

TxP2P Update

Laura J. Warren, TxP2P Staff

TxP2P is proud to announce the launch of a new website for parents of children with disabilities or special health care needs: **Navigate Life Texas!** NavigateLifeTexas.org was built for anyone who needs to find relevant, comprehensive, and accurate information about services in Texas for children with disabilities and/or special health care needs. The site was designed by parents for parents, but it's also a valuable resource for caregivers, clinicians, professionals, and support groups. A Spanish version of the site can be found at www.avancemosJuntosTexas.org. The Spanish version was translated by native Spanish speakers.

The website was created by the Interagency Task Force for Children with Special Needs and funded through TX Health and Human Services Commission. The website was developed by Trademark Media and TxP2P served as one of several sub-contractors to provide a parent voice over the past 1- 1/2 years. Creating the website has been a project that we are passionate about and we want to share it with everyone. TxP2P edited the content, hired 20 Regional Partners to locate and vet resources for use on the website, and served as a team member in decision making for the site. Be sure to check out the Regional Pages: <https://www.navigatelifetexas.org/en/regions>

We encourage everyone to utilize this resource and share with friends and others who may benefit from the site!

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TxP2P Regional Conferences: What's Ahead

Jeanine Pinner, TxP2P Staff

So, the kids are back in school... what's next? Can you use a couple of resources that will help you ensure your kids get what they need to live their best lives? Yes? Then you've come to the right place!

If you live in the **Coastal Bend** or **Rio Grande Valley** areas, be sure to register for the **3rd Annual Empowering Tools Conference (ET3)**. ET3 takes place on Saturday, October 10, 2015, at the Port Isabel Junior High School, 17001 Highway 100, Port Isabel. Texas Parent to Parent is partnering with **Point Isabel ISD** and **Region 1 Education Service Center** to bring you the 3rd Annual Empowering Tools Conference.

ET3 offers a wide variety of breakout sessions and an opportunity to network with vendors from local and state organizations, in addition to visiting with other parents and family members. Child care is available to those who register. There is no charge to attend the conference or for child care, but registration is required. Check the TxP2P website at <http://www.txp2p.org/> for developing information on the conference, to register to attend, or to register as a vendor. Register now for the 3rd Annual Empowering Tools Conference at <http://www.txp2p.org/training/registerfortraining.html>. Registration closes on the internet on Friday, September 26, 2015, but you can register at the door - we won't be able to provide child care at that point but you can still attend the conference.

Look out, **East Texas** – here we come! All right – northeast Texas here we come! We've targeted Tyler as the location for our 3rd one-day regional conference. TxP2P is partnering with the **Palestine Resource Center for Independent Living** (<http://www.palestineresourcecenter.org/>) and **Community Now!** (<http://communitynowfreedom.org/>) for our 3rd and newest one-day regional conference for families of children with disabilities and the professionals who work with them. We have tentatively scheduled this conference for February 2016, so it's just around the corner. Can you help us by (1) getting the word out to families, educators, service providers and other organizations, and (2) finding a location where we can "grow" this annual conference? Do you have any suggestions for a name for it?

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We're going to need your help getting speakers, vendors for the resource fair and more, too, so don't be shy! Email me at jeanine@txp2p.org or call me at 512-217-3558 with your suggestions – I'd love to hear from you! Visit the TxP2P website often for updates to this developing conference!

Many of you in the **DFW** area already know that the **Living with Disability Conference (LWD)** is an awesome event. But, for those of you who aren't familiar with LWD, let me tell you a little about it. First, our amazing partners: 2016 will be the 4th year for the Living with Disability Conference and TxP2P has had the privilege of working with **Community Now!** and **The Arc of Northeast Tarrant County** (<http://www.arcnetc.org/>) to bring this conference to families and professionals in the Dallas/Fort Worth area since it began. The 3rd Annual Living with Disability Conference (LWD3) took place in Hurst at the First Baptist Church on Saturday, February 21, 2015. More than 200 people attended and there were 50 exhibitors and sponsors sharing valuable information about resources for children with disabilities. We have a tentative

April date for the **4th Annual Living with Disability Conference (LWD4)** and will post the information on the TxP2P website as it becomes available, so visit our website often!



Last, but not least...you DO know about the **Navigate Life Texas** (<https://www.navigatelife.texas.org/en>) website, right???

TxP2P has been excited to work as part of the Navigate Life Texas website team for the past couple of years. This amazing website provides information & resources for kids with disabilities and special health care needs. Are you looking for information on diagnosis & healthcare, insurance, family support, education or transition? Parent or self-advocate groups in your area? How about events like conferences, walks, webinars, social events, meet-up groups, online support or workshops?

Navigate Life Texas strives to be a

“one-stop” website that brings the information to you and provides a way to narrow your search for a variety of resources based on distance, county or type of resource. Take a look at NLT’s page on Regions to locate your region. Search for resources on the Find Services, Groups and Events page. Suggest a Service, Group (can be a parent group, self-advocate group, etc.) or an Event if you don’t find it on the Navigate Life Texas website and we’ll check it out! If there’s a resource that you think should be included on NLT, Suggest a Resource to let us know. Contact us (email jeanine@txp2p.org) if there’s anything on your mind about Navigate Life Texas that we can help with or something we should know about a resource on the website. Or is you have a topic that you think is missing, please email Laura@txp2p.org with your ideas. We will be working to add new pages and videos soon. We look forward to hearing from you!

Hopefully, these resources will provide you with the information you're seeking. And, don't forget that you can call us (866-896-6001) or check out the TxP2P website for more support or information! I look forward to seeing you at one of our regional conferences soon!

LISTSERV NOTICE: We have a new listserv - TxP2P Cerebral Palsy Listserv!

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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Texas Offers Community First Choice (CFC) to Medicaid Recipients with Disabilities

Article by Community for Permanent Supported Housing

On 6/1/15, the State of Texas started offering Community First Choice (CFC), which allows Texas to provide home & community-based supports and attendant services and to Medicaid recipients with disabilities.

If an individual is **currently receiving Medicaid Waiver services** (HCS, TxHmL, CLASS, or DBMD) and the individual needs other supports, it may be possible to receive additional services using CFC. The individual's current Medicaid Waiver provider will provide services under CFC. **Contact your provider** to learn more about CFC.

If an individual is on a **Medicaid Waiver Interest List**, it may be possible to receive CFC services through a Managed Care Organization. The individual WILL NOT be removed from the Interest List even though they receive CFC services. To find out about CFC if the individual is on an interest list, call **855-937-2372**. ([Website](#):

<http://www.dads.state.tx.us/care/index.html>)

If an individual is NOT on an Interest List, go to: (<http://easychurchmedia.com/medicaidwaiver/interest-lists/>) .

To qualify for CFC, an individual must receive Medicaid. The individual may also participate in a functional assessment to determine the support required. Overnight care support for a person living independently is determined by the functional assessment.

The four services CFC offers are Habilitation, Personal Assistance Services (PAS), Emergency Response Services (ERS), and support management (voluntary training on how to select, manage, and train attendants). All services are discussed in the DADS and HHSC Frequently Asked Questions (FAQs), recently posted on the following sites. These documents will continue

to be updated:

- DADS FAQs: <http://www.dads.state.tx.us/providers/cfc/cfcfaqs.pdf>
- HHSC FAQs: <http://www.hhsc.state.tx.us/medicaid/managed-care/community-first-choice/docs/cfc-faqs.pdf>

Other Important links:

- [CFC Presentation \(http://www.hhsc.state.tx.us/medicaid/managed-care/community-first-choice/cfco.pdf\)](http://www.hhsc.state.tx.us/medicaid/managed-care/community-first-choice/cfco.pdf)
- [Texas Department of Aging and Disabilities Services CFC](#)
- (<http://www.dads.state.tx.us/providers/CFC/index.cfm>)
- [Texas Health and Human Services CFC \(http://www.hhsc.state.tx.us/medicaid/managed-care/community-first-choice/\)](http://www.hhsc.state.tx.us/medicaid/managed-care/community-first-choice/)

Looking for the Best School Placement

Rosalba Calleros, TxP2P Staff

I still remember the anxiety I felt when Alan started school 13 years ago. I didn't know if the school personnel would take good care of him, if he was ready for school or even if he would do well on the school bus. He was only 3 years old and he was leaving my side for the very first time. He was not only too young to be out there "by himself" with people that he was not familiar with but his medical needs were too many: g-tube, constant aspiration, seizures, weak immune system, incontinence, etc. In addition, he had to ride on the bus to school in his first wheelchair. I was not ready for the idea of him needing a wheelchair and I was positive he was just about to start walking anytime! Those first years were very overwhelming. I



had too many mixed feelings; I did not know how the system worked but at the same time I was grateful for having all those professionals providing services to my child. So, as they were the experts, I just let them do their job.

Just after his second ARD, I started wondering if what he was getting was the only option we really had. My curiosity told me to start talking to other parents, attend different parent support groups and educating myself. Soon, I understood more about special education, my active role as a mom and the importance of having a good communication with school professionals. So, after learning about the Free Appropriate Public Education (FAPE), the Least Restrictive Environment (LRE) provisions and spending two years in PPCD, I knew we needed to explore new horizons in a regular class. I understood that my son's needs would change over time and so

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would the plan we needed to follow. I prepared myself and talked to the committee about it and Alan started attending a regular class in kindergarten.

Even though I knew that Alan could benefit from being around his typically developing peers, that year didn't go well. At the end, I realized that I didn't take the time to learn about his other options or his current needs but I was just moved by the excitement of putting into practice what I had learned about educating children with disabilities in the regular curriculum. I then understood that I needed to get more information about the different options available, including the committee's recommendations and my son's current educational needs.

After taking the time to study all these factors, Alan went back to a self-contained class with a wonderful teacher who taught him to read and write. She prepared him for eventual inclusion in a regular classes by providing a strong base in order to succeed in

school. When Alan was just about to finish 5th grade, we called an ARD to discuss placing him in a regular classroom.

This time was different than when he was in kindergarten. Now we were making a more informed decision. I knew more about his different options. He had more tools to succeed in the regular curriculum and I had an open communication with the school personnel by making sure we were addressing his current educational needs. It was not about what I wanted for him; it was more about what he needed at that time. So, he started attending regular classes in 6th grade.

Today, Alan is a Junior in High School and attends regular classes with supports. I have learned that the perfect placement doesn't come in a recipe. It doesn't matter if a student attends a self-contained class, inclusion or a regular setting. The most important thing is to keep in mind the child's specific educational needs in a very specific timeframe.

When I look back, I realize that right now my child has very different needs than when he started attending school at the age of three. His educational needs have not stayed static and I cannot say that his education has been smooth and easy all the time. Having him attending regular classes brings a lot of challenges and lots of work. We have found people that hesitate about his ability to succeed but we have found more people with a positive attitude that believe in him and keep helping him reach his highest potential. His most recent accomplishment has been receiving the Trustee's Scholar Award for being within the 10% of the class ranking. Of course, this would've never happened without the help of all those professionals that have focused more on his attributes than his disability in all the settings that he has been through.

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:

Chase Menn *grandson of Darlene and Russell Menn*

Salaya Leal, *daughter of Tina Leal*

With deepest sympathy,

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



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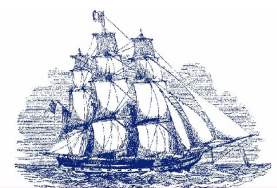
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Good nutrition is important for everyone, but VERY important for infants and toddlers. That's because good nutrition is needed for babies to be healthy, develop strong immune systems, healthy body functions, and new brain cells. Good nutrition is required for babies to achieve developmental milestones.

Providing needed nutrition is basic. Providing loving and responsive feeding gives babies the ideal environment for meeting nutritional needs, and also basic social and emotional needs. Meal times can be a special time for emotional bonding between families, children, and caregivers. Caregivers can lay the foundations of positive, stable, safe, and secure relationships during meal times.

Babies benefit from being held during bottle feeding, even when



they are able to hold their own bottles. Bottle feeding is a wonderful opportunity for eye contact, loving touch, and a soothing voice. Maybe even a song or two. As a baby gets older, a quick tickle can add laughter and joy to feeding time.

By 4-6 months babies can begin eating soft, semi-solid foods. Soon after that they take an interest in what other people are eating and drinking. As their fine motor skills develop they learn to bring food to their mouths, and sometimes get it in! They also learn to hold and drink from an open cup. This is a

messy time, so a good supply of bibs will come in handy.

Self-feeding is an important developmental milestone. Another step in this process is dropping food, bowls, spoons and cups on the floor. Again, messy, but developmentally appropriate. In spite of how it may seem, they don't do this to make you angry or give you more work, it's just a part of how they learn. A tarp or towel under the high chair can make clean up easier.

Common Feeding Problems

Sometimes, even when you do everything right, a baby or toddler will experience feeding problems. It is estimated that 25% of children will experience some type of feeding problem.

Here is a list of things that might indicate a little one is experiencing feeding difficulties:

- Difficulty sucking, swallowing, or chewing
- Vomiting, reflux and excessive drooling and/or colic
- Partial or total food refusal
- Picky eater
- Inability to try to eat foods with more texture
- Delay in self feeding
- Little to no weight gain
- Tantrums in and around meal times

Posture and seating are often overlooked and can impact a child's successful feeding. An upright posture with a well-supported head, neck and trunk can help with swallowing. The head and neck should be tilted forward (flexed) slightly with the chin bent towards the chest so the head does not tilt backwards during feeding and swallowing. This ensures that food/fluids do not enter into the respiratory tracts.

Things You Can Do

Be alert and write down any reflux, frequent and/or large volumes of spitting and/or vomiting patterns and contact your child's pediatrician if these symptoms persist.

Encourage self-feeding by allowing your toddler to pick up food and hold a spoon while eating and make note of any pickiness, delays in self-feeding, refusal to eat and tantrums during meal times.

If you suspect your child is experiencing feeding difficulties, a referral to ECI may be appropriate. Early Childhood Intervention (ECI) services can assist your family with gaining the knowledge and skills to support you and your child with these difficulties.

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

For additional information please visit the websites listed below:

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2851259/>
<http://www.nal.usda.gov/fnic/pubs/bibs/gen/infnut.pdf>



Frequently Asked Questions on Transition: Guardianship, SSI, SSDI

Pathways to Adulthood Staff

We have compiled a list of the transition areas where we get the most questions, with answers in a FAQ format. Hope it helps; we'd be glad to hear from you about other areas that would be helpful.

Guardianship and Alternatives

For more information, go to <http://txp2p.org/parents/pathwaysFinance.html#ptaFinance>

What is guardianship?

Guardianship is the legal tool for becoming the spokesperson and decision maker for someone who is not able to exercise their own legal rights and responsibilities after age 18.



How do I decide whether or not my child needs a guardian?

This is a difficult decision and one not to rush. Think about the skills you need to live in our society, then consider if your child has those skills or might acquire them or even function with some help given informally. If not, then explore the guardianship option. Also note that the process can be costly.

What are alternatives to guardianship?

Options are Power of Attorney, Supported Decision Making, Representative Payee for SSI, HIPAA form for medical providers; you can also get limited guardianship instead of full guardianship if your child can do some things for himself, but needs your authority for other areas.

When do I start getting ready for guardianship?

You are your child's natural legal guardian until the day they turn 18, so you can't do it before that day. Since the

documents required for the process must be relatively recent, start by the time your child is 17.5, giving yourself plenty of time to find a lawyer and prepare to go before the Probate Court judge.

What if I don't get guardianship right away when my child turns 18?

At age 18, your child gains all the legal rights of any adult in our society. If your child needs some help with decision making, you may be able to help them make decisions by training and coaching from the sidelines. Even if your child does need more help, an occasion when you will need authority to make decisions may not arise right away. Do note that schools will turn to your child for a signature on the IEP if you do nothing after they turn 18. To learn about legal authority required in particular situations, talk to your physicians, school staff, and attorneys familiar with the guardianship process

SSI (Supplemental Security Income)

For more information, go to <http://txp2p.org/parents/pathwaysServices.html#ptaServSSI>

pathwaysServices.html#ptaServSSI

What is SSI? SSI is federal funding for people who are elderly or blind or have disabilities. It is a monthly payment between approximately \$480 and \$730/month and leads automatically to receiving Medicaid.

When should I apply for my 18 year old?

Before your child is 18, Social Security looks at family income and resources; after age 18, they consider **only your child's income and resources**. Technically, you could apply the day he turns 18, but it might be wise to wait a month to make sure SSA is looking only at your child's assets and income. If your child received SSI before age 18 based on family income and assets, he will have to reapply at age 18.

What are the limits for resources

to be eligible for all state/federal funding (SSI, Medicaid, and Medicaid Waivers)? Your child (at age 18) must have no more than \$2000 in their name; this rule applies to ready assets, such as checking and savings accounts, trusts, and investment accounts.

Are there limits on income to be eligible for state/federal funding (SSI, Medicaid, and Medicaid Waivers)?

Yes, there are income limits. This amount varies by program and circumstances. Note the difference between earned income (from a job or self-employment) and unearned income (from state and federal funding sources). The maximum unearned income is about \$730 per month in many cases, adjusted annually. There are different limits for earned income. Check with the SSA office on the specific limits for your child

Can my child earn income and still get SSI?

Yes, however, earned income will decrease the amount of SSI received each month and there is an income threshold.

What should I do if my child gets turned down for SSI?

Appeal and be sure to send in your appeal paperwork within the stated time frame. Your SSI determination letter should tell you how to appeal. There are also professionals who help applicants appeal SSI decisions.

Can your child apply for SSI while still in school?

Yes, but be sure to put this fact on the application and bring it up at the interview. This applies to applicants between ages 18 and 22 who are regularly attending school.

How can I save more than \$2000 for my child's present and future and keep him eligible for Medicaid-based services?

Ask an estate planning professional or attorney about setting up

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a Special Needs Trust, which enables you to save more than \$2000 but not in your child's name. Also, new federal legislation, the ABLE Act, establishes a way to save more money in a person's name while remaining eligible for public funding. Stay tuned as Texas sets the regulations for ABLE accounts.

SSDI (Social Security Disability Insurance)

For more information, go to <http://txp2p.org/parents/pathwaysServices.html#ptaServSSDI>

What is SSDI? SSDI is federal funding based on someone's work history, either the parent's work history or the work history of a person with a disability.

What happens when my spouse or I retire? When you (the parent) apply for Social Security, check the DAC (Disabled Adult Child) box in the application. Your child will start to receive SSDI benefits, which amount to half the SS

amount you will be drawing down. They will also receive Medicare 24 months after starting to receive SSDI.

What happens if my child's SSDI income exceeds the limits for Medicaid eligibility? SSDI counts as unearned income; if the amount exceeds about \$730 unearned income/month, it may disqualify your child for Medicaid and the services based on Medicaid eligibility. There is a way to receive higher unearned income and still remain eligible for Medicaid; talk to your SS office and refer to Section 1634(c) of SS Act.

What happens when my child earns income that exceeds the limits to be eligible for Medicaid? If your child works and their earned income is high enough to cause their SSI payments to stop, they can claim 1619(b) of the Social Security Act which allows them to continue to work and remain eligible for Medicaid. (Income thresholds change

annually—see Social Security Online—Continued Medicaid Eligibility.) Keep in mind that waiver programs such as CLASS and HCS have their own income limits as well.

Be aware that once your child is employed, they will be earning work credits which will eventually move them from SSI to SSDI based on their own work history. An important consideration is they will no longer receive Medicaid but will start to receive Medicare in 24 months. There is a way to reinstate Medicaid if they are already on a waiver program. The provider of the Medicaid waiver can assist with the application process. Medicaid eligibility must be maintained to continue receiving waiver services.

Can you have Medicare and Medicaid at the same time? Yes, they work together very well. Your child will be a “dual eligible beneficiary” and may have access to additional benefits.

What If It Happens to You?

What if you went away for a long weekend to a family wedding and before you came home, your home was destroyed? When Hurricane Katrina hit, this happened to one of the families I talked to shortly after the storm. She and her family were in Dallas, had a child with significant disabilities, and were basically homeless. She was very concerned about her child's medications and supplies – where would they be delivered? She no longer had a mail box or home for deliveries. She didn't leave with enough supplies for more than the 5 days she was supposed to be gone. Now what?

A friend called me during December after the fires destroyed much of Bastrop the first of September in 2011. She and her son were evacuated for over 6 weeks to live in a church. When they finally returned home, there was so much smoke residue and mold, her son quickly

developed pneumonia and wound up in the hospital. When she called me at the end of December, they were still not home – they spent a long time in the hospital because he developed MRSA and was sent to a nursing home. He was re-infected numerous times at the nursing home and she was desperate to get him home.

WHAT IF your home is destroyed while you are at work and your kids are at school? That happened with the Bastrop fires and can happen should a tornado hit. Are you prepared? Does your family have a plan in case of emergency when you are home? Have you ever talked about an evacuation plan from your home? What about how to get back together if you are all at work, school, daycare, or wherever, when an emergency hits? Cell phone towers might be out in the area – what would you do?

It might feel silly to discuss this with your family and it might feel

silly to practice it, but after experiencing the phone calls we got after Katrina, it no longer seems silly to us. TxP2P urges you to develop plans for all the circumstances you could find yourself in and discuss them with your family.

The Department of State Health Services (DSHS) Children with Special Health Care Needs Program (CSHCN) has a webpage with some terrific information on it (<https://www.dshs.state.tx.us/>) There are questions and forms you can use to make a plan for your family, including what to put in an emergency kit. Check it out! Navigate Life Texas (www.navigatelifetexas.org) also has a webpage for emergency preparedness. They include tips for helping your child understand the disaster/trauma after the emergency as well. So, what if this happens to you? Do you want to be prepared? I know I do!

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Conference Schedule

Date	Conference Title	Location	Registration Information
October 10, 2015	9th Annual TXFX Fall Festival & Dance	Carrollton	www.txfx.org
October 10, 2015	3rd Annual Empowering Tool Conference	Port Isabel	www.txp2p.org
October 17, 2015	Annual InKidAble Conference	Belton	Contact Molly Clark mclark@special-children.org
November 7, 2015	Healing with Heart Caregivers Seminar	Houston	Contact Robin.spidell@bcm.edu