

TxP2P Update

Laura J. Warren, TxP2P Staff

We have two conferences coming up! The 4th Annual Living with Disability Conference in Hurst (Fort Worth area) is Saturday, April 9th, 2016, at the First Baptist Church of Hurst. We will have 4 breakout sessions with 6 different topics throughout the day. These will include sessions on special education, advocacy, STAR Kids, Care Notebooks, mental health in children, and resources. Rosemary Alexander with our Pathways to Adulthood will provide an all-day session on transition. And we are pleased to announce that we will have a Sibshop as well as childcare at the conference this year.

Our 12th Annual TxP2P Statewide Parent Conference in San Marcos is Friday & Saturday, June 17th & 18th, 2016. Registration is open now for both conferences. You can find the registration on the home page of our website, www.txp2p.org. Hope you can join us at one or both of the conferences!

TxP2P has had some shifts in staff that I wanted you to know about: We want to welcome **Greta James-Maxfield** who has accepted a position in the Family Support Team. Greta has been a Peer Mentor Volunteer with us for the past few years. You can get to know Greta a little better by reading her article in this newsletter.

If you haven’t checked out the [TxP2P Care Notebook](http://www.txp2p.org/resources/CareNotebook.html) (<http://www.txp2p.org/resources/CareNotebook.html>) and [Medical Home Toolkit](http://www.txp2p.org/resources/medHome.html) (<http://www.txp2p.org/resources/medHome.html>), do it now – they are both excellent management tools that can help you keep track of your child’s medical, school and transition needs. We hope you have a lovely spring!

Volume 16, Issue 1
Spring 2016
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Legislative Advocacy is Alive and Well

Linda Litzinger, TxP2P Staff

Advocates are preparing for the next Legislative Session, which begins in January, 2017, advocating for policies and funding on various education and long term care topics. Probably the most pressing issue is the implementation of STAR Kids Managed Care, next fall and beyond, in a manner that works for everyone. For more information, follow this link: <http://www.hhsc.state.tx.us/medicaid/managed-care/mmc/star-kids.shtml>

If you wish to be included in these efforts or to introduce a new one, please contact me. We advocate on issues that parents bring forward; your topics are our topics! Linda Litzinger, 512-922-3810 or linda.litzinger@txp2p.org.

Several parents traveled to McAllen last week to testify in a Senate Education Hearing on safety cameras in special education classrooms. Here is our photo with Senator Lucio: Christine Broughal, Linda Litzinger, Lori Patlan, Delores Zarate, Eve Caro, Deborah Tomai, Columba Wilson and Cristian Martinez.

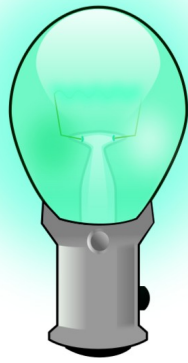


Being Prepared is Always a Good Idea

Sherry Santa, TxP2P Staff

Living in Texas, we can be faced with many forms of emergencies or disaster. As a family of a child or children with Special Health Care Needs, are you prepared? Here are a few questions to ask yourself when thinking about emergency preparedness:

Do your children know what to do and where to go in the event of an emergency? One good resource geared toward children is from the Disaster and Community Crisis Center (DCC) at the University of Missouri; they have a video series called Hunter and Eve which also includes printable coloring sheets. <http://dcc.missouri.edu/hunter-eve>.



relative that lives in another area of the state away from the disaster area is also a good person to share your information with. This would also be a good person to list as your main point of contact on your emergency plan. Make sure each family member knows to call that contact person, who will be the main person everyone can try and get in touch with. FEMA recommends to text if possible instead of calling if you have cell phone service, so that the phone lines can stay open for emergency personnel.

Do you have a back up power source for any medical equipment that uses electricity? If you have a generator, remember to only use it outside!



Do have a current care plan, including a list of medications and doctors' names and contact information? It's a good idea to make sure someone outside your family knows about your care plan! A neighbor or even a

As a family, do you have an evacuation plan? And do you practice it with your children? Ready or Not is a good resource for starting your family plans! <http://texasprepares.org/English/Family.htm>

Texas Department of State Health Services has published an Emergency and Disaster Planning Guide for Children with Special Health Care needs; you can find a PDF copy at: http://texasprepares.org/English/emergency_plan_cshcn_eng.pdf

Hopefully you can start to take small steps today to be well prepared for whatever might come our way in Texas!



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, Cerebral Palsy, Dad’s, Dyslexia, ECI, Homeschoolers, Medical Home, Medicaid Waiver, Mental Health, NICU, Rare & Undiagnosed, Spanish, Transition, Traumatic Brain Injury, 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 local groups. Contact Laura at Laura@txp2p.org to discuss moderating one for us.

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Early Childhood Intervention (ECI) provides services to families who have infants or toddlers with qualifying disabilities or developmental delays. Most ECI services are provided at home; however, services can be provided in other settings. An important outcome of ECI is that families receiving services feel they know how to support their children's development both at home and in their communities. Community settings can include day care, early education programs, library activities or simply playing in the neighborhood park or playground.

ECI services are intended to support the child and family, along with community providers, so the child can fully participate in the community experience. What this looks like will be different for every child because every child has different needs. The plan to participate should be addressed on a regular basis and individualized to meet the needs of the child and the expectations of the family. It is important to consider community activities when planning for your child. Learning new skills in other settings help children:

- learn skills that are useful for everyday life,
- interact with other children, who model the desired skills,
- practice new skills,
- experience a sense of belonging,
- develop social skills,
- be motivated to try new things,
- gain confidence in their abilities.

Parents may ask that some of their ECI services be provided in their child's day care class. ECI services in this setting are focused on coordinating learning activities with the teacher to ensure the ECI child is fully participating in class activities. This may mean adapting the activity, changing the physical environment to meet the

needs of the child, or supporting peer relationships in the classroom.

ECI may also work with the day care provider to understand how to structure tasks in smaller developmental steps to reveal the child's skill level. This allows parents and teachers to set realistic expectations for the child. As a result, they are better able to recognize and applaud the child's accomplishments. The ECI provider's role is not to replace communication between the family and the child care provider, but to offer strategies that support the child's development both at home and in the child care setting.



Some families may want their child to participate in other community activities such as story time at the library, a parent/child class, or nursery/child care activities at their church. In some cases, families may not be sure what is available to them in their communities. ECI and the family can work together to explore options and identify what will meet their needs.

What can you do to help the ECI provider find ways for your child to participate in the community?

1. Identify what experiences you think will benefit your child. If you are not sure, be open to exploring.
2. Identify activities the ECI child likes. This list will help

the ECI provider know what might be a natural fit.

3. Identify the child's strengths. An activity that focuses on your child's strengths will be more successful.
4. Think about some of the challenges that may come up. What ideas do you have about minimizing the challenges to your child's participation?
5. Be honest about your worries.
6. Be confident in your ability to know your child and to share that information with others.

What should you be prepared to share with the community provider?

1. Your goals and expectations for your child.
2. Your knowledge and expertise about your child.
3. Strategies that work best for your child.
4. How best to communicate with you.
5. In a child care class, a copy of the Individual Family Service Plan (IFSP). Enlist child care providers in supporting your child's goals.
6. Issues that you observe and ideas about what would be an improvement.
7. Your child's specific needs. What is it you expect from this experience?

To find a local ECI program in your area, call the DARS Inquiries Line at 1-800-628-5115 or search for a program at www.dars.state.tx.us/ecis/searchprogram.asp



Getting Your ARD College-Ready

Amy Litzinger, TxP2P Staff

If you're like my parents, you never miss an opportunity to tell your kid they can do anything, including go to college. You may have even noticed your child probably is capable of post school learning with their peers. You are all for your kid, and ready to prepare her for the next step after school. But how do you design your ARD paperwork to match these goals? Well, here's what I learned from my own experience. Maybe my own hindsight can help! (And don't worry, even if your child is not looking at college, some of these things will help with self advocacy and a more person-centered life.)



Elementary School

- Teach your kid his diagnosis and what he needs and why.
- Make sure your child is present during her ARD meetings

- Try to focus long-term when setting goals. Where do you see your child at the end of high school? What needs to happen at school to get him there?
- Write realistic goals. It doesn't make sense to reprimand a first grader for switching b and d, when according to therapy goals, she shouldn't even be holding a pencil yet.

Middle school

- I wish we had aligned school therapy goals with what I was doing in class. For example, in sixth grade we were learning about valence electrons in atoms. In retrospect, we should have been practicing drawing them when I was being pulled out of class, instead of something that wasn't linked academically. We fixed this issue in high school when OT started helping me with my art projects. This was especially helpful when we had to draw three-dimensional shapes because I have issues with spatial

reasoning. "How exactly does one draw a cube, when one's vision is essentially flat, and I can't hold a pencil straight up?"

- As a middle schooler with a new power chair, I wish we'd built some time in the school day to learn how to drive it safely.

High school

- Get proper documentation of your child's diagnosis and neuropsych testing, while the school district will pay for it. You will need this information for college applications and possibly SATs or ACTs. Every modification must be documented in the ARD for at least nine months before you ask for modifications on these exams. You must ask six months before your test date. If you need something, it's best to get it in the ARD at least by your child's junior year.



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:

- Travis Dafft, son of Teresa Dafft
- Harper Elle Howard, daughter of Penny & Dustin Howard
- Self Advocate Carol Thompson
- Casey Barnes, daughter of Marty & Tim Barnes

With deepest sympathy,

The Staff, Volunteers, & Board of Texas Parent to Parent



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Charting Your Course to Financial Security

The Children with Special Health Care Needs (CSHCN) Services Program



The CSHCN Services Program within the Texas Department of State Health Services, (DSHS) helps children with special health care needs and people of any age with Cystic Fibrosis through many programs and initiatives including health care benefits, case management and family and community support services.

HEALTH CARE BENEFITS

Health care benefits are available to those who:

- live in Texas;
- are under age 21 (or are of any age and have a diagnosis of cystic fibrosis);
- have a certain level of family income;
- need more health care than what children usually need;
- have a medical problem expected to last at least 12 months that limits one or more major life activities; and,
- have physical symptoms (not solely a mental, behavioral or emotional condition or delay in development)

Services to clients receiving health care benefits include:

- Medical, dental and mental health care
- Medications
- Travel expenses for health care visits
- Specialized therapies, such as physical or occupational therapy
- Medical supplies and Durable Medical Equipment
- Nutrition services and nutritional products
- Home health nursing
- Hearing and vision services
- Orthotic and prosthetic devices
- Health insurance costs
- And more...

Currently, the CSHCN Services Program has a waiting list for health care benefits. This means that new clients will not be able to receive health care benefits until they are

removed from the waiting list.

Once a child is eligible for the CSHCN Services Program, it is important to fill out the renewal paperwork every 12 months so the child stays in the program. Clients on the waiting list must also renew the application annually. Otherwise, the child may be removed from the program and placed back on the CSHCN Services Program waiting list.

To apply for the CSHCN Services Program's health care benefits:

- Call 1-800-252-8023 to get connected to either a regional office or a community-based partner organization.

When you apply for the CSHCN Services Program you will be asked to provide:

- The CSHCN Services Program application form.
- Proof of resident address.
- Proof of date of birth.
- Proof of family income.
- Paperwork or identification cards for any other health insurance.
- A CSHCN Services Program Physician/Dental Assessment Form that your child's doctor or dentist fills out with a qualifying diagnosis and what the program calls a determination of "urgent need for service." This form must be signed by your child's doctor or dentist.

We encourage families to visit the CSHCN Services Program website and apply at <http://www.dshs.state.tx.us/cshcn/>.

CASE MANAGEMENT

Case Management services are available to ALL children with special health care needs in Texas, even if they are not a CSHCN Services Program client. Case management helps children and families identify needs, establish goals, develop a plan, access services and monitor progress.

A case manager can help families with school meetings, transitioning to adulthood and finding a medical home. These services are available across the state through CSHCN Services Program's community-based case management contractors or

licensed social workers within DSHS' health regional offices. To find a case manager, visit <http://www.dshs.state.tx.us/cshcn/CSHCN-Regional-and-Local-Offices.shtm>.

FAMILY SUPPORTS & COMMUNITY RESOURCES

Support for families is available through the CSHCN Services Program's network of local, community-based partner organizations. These organizations provide a range of services including family-to-family support, information and referral, education/training and respite. Not all types of services are available in all parts of the state. To find out if there is a community-based contractor in your area, visit the CSHCN Services Program website at <http://www.dshs.state.tx.us/cshcn/Community-Based-Contractors.shtm>.

A Transition Toolkit with links to many resources for transition-age youth, their families, providers and others is available at: <http://www.dshs.state.tx.us/cshcn/Transition-Resources.aspx>.

Anyone can sign up for the program's email and/or text updates through GovDelivery at: https://public.govdelivery.com/accounts/TXHHSC/subscribe/new?topic_id=TXHHSC_207.

Visit the CSHCN Services Program website at <http://www.dshs.state.tx.us/CSHCN/> for more information. Or call: 1-800-252-8023 (Toll Free); 512-776-7355 (Austin)

Program staff are available to answer questions and guide families to supports and services.



Getting the Diagnosis

Greta James Maxfield, TxP2P Staff

Recently I was asked by TxP2P to tell my story of motherhood. Initially I felt confusion about how to tell a story that has gotten nothing but longer and more complex over time and wondered what to focus on. Well, I will start at the beginning, I guess, and jump around as needed to describe the long and winding road we've been on.

Spoiler alert **I'm still here, still standing, and I didn't forget how to smile or laugh.

My beloved, highly anticipated son was the answer to countless prayers when he arrived in 1999 after a full term and healthy pregnancy. He is such a miracle and I remember that always, since a full term gestation had been so elusive before. Upon arrival he was absolutely perfect! We could hardly believe our shiny good fortune and it erased all of the pain of longing that came before. His APGAR score was 9! The nurses joked that scores of 9 and 10 are generally reserved for the children of doctors, further reassuring us of how perfectly born he was. I immersed myself in glorious mommy-hood, complete with all manner of mommy and me classes, play dates and homemade baby food.

Incredibly this little baby boy had an astounding ability to "introduce" me to strangers, who became new friends, without saying a word. He used the methods that only babies can communicate so well-- 1) infectious laughter, 2) love of play and outdoor activity, and 3) a sweet face framed in gorgeous curls. His perfection attracted admiration and invitations from the world. Assured of a bright, bright future we accepted my son's precocious development as just another feature of the enormous gift we were granted. He began walking at an early age and spoke

right on schedule and with lovely pronunciation to boot. Little did we know that this state of bliss would last only a little more than 2 years nor that some features of this precocious development signaled emerging developmental disability. Even when I became concerned enough to seek my pediatrician's input, never ever did I imagine that it would permanently impact this perfectly limitless potential.

And then it started....or maybe more accurately, it accelerated so much so that I could not wait for the pediatric neurology appointment we had to schedule three months in advance for the first available appointment time. "It" would later be named by professionals and DSM codes but "IT" was the fact that he'd become routinely agitated during Music Together classes that he formerly enjoyed intensely and without tantrum. "IT" was that I could not leave the children's museum, especially the toy train tables, without a complete meltdown. "IT" was the fact that visitors could not leave my home without prompting tearful goodbyes from my son nor could we attend a play date like I'd become accustomed to. He was so nervous arriving as we drove up and it became unrealistic to expect him to play with the others while I drank coffee and socialized with my peers as had been routine up until then. Countless times before, he

had played and played well without direction from any adult. Maybe most impressively "IT" was his verbatim dramatic recital of stories that we introduced to him from the books that became such good companions to him that he slept with them instead of soft toys. Since my husband is a literacy expert, we devoted ourselves to literacy readiness and read volumes to our son regularly. He so enjoyed our reading to him. (We did too)! He often chose books for us to read and even screamed when they were finished, pleading for a repeat. At bedtime, if we refused to read another story because it was time for sleep, we'd hear his completely accurate rendition as he comforted himself to sleep. Never did I assume this would be considered a profile of autistic spectrum disability, but in retrospect it was a part of what was raising my internal alarm. And most of all, my son was talking too much. I know that sounds crazy but that was the thing that got my full attention. Too much talking. It was constant. And I mean constant. He woke up and this stream of consciousness would start. And we knew some of the words before they emerged from his mouth, because they were read to him at nap and bedtimes from those books he loved (and still loves) so much.

Continued on page 7



Voicing my concern met with complete dismissal by everyone I knew, including some persons with advanced degrees that reassured me that kids are weird and that mine seemed no weirder than others. There were books at the time that made this case and they became bedtime comforts to me. I felt reassured, but then the manifestations began to mount and multiply even as others around us continued to sooth my fears. And he even stopped sleeping. So at 2 yrs. and 6 months old we finally got our visit with a neurologist. Within about 20 minutes he was diagnosed with something called PDD-NOS. Seeking to quickly clarify as I struggled to keep my son content during the neurology appointment, I promptly asked, "Does that have anything to do with autism?" The doctor responded "No," and I was very relieved.

It occurred to me to ask this question because in the face of all of the reassurance from friends and family, I'd taken to joking

about being dismissed, "Not to worry; that's just the Autism kicking in." And in the interim as I waited for the neurology appointment, I'd hit the Internet Explorer. This was a long time ago in terms of the internet, but I was an early adopter when it came to accessing medical information online. I'd run into something called "childhood disintegrative disorder" and coincidentally one of my friends did too and we wondered if that was what was happening to James.....it escapes me now why that label seemed accurate but nonetheless when the neurologist said "No" to the question of autism I was so relieved. Then astonishingly my son was referred to a speech language pathologist that day. I was surprised because he spoke so very well that I never in a million years would have thought that remedy would include speech therapy. I was prepared instead for the possibility of some sort of psychological disorder that could be remedied with a little play therapy.

Well, as I said, I was an early adopter on medical searches online, so as soon as I got home I cranked up the old PC and when I typed in "PDD-NOS" and searched, all links led to "Autism." I was furious! And frightened! Confused! Confounded and very, very worried. It was nearly 4pm when we'd gotten home from that life changing appointment and that meant I might have an opportunity to get that doctor on the phone and demand...clarify... why hadn't the question of autism been answered with an acknowledgment? This would prove to be my first lesson about how meaningless the words and labels are to name amorphous conditions that defy explanation. I picked up the phone and got no one, despite persistence and resourceful phone tree maneuvering. I spent that night, as I would many times over, contemplating the unknowable future.

It's Not Denial, It's Hope!

Laura J. Warren, TxP2P Staff

I've had the good fortune to learn more about denial than most parents of kids with disabilities. I not only lived it when my son was born and through his first 3 years but I've also studied it a bit. I know that denial buys us the time we need to absorb the information we receive that might be devastating. It's processing time so you can slowly accept whatever diagnosis, syndrome, or disease you were just told about and move forward.

And I know that there are stages of denial. The 1st Stage: When someone asks me if Jason should be walking by now, I say, "NO!" and walk off cursing under my breath. The 2nd Stage: When someone asks me if Jason should be walking by now, I

say, "No, because he was a preemie but now he's getting ECI services so he'll catch up and all will be well!" The 3rd Stage: When someone asks me if Jason should be walking by now, I say, "Well, Jason has Cerebral Palsy and it's going to take him a while to learn to walk."

I have also been told many times by medical professionals as they refer someone to TxP2P that "this family is in denial." Well, many of us were. When my son was born at 1 lb., 11 oz., and we were told he had a 10-20% chance of surviving, I was totally in denial. But each day he lived was a good sign. So slowly but surely the denial turned into

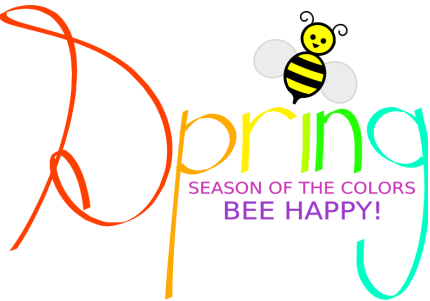
hope. On one side, I knew the possibility that he could survive was low but he was still here so maybe he would be the one who made up that 10-20%. The neonatologist and other physicians dealt with each and every issue that came up. And we still had terrible, terrible days and nights but he continued to survive. So what started as denial turned into hope and helped all of us get through his ordeal. And aren't we all entitled to a little hope?



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Conference Schedule

Date	Conference Title	Location	Registration Information
Wednesday, March 23-Thursdays, March 24, 2016	Person Centered Thinking Training	Austin	For more information go to http://www.person-centered-practices.org
Thursday, March 31, 2016—Saturday, April 2, 2016	Texas Association for Education & Rehabilitation of the Blind & Visually Impaired (TAER) Conference	Houston	For more information go to http://www.taer.org/conference
Saturday, April 2, 2016	Heart of Texas Autism Network (HOTAN) 2016 Walk/Run for Autism	Waco	For more information go to http://www.hotautismnetwork.org
Saturday, April 9, 2016	4th Annual Living with Disability Conference	Hurst	For more information go to http://www.txp2p.org