

TxP2P Update

Laura J. Warren, TxP2P Staff

We've hit another milestone - this is our 50th newsletter! If you do the math, you'll realize that we haven't quite gotten 4 a year for 14-1/2 years but pretty close. Hope you all enjoy it!

Another milestone - TxP2P is moving. We have been in the AGE Building in Austin for 14 years, since we received our first grant. It is a wonderful old building in a wonderful old neighborhood just north of the University of Texas campus. It is full of nonprofits who all share encouragement and understanding. And it is haunted, has a chiller system for AC/heat (bet most of you don't know what that is), has no hot water and almost no parking.

Due to a new partnership with United Healthcare around STAR Kids, we will be hiring several new parents to work with more of you and we just don't have any room for more staff in this space. So we will be moving to a newly renovated space out of central Austin on August 19th if all goes as planned! We hope to only have the phones and email down for a short period on that day and otherwise we'll be back answering the phones on Monday, August 22nd. Wish us luck - the first move after 14 years is a bit daunting!

Our 12th Annual Statewide Conference was a lot of fun as usual with close to 500 participants and 850 total people at the Embassy Suites in San Marcos. Our next Regional Conference is in the Rio Grande Valley at Port Isabel ISD on Saturday, October 15th. Registration should be open soon. And then in 2017, we'll be in Tyler on Saturday, October 25th. Hope to see you there!

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Inside this issue:

- ♥TxP2P Update, pg. 1
- ♥Advocacy—Legislative Update, pg. 1
- ♥Around the State—New Changes on Medicaid, pg. 2
- ♥Transition—When do I get started on transition? Pg. 3-4
- ♥From Our Families— I See You, pg. 4
- ♥Around the State—ECI: Respite: Taking time for Yourself, pg. 5
- ♥Around the State— Ready- Set- Life!, pg. 6
- ♥From our Families—My Year as a Medical Faculty at TxP2P, pg. 7
- ♥Conference Schedule, pg. 8

The Legislative Advocacy Report

Linda Litzinger, TxP2P Staff

Our TxP2P advocates are banding together to gain new legislation. Now is the time in the process to ask Senators and Representatives to write a bill for an upcoming session that begins in January, 2017. Over this summer, thousands of bills will be written to be filed beginning in October. Nine of the issues that advocates are attempting to put forward are:

- Disability-specific education to pre-school workers
- Re-file the bill for Board of Certified Behavior Analysts licensure (concerns obtaining a license to practice as a behavior analyst or assistant behavior analyst)
- New array of services for autism and similar needs
- Increased access to all waivers, especially for children

- Redefine and expand skilled nursing services
- TEA to better address mental health training to ISDs
- Priority for children in long term placements at residential treatment centers to receive emergency supports
- ISDs and Day Habs to prepare students for competitive, integrated employment and individualized placements to

comply with Workforce Investment Opportunity Act

- Licensure and oversight of Day Habilitation centers

Please contact Linda Litzinger if you have a new effort or wish to join any of these and need my help: Linda.litzinger@txp2p.org or 512-922-3810 cell.

Isela Wilson smiles after testifying about the need for increased waiver slots



New Changes for Medicaid: STAR Kids starts Nov. 1

Texas children 20 and younger with disabilities will move into the STAR Kids (<http://www.hhsc.state.tx.us/medicaid/managed-care/mmc/star-kids.shtml>) managed care program Nov. 1 and Texas Health and Human Services Commission (HHSC) is working to make the transition as smooth as possible for providers and clients.

The agency is urging providers to talk to their patients and sign them up with the STAR Kids health plans in their area to ensure Medicaid patient health care is not disrupted.



"We want to do everything we can to ensure continuity of care," said Michelle Erwin, HHSC's Director of Program and Policy. "We hope providers will talk to their clients and contact the health

plans to contract for STAR Kids. We're working to make the process as seamless as possible for providers and clients. We are working very closely with advocates and provider associations."

HHSC has already conducted a series of information sessions across the state for providers and has more planned in August and September.

STAR Kids will deliver basic medical services and long-term services and supports through a health plan the client selects. Each client will have a service coordinator at their health plan who will help find doctors, make appointments and coordinate care among various providers.

The 10 STAR Kids health plans (<http://www.hhsc.state.tx.us/medicaid/managed-care/mmc/Managed-Care-Service-Areas-Map.pdf>) are working to sign up providers who are serving Medicaid clients. There is a special focus on the following:

- Primary care
- Private duty nursing
- Personal care services
- Community First Choice

- Community-based long term services and supports including respite care.
- Behavioral health and mental health, including substance use disorder.
- Pharmacy
- Other provider types, including pediatric specialists.

HHSC's enrollment broker, MAXIMUS, will send out enrollment packets on behalf of HHSC and have enrollment sessions across the state to help clients and their families pick the right plan when they enter STAR Kids managed care.

Clients will be getting information in the mail starting in July to guide them through the process of picking a health plan. Clients can sign up for their plan by phone, fax, mail, in person at an HHSC benefits office or at enrollment events across the state.



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, Texas Network Connections, 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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When Do I Get Started on Transition?

Rosemary Alexander, TxP2P Staff

We on the Pathways to Adulthood (PTA) team are often asked the question, when should we start on transition? One answer is, from birth! Some waiting lists are years long and an early start will really help provide supports as your child matures. Another answer is, whenever you get interested. This answer is particularly useful for parents asking about when to sign up for our PTA workshop. Sometimes we have parents attend whose children are three to six years old – they are thinking about adulthood early. Some families attend whose children are in late elementary, but the majority have children 12-20, and the biggest number is 16-18, when transition really can no longer be ignored! Transition begins in earnest in the teen years, but thinking and planning can start at any time.

We have developed a Transition Time-Line for Families Planning for Life after Graduation, included below. You'll see that some suggestions are for elementary-middle school ages, while most are for age 14 and up. Knowing what lies ahead can always help you prepare, even if the next step to take is several years away. And note that the ages in some cases are flexible, like for activities to do at home, while some steps are required at a particular age.

We hope this Time-Line gets you started, at whatever age your child. Please call us and go to our website, txp2p.org, Pathways to Adulthood, for more information on all these topics.

Age of Child	Steps to Take
Anytime, ASAP	Get on Medicaid Waiver Interest Lists
By age 6	Give your child tasks to do at home
8-12	Start talking with your child about work, planning for the future; encourage interests and talents
10-12	Explore volunteer and paid jobs in the neighborhood; keep a work experience log
14 +	Have your child participate in ARD meetings
14 +	Request a planning process at school but outside of ARD process. Bring in relevant staff and community; inventory the present, discuss and document goals and needs post graduation; translate into IEP goals
14	Your child's school staff must start to include transition planning in the IEP process
14	By 9th grade, determine when your child will graduate, under what graduation plan, using what end-of-year tests
14	If planning for college, make sure student is on the graduation plan that prepares him for college
14 +	Learn about DARS transition services
14-18	Look for adult medical services to replace pediatric, how to pay for adult medical services, how to have a voice in medical issues after child turns 18
14-18	Encourage your child to begin to speak for himself to medical providers, school staff, etc.
14-18	Find ways for your child to get vocational experience on and off campus; use school services to get a job before graduation
14-17	Make sure do not have assets above \$2000 in accounts and other financial instruments in your child's name
17.5	Prepare to apply for SSI/Medicaid: prepare to provide proof of disability, low income
17.5	Consider your child's decision-making abilities and what level of assistance she will need after age 18
18	If your child needs assistance making decisions, consider guardianship or other legal instruments that allow you to speak for or assist your child with legal, financial and medical issues, such as power of attorney or a Supported Decision Making document

Continued on page 4

Age of Child	Steps to Take
18	Apply for SSI (after age 18, based on child’s income, not family’s)
18	Child graduates and gets diploma or walks the stage and stays in school for 18+ program (ARD decision); may stay in school until year students turns 22, depending on birth date
Last years of school	Find opportunities to link up with other students and families for social life after graduation
Last years of school	Sign up with DARS counselor, use DARS transition services
Last year of school	Get Summary of Performance from school; use to get college accommodations and as proof of disability
Last year of school	Move planning group from school-based to community-based; develop a network of community supports

I See You

Shannon Dingle

I see you, mama warrior.

I see your tears, even as you quickly blink them away. I see your exhaustion, even as you try to hide the yawns. I see your plodding steps, one after another to do whatever it takes for your child.

You’re wondering if you’re doing enough. You’re wondering if you should look into one more therapy or one more device or one more specialist. You’re wondering if all your pushing toward the next goal is unintentionally communicating that your child isn’t enough as he is now.

You win some. Oh, do you win! Your passion and love and knowledge of your child comes across in every bit of advocacy, rubbing off on those around you so they can’t help but join the team. You champion your child so well that you’re usually too tired to celebrate those wins, though I see your smile.

You cheer on other kids too. Maybe they’re yours, maybe they’re your bestie’s, maybe they’re in the same Sunday school class... no matter whose they are, you delight in all those typical milestones, even the ones your child may never meet. You love well. And sometimes you

go home in tears, because the dream you had for your child isn’t the reality.

So you dream new dreams. You learn IEP lingo and educational strategies and spellings of diagnoses and doctors you never thought you’d need to know. You learn to stand up to doctors and educators and others, even when they think they know more than you do. Why? Because you know your child, and that expertise is the most important credential you could hold.

After bedtime, you Google everything you can learn to serve your child well, while bingeing on The West Wing or Friends in the background because you know the episodes so well you don’t really need to pay attention. By now, you could probably ace certification tests in several areas of education, nursing, and therapy. Sometimes you struggle with small talk because you don’t feel fluent in the typical parenting lingo anymore.

But?

You wouldn’t trade it for the world. Your deepest stretch marks are the figurative ones, from being stretched in endurance and faith and trials and trust beyond any-

thing you ever imagined. You vaguely remember your college answers to where will I be in X years, and your life today is better but oh so very different from what you hoped for back then. You have no answers now to what life will be like for you or your child in a decade or more, but you know today is beautiful and hard and messy and grace-full.

I see you look at your child, and your eyes say it’s all worth it. Through your precious one, you have front row seats to the works of God displayed through disability. I see you shrug off the suggestion that your child is lucky to have you, because you consider yourself to be the lucky one.

Carry on, mama warrior. I see you, and so does God. Today may be a hard day or a good day or a good hard day. Whatever kind it is, know this: you are enough, and you are not alone.



Sometimes, the best thing you can do for your child is take some time for yourself.

What is respite?

The word respite means “break” or “relief.” Respite services are designed to offer families a break from caring for their child with developmental delays or disabilities. Respite allows parents time to take part in activities that they find relaxing, entertaining, or restful while a respite provider cares for their child.

A respite break can mean an hour to take a walk while a respite provider stays in your home to care for your child. It may be a weekend away while your child is cared for outside of your home. It can also mean time to take a nap or see a friend while the respite provider takes care of your child.



How is respite different from day care?

Day care and traditional child care are provided on a daily or regular basis so parents can go to work or school. Respite, on the other hand, is typically provided on an irregular or short-term basis to provide the parent with a break from caring for their child with developmental delays or disabilities.

How can respite help my family?

Parenting is a difficult job and every parent can benefit from a break. Caring for a child with developmental delays or disabilities presents additional challenges that go beyond the everyday stresses of parenting. As a result, you may need longer rest periods or more down time. In addition, it may also be more difficult to find a qualified person to care for your child. Respite services can provide you with the needed support.

There are several resources you can access to support your families’ respite needs. The Take Time Texas website (<https://www.dads.state.tx.us/taketimetexas/>)

administered by the Department of Aging and Disability services provides many tools and a searchable provider database to access help and support for families.

If you are a family receiving Early Childhood Intervention (ECI) services, your ECI program may have funds to help you pay for respite services. Ask your ECI service coordinator about:

- the availability of ECI respite funds,
- levels of funding based on level of care needed,
- process for prioritizing requests,
- wait list policy,
- annual hourly limit, and
- annual total dollar limit.

Also, ask your ECI service coordinator to help you find providers in your circle of friends

and family or in your community. Respite can help strengthen your whole family. It can help decrease stress and help increase your family’s health and well-being. In addition to giving you and other caregivers some rest, it may help free up time to spend with other members of your family.



Here are additional tips for finding a respite provider:

- Ask family members, friends, other parents, or your child’s doctor, teacher, or therapist for recommendations.
- Find providers in your community on the following website: www.taketimetexas.org
- Call the 2-1-1 information and referral line.
- Search for child care providers through the state’s Child Care Licensing website: www.dfps.state.tx.us/child_care.
- Contact local colleges for students studying in fields such as child development, education, nursing, physical, occupational, or speech therapy.
- Contact your local children’s hospital.

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:

Darius Hollins, son of Christine & Darius Hollins

With deepest sympathy,

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

Ready-Set-Life! The Things College Prep Didn't Prep Me For

Amy Litzinger, TxP2P Staff

School teaches you a lot about what you need to know for college. A majority of time is focused on academics. Social skills are supposed to come outside of class. I've written down a few things I wish we would've started earlier. There are a few things I wish I had known. Before you set the alarm for dropping your kids off at college...run the clock back with me first! (And don't worry, even if your child isn't college-bound, some of these ideas you can use other places, to make life more person-centered)

Elementary School

- Encourage your child to take walks or rolls around the neighborhood, especially with their peers.
- Try to achieve a balance between therapy and social activities.
- Let your kid explain what they need (or don't) to new caregivers or doctors. (How do you feel? Where does it hurt?)
- Have someone in your neighborhood babysit your child. That way your neighbors will learn more about your child, and your child will not be afraid to ask others they know for help.

Middle school

- Over the summer, drop your child off at their new middle school. Have them try to find rooms and areas by themselves. If possible, bring their new class schedule. Can they get from one class to the other without getting lost? Can they get from each class to the front door? They will appreciate not getting lost on the first day of school when everyone else is also trying to get to class.
- Try picking electives based on your child's interests, rather than necessarily being the easiest to modify. Several of my middle school and high school electives ended up leading me to classes I pursued in college. One of these might end up being your child's major. This happened with my

film class and school newspaper. My first paying job was to teach writing to my peers. I started editing in middle school. I started taking advanced art in middle school. Now I sell my paintings.

- There are many times in life where your child won't necessarily have a personal assistant. Try picking a few classes where a paraprofessional will not accompany your child. Obviously you can tailor these, but I found electives the easiest. There's less writing involved, because there's not a lot of testing. This way, I would've had more of an opportunity to learn when to ask peers for help: who is less busy, who seems willing, how to ask, and whom I've asked repeatedly. Are there some things it is inappropriate to expect a peer to do for you?
- Try homework independently. It would've saved me a lot of trouble with a few teachers who weren't sure if I was producing my own work. Also, self starting and keeping yourself on task gets harder in high school and more necessary in college and the employment world. If you do it yourself, then you really know the answer to the question "how am I going to do this, and exactly how much help do I need to get it done?" Also, it will help with procrastination more naturally.

High school

- I wish we had made it clearer that I needed space in the hallways. I wasn't interacting with my peers, because they were afraid they couldn't be themselves around the adult who was my paraprofessional. My behavior was often critiqued, and I was sometimes shepherded away from age-appropriate, but less adult behavior.
- Don't pass up any opportunities your child is able to participate in to get them ready socially for being on campus. I finally got to a place where people expected

me to be an adult when I got to college. There was no special person for me, no paraprofessional, no one showing me the ropes of how to do this, in class and very little outside. I was very lost and confused. A lot of this could've been avoided by giving me enough leash at school to practice social situations. Not that I would've enjoyed artificial situations for people with disabilities very much. They're not real enough. Even someone other than my parents debriefing me on a social situation would've worked better. I'm learning it slowly now, but we should have been more conscious of it during high school. I saw a culture of "you're on the academic track, so let's not add in any life skills". I don't think they realize how little of college and post-college life is actually based on academics.

- Hire your child's peer to come over. See if your child knows how to explain what they need from their friend if you're not there. When you come back, have everyone meet and talk about it. This will help your child figure out how to manage a person they might hire or ask to help them with their needs. It will also give both of you a lot of information about what you need to work on...before you actually need to hire someone. Also, it will give the friend an opportunity to spend quality time with your child. They will gain responsibility in the friendship, and possibly some experience to put on a resume. Before I had attendant care services, we used to do this with a friend of mine who was about three years older. Later, we ended up hiring her as an attendant. Now she's an occupational therapist. You never know what little things can lead to in the long run.

My Year as Medical Faculty for TxP2P

Maureen Benschoter

Two years ago, my son George sustained a severe, permanent brain injury from a choking accident. One year ago, I became a family faculty member for the Texas Parent to Parent program, Medical Education (MEd). Little did I know that by stepping up to volunteer for this program, I would not only be making a meaningful contribution to the education of medical professionals, but I would be nurturing my own healing from George's injury and its impact on our family.

The purpose of the MEd program is to introduce future doctors to the ins and outs of daily life for families with a medically complex child. Medical students and residents visit a faculty member (like me) in their home, and spend an intense two hours learning our childrens' stories and following us through the daily regimen of care. For many of them, this will be the only time in their whole careers that they get an in-depth look at a patient outside a medical office or hospital setting.

The young doctors are respectful, attentive, and appreciative. Some-

times they cry when they hear George's story. Almost uniformly they express awe for the tremendous amount of work required to manage George's care. Without this home visit, they simply would have no idea of the daily lives of families like mine.

During our meetings, I stress that although George's care is difficult, it is not a burden. When they encounter him as a patient, he may be sick and miserable, but at home he is mostly happy and relaxed. I try to make sure their visit captures the moment when he arrives home on the school bus. He loves riding the electric lift from the bus to the sidewalk; it always makes him laugh. That's an important part of the whole picture that I want these future doctors to see: my laughing boy home from school, the two of us enjoying a fairly ordinary experience together.

In addition to the education of medical professionals, an unforeseen benefit of the MEd program has been its contribution to my own healing over the past year. I think the healing lies in the power of story telling. I'm a big

believer that as humans, articulating our experiences, especially the painful ones, helps us recover. Telling George's (and mine and my family's) story again and again to interested, sympathetic listeners (the medical students and residents) has brought me a measure of peace. It still doesn't make sense that my active, vibrant child now has to live the rest of his life trapped in a body with spastic quadriplegia. It is unfair, and awful, and tragic. But telling his story, having it known, grants us all a bit of grace, keeps us from feeling isolated, validates the struggle. I wish George could speak it himself; I am honored to do so for him.



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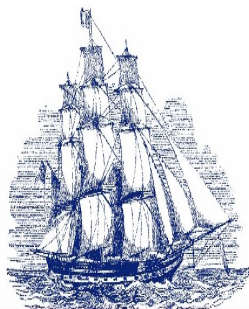
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Conference Schedule

Date	Conference Title	Location	Registration Information
August 3-4, 2016	Annual Texas Autism Conference	San Antonio	www.txautism.esc2.net
August 5-7, 2016	Abilities Expo	Houston	www.abilities.com/houston
August 8-9, 2016	Person-Centered Practices	Hurst	www.arcnetc.org/uploads/ PCT_Hurst.pdf
August 4, 2016 August 13, 2016	A Look Ahead—Pre-Conference A Look Ahead Quarterly Conference	N. Richland Hills Arlington	www.alookaheadseries.com