



A Parent's Perspective

TxP2P Quarterly Newsletter

TxP2P Update

Laura J. Warren, TxP2P Staff

What a packed spring we have planned!! We're putting on 3 conferences - **Port Isabel** on March 22, **Hurst** on March 29, and our **10th Annual Parent Conference** in San Marcos on June 13-14! In addition, we are collaborating on a conference in **Abilene** on May 2 and a **Texas Respite Summit** the day before our big conference opens on June 12. See below for additional information on the conferences and page 2 for the Respite Summit. As I said, lots going on!

Family Support - it comes in many shapes and sizes - there's a family story on page 7 that reflects how a simple gesture from a stranger can help a parent keep moving. Our conferences and trainings also offer family support in just getting families together! Now there's a way you can honor someone who helped you - the **Paying It Forward Awards**. See page 2 for more information.

And finally, I just want to thank the **staff of Texas Parent to Parent** - there are now 18 mostly part-time staff who help get all the work done that we do. I get to hear many more praises for TxP2P than they do but they are the heart of TxP2P! **Thank you, guys!!**

Volume 13, Issue 1

Spring 2014

Inside this issue:

- ♥ Around the state: **PLAN Workshop**—Page 2
- ♥ Around the state: **Paying It Forward**—Page 2
- ♥ Around the state: **Advocacy News**—Page 3
- ♥ Around the state: **TX Respite Coalition**—Page 3
- ♥ Around the state: **Medicaid Changes**—Pg 4
- ♥ Around the state: **ECL Resources**—Page 5
- ♥ Around the state: **Pathways to Adulthood**—Pg 6
- ♥ From Our Families: **The Magnetic Life**—Page 7
- ♥ Conference Calendar - Page 8

Four Conferences in Four Months!

Jeanine Pinner, TxP2P Staff

We've been hard at work to bring you four terrific conferences over the next four months. Texas is a huge state and we can't be everywhere, but we're going to be in Port Isabel, Hurst, Abilene and San Marcos between now and mid-June! Mark your calendar!

ONE: First up is our free one-day conference and resource fair for families and professionals in the Rio Grande Valley area. The **Empowering Tools Conference**, a collaboration between TxP2P and Point Isabel ISD takes place on **Saturday, March 22, 2014**, at Port Isabel High School in Port Isabel. Topics include behavior, special education legal update, person centered planning, transition care notebook, resources and much more!

TWO: We didn't forget those of you in the Dallas-Fort Worth area! We've been partnering with Community NOW! and the Arc Northeast Tarrant County to bring you the 2nd **Annual Living with Disability Conference**. This free conference and resource fair will take place on **Saturday, March 29, 2014**, at the First Baptist Church in Hurst. In their keynote address, "Love is Universal," James and Chrissy

Williams will share how their lives and experiences brought them together and how their daily lives are challenged yet strengthened by James' diagnosis of Autism. Breakout session topics include special education legal update, financial planning, preventing conflict in special education, self-advocacy, communication, resources, and so much more!

Registration for our one-day conferences is open NOW! To register for either of them online, go to <http://txp2p.org/training/registerfortraining.html> and click on "Free Conference and Resource Fair." Want to exhibit? Go to <http://txp2p.org/training/oneDayConferenceExhibitor.html> and you're on your way. Downloadable PDF documents for each event are available at <http://www.txp2p.org/>. Free child care is available for each conference, but requires advance registration. **Registration deadlines** (conference, child care and exhibit) are March 10th for the Empowering Tools Conference in Port Isabel and March 17th for the Living with Disability Conference in Hurst. CEUS are available for Social Workers, Licensed

Professional Counselors and Early Intervention Specialists at both one-day conferences. Educator CEUs are pending for the one-day conference in Hurst.

THREE: Next is the **West Texas Disability Resource Conference** on **May 2 & 3, 2014**, at the Hilton Garden Inn in Abilene. This event provides an opportunity to address topics of critical interest for Texans with disabilities, family members and professionals working in independent living, vocational rehabilitation and disability-related fields. Attendees will learn about public policy issues, systems advocacy skills and individual advocacy skills, plus strategies of dealing with activities of daily living with a significant disability; will interact with peers and community leaders to become better informed consumers; view exhibits, and more. The West Texas Disability Resource Conference proposes to deliver essential information and connect underserved west Texans with these resources. Conference organizers are Coalition of Texans with Disabilities, Community NOW! and Texas Parent to Parent.

Continued on Page 2

Co-hosts include ABLE Center for Independent Living (CIL), Burkhart Center for Autism Research (Texas Tech), Panhandle CIL, LIFE/RUN CIL, and Texas Panhandle Centers Behavioral and Developmental Health. To register or for more information about the conference, go to <http://www.txdisabilities.org/news-events/west-texas-disability-resource-conference>.

FOUR: Last, but by no means least, is our **Tenth Annual Parent to Parent Conference** in San Marcos on Friday and Saturday, **June 13 & 14, 2014!** If you've been to our two-day annual

conference before, you know it provides more than 60 different sessions over two days, a conference-within-a-conference for teens and young adults with and without disabilities, a family gathering complete with entertainment for the entire family, the best child care on the planet and an abundance of fantastic exhibitors. The hallmark of our annual conference is its atmosphere of camaraderie, collaboration and support. Families and professionals come together to work in partnership for the best possible lives for our children. Bring the family and **help us celebrate our wonderful TxP2P**

DADs! We do know that this is Father's Day Weekend and that means some of you will not be able to attend but for the dads who do come, we have some special events for you! Stipends for registration and/or lodging may be available for those in need. We have already heard from Education Service Center Region 13 (Central Texas) that they have funding for parent & children's registration fees. Look for more information on our website or call us at 512-458-8600 or 866-896-6001. Registration opens the first part of March at www.txp2p.org.

We look forward to seeing you soon!

2-day Transition Workshop – Learn How to Build a Safe and Connected Life for Your Child's Future

PLAN (Planned Lifetime Advocacy Network) is Coming to Central Texas

Pathways to Adulthood, TxP2P

Do you worry about what your child will do after leaving public school? Do you have a plan where they will live and what they will do all day? Come hear from the people who helped us create the TxP2P Pathways to Adulthood Program on how to answer these questions. TxP2P is pleased to host Ted Kuntz from PLAN (Vancouver, Canada) for a 2-day workshop in Austin at the Region 13 Education Service Center on March 31st (9:00 a.m. – 4:00 p.m.) and April

1st (9:00 a.m. – 1:00 p.m.). Ted will share his journey with his son, Joshua and why and how to start a personal network for your child. He will talk about how to take full advantage of the gifts and opportunities life offers and how he has made peace with his life. We will also have a panel of Texas parents who have started a network for their child. Materials and working lunches will be provided at no cost. Registration is open on our website at www.txp2p.org but space

is limited. For more information, contact Cynda Green at cynda.green@txp2p.org or at 512-458-8600 or 866-896-6001, ext. 113.



Texas Parent to Parent Presents...Paying it Forward Awards

Jan DiMare, TxP2P Staff

The TxP2P **Paying It Forward Awards** recognizes the best in Family Support for families of children with disabilities, chronic illness or special health care needs. There are two categories: **Champion Parent Category** (support provided by another parent or family member of a child with a disability) and **Champion Professional Category** (support provided from professional, service provider or anyone without disability experience). The winning stories will receive a trophy and free registrations to the TxP2P Annual Parent Conference for the winner and the parent who nominated them.

So, what do you need to do?

- Write a one-page story and include a photograph of your family or child (500 words or less)
- Complete Nomination Form on-line
- Submit your entry no later than March 14th, 2014
- You will hear from us if your story is a finalist and will be included in the on-line voting no later than March 19th and the finalists will be posted on our website for voting by the public
- We will contact you by April 25th if you are one of the two winners
- We will announce the winners at the conference on Friday,

June 13th

TxP2P will use these stories after the award contest as family stories for grants, fundraising and raising the awareness of the importance of family support for our families.

Submit your nomination form, story, and photos on-line or email to: jdimare@txp2p.org; www.txp2p.org



Advocacy News!

Linda Litzinger, TxP2P Staff

In anticipation of the upcoming legislative session, groups of parents have joined forces to create policy change. I am available to help you with any issue, yet here are some that parents are already working on:

Elimination of aversives: Aversives are negative behavior strategies created generations ago by educators; strategies that most people wouldn't dream of using today, yet they are still in practice and current educational law, family law and penal law vary on this issue. A proposed bill eliminates negative strategies and should result in better training on positive behavior supports. Co-leaders of this group are Mara LaViola and Stacy Ford.



Cameras in Classrooms: This bill places cameras (for safety) in classrooms where students are non-verbal, and any suspected injury or abuse would necessitate viewing of the footage by personnel at TEA. While these cameras are for confirming assault or exonerating staff, they are not for evaluating

educational quality such as placements or curriculum. Stacy Ford is the lead.

Successor Guardians: Parents who are guardians of their adult children usually want to be succeeded in their role by someone they designate, rather than a court-appointed hired guardian. A consortium of disability groups has thus drafted several guardianship reform bills. Amy Connors is the lead parent for our TxP2P advocates.

Alternatives to Guardianship: One of these several guardianship bills develops alternative supports to a person with a disability so that in some cases guardianship might be unnecessary. Pat Alvarez is the lead parent.

Testing at birth: Five years ago, Deborah Clarke Trejo assembled parents and successfully passed a bill for testing at birth for Velocardiofacial syndrome (she led this independently of TxP2P; we take no credit!). Today, we have two parents who similarly hope to legislate for testing at birth, one for autism, another for

vision disabilities. Please advise if you wish to join one of them.

For all the varied issues above, parents are involved in finding sponsors at the Legislature, as well as speaking to the Legislative Budget Board about related funding.

Further activity...

Every twelve years each state agency is evaluated by the Sunset Commission and reviewed for renewal. Parents are having meetings with the Sunset Commission about experiences with DARS Vocational Rehab, for example, if you wish to also be included. Please let me know if I can help facilitate meetings with *any* agency.

If any of these topics spur your interest, or give you an idea to bring forth another issue, please do not hesitate to ask me for help with getting started. We host weekly conference calls for advocates on Wednesday evenings. The advocacy listserv is the best way to learn about the topic of each call. To join, send an email to: txp2p-AdvocacyListserv-subscribe@yahoogroups.com.



Texas Respite Coalition, DADS and TxP2P Host a Respite Summit June 12th, 2014

Laura J. Warren, TxP2P

TxP2P has a new strategic partner, the Texas Respite Coalition. The Coalition was formed to assist the Texas Department of Aging and Disability Services (DADS) to develop strategies to reduce barriers in accessing respite services, improve the quality of respite services, reach underserved populations, and provide training, education and support to parents and family caregivers for children, youth, adults and seniors.

The Coalition has been responsible for the development of the **Take Time Texas** website for parents, caregivers and providers, www.taketimetexas.org; creating of

the *Texas Inventory of Respite Services* - a searchable database of over 1,000 respite care providers; publication of marketing materials and articles to promote respite care; and sponsored a series of respite webinars and forums to share information and ideas. Please take time to go to the website and review all of these items. **And if you know of a respite program that is not on the website, please send information to me at Laura@txp2p.org.** I'll pass the information on to get it on the inventory.

In partnership with TxP2P, the

Texas Respite Coalition and DADS will host a one-day summit to get input from families and caregivers across the lifespan, including TxP2P families to develop priorities for a state strategic plan on respite care, provide input on the role of the coalition, and get feedback from parents and caregivers. It is an opportunity to discuss collectively what we want in the future. Please save the date for the summit on June 12, 2014, the day before the TxP2P Conference. Registration will be available on the TxP2P website, www.txp2p.org and we'll have some stipends for parents to attend.

ECI Website

As families and professionals increasingly use the Internet to access knowledge and assistance, ECI continues to make resources and information available online through its website: <http://www.dars.state.tx.us/ecis/>. There are a variety of materials available, such as, videos, publications, resources and much more.

Here are a few highlighted areas:

ECI Videos

DARS/ECI created these videos to help educate and inform families and professionals about ECI. The videos are available on YouTube and can be accessed via laptops, smart phones, and other devices. Accessibility features include closed captioning and online transcripts in English and Spanish. To view the new videos, visit <http://www.dars.state.tx.us/ecis/videos/index.shtml>. Here is a summary of each video.

"About Texas ECI" (10 minutes)

The "About Texas ECI" video provides a brief overview of our services and explains how ECI partners with families to support their child's development. In this video you will learn how ECI professionals work with parents to meet a child's needs. You will also learn about the enrollment process, how and where services are provided, how services are paid for, and other ways that ECI provides value to children and families.



"Texas ECI: Family to Family" (8 minutes)

The "Texas ECI: Family to Family" video offers a parent's

perspective for families who have been or may be referred and who would like to learn more about ECI services. Families talk about their experiences with the program and how their child and family benefited from ECI. You will hear how important the parent or caregiver is to their child's success and how ECI staff work together with the parent or caregiver to help their child.

"Parent to Parent: Knowing Your Rights" (11 minutes)

The "Parent to Parent: Knowing Your Rights" video complements the ECI Parent Handbook, encouraging families in ECI to understand and exercise their rights. It also encourages parents to feel free to ask questions if they don't understand something being said by an ECI professional or something in the handbook. It provides an overview of some, not all, of a family's rights, such as consent, prior written notice and confidentiality.



ECI Brochures

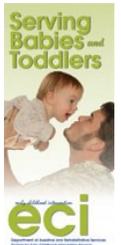
ECI currently offers brochures for parents, caregivers, professionals, and community supporters. Many of the brochures are available in Spanish and Vietnamese as well as English. To see a list of the brochures, visit: <http://www.dars.state.tx.us/ecis/publications/index.shtml>



Here are a few that are available to order:

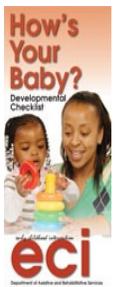
Serving Babies and Toddlers

This brochure provides general information about ECI's unique services and support as well as contact information for making a referral.



How's Your Baby?

This brochure provides a developmental checklist of skills, like walking and talking, that children usually master by certain ages and a list of "red flags" to watch for as a baby grows.



The ECI Growth Chart

The growth chart informs parents about the developmental stages to watch for during the child's early years as they record child's growth.



These brochures can be ordered through our online ordering system at no cost.

The system is user-friendly and allows for orders to be placed quickly and efficiently. If you're interested in placing an order, visit <http://www.dars.state.tx.us/ecis/materials.shtml>. If you have any questions about the online ordering process, contact Susan Drapela at susan.drapela@dars.state.tx.us. Stay tuned for more information on the ECI Resource Guide and the ECI Library collection in our Summer Newsletter!

Thank you to our 2013 Corporate Sponsors!!



Texas Children's Health Plan
The best decision a family can make.
1-800-990-8247



Texas Children's Hospital



RICHARD P. SLAUGHTER ASSOCIATES, INC.
Charting Your Course to Financial Security

Pathways to Adulthood: Thinking about Post-Secondary Opportunities

Rosemary Alexander, TxP2P Staff

If you are thinking that a competitive college degree is not in your child's future but you would still like for your child to have post-secondary learning opportunities, here are some options in Texas and information on what DARS will pay for:

DARS (Texas Department of Assistive and Rehabilitative Services) can help pay for college if the individual meets the eligibility criteria to receive services, college is a reasonable and necessary part of preparing them for work (and their specific goal), and they are functioning at an appropriate level to successfully complete college courses. The money does not have to be paid back. To be eligible for DARS services, a person has to have a physical or mental impairment, the impairment must constitute a substantial impediment to employment, the individual must require vocational rehabilitation services to prepare for, enter, engage in or retain gainful employment, and be capable of achieving an employment goal.

Appropriateness for college is most often determined by reviewing testing/records from the school, as well as testing done by DARS. Once it has been determined that DARS will sponsor someone for college, the student must go to school full time (minimum 12 semester hours), apply for the Pell Grant, and maintain at least a 2.0 grade point average.

Here are some of the current college options for Texans with disabilities:

College Living Experience: in Austin, TX

Students are enrolled in area college programs and live in supervised apartments.

"Students at College Living Experience are encouraged to pursue their post secondary program of interest so services can be tailored specifically to their educational needs.

As such, CLE collaborates with a variety of schools and programs including universities, community colleges, and vocational programs, while students work towards their Bachelor's Degree, Associates Degree, or certificate.

Each week, our student's CLE schedules are filled with one-on-one content-specific tutoring, group tutoring, and supervised study halls. With guidance and instruction from professional tutors, students also receive coaching in planning, organizing, managing time, strategizing, and executing. "<http://experiencecle.com>

Austin Community College: STEPS — Skills, Training and Education for Personal Success: in Austin, TX

STEPS is a program for adults with intellectual and developmental disabilities interested in gaining skills to enter the workforce or continue to develop their education. STEPS provides a wealth of support to help adults achieve their individualized goals. Working together with agencies and schools, we provide comprehensive supports through their entire two years leading towards increased independence and employability.

STEPS offers many levels of support, choices and plans for students. Please contact <http://austincc.wix.com/accsteps> for information on how to apply.

West Texas A&M University: Where the Learning Continues (WTAMU): in Canyon, TX

Created in 2004, WTLC provides a post-high school educational experience for high functioning young adults with intellectual disabilities. The four-year program reinforces subjects learned in high school, like math and vocabulary, and further builds skills for independence. Students attend class Monday through Thursday from 8 am to 11 am on the WT

campus during the fall and spring semesters. After completing 8 semesters, students participate in the WTAMU commencement ceremonies earning a certificate of completion. <http://wtamu.edu/academics/eod-where-the-learning-continues.aspx>

Texas A&M University: Post-secondary Access and Training in Human Services (PATHS): in College Station, TX

The PATHS Certificate Program is your path to a successful career as a Direct Support Professional working with people with disabilities. The PATHS Certificate Program is a program offered at the [Center on Disability and Development at Texas A&M University](http://centerondisabilityanddevelopment.tamu.edu) that will prepare graduates to be *Direct Support Professionals*. This two semester certificate program prepares graduates for employment in a career serving people with disabilities. <http://paths.tamu.edu/>

Houston Community College: VAST Academy: at the Central VAST Academy Location in Houston and the Northwest VAST Academy at the Spring Branch Campus

VAST Academy provides post-secondary transition programs and comprehensive support services which lead to meaningful credentials, employment and independence for differently-abled individuals. Opportunities include vocational certificates, pre-college and freshman success "bridge" courses, career readiness credentials, internships and employment assistance offered through an inclusive, relevant and affordable avenue. <http://vast.hccs.edu/>

Lone Star College-CyFair: CCDEL: in Cypress, TX - one of 5 colleges in the Lone Star College System, Houston area

Continued on Page 7

Pathways to Adulthood: Thinking about Post-Secondary

Opportunities

Continued from Page 6

Lone Star College-CyFair offers students with disabilities the opportunity to gain a Customer Service Certificate through the College of Careers and Development for Exceptional Learners (CCDEL.)

“Through this certificate program, students learn the skills necessary to run a help desk, to deal with challenging customers, as well as to communicate more effectively

with co-workers,” said Director of Continuing Education Kenya White.

CCDEL is a unique program designed to meet the needs of motivated adults with developmental disabilities who wish to further their education beyond a high school level in order to provide skills that can be utilized for employment. Students complete an internship on campus

to learn real life applications in a customer support environment.

“All CCDEL courses are tailored to provide successful life application skills that can be utilized for employment,” said White. “Our purpose is to not only provide students with exceptional workforce training and skills, but to foster social and financial independence.”

<http://www.lonestar.edu/news/20518.htm>

Joshua Florence, TxP2P Parent

The Magnetic Life

I would like to start off with a quick lesson in physics (please do not tune me out just yet because I said physics). By definition, a magnet is a material or object that produces a magnetic field. The magnetic field is an invisible force that is responsible for the attraction of objects like iron and opposite poles, as well as repelling other magnets with the same pole. The life of a magnet is full of what are called magnetic moments. Without getting too far off track, we will define a magnetic moment as an action that occurs between the poles causing an attraction or repelling.

I have learned many lessons over the past three years as a parent of a child with special health care needs. There are many things in our life that shape who we are but are kept hidden in the depths of our hearts and minds. Disability is not usually one of them. It's hard not to notice the person in the wheelchair, the little girl who is walking “funny”, the boy who drools or the kid that is yelling and screaming like a two-year old having a tantrum but is clearly in his teens. Yes, disability is something that we often have to wear so that all can see, sometimes by choice but often not. It is this exposure that allows what I like to call Magnetic moments to occur.

Elle had only been out of the NICU (Neonatal Intensive Care Unit) for a couple of days, but as her father, I had made my mind up that I was not going to let her “special needs” stop us from doing anything, so we ventured out. Sharon, my wife, was much more hesitant, she wasn't sure if it was the right time to be getting out. You see, Elle had a G-tube placed two weeks prior and we were

on an “every three hour feeding” schedule. After finishing a few errands to pick up some medications, we decided to go to one of our favorite lunch places. It was time to feed Elle as well. No matter how discrete you try to be, it is hard to hide the fact that you are hooking up a tube to another tube that is coming out of your baby's stomach. Once everything was hooked together, Sharon sat in the booth and held Elle while I stood next to her holding the syringe pouring formula into it. All of a sudden the syringe came out of the extension and the formula dumped all over Sharon and Elle in the booth. Sharon sat there, soaked and almost in tears as she said, “I TOLD YOU THIS WAS A BAD IDEA!!!!” I replied, “Everything is okay, we are fine.” As I started to clean up the mess, Sharon whispered, “Now those two ladies are just staring at us!!” I turned and looked over my shoulder, there sat two older ladies across the way watching us. We quickly finished eating, packed everything up and began to leave. As we walked out, one of the two ladies who had been staring at us reached out and stopped Sharon. “Ma'am...” I froze and thought to myself, oh crap, here we go. Just as tears began to well up in the lady's eyes, she shared, “I just wanted to tell you, that you have a beautiful family.” I was speechless, and did not know how to respond. I looked over at Sharon as she said “Thank you” while crying.

Over the next few months, I would often think back to that day. It was in that moment that I realized that not everybody that is staring is staring for the wrong reasons. You see, that day

we had a magnetic moment. It was a moment, we were placed in a situation and realized we had put our “-“ side out. Instead of pushing us further away with another negative, that lady recognized that we needed her “+” side. It was something so small, something she probably will never remember, but I will remember it for the rest of my life. Our life is full of these moments, times were we see someone and realize they could use an encouraging word, “Hey - look at how awesome you walking!” or, “I love your wheelchair!” Or something as simple as, “Your daughter is beautiful” can impact a life and change the way they see world. You get to make the choice. Am I going to repel them away by not saying anything, or do I pull them closer, making them stronger? Life is full of these magnetic moments; why not focus on making them positive.



Texas Parent to Parent
 3710 Cedar Street, Box 12
 Austin, TX 78705-1450

Toll Free: 866-896-6001
 Local: 512-458-8600
 Fax: 512-451-3110
 Website: www.txp2p.org
 Email: txp2p.org

ADDRESS SERVICE REQUESTED

NONPROFIT ORG
 US POSTAGE
 PAID
 AUSTIN, TX
 PERMIT NO. 657

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.



GLOBAL
 PRINTING SOLUTIONS
A Solution for All your Printing Needs

THANKS TO GLOBAL PRINTING SOLUTIONS FOR PRINTING THIS NEWSLETTER AT A REDUCED COST FOR TXP2P!

5114 Balcones Woods Dr., Ste. 309, Austin, TX 78759
 512-794-8000, www.gpsaustin.com

Conference Schedule

Date	Conference Title	Location	Registration Information
Saturday, March 22, 2014	Txp2P & Port Isabel ISD presents "Empowering Tools Conference"	Port Isabel	For more information go to: www.txp2p.org
Thursday, March 27 - Saturday, March 29, 2014	TXAER Annual Conference	Austin	For more information go to: http://www.txaer.org/conferences.html
Saturday, March 29, 2014	2nd Annual "Living with Disability" Information and Resource Conference	Hurst	For more information go to: www.txp2p.org
Saturday, April 26, 2014	Spina Bifida of Houston Gulf Coast 1st Annual Walk & Roll	Houston	For more information go to: http://www.walknroll.kintera.org/sbhgc
Friday, May 2 - Saturday, May 3, 2014	West Texas Disability Resource Conference	Abilene	For more information go to: http://www.txdisabilities.org/news-events/west-texas-disability-resource-conference .
Friday, June 13 - Saturday, June 14, 2014	10th Annual TxP2P Conference	San Marcos	For more information go to: www.txp2p.org