



TxP2P Update

Laura J. Warren, TxP2P Staff

Over the past 14 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. Since 2002, TxP2P has been empowering families through parent-to-parent networking, education, and information. All our work takes funding and this is the time of year when we ask for your end of year donation (if you have any funds to make donations – if not, please take care of your own family first).

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 14 years and has built a solid foundation of support for families raising a child who has a disability. Now, as we enter 2016, TxP2P needs to focus on the sustainability of this non-profit organization to ensure that it will be around to meet the needs of more Texas families raising a child with a disability, chronic illness, or other special health care need.

We are very sad to announce that Jeanine Pinner has made a decision to go back to the federal workforce and leave TxP2P as of December 11th. We will miss her and her enthusiasm, knowledge, and hard working attitude. Thank you Jeanine, for all you have done in the past 10 years to move TxP2P forward!

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Inside this issue:
♥Around the State: Supported Decision Making: A New Alternative to Guardianship, page 2
♥Around the State: ECI— Strategies to Help Guide Better Behavior, page 3-4
♥In Memoriam - page 4
♥Around the State: BridgingApps— Technology Ideas, page 5
♥Frequently Asked Questions on Transition: Medicaid Waivers and related programs, page 6-7
♥Around the State: Access to Health Care through the Marketplace, page 7

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



New Ideas That Can Change the World

Linda Litzinger, TxP2P Staff

This is a thankful time of year! What comes to mind, for me, are our parents who have new ideas that can change our world. For example, we have an advocate (a father) wanting Texas to place a minimum of 3 questions about special education on the state teachers’ exam for a regular education degree. At our Texas colleges and universities, the regular education track would thus delve farther into special education topics. Future educators in regular education would be better prepared for having students with IEPs in their classrooms. This one change in the state exam would change the curriculum. Bingo!



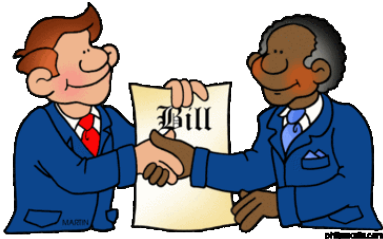
It’s so brilliant!

What is the next step for our parents and their self-advocate sons or daughters with a new idea? It is to find a Texas legislator to write your idea into a bill. Legislators each have a format for submitting a new idea to them. I can help you discover this format. Typically, they want to know what it might cost, what other states are doing about it, who would support the idea, who would not, has it ever become a bill before, and if so, what was the bill's wording and what caused it to not make it into law.

Now is a good time in this process for doing this research and making the ‘ask’. This summer, legislators will be asking the Legislative Council to draft their bills, in anticipation of a January 2017 session. Now is also a good time to gather other parents who want to

help and to contact other organizations who might support the cause.

If you are thinking about a new idea or some needed funding, please do not hesitate to contact me. I’d love to hear from you and work with you through this process. Your agenda is mine as well! Here is my contact information:



Linda.Litzinger@txp2p.org
or my cell is 512-922-3810.

to Guardianship

Megan Morgan, Policy Fellow for The Arc of Texas

During the most recent legislative session, Texas made history by becoming the first state to legally recognize supported decision-making as an alternative to guardianship for adults with disabilities. At the heart of supported decision-making is a simple premise: all people use help to make important life decisions. Supported decision-making allows individuals to make their own decisions and stay in charge of their lives, while receiving any support they need to do so. To use a supported decision-making agreement, a person with a disability chooses an adult they trust to serve as their supporter. This may be someone like a parent, friend, or former teacher. It is important to know that the supporter cannot make a decision *for* the person with a disability. The supporter can, however, help the person with a disability understand the options, responsibilities, and consequences of their decisions. The supporter can also help the person obtain and understand information relevant to their decisions and communicate their decisions to the appropriate people.

After an individual with a disability asks someone to be their supporter, they should explain to the supporter what types of decisions they need help making. When both parties feel ready, they will fill out a written plan called a supported decision-making agreement, which explains what decisions the supporter can help with and what information the supporter can access. Doctors, service providers, educators, and others are legally required to accept



the agreement. This means that if the person with a disability so desires, his or her supporter can do things like talk to doctors about private medical information, discuss service coordination with providers, and participate in Individualized Education Plan (IEP) meetings. Supported decision-making agreements are an excellent self-

advocacy tool that people with disabilities can use to make their own decisions while having the support they need.

Through legally recognizing supported decision-making as an alternative to guardianship, Texas is providing individuals with disabilities and their families with another option to consider as individuals transition into adulthood.

To download a blank supported decision-making agreement form, please visit The Arc of Texas website at <http://bit.ly/1NuTCYE>

For more information on supported decision-making, visit the websites below. You may also contact Megan Morgan, [Policy Fellow for The Arc of Texas](#), at mmorgan@thearcoftexas.org or 1-800-252-9729 ext. 7753.

National Resource Center for
Supported Decision-Making
[http://
supporteddecisionmaking.org/](http://supporteddecisionmaking.org/)

Texas Guardianship Reform and
Supported Decision Making
www.grsdm.org

LISTSERV NOTICE: Yahoo Groups will no longer allow us to “add” people to our listservs - we can only invite you to join. Unfortunately, many of our invitations go into spam and you never see them. Another way to join the listservs is to send an email to the moderator and ask to subscribe. Contact Susan.Prior@txp2p.org if you want to join the any of the following: Advocacy, ADD/ADHD, Autism, Bipolar, Cerebral Palsy, Dad’s, Dyslexia, ECI, Homeschoolers, Medical Home, Medicaid Waiver, Mental Health, NICU, Rare & Undiagnosed, Spanish, Transition, Traumatic Brain Injury, or local area Listservs (Amarillo, Austin, Bryan/College Station, Coastal Bend/Corpus Christi, Dallas/Ft. Worth, El Paso, Houston, San Antonio, San Marcos, Rio Grande Valley, & Waco/Temple). If you want to moderate a local listserv for your area, we’d love to set up more local groups. Contact Laura at Laura@txp2p.org to discuss moderating one for us.

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Challenging behavior rears its head in many ways. Screaming, throwing things, biting, head banging, pinching, and refusal to do daily activities are just a few examples of challenging behavior one might be dealing with. One of the best ways to deal with negative behaviors is to implement strategies before your child has lost control to help guide better behavior and prevent challenging behavior. These strategies should be used regularly to help set routines and patterns of expectation that let your child know what to expect.

Maintain routines. Having general routines helps you and your child know what to expect from your day. Routines also give children a sense of comfort and stability and can be a great time to reconnect with your child, for instance, making snuggling part of the bedtime routine. Routines can be looked at from a daily perspective. For instance, a routine might include waking up, getting ready for school, going to school, going to physical therapy, coming home and eating dinner, having quiet time, and going to bed. Routines can also be broken down into smaller segments: getting ready for school might consist of getting dressed, eating breakfast, brushing teeth, combing hair, and gathering any tools or resources needed for school. When there is going to be a change in routine, letting your child know in advance, when possible, can help her cope with the change. This can be done by talking about the change or showing a visual to illustrate the change, for example, showing a picture of grandma and talking about her coming to visit before she arrives. Routines should be specific to your child's and family's individual needs.

Use transition warnings. To decrease challenging behavior, plan your schedule to build time into your activities for transitioning. Many children have a difficult time stopping their activities to move on to another one, especially if they don't feel like they are done with the activity. Let your child know it's almost time to stop and move on to the next activity. Sometimes it helps to use a visual from the next activity to show what is next. For example, as you transition to another activity you may give your

child a familiar bath toy for bath time or a plate for mealtime. Give your child time for an activity to wind down or allow them to finish an activity, if possible. It can be helpful to have a basket for "in progress activities" to put things in if your child isn't finished, but remember to consistently come back to the basket and activity for this strategy to work.

Try to avoid challenging situations. **Plan your day and activities to occur when your child is not hungry, tired, or overwhelmed.** This strategy seems pretty obvious, but as adults, we have a lot to accomplish and we sometimes wonder if we can fit in one more activity or errand, and sometimes the answer is "no," not peacefully at least! The answer, alternatively, could be that the extra errand or activity can come after a snack, a nap, or a sensory break where your child can get away from the noise, lights, and activities to recharge.

Learn your child's cues for needing help. Kids often give us behavioral cues before they lose control and engage in challenging behavior. Common cues are whining, rocking, getting louder, and becoming tense. If you are fortunate enough to receive these cues, you have an opportunity to intervene by talking softly to your child, showing empathy, offering a suggestion of what he can constructively do with his feelings, implementing a sensory calming strategy, or changing the environment.

Use clear language to direct your child. One of the best ways to see a decrease in challenging behavior is to teach better behavior. A way to do this is to tell your child what behavior you would like to see. Instead of "don't bite your arm," you can say, "if you need to bite, use your chew tube." A more positive way to say, "don't hit," could be "use your words/signs/communication device to let me know what you need." You could also show a child what better behavior would look like by modeling the behavior yourself, using stuffed animals or puppets to

act out the behavior, or reading children's books about behavior together.

Reinforce positive behavior. Children will continue to do what is reinforced. If they are able to get what they want using negative behavior, they will continue to use that behavior. For example, if screaming in the store results in getting candy or a toy so he'll be quiet, the screaming will continue. If asking nicely results in a treat, you are more likely to see him use his words to ask for things he wants. It is often easier to give the negative behavior more attention because it's more noticeable, so it takes effort to catch the good behavior. If you have made suggestions on a better way he can get what he wants, make sure this new, more positive behavior works and that you make efforts to notice the new behavior – or he will decide the negative behavior is more effective! Try to notice when your child does something nice or handles her frustration well and tell her how proud you are of her. Children love to please their parents.

Offer choices throughout the day. A great strategy for helping children feel important and independent is letting them choose items and activities in their daily lives. Even getting to choose small, seemingly irrelevant things like water or milk, red shirt or blue shirt, bath first or books first, or which fruit to eat, can help your child feel more in control of her daily life. Feeling more in control over time can translate to better behavior. Offering choices when your child is showing signs he's about to lose control can also be helpful. Examples of some possible choices are, "I can see you are getting overwhelmed. Would you like to put your headphones on for five minutes or sit in your quiet place for five minutes?" or "I see you're having a hard time putting your shoes on. Do you want help or do you want to keep trying?" Note that in each situation, only two choices were given. It's important to keep choices to a minimum when children are upset, since too many options can contribute to feeling overwhelmed.

Continued on page 4

Red flags. Below is a list of behaviors or red flags that can keep your child from learning. If they happen often, contact Early Childhood Intervention (ECI) for help with social-emotional development. To find a local ECI program in your area, call the DARS Inquiries Line at 1-800-628- 5115 or visit www.dars.state.tx.us/ecis/searchprogram.asp

Baby

- Does not smile, move or look at you when you talk or play with her
- Does not want to be held
- Does not make sounds by 3 months
- Does not babble by 6 months

Toddler

- Has tantrums that last 20 minutes or longer
 - Breaks things on purpose
 - Hurts or bites other people or himself
 - Does not look at you when you call his name
 - Does not play with toys
 - Does not have any pretend play by 24 months
 - Does not enjoy being around and watching other toddlers
 - Flaps hands, rocks or sways over and over
 - Does not point at objects she wants
 - Has no words by 12 months
- At any age**
- Is fussy or cries a lot, even when

- not tired or hungry
- Has trouble falling asleep or staying asleep
- Does not notice people
- Is unhappy most of the time
- Is anxious most of the time
- Any loss of speech or babbling, or social skills

Additional resources:
<http://www.zerotothree.org/child-development/>
<http://csefel.vanderbilt.edu/>

Hands are Not for Hitting by Martine Agassi

Teeth are Not for Biting by Elizabeth Verdickem



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:

- Ezra Jasson, son of Kristi and Euclides Jasson
- Hallie Brody, daughter of Abby and Jerry Brody

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



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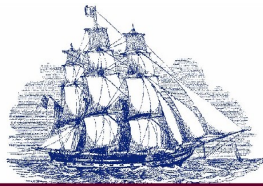


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Charting Your Course to Financial Security

Technology Ideas for the Holidays

The holidays are a great time to get new technology! It is often difficult to find the perfect gift for a child or adult with special needs. A tablet or technology accessories are often a great solution to gift-giving dilemmas. If you are considering gifting technology for the holidays, you may appreciate some guidance on sorting out which device to purchase, must-have accessories and apps to buy with those iTunes and Google Play gift cards. We, at BridgingApps, can help you.

Tablets—Touchscreen tablets are very engaging to all and can be game changers for children and adults with special needs. The touchscreen interface requires fewer cognitive skills and fine motor skills to use successfully. The app stores are filled with excellent educational apps. Tablets are easy to use and are highly portable. All of the tablets, especially the Apple iPads, have excellent accessibility features built in. Touchscreens are engaging and motivating as they provide interaction and give instant feedback. Tablets can be used for educational purposes such as educational skill building apps, audio books and screen readers, help with written expression and communication, as a start. Tablets are also great for recreational and social purposes.

Smaller tablets are quickly becoming a favorite technology device for children. They fit well in small hands, are easy to carry around, and offer accessibility features that full sized tablets boast. Parents are purchasing them for educational support, organizational tools and entertainment for children and adults with special needs.

Here are some of the tablets available this season:

Full Size iPad or iPad Air - For anyone with fine motor or vision difficulties, a full size iPad is an excellent choice. There are more educational and therapeutic apps in the Apple Store compared with the other app stores.

The iPad also has excellent built-in accessibility options. The iPad also comes with a 1-year warranty and you can purchase a 3-year extended warranty called Apple Care. **iPad Mini** - The iPad Mini is identical to the iPad except for the smaller size. An iPad Mini is easier to carry around, which is definitely a plus if using the iPad for augmentative communication. The smaller size can be difficult for people with fine motor challenges.



Google Nexus Tablet - The Google Nexus tablet is a good value and has an increasing app market. They also have growing accessibility options; however, the accessibility options are not as robust as the Apple products. **Kindle Fire** - The Kindle Fire is an inexpensive tablet that works for some families, especially for those just looking for an excellent e-reader and audiobook player. There are fewer apps available on these devices, especially educational and therapeutic apps. A Kindle Fire can be purchased for about \$60.

Accessories including cases are also an essential part of your technology plan. It is very important to put the tablet immediately in a heavy duty, protective case before gifting to a child.

Additional accessories that we like are:

CHAT Bag- This bag fits over a variety of protective cases and has an adjustable strap. It can be especially useful for children who are non-verbal and use a tablet as a communication device, as it allows the user to have the screen exposed at all times. Designed for the iPad and iPad Mini, and can custom order to fit other tablets.

\$30.00 CHAT Bag can be purchased at <http://www.chatbag.net/>

Ion Clipster - Paired with a mobile device, the ION Clipster Ultra- Portable Bluetooth Speaker with Built-In Clip is a cool and functional way to magnify sound from an iPad, Nexus or Kindle. Easy to use, available in several colors, rechargeable, portable and quite loud, the Clipster is a must-have technology accessory for individuals who use their tablet for speech communication. \$14.99 - \$49.99 Ion Clipster can be purchased from Amazon. **Adaptive Styluses:** ShapeDad at <https://www.etsy.com/shop/shapedad> has a huge variety of adaptive styluses for different needs. Last but not least, here are some fun holiday apps!

Starfall Christmas

Holiday Charades

Chai on Chanukah

Peekaboo Presents

Decorate the Christmas Tree with Elf on the Shelf

Sleeps to Christmas Lite

If you are interested in searching for more apps, browse our extensive app lists created by parents and professionals, or sign up for our newsletter; please go to BridgingApps.org. BridgingApps, a program of Easter Seals Greater Houston, is a community of parents, therapists, doctors, and teachers who share information about using mobile devices (iPad, iPhone, and Android) with people who have special needs. We are also offering a free course on Udemy called Getting Started With Mobile Devices for Special Needs. Here is the link to register for the course: <https://www.udemy.com/getting-started-with-mobile-devices-for-special-needs/>

Happy Holidays from BridgingApps!



Frequently Asked Questions on Transition: Medicaid Waivers and related programs

TxP2P 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.

Medicaid Waivers

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

What are Medicaid Waivers?

Medicaid Waivers are long-term supports and services provided by a state/federal partnership for people who need assistance with daily living. The purpose of the Waivers is to keep someone living in the community rather than an institutionalized setting. The same income and resource limits apply as for SSI, but Waivers are the one program based on the assets of the child even under age 18 rather than a family's.

Why is there such a long waiting list? Are there new programs?

The State of Texas has been slow to fund these programs; however, in the Legislative session of 2013, the state added waiver-type services to STAR+PLUS for people at age 21 who are nursing-home eligible. If your child receives Medicaid, she should receive a letter at age 21 directing her to select a STAR+PLUS MCO (Managed Care Organization) for health services. Another new funding source is Community First Choice (CFC) (June 2015) for people with disabilities of all ages; check with your Local Authority for more information. Additional information on CFC is below.

How do I get my child on the Medicaid Waiver interest (waiting) lists?

There are several different Waivers. Call 877-438-5658 for CLASS and similar programs; contact your Local Authority for HCS and related waivers. You do not have to prove

eligibility when you get on the interest list. You must keep your contact information up to date at both sites. (To find your Local Authority, go to <https://www.dads.state.tx.us/contact/search.cfm>)

What happens when my child's name comes up on the interest list?

He or she will receive a registered letter from the funding agency. You will be given information about the programs and choices available. You will have to choose a case management provider. If your child proves to be eligible for that waiver, you will create a budget with the assistance of a case manager. Medicaid Waivers give choices to the recipient and family about how to use the program and which services to use from a list of available services.

What is CDS (Consumer Directed Services)?

One of the choices for Waiver services is the CDS model, which empowers the person receiving the service (or someone given that authority) to be the employer of record for attendant care and respite providers. Choosing CDS provides more control over who will work with your child than if you use care providers employed by an agency; you will also be able to pay them at a higher rate. Note that this model requires more effort on your part.

What happens when my child is receiving one Waiver service and his name comes up on another Waiver?

You can only use one Waiver at a time; you'll need to do the research to decide which Waiver will best suit your child. It might help to talk to other parents whose children receive Waiver services; call the TxP2P office to connect with community wisdom. See this chart for a comparison of all Waivers: http://www.dads.state.tx.us/providers/waiver_comparisons/index.html

[waiver_comparisons/index.html](http://www.dads.state.tx.us/providers/waiver_comparisons/index.html)

What is Community First Choice?

The following information about CFC is taken from this website: <http://www.hhsc.state.tx.us/medicaid/managed-care/community-first-choice/>

A federal option, called Community First Choice, allows states to provide home and community-based attendant services and supports to Medicaid recipients with disabilities. This option provides states with a 6 percent increase in federal matching funds for Medicaid for these services.

To be eligible for Community First Choice services an individual must:

- Be eligible for Medicaid.
- Need help with activities of daily living, such as dressing, bathing and eating.
- Need an institutional level of care.

Community First Choice Services include:

- activities of daily living (eating, toileting, and grooming), activities related to living independently in the community, and health-related tasks (personal assistance services);
- acquisition, maintenance, and enhancement of skills necessary for the individuals to care for themselves and to live independently in the community (habilitation); providing a backup system or ways to ensure continuity of services and supports (emergency response services); and

Continued on page 7

- training people how to select, manage and dismiss their own attendants (support management).

Texas began the Community First Choice program on June 1, 2015. This means:

- Individuals on a 1915(c) waiver interest list who meet eligibility and coverage requirements may be eligible to get Community First Choice services.
- Individuals already getting

services through a 1915(c) waiver will continue to get those services as they do today from their existing providers.

To access CFC, go to your Local Authority for people over 21. (To find your Local Authority, go to <https://www.dads.state.tx.us/contact/search.cfm>) For those under 21, go to the Department of State Health Services (call the Texas Medicaid & Healthcare Partnership (TMHP) PCS Client Line toll free at 1-888-276-0702, Monday through

Friday, 7 a.m. to 7 p.m.) For more information, go to <http://www.dads.state.tx.us/providers/cfc/> General information about CFC

<http://www.hhsc.state.tx.us/medicaid/managed-care/community-first-choice/docs/cfc-faqs.pdf> CFC Frequently Asked Questions

<http://www.dads.state.tx.us/providers/communications/2015/letters/IL2015-29.pdf>

Access to Health Care through the Marketplace

Lauren Agoratus M.A., Family Voices New Jersey

The Urban Institute and Robert Wood Johnson Foundation have reported survey results on access to health care for people with disabilities. People with disabilities had two to three times more difficulty accessing health care services, including insurance, than individuals without disabilities. Common problems included:

- Affordability was a concern. (According to one study, adults with disabilities are nearly twice as likely as others to report an unmet need for general doctor care because they cannot afford it or because their health plan will not pay for a treatment.)
- Doctors or hospitals did not accept their insurance.
- Transportation was a barrier.
- There were delays in getting needed appointments.
- Offices were not physically accessible.

Addressing Obstacles

There are many ways that families can make sure these barriers are tackled. During enrollment, parents can make sure their child’s doctors, therapists, hospitals and pharmacies are in the plan’s network. This information should be verified by calling the providers directly, as sometimes the online directories are inaccurate.

Parents should also check to make sure the plan covers the medications their children need by checking the plan’s “formulary” (list of covered

drugs) and checking the cost of those drugs. Some plans have different “tiers” of coverage with different co-payments and may also have different prices for mail-order drugs. It is important to realize that a plan’s provider network, medication formulary and co-payment levels may change from year to year.

As far as affordability, parents need to look at out-of-pocket costs, not just premiums. Consumers using the Federal Marketplace this year will have access to a new tool on [Health-Care.gov](http://HealthCare.gov) that will enable them to see the total cost of a plan, including premiums, deductibles and cost-sharing. A similar tool will be available on the website of Enroll America.

Families should also appeal any claims being denied (only one-third do), as about half the time the decision will be reversed in their favor on the first try.

Families can also look at a providers' office locations during enrollment to determine their distance from home and if they are readily accessible by public transportation. They can also contact providers to ensure that their offices and equipment are physically accessible. Before enrolling, families can ask plan providers how long it usually takes to get an appointment. Once enrolled, families may be able to reduce waiting times by asking to be notified if an appointment becomes available due to a cancellation.

In summation, some common affordability and access obstacles can be avoided by careful research

before selecting a health plan.

RESOURCES:

HealthCare.gov:

- See plans Before you Buy: <https://www.healthcare.gov/see-plans/>
- How to Keep Your Doctor: <https://www.healthcare.gov/choose-a-plan/keep-your-doctor/>
- Tips on Comparing Plans: <https://www.healthcare.gov/choose-a-plan/comparing-plans/>

National Disability Navigator Resource Collaborative
- Beyond Coverage: Accessing Care National Disability Resource Navigator Resource Collaborative: <http://www.nationaldisabilitynavigator.org/2015/09/29/beyond-coverage-accessing-care/>

Urban Institute:
- Health Reform Monitoring Survey: <http://hrms.urban.org/quicktakes/Many-Adults-Have-Problems-Getting-Health-Care.html>

This tip sheet is based on an ACA blog authored by Lauren Agoratus, M.A. Lauren is the parent of a child with multiple disabilities who serves as the Coordinator for Family Voices-NJ and as the southern coordinator in the New Jersey Family-to-Family Health Information Center, both housed at the State-wide Parent Advocacy Network (SPAN) at www.spanadvocacy.org.

Texas Parent to Parent
3710 Cedar Street, Box 12
Austin, TX 78705-1450

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Conference Schedule

Date	Conference Title	Location	Registration Information
Sunday, Feb. 7- Tuesday, Feb. 9	2016 Inclusion Works Conference	Houston	www.thearcoftexas.org
Thursday, Feb. 18- Friday, Feb. 19	2016 Texas Transition Conference	Dallas	www.ttc.tamu.edu
Saturday, Feb. 20	2016 TAPPestry Conference	San Antonio	www.esc20.net/tappestry
Thursday, Feb. 25- Friday, Feb. 26	Central Texas African American Family Support Conference	Austin	www.ctaafsc.org
Saturday, Feb. 27	TxP2P One Day Conference	Tyler	www.txp2p.org