

TxP2P Update

Laura J. Warren, TxP2P Staff

Over the past 13 years, **Texas Parent to Parent** has grown and become a true statewide resource for Texas families of children who have disabilities, chronic illness, or other special health care needs. Some of you have donated to us and most believe in our mission. Since 2002, TxP2P has been empowering families through parent-to-parent networking, education, and information. And of course, it is the time of year to ask for your end of year donation (if you have any funds to make donations – take care of your own family first) but this year, we have a new twist!

TxP2P has received a very generous donation that we plan to use a portion of to start an account to provide a safety net for Texas Parent to Parent. We are not able to do this with grants and contracts that we receive to grow the programs of TxP2P but we can with this donation (the other portion of the donation will allow us to hire another staff person to support parents). So, we are asking for your support to match \$10,000 of this donation so we can double what we put toward the sustainability of TxP2P. It currently takes more than this amount to pay for one month of operations but it will come very close to accomplishing one month of operating expenses in the bank.

If you are able to make a donation this year, please consider making it to **Texas Parent to Parent**. Now, in its 2nd decade of operation, TxP2P needs to rely more heavily on private donations to support our programs and operating expenses. Thanks to the generosity of individual donors like you, TxP2P has grown over the last 13 years and has built a solid foundation of support for families raising a child who has a disability. Now, as we enter 2015, TxP2P needs to focus on the sustainability of this non-profit organization to ensure that it can be around to meet the needs of ALL Texas families raising a child with a disability, chronic illness, or other special health care need.

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Our staff & Board of Directors hope you all have a wonderful holiday season!

2015 Marketplace is now open!

The 2015 Marketplace is open now. You can apply and enroll in health coverage. If you're eligible, the Health Insurance Marketplace can help you find affordable health coverage. Most people who apply [qualify for premium tax credits and other savings](https://www.healthcare.gov/lower-costs/) (<https://www.healthcare.gov/lower-costs/>) based on their income. A family of 4 may receive credits if their income is lower than \$95,000.

If you already have 2014 Market-

place coverage, you'll be receiving important information about [how to keep your coverage for 2015](https://www.healthcare.gov/keep-or-change-plan/) (<https://www.healthcare.gov/keep-or-change-plan/>).

Here are 3 key dates you should know:

December 15, 2014. Enroll by the 15th if you want new coverage that begins on January 1, 2015. If your plan is changing or you want to change plans, enroll by the 15th to avoid a lapse in coverage.

December 31, 2014. Coverage ends for 2014 plans. Coverage for 2015 plans can start as soon as January 1st.

February 15, 2015. This is the last day you can apply for 2015 coverage before the end of Open Enrollment.



Interview with Natwon Brooks – a young self-advocate!

Linda Litzinger, TxP2P Staff

A few times a year, our TxP2P Advocacy Network teaches Legislative Advocacy in our state Capitol, learning how to visit legislators and to testify in a mock bill hearing. One of our conferees last month was Natwon Brooks, age 20, from Houston. Natwon has agreed to share a little about himself for this newsletter, including public policy he wishes to change...

Do you think that the educational system equipped you for adulthood?

In Houston, the schools are different; they only care about the attendance count. A few teachers were good but the rest didn't really care much.

How do you cope with your disability (Asperger's) in your community college classes?

At first, I didn't know what to ask for in the way of support services at LoneStar College, or who to talk to. I was on the fence about disclosing that I qualify for 504. Eventually, I came forward; I am given a quiet room for testing and I have a note taker for my

English class. I have no major yet but I have a goal of attending Houston Community College and owning a gaming company.

So, do you work with games in your job?

No, I pack items for shipping for Amazon.com. For me, hearing and conversing is easy, but reading is totally different. Amazon trains and explains well, and makes it easy. In contrast, McDonalds asked me a ton of written questions in the interview process, and for me this written exchange was difficult to understand, and I didn't hear back from them.

How do you feel about SSI being dropped after you finished high school, when it was difficult to recertify as an adult with a disability? Does this have an impact on you supporting yourself?

I would be on the street if not for my mom.

If you could go to Legislators in our Capitol and change state policy, what would you ask for?

Information about supports is

lacking at every age. I didn't hear about DARS supports during high school. Everything comes too late to help. This is what I would advocate for and try to change.

Thanks to Natwon for sharing this information - it has been a pleasure to get to know you.

We will be teaching another



course in the Capitol this spring and hope to see more great self-advocates, as well as parents!

For questions about future training, please contact Linda at 512-922-3810 or at linda.litzinger@txp2p.org.

Update: Task Force for Children with Special Needs Website

Jeanine Pinner, TxP2P Staff

The Task Force for Children with Special Needs (TFCSN) website is on target for the launch date of June 30, 2015. We can't wait to share it with you!

The TFCSN website promises to be a wealth of supportive and technical information for families of children with disabilities, chronic illness and other special health care needs. Not only will you find terrific articles, stories and videos from other parents, but each part of the state will have its own regional page with information about services, groups and events specific to that area of the state. You will be able to search the website for information and support in your area of the state

and from there, it's a short hop to connecting with organizations and



groups providing critical services, support and events.

It's an ambitious project with equally ambitious goals – a website for parents by parents. It's personal, current and relevant. You will likely see photos of children and families you know – maybe even your own!

We are still working on gathering resources (services, groups & events) for every area of the state and invite you to contribute to this exciting project by sending us information about resources in your area. Please email Jeanine@txp2p.org with basic information (name, contact info, description) about groups, organizations and events in your area that are beneficial to families of children with disabilities and I'll get the information to the right place.

Thank you for your help in making this a premier resource website in Texas for families of children with disabilities, chronic illness and other special health care needs!

Adults with Intellectual Disabilities as Mentor-Teachers

Elaine Eisenbaum, MSW
The University of Texas at Austin

This fall, I had the opportunity to teach an undergraduate course, Introduction to Disability Studies, at the University of Texas School of Social Work. This was my second time to teach the course and I was itching to try something new. I wanted to include adults with intellectual disabilities in the classroom in some way.

After speaking with a colleague in Canada who has a similar approach, I



decided to implement a co-teaching model in which adults with intellectual disabilities would serve as mentors to the students in my classroom throughout the semester. I was fortunate to receive funding from the Down Syndrome Association of Central Texas that allowed me to hire and pay stipends to five adult mentors who were selected through an application and interview process. In preparation for the semester mentors attended an orientation to get ready to be classroom leaders. During the semester mentors attended a portion of each week's class sessions and worked with

students on semester-long small group projects. The idea behind this classroom model was to give students the opportunity to learn from people with intellectual disabilities about their lived experiences and to get to know them through collaborative work.

My philosophy has long been that forming relationships provides an important foundation of understanding that cannot be obtained from a textbook. I have to admit, I thought the model would work well, but as a bit of a constant-worrier, I was still a tad nervous. *How would it go? Would everyone feel included? Would the groups, given relatively loose instructions for the group projects, come up with good ideas?* In the end, my worries were for naught. I envisioned a classroom in which students would benefit from learning from mentors and mentors would have an opportunity to gain leadership skills and work experience; and that is exactly what happened. The groups worked together enthusiastically. Mentors tried new things, overcame nerves and contributed to the group project in all aspects of the work. Students expressed not only their enjoyment in working with mentors, but also the realizations and new understandings that arose from the process. One student recently commented that she'd never talked with an adult with an intellectual disability as if that person was a

peer until working with the mentor in her group.

This course has only strengthened my belief that inclusive classrooms at the post-secondary level are of great importance. Too often our college students are taught skills for “helping” people with disabilities, but not taught how to work alongside them and with them. It’s beneficial for students to learn about supporting people with disabilities, but people are best supported when they are respected and valued. This semester the classroom mentors taught students so much, including giving



them a better understanding of the abilities and contributions that people with intellectual disabilities can and do make to society. The work that mentors provided significantly enhanced the classroom experience for students (and for me!). It has been a true pleasure to teach this semester and I look forward to continuing this classroom model in the future!

LISTSERV NOTICE: Yahoo Groups will no longer allow us to “add” people to our listservs - we can only invite you to join. Unfortunately, many of our invitations go into spam and you never see them. Another way to join the listservs is to send an email to the moderator and ask to subscribe. Contact Susan.Prior@txp2p.org if you want to join the any of the following: Advocacy, ADD/ADHD, Autism, Bipolar, Dad’s, Dyslexia, ECI, Homeschoolers, Medical Home, Medicaid Waiver, 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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Bumps in the Road

By Rylin Rodgers, Training Director, Family Leadership Coordinator, Riley Child Development Center

Looking back to my now teenage children's early childhood, my first thought was my "white limo" fantasy. When my son was hospitalized as an infant, and the complexity of his condition was not yet clear, my husband and I saw another family leave the children's hospital in a limousine. That family was celebrating a successful surgery, resolution of the child's issues and a return to life as normal. This would be their last hospitalization, and they were going home for good in style. We turned to each other and pledged to do the same when our turn came, which would surely be soon. We would get through this current crisis, and we would move on with the normal life we had planned for our son. But that limo ride never came for our family, and it never will. In fact, in many ways we have instead been on a very different and unexpected road, with wide variance in vehicles and driving conditions.

What I have learned from this journey is immense. First, while raising children who have special health care needs is the road less traveled, we were not alone. The families before us forged a path. The families currently on the road with

us are the most wonderful traveling companions: giving, resourceful and resilient. And after a while I started to notice the families who followed, and hoped we were smoothing some of the bumps on the road for them. And while some sections of our road are built by families alone, most of our journey has been supported by professional builders.

The providers who partner with individual families and those who are working on system-level road design have both a tremendous impact. Home visiting systems give families access to tricycles and training wheels with the support they need to travel their own paths. Primary care medical homes are more than a roadside tune-up shop. They provide whole child medical care and the partnership each family needs to navigate its course. Subspecialty providers give the critical care for very complex needs when sudden breakdowns occur. Financing the raising of my children has been a part of the journey in a constant state of change. At the moment families have increased chances of being insured on the road, but too many still can't meet minimum coverage standards. Care coordination pilots

are building the network needed to turn on the GPS system for families. The pit crew that supports our journey is extensive and endlessly important: therapists, medical equipment suppliers, teachers, community partners, even political leaders. It takes them all!

In the beginning, I didn't know what I would need to effectively parent Matthew and Laura. Frankly, I had little knowledge of the world of systems and supports that would be crucial to their success in growing and learning. What I know now is that the road system out there is not yet perfect – there are bumps, potholes, unpaved stretches and detours – but it is there, and amazing folks are working every day to smooth the journey and to build new and better highways. I thank you for putting on the work vest, even in less than ideal conditions. I urge you to continue to be alert to the needs of the travelers, point out the shortcuts, move the barriers and cheer the journey. Sometimes, I still wish for the limo ride, more often I am aware of what I would have missed and that my family was meant to be on this road.

Did You Know . . . ?

There are a million reasons to avoid having a conversation about the end of life. But it's critically important. Consider the facts:

- More than 90% of the people think it's important to talk about their loved ones' and their own wishes for end-of-life care.
- Less than 30% of people have discussed what they or their family wants when it comes to end-of-life care.
- 60% of people say that making sure their family is not burdened by tough decisions is "extremely important"
- 56% have not communicated their end-of-life wishes

Source: National Survey by The Conversation Project 2013

- 70% of people say they prefer to die at home
- 70% die in a hospital, nursing home, or long-term-care facility

Source: Centers for Disease Control (2005)

- 80% of people say that if seriously ill, they would want to talk to their doctor about end-of-life care
- 7% report having had an end-of-life conversation with their doctor

Source: Survey of Californians by the California HealthCare Foundation (2012)

- 82% of people say it's important to put their wishes in writing
- 23% have actually done it

Source: Survey of Californians by the California HealthCare Foundation (2012)

One conversation can make all the difference.

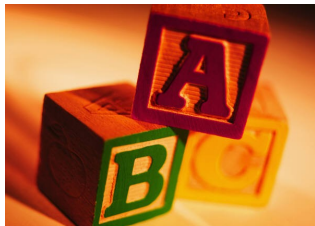
www.theconversationproject.org, Institute for Healthcare Improvement www.ihl.org



What is Early Childhood Intervention?

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

At Texas ECI, we know that parents are the most important person in their child's life and they know their child better than anyone. Parents are their child's first and best teacher. ECI encourages parents to join in every step of the process, from deciding on what kind of support their child and family may need to working daily with their child to help him grow and learn. Read how the Phonharath family and ECI worked



together to promote Kai's development.

After a sonogram, Sabaiphone and Phonevilay Phonharath of Fort Worth, knew their baby boy, Kai, wasn't growing as fast as typical babies but everything else seemed normal. "His brother, Kel was small, I was small, so I wasn't worried," commented Sabaiphone. Kai was born 5 weeks early and only weighed 4 pounds; therefore, he was required to stay in the neonatal intensive care unit for almost 2 months. He was an active

baby but it wasn't until the doctor did a blood test that his parents discovered he had Down syndrome.

The hospital staff connected the family with the DARS Division for Early Childhood Intervention Services (ECI). Within a week of being home, Kai and his family had their initial appointment and within 3 weeks were receiving services. "I was very happy how quickly ECI became involved because I was very shocked by Kai's diagnosis and scared. They were very helpful to us," said Sabaiphone.

ECI and the family identified goals for Kai and developed a plan. One of Kai's goals was to improve his eating. He is currently on a feeding tube and only eats a little by mouth. The ECI occupational therapist showed the family oral stimulation techniques they could use to help improve his eating abilities. She taught Kai's parents to stretch his cheeks and use a "chewy tube" to help strengthen his chewing since he has minimum tongue movement. "You never pay attention to how you eat but with him his tongue only stays in the middle so that's what we are working on," said Sabaiphone. The parents have built a routine for him and he is eating and chewing more which is exactly what they wanted to accomplish.

Another priority goal for the family was improving Kai's motor skills. The family has been taught a lot of muscle exercises for his trunk. Kai has learned to roll and crawl but he's really been working on "cruising" furniture and walking. Kai's parents give credit to their older son Kel, for his patience and

love for his brother. Kel is an active participant in his brother's daily routines. ECI staff provided guidance to the family on incorporating Kai's activities so he could help with his brother's development. Kel encourages Kai to walk by standing with their mom to get Kai to walk between them. "He is a true champion for his brother," stated Sabaiphone.

Kai likes anything that vibrates, loves to bang things and is always active and never still. "ECI therapists have been very helpful in showing me what to do feeding-wise and exercise-wise so he can develop as much as he can at each stage. We are so thankful for ECI being supportive and encouraging," commented Sabaiphone.

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

Remember anyone can make a referral to ECI. Over 28% of our referrals come from parents, other family members and

friends. To locate an ECI program near you, call the DARS Inquiries Line at 1-800-628-5115 or visit <http://www.dars.state.tx.us/ecis/gram.asp>



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Transition to Adulthood - The Big Picture for all Ages

Rosemary Alexander, TxP2P Staff

So what's the big deal about transition? Why do we all keep talking about it? When should it happen?

Transition is the natural process of your child's moving from childhood to adulthood, but that process for a child with disabilities involves many decisions and changes that may concern families. The goal of transition is having services, a structure, and a life ready when your child graduates from public school. If you don't do the planning and preparation, your child may have nothing to do and no one to do things with after graduation. A good life after graduation happens when parents, the child, the school and others do the planning and preparation. So how do you make this happen?

The emotional hurdles of transition.

Parents often feel anxious about their child's future, overwhelmed by decisions and changes, and afraid of the unknown; these emotions can stop parents from working on the future. Here are some ideas that have helped parents prepare emotionally for their child's transition:

- Find someone to support you through this process; connect with a parent group or another parent or find a teacher sympathetic and knowledgeable about transition.
- Learn all you can about what comes next.
- Create a positive vision of your child's adult life.
- Have faith in your child and yourself.
- Start planning, no matter how you feel.
- Contact organizations that provide support and information about transition, such as the Texas Parent to Parent Pathways to Adulthood program.

When should you get started?

Begin whenever you become aware of the issues, whatever your child's age. Of course, you'll have

a different focus depending on your child's age and disability. Transition is continuous and evolves over time. Even after your child is an adult, the process still goes on as his needs change.

One concrete thing you can do now is get your child's name on the interest lists for the Medicaid Waiver programs; the wait for these helpful programs in Texas is many years long. (For more information on Medicaid Waivers, go to www.txp2p.org, Pathways to Adulthood, Services and Supports.)

What should you do while your child is still in elementary school and early middle school?

Most parents want their children to work as adults, so start at a young age preparing your child to be ready to work. Encourage her to do household chores and notice what he is good at and when he needs extra assistance. Your observations can help in future planning.

Encourage the social skills that will help your child to make friends, get along with co-workers, and live with a roommate. Also encourage your child's interests, which can provide a link to work and social opportunities later on. Notice what motivates him or her.

What should you do in the teen years (later middle school and high school)?

A good starting point is to participate in a planning process of some kind; spend a few hours with your child and school staff, friends, relatives, or anyone who can contribute to a discussion about your child's future. During this discussion, you can look at where your child is today and then what goals your child might want to accomplish and the steps needed to accomplish them.

Remember, in a planning process, begin with your child; give him or her the time and opportunity to voice his interests and desires, what she is good at, what her goals are. If your child is non-verbal,

include him or her as much as possible and turn to the other participants for answers; encourage them to speak for your child based on their observations of his behavior in a wide variety of situations.

Even if you don't hold a formal planning process, start the conversation with your child about the future. Now is also the time to encourage your child to take a more active role in decision making and self-help, as far as is possible, and give your child the opportunity to try out new skills.



Many parents are concerned about financing the future and need to learn about what services are available after age 18. For most government funding, a person must show that he or she has low-income/few resources and has a disability. Income and resource eligibility is based on a family's before age 18 and the individual's after age 18, so a youth may qualify for such assistance as SSI and Medicaid after age 18 who did not before. Someone who was receiving this assistance through their family before age 18 must reapply after 18, when the basis for eligibility changes. (For more information on funding programs, go to txp2p.org, Pathways to Adulthood, Services and Supports.)

Ensuring that your child will be eligible for public funding at age 18 requires that you look at family financial resources. The goal is to be sure that no resource, such as a banking or savings account, exists in your child's name. Estate planning can help you consider this issue.

Continued on page 7

Age 18 is also a legal milestone: our society views a person at this age as competent to sign documents, make medical and financial decisions, and speak for himself. Parents must be prepared to decide if their child at 18 can make his own decisions or if you will need a legal arrangement to speak for your child, such as guardianship or power of attorney. (For more information on estate planning and guardianship, go to www.txp2p.org, Pathways to Adulthood, Legal Issues.)

You are learning more about your child during these years, and you'll

begin to see where your child is headed. This knowledge will help you to prioritize your transition efforts. Here are some transition issues you may need to consider (more information on all these issues at www.txp2p.org, Pathways to Adulthood.)

- Adult services
- Guardianship or an alternative and estate planning
- What to focus on in remaining public school years
- Post-secondary education
- Medical transition
- Employment
- Home

- Social opportunities and networks of support

How to get started

What many parents who have gone through transition have found is that it helps to talk about the future. Start a conversation with school staff, friends and relatives, and your child. Sharing your hopes and fears and starting to build a concrete picture of the future will lower anxiety and build optimism. Imagine your child living a good life after graduation—now start to put the pieces in place for that life.

Is He a Little Man?

Debbie Wiederhold, TxP2P Staff

So what do you do with the stares, comments, etc. from people as you go out in to the community/world with your child who just happens to look different? Do you take a moment and politely educate the uneducated? Or do you give them a “look” and walk away with disgust in your eyes? What is the right message? Some days you just want to stay home – it’s just easier to do that than explain or not explain, the whole time protecting your child.

I’ve seen the stares, heard the comments and tried to make a difference when I can – mainly for my child, but also for the others that come after us.

We were recently out of town for two days of doctor appointments for my son. We saw the stares, etc. but kept doing what we needed to do. After checking in for an appointment the second day, we’re sitting off to the side and a young boy came running over to us – with me already cringing, thinking “how do I handle

this stare or comment” and then he looked at me with a big grin on his face and said “Is he a Little Man?” I just smiled at the little boy and said “Why YES he is!” and then he ran off to his Mom who was checking him in for his appointment.

That day, even with the other stares and comments, was a good day – someone, even if it was a little boy, had seen my son for who he is.

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:

- Mia Mikayla Morgan, daughter of Maria & Jose Alvarado
- Kennedy Laury, daughter of Angela Laury
- Caelan Koch, daughter of Kendra & James Koch
- Caitlyn Kennedy, daughter of Catherine & David Kennedy
- Keven Lewis, son of Mary & Richard Lewis
- Joy Wahome, daughter of Sabina Kironji
- Dr. Robert Ehrlich, former Austin PICU Intensivist & Pediatric Cardiologist

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

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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.



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Conference Schedule

Date	Conference Title	Location	Registration Information
Wednesday, Feb. 4- Thursday, Feb. 5, 2014	2015 Inclusion Works Conference	San Marcos	http://www.thearcoftexas.org/site/ PageServer? pagename=events_inclusion_conference
Saturday, February 21, 2014	2015 TAPPestry Conference	San Antonio	http://www.esc20.net/tappestry
Thursday, February 19-February 20, 2014	2015 Texas Transition Conference	Dallas	http://ttc.tamu.edu
Sunday, March 1- Tuesday, March 3, 2014	2015 FIRE Statewide Independent Living Conference	Austin	http://conferences.txsilc.org