A Parent’s Perspective

TxEI Update
Laura J. Warren, Executive Director, TxEI

We are very excited to tell you that we recently upgraded our website (www.txp2p.org) and made it mobile friendly. You won’t see any major differences when you look at it on a computer but you will notice a huge difference if you use your smart phone. We are also updating our Spanish version of the website so that all the pages will be available in Spanish, translated by native Spanish-speakers. It will soon be a mirror image of the English version and will be much easier to use. If you find any problems with the new site, please let us know by emailing Randall at Randall.Alexander@txp2p.org.

We are also starting the process to get our Website Resource Directory updated. If you know of or run across a problem with any of the resources, please contact Susan at Susan.Prior@txp2p.org. Also, contact Susan if you want us to add a new resource to our Resource Directory.

And don’t forget, we have our South Texas Parent Conference in the Rio Grande Valley in San Juan at the PSJA Early College High School on Saturday, October 14th. We hope to have 16 breakout sessions for you to choose from. If you want to do a presentation for us, please contact Cynda at Cynda.Green@txp2p.org. We are accepting Speaker Proposals until August 31st. The conference is free and childcare, Slidshop, and Spanish translation is available if you register before October 7th. Hope you will join us.

We are finally having an Open House to show off our new offices. We are planning to combine our Open House and annual fundraiser, Vine to Wine, on Thursday, November 2nd. Watch for more details soon!

I hope you all had a good summer! I know that you are probably preparing for the kids to go back to school and wrapping up your summer activities; you’ll find several articles in this newsletter on going back to school—good luck with the new school year!

Legislative Special Session Update
Linda Litzinger, TxEI Staff

Here is an update on what is happening at the Texas Capitol during this Special Session of the Legislature:

PT, OT and speech therapy: The House hopes to restore therapy cuts enacted over the last biennium, affecting these programs: StarKids, ECI, and the MDCP, CLASS and DBMD Waiver Programs. These cuts have caused therapy providers and ECI programs to close across Texas, creating an access-to-care issue.

Testimony from parents was dynamic, and this bill passed out of House Appropriations, then the whole House. It is presently in the Senate who initiated these cuts 2+ years ago.

StarKids’ MDCP program: The House Appropriations committee discussed the record number of children being denied the MDCP Medicaid Waiver as a result of annual reassessments that are using a new assessment tool. In one month, the number of children denied at reassessment was four times that of all of 2016. During testimony, parents asked House Appropriations to tell Texas Health & Human Services Commission to continue coverage until this new test is corrected.

Special Education: The Senate’s special education bill offers public students with disabilities some tuition for private schools. Note: these schools do not necessarily provide IDEA supports. Also, this bill would not cover students who have already exited public schools. 80-100% of this program’s funding is to be used for students seeking private tuition for an annual maximum of $10,000/student. The remaining 0-20% of the program is for students utilizing special education who remain in public schools (for school fees, after-school programs, instructional supplies, school supplies, transportation to a different school, after-school child-care, tutoring).

- Public schools must advise families in writing of their opportunity to seek private education. Public schools must list IDEA supports provided in the public sector; they must inform that private schools are exempt from providing IDEA supports.
- A private school must itemize all costs. Some bill their students for therapists and paraprofessionals; others include all costs in their tuition. (There is a great range of tuitions.)

The Senate and House are quite polarized, thus it is predicted that few bills will reach consensus in time.
Back to school often leads to mixed emotions for all of us—students, parents and teachers. Families handle this in a variety of ways. As a parent, you can prepare your child with a disability in a variety of ways. The following suggestions could reduce the anxiety level for you and your child and help you get ready to start the new school year.

Work ahead of time to reduce stress and anxiety.

- Share the story of your own school years, walk down memory lane and focus on the "pros" that relate to your child.
- Go shopping. Gather school supplies. Take your child to purchase items, checking off items as you collect them in the cart, smelling the crayons, pencils, etc. Shop for new clothes, trying on new clothes and tennis shoes.
- Reconnect with friends and the natural support system in your neighborhood; call parents of last year's classmates, PTA members, etc.
- Do a dry run, a rehearsal or practice to figure out how much time you will need to be ready each morning.

Start some general routines or guidelines to prepare your child.

- Establish a bedtime routine a couple of weeks before school starts by having your child in bed on time; focus on the time and read a book. This will help your child become accustomed to going to sleep on time and getting up early.
- Review or talk with your child about the routines for after school, homework, reading, or dinner. Remind your loved one that last year's routines might work or might need to be tweaked.
- Take a leisurely visit to the school. Discuss it with your child, whether he is returning to the same school or a new school.
- Arrange to meet the teacher before the first day of school. It is acceptable to ask the teacher to look at the classroom roster. Talk to your child about new classmates, returning classmates, and peers your child already knows.
- Be up to date on vaccinations; have your paperwork in order so that it does not bring stress to you and your child.
- If your child will be using bus transportation, find out about the route, the pickup/drop off location and times.

When school begins, there are always meetings about your child's educational needs, so be prepared, positive, and proactive.

- Come prepared with positive anecdotes about what your child has accomplished and suggestions or strategies that help your child.
- At meetings, inquire about who the participants are and in what capacity they interact with your child.
- The ARD meeting will discuss IEP, BIP, LRE and other educational needs. Here is a helpful list of special education acronyms from Parent Companion if you need to brush up on these terms, or have a match through TxP2P with a parent who is experienced with the ARD process. (Call Toll Free: 866-896-6001 or Austin: 512-458-8600 to learn more about having another parent as a mentor.) Here are two websites that explains more about the ARD process:
  - TexasProjectFirst: http://www.texasprojectfirst.org/

Communicate and stay involved all year long, and it will be the best year yet.

Back to School

Mary Jane Ledesma, TxP2P Staff

- Create a folder or binder where you can keep long-term information, state and local resources. Have a meetings journal where you can record brief notes about decisions and comments made.
- During meetings, have strategic seating for your spouse and advocates so that everyone can express his or her opinions/suggestions freely without reproach.

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As the mercury rises, so does the Texas mosquito population. This year, Dallas County has already reported several cases of West Nile Virus, and Texas recently had its first suspected case of local exposure to Zika Virus in Hidalgo County. It may surprise you to learn that mosquitoes, with the diseases they carry, are the most deadly creature on the planet. And while malaria, the biggest offender, is not currently an issue in the U.S., Chikungunya, West Nile, Yellow Fever, Dengue, and, of course, Zika are still a potential concern.

Texas is particularly vulnerable to mosquito-borne illnesses, because of its location and climate. Texas has no off-season and we are currently approaching the peak of mosquito season. Zika is particularly problematic because it usually includes no symptoms, making it hard to track, and causes devastating neural abnormalities to babies exposed prenatally. Recently, a study (https://www.houstonpublicmedia.org/articles/news/2017/05/15/200974/study-finds-knowledge-gaps-among-pregnant-women-as-texas-prepares-for-more-zika-cases/) done by the U.T. Medical Branch (UTMB) Galveston surveying pregnant women in Southeast Texas discovered that many pregnant women were lacking knowledge in several aspects of Zika and that public education is exceedingly important in stopping the spread of Zika.

One area where pregnant women needed more information was on transmission of Zika. In fact, less than half of the women surveyed knew that Zika Virus was a sexually transmitted infection. Zika virus has no symptoms in 4 out of 5 people, so having sex with someone who traveled to an area with local transmission, can spread the virus without showing a symptom or clue that anyone has been infected.

As a result, the Centers for Disease Control and Prevention (CDC) is recommending that any pregnant woman who has a partner who has gone to an area with local Zika transmission, use a condom for the duration of the pregnancy, regardless of whether or not there are symptoms in either person. Furthermore, anyone who is attempting to get pregnant should wait until the virus has cleared their system before conception. Women must wait 8 weeks after possible exposure before becoming pregnant. Men, however, need to wait a full six months in order to ensure the virus has completely cleared from their body before they attempt to have a baby.

Due to a lack of symptoms in this virus, the CDC uses travel history to determine if a person has a potential exposure to Zika Virus. During the UTMB survey, they discovered that most pregnant women knew that they must be careful about traveling to certain areas where they may be exposed to Zika. However, most women did not actually know where those areas were. In the U.S., we have a few cases of local transmission of Zika, with the bulk of Zika cases being travel-related, meaning the individual traveled to an area with local transmission.

So, where is widespread transmission occurring? To find out more, check out the CDC’s Zika Travel Information (https://wwwnc.cdc.gov/travel/page/zika-travel-information) webpage. It includes a general overview of travel risk. It also allows people to input the specific location where they will travel and find more detailed information about the risk of Zika exposure there. Generally, areas that are closer to the Equator have a higher risk of Zika transmission. This includes areas in the Caribbean, South America, Africa, and Asia.

Another issue discovered in the UTMB Study is that only 40% of women surveyed were using mosquito repellent. Almost half of those who did not use mosquito repellent did so because they were worried about using it during pregnancy. Women might be reluctant to use any chemical during the nine months while their baby is growing. However, the Environmental Protection Agency (EPA) has determined more than once that DEET is safe and unlikely to be a problem for a pregnant woman or her baby. In fact, when comparing the potential problems when using DEET and the potential brain abnormalities for an infant born with Congenital Zika Virus Syndrome, doctors and scientists agree that the benefits outweigh the risks.

WebMD produced a video (http://www.webmd.com/baby/video/safe-bug-sprays-during-pregnancy-2016) explaining to pregnant women about the safety of DEET when applied correctly and how to use mosquito repellent safely while pregnant. Also, staying indoors, using mosquito nets, wearing long sleeves and pants, and using permethrin-treated clothing can help prevent the exposure to the Zika virus. If cost is a factor, individuals with Medicaid, CHIP, and CHIP Perinatal can get up to two cans per month of free mosquito repellent at their local pharmacy without a prescription. Measures to prevent mosquitoes (https://www.cdc.gov/zika/pdfs/LowLit_FS_WhatToKnow.pdf) in your community, like dumping out standing water and using mosquito dunks, can also help prevent the spread of Zika in Texas.

Due to the nature of the mosquitoes that transmit Zika, it has spread rapidly through communities in South America. While currently most of the cases in the United States are travel-related, we are primed for widespread Zika transmission. With the potential of mosquitoes year round and travel hubs in Austin, Dallas, Houston and along the border, Zika could strike in our communities. Prevention is the key to protecting babies from the devastating effects of Congenital Zika Virus Infection and keeping Zika out of our communities. To learn more about Zika transmission (https://www.cdc.gov/zika/transmission/index.html) and prevention (https://www.cdc.gov/zika/prevention/protect-yourself-and-others.html), check out the CDC’s Zika Virus web page (https://www.cdc.gov/zika/index.html) and the Texas Department of State Health Services page (http://www.texaszika.org/).
We want to share our condolences to our TxP2P families who have lost a child recently:

Mona Mae, daughter of Mira & Gabriel Lopez
Barney Cruz IV, son of Lanita & Barney Cruz

With deepest sympathy, the Staff, Volunteers, & Board of Texas Parent to Parent
Gross Motor Development

Even though some children may take a little more time to develop their gross motor skills, they can still join their peers in daily activities to increase their strength, balance and coordination.

Toys and equipment a childcare provider may already have for gross motor development include:

- Small push-pull toys and riding toys without pedals
- Gyms that allow infants to grasp or kick at items
- Large blocks or construction toys
- Balls of various sizes that can be rolled, thrown, or kicked
- Indoor and outdoor climbing and swinging equipment appropriate for a child their age

If you are a parent and your child is receiving ECI services, your ECI professional can work with the childcare provider to integrate sessions into their existing class routines. The ECI staff person may also help them arrange their classroom, suggest new or different ways to use the toys and equipment in the class, or plan activities that help all children develop gross motor skills.

Resources

Here are some helpful resources you can share with your childcare provider about gross motor activities for all of the children in the class.

- Play Activities to Encourage Motor Development in Child Care
- Perceptual and Motor Development Domain
  http://www.cde.ca.gov/sp/cd/re/itf09percmotdev.asp

Early Childhood Intervention services (ECI) are provided 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. These settings can include childcare, early education programs, library activities or simply playing in the neighborhood park/playground. Often times the parent or caregiver will request for some services to be provided in the childcare setting, if applicable.

ECI can work with a childcare provider who may have a child in their infant or toddler class who needs extra help with the development of gross motor skills. These are skills that use the larger muscles of the body. Children with gross motor delays may have difficulties with their balance, body strength and overall mobility. There are toys for infants and toddlers they may already have in their class to help children develop gross motor skills.

Reasons to Build a Network

Linda Jones, TxP2P Texas Network Connections

In our last issue, we introduced Texas Network Connections, a service provided by TxP2P that provides trained facilitators to help parents and people with disabilities establish a personal support network. A network is a group of committed individuals who meet 2-4 times a year to be the intentional community of caring that supports a person with a disability as they live and age in their community.

So what does it take to start a personal network? Basically, it takes a decision to get started. Here are 10 reasons why you should:

- Establishing a fully functional network takes time (2+ years) and the sooner you get started, the better.
- Having a network gives others an opportunity to enjoy the benefits of knowing your child.
- You can never tell when you might really need the support of a network and there is no sense in waiting for a crisis.
- Starting a network will assist you in envisioning a positive future for your child.
- Having a network lets others clearly know what you want for your child.
- Having a network brings peace of mind to families.
- Having a network will expand your child’s circle of friends and is an antidote to isolation.
- Social ties are necessary for good health.
- There is a do-it-yourself manual on the TxP2P website, and staff are available to help you.
- Starting a network is one more thing you can check off your to do list!

In summary - just do it!!

If you are interested in exploring more information about networks, please refer to our section on the TxP2P website http://www.txp2p.org/parents/TexasNetworkConnections.html or call Linda Jones, our consultant who works on networks, at 512-659-8682.
Public school is the last mandated service that a student with a disability can access. After graduation, a person must apply to get services and supports and prove eligibility through income as well as disability. Public school is the last opportunity for free education, with a wide range of modifications and a requirement for parent input. Make the most of public school services as you plan for your youth’s transition to adulthood. Here are a few ideas to consider while you and your youth plan in the school setting:

- **Create a vision for the future.** Ask for a planning session at school to discuss your youth’s future. Many districts have planning tools and interest/vocational inventories in place to help with this process. Invite your youth, family, and friends, as well as relevant school staff, to your planning meeting. Be sure that you are clear on when your youth will graduate (ask staff to explain graduation options) and that your youth has a voice at the meeting. [http://www.transitionintexas.org/Page/115](http://www.transitionintexas.org/Page/115) (Zoom in, print is very small)

- **Build a team with school staff.** Find those people at your school and in your district who are knowledgeable and passionate about transition. These staff members might be teachers, administrators, family support personnel, job support personnel, or even related services providers. Also, note that every school district must designate a TED, a Transition and Employment Designee; get to know that person in your district. You can find your TED at [http://framework.esc18.net/display/Webforms/ESC18-FW-CountyInformation.aspx?ID=Transition](http://framework.esc18.net/display/Webforms/ESC18-FW-CountyInformation.aspx?ID=Transition) (LEA = your school district)

- **Know what IDEA says about transition.** Transition services as outlined in $300.43 of IDEA means a coordinated set of activities for a child with a disability that...

1. Is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child’s movement from school to post-school activities, including postsecondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation;
2. And is based on the individual child’s needs, taking into account the child’s strengths, preferences, and interests; and includes:
   - Instruction
   - Related services
   - Community experiences
   - The development of employment and other post-school adult living objectives
   - If appropriate, acquisition of daily living skills and provision of a functional vocational evaluation.


- **Be sure your youth is involved as much as possible in the decision-making process and has input into all planning.** Your son or daughter can learn how to be involved in the ARD/IEP process so that eventually he or she can perhaps lead the ARD meeting and help write goals, or at least be an active participant. Students who are less verbal can provide input through a communication device. The ARD meeting is a perfect opportunity for your youth to develop self-advocacy skills. For more information, Google student-led ARDs (for Texas examples) and student-led IEP meetings (for examples outside Texas). Another great website: [www.imdetermined.org](http://www.imdetermined.org)

- **Be sure that your youth is gaining vocational skills and experience.** Ideally, transition services include training and work experience on-campus and off-campus, and if appropriate, paid employment by graduation. Your school district can bring in a Texas Workforce Commission (TWC) transition specialist by age 14 to support vocational exploration and training. (Note: DARS is now TWC.) [http://www.twc.state.tx.us/jobseekers/vocational-rehabilitation-youth-students](http://www.twc.state.tx.us/jobseekers/vocational-rehabilitation-youth-students)

- **Help the school staff to connect with businesses and non-profits in the community where students can find work experience.** Remember that transportation may be an important factor after graduation; make sure that work opportunities are located in the community where your youth can access them (car, bus, carpool, other) when the school can no longer provide transportation. [https://www.txp2p.org/services/services-for-parents-pathway-to-adulthood-life-after-graduation](https://www.txp2p.org/services/services-for-parents-pathway-to-adulthood-life-after-graduation)

- **If your youth will stay in school after age 18,** find out what your school district provides for students between ages 18 and 22. Be sure that any 18+ program is truly focused on what a person will do after graduation, not just a re-hash of what he or she has been doing for the last 4 years of high school. Use this opportunity so that your youth is ready for the first day after graduation. **NOTE:** Students who receive modified content in at least one course for state graduation credit are eligible to continue for services after meeting credit and assessment requirements for graduation. Ask your ARD committee when eligibility for FAPE (free and appropriate public education) will end. [http://www4.esc13.net/18-plus](http://www4.esc13.net/18-plus) If your youth did not receive any modifications in course work, he or she will not be eligible for an 18+ program.

*Continued on page 7*
Families frequently use UHCCF grants to help pay for treatments associated with medical conditions such as cancer, spina bifida, muscular dystrophy, diabetes, hearing loss, autism, cystic fibrosis, Down syndrome, ADHD and cerebral palsy. For example, families have used grants for physical, occupational and speech therapy, counseling services, surgeries, prescriptions, wheelchairs, orthotics, eyeglasses and hearing aids. To be eligible for a grant, a child must be 16 years of age or younger. Families must meet economic guidelines, reside in the United States and have a commercial health insurance plan. Grants are available for medical expenses families have incurred 60 days prior to the date of application as well as for ongoing and future medical needs. Families do not need to have insurance through United HealthCare to be eligible. Parents or legal guardians are encouraged to apply today at www.UHCCF.org.

Thank you to our Conference Sponsors of 2017!

Child Medical Grants are Available from the United Healthcare Children's Foundation

Families in need of financial assistance for child medical care costs are encouraged to apply today for a United Healthcare Children’s Foundation (UHCCF) grant. Qualifying families can receive up to $5,000 per grant, with a lifetime maximum of $10,000 per child, to help pay for their child’s health care treatments, services, or equipment not covered, or not fully covered, by their commercial health insurance plan. Families frequently use UHCCF grants to help pay for treatments associated with medical conditions such as cancer, spina bifida, muscular dystrophy, diabetes, hearing loss, autism, cystic fibrosis, Down syndrome, ADHD and cerebral palsy. For example, families have used grants for physical, occupational and speech therapy, counseling services, surgeries, prescriptions, wheelchairs, orthotics, eyeglasses and hearing aids. To be eligible for a grant, a child must be 16 years of age or younger. Families must meet economic guidelines, reside in the United States and have a commercial health insurance plan. Grants are available for medical expenses families have incurred 60 days prior to the date of application as well as for ongoing and future medical needs. Families do not need to have insurance through United HealthCare to be eligible. Parents or legal guardians are encouraged to apply today at www.UHCCF.org.
## Conference Schedule

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<td>Oct. 5-6, 2017</td>
<td>Baylor College of Medicine’s 18th Annual Chronic Illness &amp; Disability Conference</td>
<td>Houston</td>
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<td>Nov. 3, 2017</td>
<td>East Texas Transition Conference Door to the Future</td>
<td>Palestine</td>
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<td>Inclusion Works</td>
<td>San Antonio</td>
<td><a href="http://www.theartoftexas.org/events">www.theartoftexas.org/events</a></td>
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