume 12, Issue 2

Summer 2013

Inside this issue:

- ♥ **Around the State:** Finishing up the 83rd Legislature - see page 3
- ♥ **Around the State:** ECI Supports Families - see page 3
- ♥ **Around the State:** Parent Leaders - see page 4
- ♥ **Around the State:** When a Disaster Happens, Will you be Ready? - see page 5
- ♥ **Transition:** What's Up with PTA - see page 6
- ♥ **Around the State:** Is this the Year for Overnight Camp? - see page 6
- ♥ **Around the State:** Happy Father's Day - see page 7
- ♥ **Conference Calendar -** Page 8

2013 TxP2P Conference Is Coming!!!!
July 26-27, 2013
Embassy Suites, San Marcos

Health Care Reform – What does it mean to your Family?

Affordable Care Act – Obama Care

Whether You Agree or Not, There are Good Changes on the Way

Laura J. Warren, TxP2P

TxP2P has the Family to Family Health Information Center grant for Texas and because of that, I have slowly learned more and more about the Affordable Care Act (ACA). I have never had to purchase health insurance - I grew up in the 50's & 60's when insurance was provided through your Dad's

job. Since then, I got insurance either through my job or my husband's. When my husband retired and COBRA ran out, we started looking for insurance and what a shock it was! I have watched costs go up and benefits go down since I was in my 40's but when you are in the private market for insurance,

you finally realize what everyone is talking about. What fit our budget was the highest deductible and basically only catastrophic coverage. Our prescriptions and doctor visits are not covered. My son, who almost never goes to the doctor but was a preemie and has

Continued on Page 2

Health Care Reform – What does it mean to your Family?

Continued from Page 1

mild Cerebral Palsy, was denied twice before we had to go to the Texas High Risk Pool Insurance Plan to get his insurance. And we're the lucky ones who can get insurance! Now, I can't wait until January 2014 when all the benefits of the ACA will take effect.

What we will get from ACA in 2014:

Adults with pre-existing conditions can no longer be denied insurance OR have to pay more for it *OR in my language - my son can't be denied insurance again!!*

In 2010, insurance companies can no longer set **lifetime limits** on your care AND in 2014, they cannot set a limit on a dollar amount spent on specific care *OR when a child is born and spends the first year in the hospital, insurance won't run out before they come home!*

Creates a **Health Insurance Marketplace**: The Marketplace is designed to help you find health insurance that fits your budget, with less hassle. You can compare all your insurance options based on price, benefits, quality, and other features that may be important to you, in plain language that makes sense. There will also be a toll-free hotline for consumer support, "Navigators" for consumer assistance (*these won't be commissioned insurance agents*), and online resources. Open enrollment in the Marketplaces starts October 1st, 2013.

Families will be eligible for tax credits that will help pay for insurance premiums based on income and the size of their family as well as assistance with out-of-pocket expenses such as co-pays, deductibles, and co-insurance. *Many families will be eligible for this help – one report I heard helped families with incomes over \$92,400 for a family of 4.**

Small business owners will get more relief with tax credits and affordable insurance choices in the new competitive Health Insurance Marketplace in every State. *TxP2P might be able to offer health*

insurance to our staff!

What we already have from ACA:

Children with pre-existing conditions can no longer be denied insurance OR have to pay more for it. *Have any of you decided not to change jobs because you would lose insurance for your child? We certainly faced that when our son was younger.*

Young adults get an extra year on their parent's insurance, until age 26 instead of 25 even when they don't live with their parents.

You and your family can get some free preventative care - see this site for a list of care covered: http://www.healthcare.gov/news/factsheets/2010/07/preventive-services-list.html#Covered_PreventiveServicesforAdults *There are exceptions, determinations and grandfather clauses on this piece of the law but if I can get my annual physical for no co-pay, it's still good!*

Of course, as with any medical care, covered services will still have to be considered "medically necessary," there will be exclusions and limits and prior authorizations. Nothing new there!

How many of you struggle to find doctors who will take your insurance? Or a doctor who will see your child and has the expertise to care for your child? Or one who wants to provide a medical home for your child? Another aspect of the Affordable Care Act is to reduce costs and increase access to health care – here are some of the ways it will do this:

Invests in training and supporting thousands of **new primary care doctors** and nurses by providing bonus payments, scholarships and loan repayment, and new training opportunities.

Builds and improves community health care centers that take Medicaid.

Insurance companies cannot rescind or take away coverage when people get sick just because of an unintentional mistake on an application. It also provides for a

new right to appeal an insurance company's coverage decision and provides consumers with information and assistance to give them more control over their health care decisions.

The health insurance companies have to meet the 80/20 rule, or Medical Loss Ratio, where they must spend at least 80 cents of your premium dollar on your health care or improvements to care. If they don't, they must provide a rebate to their customers. *We received a rebate last year!*

For the first time ever, insurance companies must publicly justify any rate increase of 10% or more. And the law gives States new resources to review and block these premium hikes.

Insurance companies must provide clear, consistent and comparable information about their health benefits & coverage.

The Affordable Care Act creates a new type of non-profit health insurer, called a Consumer Operated and Oriented Plan (CO-OP). These insurers are run by their members. CO-OPs are meant to offer consumer-friendly, affordable health insurance options to individuals and small businesses.

For more information on any of these options, check out the website www.healthcare.gov or in Spanish, <http://www.cuidadodesalud.gov/law/index.html>

For more information on the Health Marketplaces:

<http://www.healthcare.gov/marketplace/about/eligibility/index.html> and <http://marketplace.cms.gov/index.html>

*From Henry Kaiser Family Foundation:

FAQ's: <http://kff.org/health-reform/fag/health-reform-frequently-asked-questions/>.

Subsidy calculator: <http://kff.org/interactive/subsidy-calculator/>. Each exchange is required to provide a calculator on their website.

Finishing Up the 83rd Legislative Session

Linda Litzinger, TxP2P

As we finish this 83rd legislative session, I would like to recognize each and every person who contacted or visited legislators, testified in bill hearings, attended agency stakeholder meetings, and stayed informed of proposed ideas.



I would like to highlight two different kinds of advocates from this session: those who live far from our Capitol and those who can drive the round trip in a day.

Carol Thompson is from Shallowater in the Panhandle & recognized changes in health care after Star Plus managed care came to her



Lubbock area. Critical therapeutic appointments (Physical, Occupational, Cardiac and Pulmonary, etc.) were suddenly denied if you

weren't post-surgery. Medicaid rides were also denied, especially for patients referred to a specialist in another city. The local economy was affected because transportation entities lost so much business. Carol had a meeting with judges from surrounding counties to get them involved so they could approach TX Health & Human Services Commission (HHSC) in unison. Carol's experience with managed care informed other advocates in this legislative session as they discussed Senate Bill 7 which will eventually roll every Medicaid recipient onto managed care. She is also concerned that Medicare beneficiaries are being marginalized by new Texas Medicaid policies, merging them into managed care as dual-eligible's. As a result of her advocacy, she recently received the Hub City Access Christie Gutierrez Award for improving community access for individuals with disability in the Lubbock area.

A second example is Lore Mason from Houston who made fourteen trips to Austin during the legislative session. This called for great understanding of the issues, tremendous stamina, plus support at home. Lore was

instrumental in calling attention to two issues as waiver reforms were debated: employment disincentives associated with waiver reform and a need for better Star Plus assessment tools so that people with intellectual disability will qualify for services. Lore is the legislative chair for the Down Syndrome Association of Houston



and also serves on the Harris County MHMRA IDD Project Advisory Committee. She is pictured with Senator Rodriguez.

I am very impressed by all of our advocates who became active during this session. We will continue to have our weekly teleconferences, changing it up a bit so that teams will emerge who have ideas for the next legislative session. Contact me if you would like to be involved:

Linda.Litzinger@txp2p.org



For over 30 years, Early Childhood Intervention (ECI) has provided early intervention services to Texas families with children from birth to 36 months of age who have developmental delays or disabilities. ECI professionals and families members incorporate activities into the child

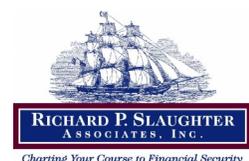
ECI Supports Families

and family's daily activities to promote the child's development. At Texas ECI, we know that parents are the most important person in their child's life and they know their child better than anyone. Parents are their child's first and best teacher. ECI encourages parents to join in every step

of the process, from deciding on what kind of support their child and family may need to working daily with their child to help him grow and learn. Read how the McDaniel family and ECI worked together to promote Kolt's development.

Continued on Page 4

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Going into their ultrasound appointment, J.D. and Shay McDaniel were focused on expectant parents' typical questions: "Who will he look like? His brother Seth or Luke?" But a few minutes into the appointment, they heard the devastating diagnosis for their third child, Kolt.

Kolt had congenital heart defects and at best, a 20 percent chance of living. "The doctors told us that we probably would never hear him cry," Shay said.

To everyone's surprise, when Kolt was born that February morning, his parents heard their son cry. "It was music to our ears," Shay said. Doctors performed an angioplasty and open-heart surgery within the first week of Kolt's life. Six months later he had a second heart surgery and was awaiting a third. While Kolt was in the pediatric intensive care unit, the hospital staff told the family about the DARS Division for Early Childhood Intervention Services (ECI). ECI professionals immediately stepped in to coordinate nutritional, physical, and occupational therapy for Kolt and his family.

Kolt's condition and medication made it hard for him to gain weight. During his first six months of life, he struggled to eat just six ounces of formula a day. Once he could eat solid food, an ECI dietician worked with the family and created techniques that helped Kolt with his eating habits. After a while, Kolt was out-eating his big brothers.

While Kolt advanced mentally, his physical development remained a challenge. The ECI physical therapist recommended practical suggestions and activities that the family could include in their daily routines to help Kolt. "They showed us how to use things from our home, which was very convenient," said Shay. The family filled a basket with toys and Kolt pushed it across the room as he learned to walk.

Providing ECI services at home helped reduce exposure to bad weather and infectious surroundings for Kolt, who was at higher risk for infection. Each of Kolt's ECI team members travelled more than 70 miles round-trip each visit to work with him and his family in

the Lubbock area. "They always kept our family's best interest in mind, and we were so grateful for that," said Shay.

Now Kolt loves football and playing with his brothers. "We set big goals for him," said Shay. "ECI understood Kolt's fragility, yet pushed him to do his best. He met his goals through his hard work and his ECI team's hard work. We are so thankful to ECI."

If you would like to learn more about how ECI helps families, watch our "[Texas ECI: Family to Family](#)" video which offers several families' perspectives on ECI services. Families share their personal experiences and explain how ECI's approach strengthened their confidence to be active participants in their child's development.

Remember anyone can make a referral to ECI. Over 27% of our referrals come from parents, other family members and friends. To locate an ECI program near you, call the DARS Inquiries Line at 1-800-628-5115 or visit <http://www.dars.state.tx.us/ecis/searchprogram.asp>.

Parent Leaders – Use Your Experience to Make a Difference

Laura J. Warren, TxP2P Staff

I am probably one of the most reluctant parent leaders that you will ever meet! I hate public speaking – I'm much happier working at my desk than in meetings. I never set out to be the Executive Director of TxP2P - I came back to the office one day from a meeting and was told that was my new title (there were only 3 of us back then)! But I was taught by my mom, both in words and actions, that if you can make things better for others, you do. Not for the rewards you reap but because it helps! So when my son, Jason, survived the NICU and continued to grow and thrive, I came to a decision time – do I forget what we went through and go back to a job in architecture or do I help others



get through the NICU (Neonatal Intensive Care Unit) experience? About that time, Jason was diagnosed with Cerebral Palsy and the decision was made – we were in this disability thing for life.

So how do you become a parent leader and what does it mean to be one? There are as many different paths as there are parents. We had a mom call once who only wanted to talk with one

staff member because she was embarrassed that she cried so much – she went on to be very active in the Texas Legislature and made a difference for thousands of Texas families. Others call to start a parent group for support, respite, emotional support, to change their school, or something else they felt was needed in their community. Our staff has been working in parent support for so long that we have talked to someone about almost anything you can come up with – so if we don't know how to help you do what you want to do, we probably know someone who does.

At TxP2P, we see becoming a volunteer as the first step to

Continued on Page 5

leadership. You “Pay it Forward” – someone provides you a shoulder to cry on or a hand-up to make necessary changes and you turn around and do the same thing for another parent who is just starting on this journey. You can become a TxP2P Supporting Parent Volunteer and provide support for families who have children like yours or for

an issue you have faced such as NICU or Transition experiences. Then maybe you move on to Legislative issues through our Advocacy Network or display our materials at a fair or speak at a conference through the Speaker & Outreach Network or become Family Faculty and train Pediatric and Family Practice Residents through our Medi-

cal Education Program. Maybe then you go on to start a parent group and get support through our Parent Group Network. These are all examples of parent leadership! So, do you want to be a parent leader? If so, contact us – we can help! 866-896-6001 or email me at Laura@txp2p.org

When a Disaster Happens, Will You be Prepared?

Susan Prior & Laura J. Warren, TxP2P Staff

When a disaster hits, your first thoughts likely are about your family members: Where are they? Are they OK? How do we get through this? Disasters can strike quickly and sometimes without warning. One thing we learned from the calls we received after Katrina, you just never know what could happen and you need to be prepared. Few of us are.



One family who had a child with significant health care needs went to Dallas from New Orleans for a family wedding – their home was destroyed in the storm while they were gone. Any information, medications, or equipment for their child that they didn’t have with them were also gone. With what you have in your phone or wallet today, could you rebuild your child’s medical or medication needs? Do you ever leave home

prepared for it not to be there when you return? That’s what we heard from families on those calls: “Without a mailbox, how will we get our SSI check or Medicaid approval letter?” “I don’t have an address to tell our insurance company where we are!” “We can’t pay for the things we need for our child!”

Another aspect of disasters is that your family may not be together when they happen, so it is important to plan for a disaster in advance. How you will get in touch with each other or where you will meet afterwards; what you will do in different emergency situations? The only thing Texas doesn’t have currently are avalanches or volcanoes – we have floods, hurricanes, tornados, fires, etc. Very few people plan for this



type of experience and once it happens, it’s too late.

After Katrina, the state of Texas worked on gathering information to help Texans plan for when disaster strikes. The website, “Ready or Not? Have a Plan” (www.texasprepares.org), can help you prepare. It steps you through creating a plan for your family, including an Emergency Essentials Kit. It has everything you need, including documents to print out. There’s also a website specifically for people with disabilities – Disaster Preparation for People with Disabilities or Disability 911, www.ilru.org/html/projects/disasterPrep. Between tornados happening now and hurricane season starting in June, it’s a great time to make a plan!



★ **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,
★ Dad’s, Dyslexia, ECI, Homeschoolers, Medical Home, Medicaid Waiver, NICU, Spanish, Transition, 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 of these local groups. Contact Laura at
★ Laura@txp2p.org to discuss moderating one for us.
★
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★
★*****

What's Up with PTA? Pathways to Adulthood: Our First Year

Rosemary Alexander, TxP2P Staff

In July 2012, TxP2P received a federal grant* to fund Pathways to Adulthood, a program to help families of children with disabilities to plan for and create high quality lives for their children after graduation from public school. After 9 months of work to build our program, here's a list of what we can do for families:

- ♥ present workshops around the state on the major transition areas that parents need to understand as they plan for the future and ideas for building work, living and social support opportunities (so far, we've presented in San Antonio, San Marcos, Lubbock, Amarillo, Ft. Worth, Houston, Austin, Waco, San Benito to about 125 parents)
- ♥ link a parent concerned about transition to a trained Supporting Parent Volunteer, who can assist the requesting parent through the emotional transition journey (we will have our first transition volunteer training the day before the annual conference, July 25, 2013, in San Marcos; please sign up if you are interested in becoming an SPV for transition)
- ♥ assist a small group of parents to form a Transition Action Group (TAG) to help one another with individual transition hurdles and explore group goals, such as social, work and living collaborations (we

have started 3 TAGs in Austin, 1 in San Antonio, and have interest and contacts in several other sites)

- ♥ provide information on key transition areas with links to relevant websites on our transition webpage (see txp2p.org, go to Services and then to Pathways to Adulthood where you'll learn about planning, services and supports, legal issues, public school transition, medical transition and more)
 - ♥ provide 2 full days of workshops on transition topics at our annual conference (July 26-27, 2013, in San Marcos, see txp2p.org for details)
 - ♥ assist parents who get in touch with our office by answering transition questions, supporting parents with their transition fears and worries, and linking them with resources (the phone is usually answered by Cynda Green, who is working 30 hours per week on PTA; when needed she refers parents to me for more in-depth transition issues or Monica Castillo who speaks Spanish and is learning the transition landscape)
- In the second year of the grant, we will continue to improve all services started in the first year (listed above) and in addition:
- ♥ build an active group for sharing questions, answers, ideas and

resources through the TxP2P Transition Listserv

- ♥ expand the number of trained mentor parents
- ♥ expand the number of TAGS and provide find new ways to support TAG facilitators around the state
- ♥ bring to Texas a speaker from PLAN of Vancouver, a parent group that has been highly innovative in building high quality of life for adults with disabilities
- ♥ explore ways to fund this program after the grant ends in June of 2015

So, please give us feedback about your transition issues, call us when you need one of these services, and consider getting involved by hosting a workshop, becoming a support parent or starting a TAG in your area. Remember that planning NOW - whatever age your child - by gaining support, information and ideas about transition will pay off later. Start with a vision, move to planning, and finally start with one thing you can do now to improve your child's chances for a high quality life after graduation!

*TxP2P received the grant in collaboration with TX Children's Health Plan in Houston.

Is this the Year for Overnight Camp?

Reprinted from National Down Syndrome e-Newsletter

Getting ready for an overnight camp this summer? You may be a little anxious, especially if this is the first time your child or young adult is going off to sleep-away camp. Here are a few tips that we first printed a couple of years ago, that we hope will help you get ready for this big event!

Become familiar with the camp. If possible, visit ahead of time. If that's not possible, go to the camp's website or browse through brochures and talk to your son/daughter about what to expect.

Check into the camp's policy about mail, phone calls, and care packages. Many camps do not allow phone calls. If mail is allowed,



send a letter in advance or leave it with the counselor for the first or second day. Focus on how proud you are of his independence and

how much fun he will have.

Go over the packing list well ahead of time, and start packing a week or so in advance to eliminate that last minute scrambling for things last flash-light batteries or water shoes.

Do not pack new clothes - camp is generally dirty business with all of the arts and crafts, hiking, etc. Make sure all clothing and other belongings are marked with your child's name.

Involve your child in packing so

Continued on Page 7

so she knows what she's bringing and where to find it in her duffel bag. Consider including a favorite stuffed animal or a nightlight if your child sleeps with one at home. (Check with the camp about nightlights or white noise machines if your child is used to sleeping with those.)

Don't forget medications, packed in original containers and with clear directions on when to take them.

If your camper is on a special diet for celiac disease, diabetes, allergies or any other reason, talk to the camp director well in advance to make sure the diet can be accommodated.

Parents of first timers, line up a support team for yourself to help you resist the urge to go get your child in the middle of the week!

Remember, a camp experience increases skills and enhances self-

confidence in campers, while giving parents a little respite. Camping programs let participants discover and explore their interests, values and talents. Also, camp provides an opportunity to learn to problem-solve, make social adjustments to new and different people, learn responsibility, and gain new skills to increase self-esteem.

Good luck - and have fun!

The Father's Day Card . . .

I was looking for a Father's Day card - among the dozens and dozens everywhere,

So many perfectly worded sentiments, for ordinary father's without a care.

"We'll pamper you dad!" - "You're the greatest!" - "Now lie down, relax, or play!"

"Do all the things that you love to do, on this your special day!"

"Yeah right, if only..." I chuckled. But for real dads - where are the cards for them?

The dads who have children with special needs; the dads who've become extraordinary men.

The dads who gave up weekend fishing, and now only dream of a game of golf, The dads whose sons are in the hospital, because of pneumonia from a simple cough.

So many things about life they don't get, those carefree dads who have not a clue, About what it's like to have a ten year-old son, who cannot even tie his own shoe. About what it's like every day at the office, hearing others brag about their kids triple-play, Knowing if he tried to talk to them, they would stare blankly and not know what to say.

Many kids choosing bright shiny cards, with a button that says, "Dad, you're my hero!" But what truly makes them a hero, those buying the cards do not really know. That heroes are dads who accept that their child, will not ever be a little-league champ, Who instead cheer them on at therapy, while longing to take them to Boy Scout Camp.

Heros are the men who day and night work hard, and yet find they are always broke, Because of the expenses, medical bills, & challenges, of a never-ending financial yoke. They are the men who would gladly give their life, for a treatment that would cure their son, They are the men who understand the victory, in each tiny battle that their child has won.

I give up and am too tired to keep looking, for that elusive 'Special Father's Day card. I have to laugh at the irony that this too is something else that shouldn't be hard! So instead I'll write down on a piece of paper, "I love you with all of my might!" From the son who knows that his hero is the daddy who cries as he prays for him each night.



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