

TxP2P Update

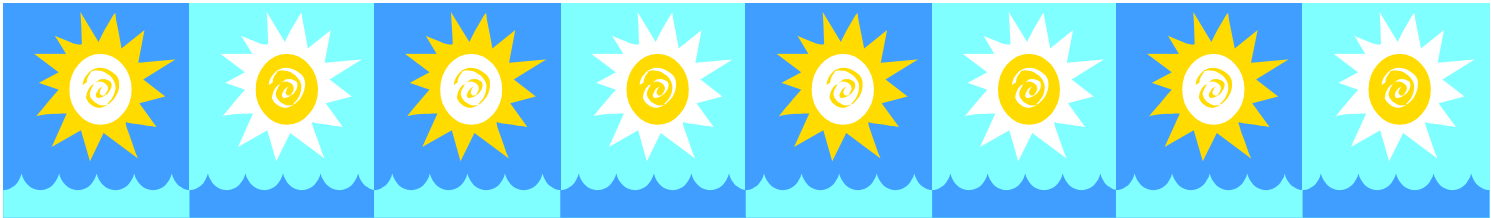
Laura J. Warren, TxP2P Staff

Our 11th Annual Conference is about 2 weeks and we are scrambling to get ready for it. We'll welcome over 800 people this year, including over 500 participants including 60 self-advocates, 80 speakers, 60 exhibitors, 60-70 kids in childcare, and many workers, volunteers, and helpers. We have a great line-up of speakers, door prizes, raffle items (including a t-shirt quilt of the TxP2P conference t-shirts, tickets to ACL Concerts, and more), and exhibitors for you to all enjoy! Can't wait to see you all!

We also want to welcome Beth Coke to our TxP2P staff as a Family Support Team member. Beth has been a long-time volunteer and we are thrilled to have her. You can learn more about her in an article she wrote in this newsletter.

The Task Force for Children with Special Needs Website will launch the end of June! We'll have a few highlights of the website plus a booth where you can learn more about it. TxP2P has been working on this website for about 3 years and can't wait to see what you think of it. There will also be a statewide celebration for the website on August 1st, 2015. More information to follow soon!

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Inside this issue:
♥Pathways to Adulthood - Finding & Hiring Attendant Care, pg. 2
♥Around the State - Mothers' Milk Bank, pg. 3-4
♥In Memoriam - pg. 4
♥Around the State - ECI: Developmental Red Flags, pg. 5
♥Around the State - Texas Community Health Workers, pg. 6
♥From our Families - Beth's Family of 8, pg. 7
♥Conference Schedule - page 8



Legislative Advocacy

Linda Litzinger, TxP2P Staff

Greetings! At the writing of this article (two weeks from the end of the 84th session), it is too soon to give a Legislative Readout. There have been some twists and turns and surprises, due to sessions with long filibusters that caused hundreds of House bills to die. Some Senate bills still have a chance in the next week.

What I can report is that we have had extremely busy parents giving their all for various causes: Positive Behavior Intervention Supports, safety cameras in self-contained classrooms, Cannabis oil for acute epilepsy, Sunset Commission reorganization of blind and autism services, licensure of behavior specialists, more choices for

guardianship, better wages for attendants, no wage cuts for Medicaid therapists, funding for waiver slots, and many more.



Our parents have met helpful legislators and reaped the benefits of starting a year early to find bill authors. They chose the right timing for approaching Governor Abbott's policy specialists. For three bills, they worked with a lobbyist. After making around 500 legislative visits, they met and

became friends with nearly every staff member and have once again confirmed that staff members are the excellent backbone to the process.

Kudos to too many parents to name here! You are the reason why Texas is making progress. Thank you for every mile that you drove, every day that you spent making visits, every hour that you waited just to testify for 3 minutes, and to your families for covering the bases without you. See you next session!

Fondly,
Linda, Amy, Jan and the rest of the TxP2P staff

Finding and Hiring Attendant Care

Rosemary Alexander, TxP2P Staff

Several of us in the TXP2P office have been searching for new attendants recently for our young adult children. (**If you aren't sure what an attendant is, check the bottom of this article.) Here are some of the things we've learned through experience. If you have a good story or tip, email it to me and I'll share via the newsletter – Rosemary.Alexander@txp2p.org

How to find people to hire

Reach out to your network of family, friends and acquaintances. Tell everyone you know that you are looking and tell them to tell their friends. Use a neighborhood or school listserv, Facebook or whatever way you communicate online.

Write an ad and put it out there, at www.Care.com, www.Craigslist.com, neighborhood listservs, or print it and put it on a bulletin board at a school, church, therapy office, or somewhere it's likely to be seen by people interested in working with your child. Send your ad to friends and ask them to share it with people or groups they know.

Students at universities and community colleges, particularly those majoring in education, special education or any of the helping fields, may have a real interest in working with your child. Get your ad out to students by contacting the department chair, department secretary, a university website for want ads, or any contacts you might have on campus.

Public school staff who work in special education might be interested, particularly on weekends or in the summer when they aren't working. Ask around at your school or a school near your home.

Get creative. I tried sending my ad to my yoga teacher, who sent it out to an email list of yoga teachers, thinking this is a population of caring people who work part-time. A friend of mine ran an ad on Craigslist but not under the category *health care worker*; rather she put the ad under *musicians*, because her son loves music. She found a guy who had just moved to Austin to play in a band but really needed a day job!

Here are some additional comments from TxP2P staff:

Patty: I read posts on Craigslist in the

"part time" list. You can often find people looking for attendants. I try to put enough information into my ad which describes my child in a positive light but underscores the severity of her condition so that when I ask for applicants to have experience, they understand what I am looking for.

Linda: We have a list of required tasks, and another list of things that are more fluid. For example, the job must begin and end with bathroom help, as this is the most needed task. Beyond personal care and homework, the rest is more fluid.

Rosalba: I still struggle to hire people I don't know... I always look around among my friends or my friends' friends and people working with Alan at school or people around us. I have never hired anybody I don't know. I know, I'm not a big help! About how I manage them, I'm still learning and every single one is a learning experience...

Susan: I was very lucky finding my first attendant for my daughter. We found her via a friend who had her as an attendant as well. I lost touch with her when she stopped being my friend's attendant. Then out of the blue one day, my son mentioned that he met someone that knew my daughter and me. It happened to be this same attendant. So, I got her contact information and asked her to work with my daughter and she was thrilled to do it. We have had her over a year now. Finding a good attendant that becomes a part of your family is a rare and wonderful thing! Hope that helps!

Melissa: I used [Care.com](http://www.Care.com) and Life Coach/Companion is how I listed the job where we received the most applicants. Staying positive and presenting your family member in a good light while clearly stating their needs seems to work well.

Cynda: I have found that by changing the title of what I am looking for on [Care.com](http://www.Care.com) from Health Care to Nanny, I increased the number of applicants that were interested in the position. Be creative with the title and give additional information in the job description.

How to interview those who respond

After you have cast your net out to find an attendant, you'll sooner or

later hear from a few who are interested. Most of us who do this routinely advise the following steps:

Start with a phone interview—try at this stage to weed out people who are obviously not going to work out. Be prepared with key questions, such as, are you free on Friday nights? Do you have a car? Do you live in my end of town? Do you have experience with Autism? In other words, your make-or-break issues should be your key questions.

Next is a face-to-face interview, but not in your home and not with your child present. I like to meet at Starbucks. It's just a precaution to start in a neutral place, where you can walk away without revealing a lot to the other person. Play it by ear. If you like what you see and hear, then start to tell her about your child. Ask why the candidate is interested in this job and what past experience he or she has in this field. Get to know them a little bit.

If this step goes well, you're ready to have them meet your child and learn more about the job to see if it's a real fit. You might check references before this step and you can do a low cost on-line criminal background check (online at the [Texas Dept of Public Safety](http://www.texas.gov)). If you are using a funding source for a Medicaid waiver, they will do more in-depth checking later. Try to make sure this person will work out before you go to the trouble of doing the new hire paper work (if using a Medicaid Waiver) and training him or her.

We welcome your input about finding, hiring, training and retaining attendant care for your child. Please send in comments for future newsletters. Good luck with this process!

**An attendant is a person who takes care of your child, possibly paid through a state funding source, such as CLASS, HCS, TX Home Living, STAR+PLUS or MDCP. (If this is Greek to you, see our website, <http://txp2p.org/parents/pathwaysServices.html#ptaServices>). If you use the Consumer Directed Service (CDS) model (<http://www.dads.state.tx.us/providers/CDS/>), you or your adult child is the employer of record and does the recruiting, hiring, training and managing of an attendant instead of an agency. You will turn in time sheets every 2 weeks to an agency that pays the attendant; this agency also does the taxes and the new employee paperwork.



Mothers' Milk Bank at Austin - A Precious Resource for Families of Preterm and Critically Ill Infants

Mary Jo Miller, TxP2P Staff

Mila & Felo's Story

Tory and Rafael's twins were born early, at 26 weeks gestation. Camila (Mila) and Rafael (Felo) both weighed 1 pound and 15 oz. when they were born at Doctors Hospital Renaissance in Edinburg. Mila had an issue with her heart but quickly became a "feeder/grower" (a premature baby that is stable who needs to eat and get bigger before being discharged). Felo had more issues and complications. He had a perforation of the intestines at 2 weeks, which became septic and he lost 8 % of his bowel to necrotizing enterocolitis (NEC). After 3 months in the NICU both twins were discharged. Tory was supplying both twins with her milk.

After a short time at home, Felo became very sick and was readmitted to the NICU. He was transferred to Texas Children's Hospital in Houston and what Tory and Rafael thought would be 3-4 week stay became one of 3.5 months. During his stay in the NICU in Houston, Tory's stash of frozen milk ran out and she wasn't able to keep up with the needs of both twins.

Felo began receiving regular shipments of donor milk from Mothers' Milk Bank at Austin. When he was discharged he went home with a prescription for donor milk because he did best with breast milk as a major source of his nutrition. (He also had a central line and IV nutrition to help him stay healthy and gain weight.) As his needs increased so did the amount of donor milk that was shipped.



The twins are 21 months old now. Both receive ECI Services from Easter Seals Rio Grande Valley. Mila is now talking and walking and Felo is making progress. He is more advanced with his cognitive skills than his gross and fine motor skills. "I am forever grateful to the Mothers' Milk Bank at Austin

(MMBA) and the donor's especially. Without them my son might not be alive, or thriving like he is now," Tory said.

The family was recently the "poster family" for the March of Dimes walk in the Rio Grande Valley.

Breast Milk is Best for Preterm Babies

Research has demonstrated that breast milk is the most effective strategy to protect infants against

NEC. It is the most common cause of gastrointestinal emergencies in the NICU. The American Academy of Pediatrics recommends all preterm infants should receive human milk and if the mother's milk is not available then pasteurized donor milk should be used. If you would like more information on recent research and information on this topic the Department of State Health Services recently hosted a Grand Rounds webinar: [The Importance of Breast Milk Use in the NICU.](#)

Ike's Story

Kari Anne Roy went from being a donor to a recipient of milk from the Mothers' Milk Bank at Austin. When her son, Ike, was born at 28 weeks he was 2 pounds, 5 oz., she had more milk than Ike could eat so she went through the process of being approved as a donor. Ike spent 8 weeks in the NICU and came home at just over 4 pounds. At 5.5 months he caught his first cold. His pediatrician sent him by ambulance to Dell Children's hospital because he was having trouble breathing. The cause of his breathing problems was an improperly formed trachea. His parents were told that a portion of his trachea was about the size of a coffee straw. A tracheotomy was performed and the opening in his throat was placed just below the obstruction. Once home he needed round the clock nursing.

Breast milk was the only thing Ike would tolerate. And when Kari could no longer supply him with her milk the family depended on the Mothers' Milk Bank at Austin for donor milk. Due to the financial stress of Kari being hospitalized for 5 weeks waiting for Ike to be born Kari applied to be covered by the MMBA's Charitable Care Program.

When Ike was almost 2 he was hospitalized in Cincinnati for trachea reconstruction surgery. The surgery required removing one of Ike's ribs and using it to widen the area of his trachea that was too narrow. "So we were up there for quite some time, in fact we did a lot of travel to Cincinnati before the surgery-lots and lots. And the Milk Bank was fantastic at helping us. At that time there were no milk banks in that area so they shipped it all up there so we could have it," said Kari Anne.



Today, Ike is 6 years old and just finishing 1st grade. This is the first summer in 4 years that the family won't be going to Cincinnati for a follow-up visit. For a while they were up there every 6 weeks but he has been released from care there. He is doing phenomenally well. "He gets pneumonia more than the typical kid but, other than that he is flying around the house," Kari Anne reports.

Mothers' Milk Bank at Austin

The MMBA is a nonprofit organization that relies on healthy, lactating women to donate their extra breast milk for tiny babies in need. A baby might receive donor milk because of preterm birth, failure to thrive, immunologic deficiencies and other conditions. Donor milk might be necessary for a short time or a longer period.

[MMBA](#) is always looking for donors. Someone can make a one-time or ongoing donation of milk that is already frozen. Donors live in Austin, anywhere in Texas or even in another state. There are multiple drop off points in Austin, Houston, San Antonio and in a couple of other locations outside of Texas. Arrangements can be made to ship milk to Austin, as well.

Continued on page 4

Charitable Care Program

The Charitable Care Program ensures that no infant with a medical need is denied donor milk due to a lack of insurance or financial resources. Texas Medicaid pays a portion of the milk fee for qualified babies but there is a significant percentage of the fee that is not covered, in addition to any shipping costs. The MMBA’s Charitable Care Program makes sure that the sickest and most fragile babies are served regardless of a family’s ability to pay. The first step in applying for the Charitable Care Program is to complete an [application](#) for assistance.

Mothers’ Reflections

Kari Anne suggests if your baby is in the NICU and you are unable to produce enough milk or your baby is not receiving breast milk approach your neonatologist and

ask about a prescription. Don’t worry about your insurance or who is going to pay for it. MMBA will help.

Kari Anne also encourages moms to become breast milk donors. People may be intimidated and think the donor approval process is difficult but Kari speaks from experience: “It is not hard to be a donor at all-it is not difficult.” She stresses how much a person is giving by donating. There is also satisfaction in the knowledge that you are helping a tiny or critically ill infant.

Tory never dreamed her babies would end up in the NICU but what she learned was that prematurity does not discriminate. She says: “If you don’t have the NICU experience it is hard to realize what someone is going through.” She built a network of support

with other moms who had a 24 week preemie. She keeps in touch with a group of moms she met when she was in the NICU and she has helped others through their journey.

TxP2P NICU Network

TxP2P has a network of volunteers who can provide emotional and informational support to parents who are experiencing the NICU journey. Do you need support or is becoming a support volunteer something you would consider? Contact us at 866-896-6001 (toll free) or register your interest [online](#).



In Memoriam

One thing we learned a long time ago is that among children with disabilities and special health care needs, some leave us way too early. It’s a sad reality we all hope will not happen but some of us will grieve our child’s death. All of us here at Texas Parent to Parent are deeply saddened when we hear of a family’s loss and grieve with you.

We want to share our condolences to our TxP2P families who have lost a child recently:

- Noah Henderson, *son of Devyn and Nathan Henderson*
- Ethan Trinidad, *grandson of Yolanda and Juan Flores*

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



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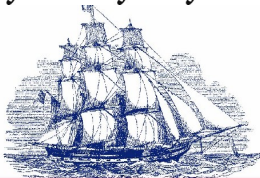


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Charting Your Course to Financial Security

Texas Community Health Workers (CHWs)

Empower Families of Children with Special Health Care Needs (CYSHCN)

Beatrice Smith, Texas Department of State Health Services, Office of Title V & Family Health
Community Health Worker Training and Certification Program Coordinator

Community Health Workers (CHWs), also known as promotores de salud, are defined as the cultural mediators or the link between health care and social services and the underserved communities. A promotor(a) or community health worker is a trusted member, and has a close understanding of, the ethnicity, language, socio-economic status, and life experiences of the community served.¹ A parent of a child with a disability can become a CHW – read on to learn how. It's the combination of connectedness, credibility and commitment to the community² that has placed CHWs as accepted members of the healthcare workforce. CHW is a blanket term for a wide variety of titles held by CHWs in the U.S. health care and social services industry: outreach worker, health ambassador, health advocate, peer advocate, public health aide, community health liaison, etc.

CHWs assist people to gain access to needed services and build individual, community, and system capacity by increasing knowledge about their health and self-sufficiency through a range of activities such as outreach, patient navigation and follow-up, community health education and information, informal counseling, social support, advocacy, and participation in clinical research.³ CHWs/promotores are active in rural or urban settings, or in border regions (colonias) linking underserved communities with different cultural beliefs to quality health care services.

Over 3,000 CHWs are currently certified by the Texas Department of State Health Services (DSHS), some of whom may be parents of CYSHCN. CHWs, parents of CYSHCN, can be trained to lead support groups for other parents with CYSHCN with a diagnosed health need (asthma, autism, cerebral palsy, Down syndrome, developmental delays, muscular dystrophy, etc.). Support groups include discussing related topics, sharing experiences, advocacy, directing parents to community resources and appropriate health services, community-based therapies, counseling, early intervention and special education. DSHS also

approves continuing education materials for CHWs related to parenting children with disabilities, chronic illness, and other special health care needs.



Texas parents of children and youth with special health care needs (CYSHCN) can become certified CHWs to provide guidance, encouragement, education, and peer-support and mentoring for other parents of CYSHCN. State certification and training validate the CHWs as well-trained professionals in the health care system.

CYSHCN can benefit from CHWs when receiving coordinated ongoing comprehensive and culturally competent care to maintain their physical health, mental and emotional health, and development. CHWs can provide support in accessing a Medical Home, parent case management, educational training and workshops information and referral services to groups like Texas Parent to Parent.

In May 1999, Texas was the first State to adopt legislation related to the use of CHWs. In 2001, the Texas Department of Health implemented the training and certification program for CHWs, and adopted a system of credentialing based on the eight areas of "core competencies" identified in the 1998 National Community Health Advisor Study (communication, interpersonal, capacity building, service coordination, advocacy, organizational, teaching, knowledge base on specific health issues, etc.). Per Texas statute, CHWs who are compensated for their services are required to be certified.

CHWs have a successful track record of improving health outcomes and care delivery and reducing health care costs. As resourceful members of health care teams, CHWs assist patients in managing chronic

conditions (diabetes, hypertension, heart disease, HIV, TB and malaria), coordinating care for patients, and helping with patient-provider communication. CHWs are familiar with screening programs (e.g., mammograms, colorectal screening), leading education and prevention activities (e.g., diabetes, early intervention, and asthma education), and participating in specific interventions (e.g. controlling blood pressure).

For Texas CHW certification, call 512-776-2208, or visit the CHW Training and Certification Program website: <http://www.dshs.state.tx.us/mch/chw.shtm>

References

1. 25 Texas Administrative Code, §§146.1-146.12, Rules Regarding Training and Certification of Promotores or Community Health Workers, §146.1. Definitions. (14), p. 2 Effective 12/31/2011 Available at: <http://www.dshs.state.tx.us/mch/chw/progrule.aspx>
2. Carl Rush, MRP, Research Affiliate for the Project on Community Health Worker Policy and Practice, University of Texas Institute for Health Policy, *MPH Interview*, 11/12/2014 - Available at: <http://mhpsalud.org/exclusive-interview-chw-expert-carl-rush/>
3. 25 Texas Administrative Code, §§146.1-146.12, Rules Regarding Training and Certification of Promotores or Community Health Workers, §146.1. Definitions. (14), p. 2 Effective 12/31/2011 Available at: <http://www.dshs.state.tx.us/mch/chw/progrule.aspx>



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Beth's Family of 8

Beth Coke, TxP2P Staff

I'm a mom to 6 wonderfully complex children. We have 4 boys and 2 girls, and 5 have a disability of some sort. We have everything from CP, Autism, Blindness and ADHD to Hydrocephalus, Depression, OCD, and seizures. My first two were born a little early, but basically healthy and happy, typically developing babies/toddlers.

When I became pregnant again and we found out it was twins, I couldn't have been more excited. When one twin developed a problem at 28 weeks (Hydrocephalus), I was devastated. I had never met anyone with a disability, much less raised a child with one.

I had two perfect toddlers, how did this happen? I could never have imagined how life was going to change.

I had the twins, and the Hydrocephalus while daunting at times, was manageable. It was something I understood. When her twin brother began to show signs of a disability (Autism, OCD, ADHD), I refused to believe it. I told myself he was just quirky.

I kept telling myself that, until I couldn't anymore and a doctor's nurse confronted me about it. I didn't want him to have Autism. It doesn't make sense to me. My daughter's Hydrocephalus and the results make sense: "A happened and B, C, and D are a result of that." With Autism, "A happened, so the sky is green and giraffes sing lullabies," and I still struggle with understanding.

We went on to have two more sons after that. One also has Autism and the littlest is too young to know yet. As it turned out, the oldest two also had some challenges that would be revealed with time.

When asked how I parent so many kids with such different needs I laugh and say, "I didn't realize I had a choice

to opt out." So, how do I really do it? I'm not sure. I have to try to keep a sense of humor. I wouldn't make it through a single day without the ability to laugh some things off.

I try very hard not to sweat the small stuff. A diaper blow out, while not fun is manageable. Sure it always happens at the worst time possible when I'm needed in a hundred other ways, but the world won't fall apart if I take 5 minutes to deal with the mess.

I lean heavily on my husband, and he on me. I have also had to come to terms with just being human, and that I screw up, a lot. I apologize to

It's difficult having people (attendants, therapists, case managers) in your life every day. They all mean well, but it is difficult as an adult and as a parent to have to be answerable to other people about your own children and life. They aren't family members, but very much know all your business and see all your messes. Also, kids being kids, they try to get these other adults to do everything for them.

I don't do confrontation well when things are not going as they need to, and avoid it at all costs whenever I can. I had to learn (am still learning) to deal with it. To stand up and say enough, when I have had enough.

There are times I take a break from therapies and attendants. I used to feel guilty about it, but I have come to learn that we all need a break. My children's basic needs are being met and a short time of no therapy isn't the end of the world.

Life is never boring at my house, and we have had to adjust our dreams. Our dreams for the kids' futures, our dreams for our future as a couple. We find joy in the little things, because there isn't a lot of time for breaks and finding a babysitter for my

group is impossible and/or amazingly expensive. I have a difficult time remembering life before disabilities, though to be fair I have a hard time remembering life before kids too.

The future looks different and I have moments of mourning for what was planned or what could have been. Then one of my kids does something, good or bad, and I refocus on where I am needed. It's hard, there's no point in sugar coating it, but I have learned more about the world and myself than I ever would have otherwise. For that alone, I would do it all again and again and again.



my children often. They don't always get it right and neither do I. I try very hard, and fail as much as I succeed.

We have attendants who come in, therapists as well. Organization is key. The best tool we have come across is Google calendar. I have one that my husband and I share. We can both add to it, and set reminders, so we are always on the same page when it comes to appointments and therapies. We also have several white boards around the house for things like medications, food logs, etc. There is also a legal pad that we make notes on for what is coming up, or still needs to be done. My husband was never a list maker and he is still learning.

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Conference Schedule

Date	Conference Title	Location	Registration Information
Tues. June 9 - Wed. June 10, 2015	Texas Assistive Technology Network Statewide Conference	Houston	http://www.Texasat.net
Fri. June 12 - Sat. June 13, 2015	TxP2P 11th Annual Statewide Parent Conference	San Marcos	www.txp2p.org