



TxP2P Update

Laura J. Warren, Executive Director, TxP2P

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Hope all is going well with you all and you are managing the heat the best you can! We still have the threat of hurricanes through September so don't forget to stay prepared. We covered Emergency Preparedness in our last newsletter and have covered the precautions for the Zika virus in this one – **please read it** – it's very important for pregnant women or anyone hoping to get pregnant soon, women and their partners!

We also have several back-to-school articles in this newsletter that might help as you prepare to send the kiddos back to school. In addition, there are several on transition, including an ingenious tool called Visual Transition Planning – this helped my son start visualizing what life was going to bring after school ended. We highlight a couple of new ventures TxP2P is doing (Employment Story Bank and Texas Network Connections) and finally, an article about a helpful dog named Earle.

Our 14<sup>th</sup> Annual **TxP2P Statewide Parent Conference** has come and gone - Zach Anner was a great success as our keynote and we decided to invite his mother to come speak for next year's conference – she said it might take a year to figure out what she did right with Zach but she'd share what she can. We'll keep you posted! You can find the handouts from the conference on the sidebar of our home page, [www.txp2p.org](http://www.txp2p.org).

Our **South Texas Parent Conference** in the Rio Grande Valley will again be in San Juan at the PSJA Early College High School and will be on Saturday, October 20<sup>th</sup>. Call for speakers is still open - If you want to do a presentation for us, please contact Cynda at [Cydna.Green@txp2p.org](mailto:Cydna.Green@txp2p.org) or go to the home page sidebar ([www.txp2p.org](http://www.txp2p.org)) for more information. We are accepting Speaker Proposals until August 24<sup>th</sup>. Registration is open and on the homepage of our webpage, ([www.txp2p.org](http://www.txp2p.org)).

Please stay in touch and stay cool!

Save the Date for TxP2P 2018 Awards Celebration (formerly Vine to Wine)

September 20th, 2018

Better Business Bureau Building, 1805 Rutherford Lane, Austin 78754

TxP2P Office Open House 3:30 - 5:30 p.m.

TxP2P Awards Celebration 5:30 - 7:30 p.m.

Guardianship Advocacy!

Check out this 45-minute virtual course available on Guardianship or Alternatives to Guardianship: <https://guardianship-txcourts.talentlms.com/learner/courseinfo/id:144>. Specifically the course covers: Types of Guardianship, Alternatives to Guardianship, Procedures to Establish a Guardianship, Duties of the Guardian and Reporting Requirements. If you plan to seek guardianship, you will need to print out a certificate of completion of the course.

Due to a new statewide procedure, guardians will also pass a background check, and each guardianship will be registered in a new statewide database.

Additionally, the Texas House is hosting an interim hearing on guardianship in the Capitol on August 14<sup>th</sup>, at 1:00 p.m. in room E2.026. The hearing will cover several guardianship topics: <https://capitol.texas.gov/tlodocs/85R/schedules/pdf/C3302018081413001.PDF>

Linda Litzinger, TxP2P Staff

Should you want assistance in navigating this event, please do not hesitate to call Linda and Amy Litzinger at 512-922-3810 or email them at [Linda.Litzinger@txp2p.org](mailto:Linda.Litzinger@txp2p.org).



# Back to School: Lights, Camera, ACTION (Plan)

Sherry Santa, TxP2P Staff

As we begin to think about our kids going back to school, most parents think about the never-ending supply list, new back to school clothes, and fresh haircuts, so our kids will all be picture perfect for the first day back at school! But when your child has a disability or other special health care need, you have extra things to think about. For our family, it is our daughter's "Action Plan."

Our daughter has migraines and asthma, which both require an Action Plan from the doctor, and of course, that means an appointment with each doctor. For the migraines, we try to schedule her check-up with the neurologist right before school starts, then we'll have an up-to-date plan

ready for the first day of school. For her asthma, we schedule her well-child-check with the pediatrician, when she can write up this academic year's plan.

Last year, I dropped the ball on these steps! Our daughter had gone for months without a migraine, so when the neurologist needed to reschedule the end of summer checkup, I wasn't concerned. I said, no problem, we will take an appointment during holiday break. Little did I know her migraines would come back full force within a few weeks of school starting! Since we didn't have a new up-to-date action plan, I had to pick her up from school each time a migraine started, sometimes multiple times

a week.

Not only was it hard on me to leave work, it was hard on her having to start medicine 30 minutes or more after the onset of the headache. Headaches that may have been possible to stop with one early dose of medicine instead became full blown migraines. Without



the Action Plan, the only option the school nurse had was to call me at the onset of each one. This year, I will stay on top of our regular schedule and have both the asthma and migraine Action Plans in place on day one of the new school year! That way she can stay at school in her adorable new school outfit!

## Visual Transition Planning

Rosemary Alexander, TxP2P Staff

Thinking about the future after your youth graduates from public school can be scary, but the more planning you do, the better your son or daughter will be prepared to live a good life as an adult. And school is a great place to do some planning. Plans made with school staff will enable you and your youth to develop a vision for the future, and that vision should become the basis for IEP goals. Your plans will give school staff a blueprint for working on the skills needed to make that vision a reality.

Visual Transition Planning (or VTP) is one tool available to schools and families to carry out a planning process. Its purpose is "to brainstorm possible future outcomes by most effectively and efficiently utilizing all of the resources available." (From Texas Project First—here is the template for VTP: <http://texasprojectfirst.org/pdf/VTPTemplateAdapted.pdf>)

A VTP meeting can be held at school with teachers and other school staff, the student and family, and anyone else the family asks to contribute. It should take perhaps 1.5 hours, and ideally school staff can host and

facilitate the meeting.

The meeting starts with a positive discussion of the student's strengths, preferences, interests and needs. This is the time for your youth to brag about what he is good at and likes to do, as well as what supports are needed. During the process, the student is always given a chance to speak up; if he is non-verbal, perhaps he can use an output device or depend on others to express his strengths. Everyone around the table will also contribute what they know about the student.

The discussion will turn to what the student wants to do in the future: what are her employment goals, post-secondary education options, recreation and leisure goals, independent living goals, and community participation goals? Then the group writes down what skills the student already has to meet those goals, in each of the 5 areas. Finally, the meeting ends with picking a goal (or several goals) and writing down what is needed to accomplish that goal. The chart gets very specific, listing steps, who can help and a deadline for accomplishing each step.

"Transition planning is an integral

part of the overall IEP. It is not a separate document or a separate process. It is not an afterthought after the rest of the IEP has been created. Transition planning should guide the creation of the rest of the IEP." "Transition planning is exactly what it says...*planning*. The ARD committee comes to a shared vision with the student and his/her family and creates a plan for getting there. Those plans become reality through the *course of study* (<http://texasprojectfirst.org/node/267>) and *goals and objectives* (<http://texasprojectfirst.org/node/200>) written into the IEP as transition services." (quoted from <http://www.texasprojectfirst.org/node/225>). Ask the transition specialists in your district if they can facilitate a VTP process. It will help school staff to write meaningful IEP goals, based on student and family input. It will bring families into the transition process. And it will allow students to voice their hopes and dreams for the future.

If your district is unaware of this tool or a similar tool, ask them to learn about it from their Education Service Center and websites such as [www.texasprojectfirst.org](http://www.texasprojectfirst.org).



## Beyond ECI: Next Steps for Your Child

**D**oes your child receive services from the Early Childhood Intervention program (ECI)? If so, you and your ECI team have developed outcomes and activities to help your child grow and learn, addressed your child's health needs, and addressed the needs of your family. Now that your child is getting older, it is time to start planning for when he or she leaves ECI.

All children must exit ECI by their third birthday. We call the process of exiting out of ECI "transition." Successful transitions require planning ahead with your ECI team and other partners, such as community service providers. Your ECI team will work with you to develop steps and services for transition that are specific to your child and family when your child is between 27 months old and no later than 90 days before your child's third birthday. Your ECI team will assist you in finding resources for your child and family for when your child is no longer enrolled in ECI.

### Choices for your child after ECI

There are many options for your child after he or she exits from ECI. You and your ECI team can determine what choices will be best. Your service coordinator will help you determine what might be needed for your child to participate in any of the following:

- Child care settings
- Private therapy
- Charter schools
- Head Start
- Parent's Day Out programs
- Community recreation programs
- Neighborhood play groups
- Library story hours
- Classes for children, such as art, music, gymnastics or swimming
- School district Preschool Programs for Children with Disabilities (PPCD).

### Questions to help you decide:

- What does my child like to do?
- How do I want my child to interact with others?
- What are my goals for my child in the next year?

### Choices for your child in your community

Your service coordinator will help you explore options and schedule transition meetings with the organizations or programs in your community that you might like your child to attend after he or she exits from ECI. Your service coordinator and other team members can also provide strategies to help your child fully participate in these programs and activities.

Attending a transition meeting does not mean your child has to enroll in the program you are considering. These meetings will give you a chance to learn more about the services offered, find out about next steps and ask questions.

Remember, transition is a time to look at all of your child's options. Your child can enroll in both community programs/activities and the school district PPCD. If you are considering several options, you may have more than one meeting. If you are considering a group program for your child, the meeting may include visits to the program sites.

### Things you may want to ask about include:

- Eligibility requirements
- Scheduling
- Costs/Insurance
- Transportation
- Documents needed to enroll in the program
- Any special diet needs for your child
- Giving and/or storing your child's medication
- Special accommodations such as wheel chair ramps.

### Things you may want to share include:

- Important information about your child and family
- Your hopes and dreams for your child
- Your child's favorite toys and activities.

### Choices for your child in your local school district

Public schools have services called the Preschool Program for Children with Disabilities (PPCD) that begin for

eligible children on their third birthday. If you want to explore PPCD services, and you give your approval, you will participate in a transition conference with representatives of your school district and ECI.

The transition conference usually occurs three to nine months before your child's third birthday. The meeting will be conducted in your native language using words and terms you can understand. To get the most from this conference, let your service coordinator know if you need translation or interpreter services, including sign language.

### At the conference, the school district or ECI staff will:

- Explain eligibility requirements for PPCD services
- Explain the evaluation procedures for determining eligibility
- Explain the steps and timelines
- Explain your parental rights
- Explain the different types of information that may be needed from you
- Answer your questions and consider your concerns
- Discuss extended year services and locations where services may be provided
- Explain that children may receive PPCD services in pre-kindergarten classes and community settings such as preschool or Head Start.

### To help school district staff understand your family, you can:

- Share ideas for goals and objectives that are important to your family
- Invite to the conference friends, relatives, and child care staff who may have useful information
- Describe your child's current activities and routines
- Describe what you want for your child in terms of future activities and routines

**Note:** The school district program will address your child's educational needs, but unlike ECI, it does not address family needs. Before you transition out of ECI, your service coordinator will help you access services to meet your family's other needs.

For additional information on your child's transition, please contact your ECI service coordinator.





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## Zika Threat



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The heat is rising, and so are the number of mosquitoes! While the news stories have faded, Zika virus is still a serious concern for pregnant women and their babies! Due to the rate of disabilities associated with Congenital Zika Syndrome, it is imperative that all pregnant women takes precautions to protect their baby! What's more, most people who have Zika have no symptoms. Men and women are at risk from Zika if they are planning to start a family.

Help protect yourself and your neighbors by removing standing water, yard debris, and litter. This reduces the number of mosquitoes in your neighborhood and lessens the chance of mosquito bites.

Also, help protect yourself outdoors by using an EPA approved repellent. Check out this article (<https://www.npr.org/sections/goatsandsoda/2018/06/30/623865454/a-guide-to-mosquito-repellents-from-deet-to-gin-and-tonic>) to learn more about which

mosquito repellants are the most effective.

Please also remember as you are traveling this summer that nearly all of the cases of Zika in the United States are travel related! If you are looking to vacation outside of the U.S., hop over to the CDC's Zika page (<https://wwwnc.cdc.gov/travel/page/world-map-areas-with-zika>) to learn about the Zika risk in your travel destination.

## Back to School: Lunch!

Liz Hong, TxP2P Staff

Back to school means many things to many people, but if you're like me, the most dreaded is school lunch! My son has sensory processing disorder, and his Spidey Sense tingles if he gets anywhere near a sandwich with a different brand of peanut butter. My daughter, on the other hand, just doesn't like to eat and will throw away a whole lunch box of food.



August and September are our trial months, when we buy more expensive lunch foods and throw away too much waste as we try to discover which foods each child will no longer touch and which foods hit that balance of quick and easy but still healthy enough the lunch police won't try to give me a ticket!

I've read the stories about lunch shaming, when a mom sent --gasp-- Pop Tarts or Oreos and her kid's lunch gets thrown away or withheld, or the mom gets a nasty letter about healthy foods helping students learn. Let's be real here: in a perfect world, healthy lunches and plenty of sleep and exercise **would** help our kids learn,

but reality is, some food will help more than no food. As parents in a less-than-perfect world, we know we **have** to make compromises and figure out where we are willing to bend, and where we aren't.

In our house, we save food battles for dinner time. Nothing says welcome home from work and school like a battle over peas. It isn't ideal, but I cannot win a battle during the school day if I'm not there. Unless my kids are happy to eat it, or I am willing to pay money to throw it away, I don't put it in their lunches.

My Super Mom trick here is baby carrots. Maybe someday my kids will choose to eat them, but in the meantime, I don't mind adding them in if I am feeling the judgy stares. Plus, my kid felt like it was a win when he got to chuck them or give them away without my knowledge and was more willing to eat the other stuff. It isn't exactly the most conscientious thing to do, but it helped me get through the lunch time drama.

When my babies were born, I wanted the best and most healthy foods for them. I wanted them to eat fresh fruits and veggies, munch on whole

grains and dive into healthy meats. As reality set in, I realized that compromises must be made. Yes, I still give my kids fresh whole fruits at dinner, and they love so many of them.

At school, however, that apple looks like dog food compared to their friends' lunches and ends up in the trash. At school, they eat the canned fruits and applesauce pouches or strawberries sprinkled with sugar that they love. I have given up the quest for whole grain products and agreed to the Un crustables that they like and pick out themselves. As for snacks, I buy the over-priced snack packs from time to time, because giving them control over their food choices and making it fun for them, helps encourage them to eat. Sure, their lunches don't look like they belong on Pinterest, but they get the job done.

If your child is struggling with lunch time troubles, adding choices and making lunch fun can go a long way towards getting your child to eat. If all else fails, remember there is nothing wrong with a pop-tart "dessert" in the lunch box.

## 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:

Dean Romero, son of Justin and Sabrina Romero

Kaitlyn Davila, daughter of Missy Davila

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

**New Resource: Creative Job Story Bank**

This idea was born 3+ years ago at the Texas Transition Conference when Denise Geiger, Transition Specialist in Leander ISD, casually mentioned that she had 12 students in life skills classes that were working and/or volunteering. After finding out what some of her

Through a collaborative effort, this promising star is born. To help the site become a valuable resource for youth, young adults, parents, teachers, transition specialists, VR counselors, OT's, PTs and many others, we need to build up the content. We want the site to showcase what's possible and the many ways adults with disabilities in Texas - particularly those with high support needs--are contributing by

Many thanks for helping us collect stories and build a treasure chest of ideas for adults with disabilities in Texas!

**Courtney Craig**

"It's been really fun," said Kirstyn in regard to life with Earle since their graduation from the program. "He can do stuff for me. He can pick up things, and he can get things and

"It's an amazing, life-changing thing for her to have him," Kristin said. "It is such a gift that Canine Companions gives to children and adults who really need that companion."

Canine Companions is a nonprofit 501(c)3 that provides assistance dogs to children and adults with physical, cognitive and developmental disabilities free of charge. Canine Companions trains four categories of dogs – service dogs, hearing dogs, facility dogs and skilled companion dogs. Skilled companion dogs are trained to work with an adult or child with a disability under the guidance of a facilitator. For more information about the Canine Companions facility in Texas, visit [www.cci.org/southcentral](http://www.cci.org/southcentral). To apply for an assistance dog, visit [www.cci.org/apply](http://www.cci.org/apply).



# Helping Your Child Run the Show: Running Your Own ARD Meeting

Amy Litzinger, TxP2P staff

*This is part three of a three part series on helping your child learn and practice self-determination skills.*

**As a little kid:** I learned things that would be necessary to know for an ARD meeting. Things like what is my diagnosis. Mostly what it is called. That my muscles don't talk to my brain well. And that I use a chair. Or what I need help with. Or how I'm different, and how I'm the same as everyone else. Also what I like and don't like about school.

**Older kid:** My job was to go to the meeting and introduce myself. Start talking in parts of the meeting where electives are being selected and choices are being made. I was very focused on being present in the room even when I'm not leading the discussion. It's very important to pay attention. Nothing gets talked about without me knowing about it.

**Middle school:** I lead the meeting, but I asked other people to step in and lead sections of the meeting where I have less expertise or feel less confident. Electives are big here, and some of them require applications. I start making my own goals for therapies, based on what is actually achievable, and balance that with my academics. ARD committee chooses electives based on what fits the therapy schedule. Advocating for less paraprofessional time is harder, this is an ongoing discussion throughout middle school and high school. Electives help with this dilemma. Start thinking about testing in eighth grade.

**High school:** We were gearing up for Dismissal! I still didn't know everything, but I was definitely in the lead. No one said anything without going through me first. A big goal of the ARD meeting was making high school as much like post-graduation life as possible. This was difficult, and required much more advocacy on my part. Lots of discussions about disclosure, and fitting my modifications to be more like what I would receive in the college setting, in order to prepare for standardized testing. In many cases, there were many things about my typical graduation path about which the special education department was not yet informed. Gathering information first, having a written plan for the meeting, and bringing food was important to my doing well in this setting. I learned not to be afraid to call a second or third meeting when necessary. At 18, I invited my parents to my ARD meeting. Guardianship is not needed for this, only student consent. Note: now I have many teachers, who are all very busy. I would get frustrated frequently during the first few weeks of school that teachers did not have time to read the packet created by the ARD committee. So I started making a list of things my teachers needed to know within the first two weeks, until we all had time to read it or to meet again.

**College:** Surprise! There aren't any ARD meetings. Instead I have to go to the disability support office myself and disclose my disability to

them. They decide my modifications based on a standardized formula, similar to the formula I got used to during standardized testing. They sent a very basic sheet to my professors, regarding what I am eligible to receive for testing purposes. Using my high school experience, I created my own letter to my professors based on what I would've created if there had been an ARD. This is not an ARD document or a traditional "one pager". It doesn't include everything that I might be entitled to, but it does include what I need. It is also a more well-rounded introduction to me as a person and how I fit into the classroom, rather than a form letter, with only legally required information. It allows me to be in control of my own disclosure and how I present myself.

**Grad school:** Surprise! There isn't even an office of student support, and the Dean's office is new to disability. Time to refine my letter. Write exactly what I need and why. Back it up with research. They want to help, they just don't know how. Shaping and education is key.

**Employment:** I change my letter to what I need in the work environment. I also add more content about what I can do and how I can contribute. Plus more opportunities for face-to-face discussion and asking questions.



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# Spotlight on a TxP2P Program

## Focus on Texas Network Connections – Create a Caring Network

Linda Jones, TxNC, TxP2P

**A** relatively new development in the landscape of disability is the fact that, due to advances in medical technology, children with disabilities not only grow into adulthood, but can also outlive their parents. If the parents have been the primary caregivers in the life of their child then their incapacity or death is likely to leave a huge gap and can seriously compromise the well-being of their adult child. This reality, combined with the competition for scarce government resources, should be cause for concern.

As the parent of a child with a disability, chances are that you have heard this phrase from friends and/or family members more than once - "Let me know if there's anything I can do." People want to help. We are built to care. Why not harness that caring into a personal support network for your son or daughter? Networks are a great way to enrich the present and prepare for the future!

That's what Texas Network Connections (TxNC) is all about – establishing a structure of on-going support for a person with a disability, during the course of that person's life and even after their parents are no longer able to care for them. This program was launched by Texas Parent to Parent after Rosemary Alexander visited and was trained by the PLAN (Planned Lifetime Advocacy Network) Institute in Canada.

Rosemary was so inspired by the model she saw in operation that when she came back she started a network for her son, Will. Fifteen years later and that network is still going strong. In collaboration with Denise Sonleitner, along with the support of Texas Parent to Parent, Texas Network Connections (TxNC) was born in 2015. After retiring from her career in health and human services, Linda Jones joined the TxNC team last year.

To date TxNC has launched **over 20** networks! Most are located in Central Texas and expansion efforts are also underway in the Houston and Dallas-Fort Worth areas.

So how do networks function? Members of personal networks meet 2-4 times a year to be the intentional community of caring that we all need throughout our lives and that a

person with a disability especially needs as he or she lives and grows in their community. A major goal for network members is to learn about the person at the center – their dreams, talents, likes and dislikes, and what services are required for that person to live a good life.

In the process, network members get to know each other as well, thus forming an intentional community that necessarily includes the person at the center. Members celebrate birthdays and other important occasions. They lend their expertise and experience in problem solving and, most of all, they bring love and caring to the circle.

TxNC has two methods for implementing personal support networks – we provide 1) a facilitator to guide you in the process, or 2) a do-it-yourself manual.

For a fee, a facilitator trained by Texas Parent to Parent in personal support network methodology will assist you in the three phases of network development – exploration, formation, and maintenance.

The facilitator will spend time with you, your family and the person at the center of the network to explore the dreams and visions of the person, short and long term goals, concerns and issues, etc. The facilitator will help you identify and invite potential network members to an introductory meeting where the concept of a personal network will be explained along with the expectations and benefits.

After this meeting, the facilitator will follow up with meeting attendees to determine who wants to be a member of the network. Next, the facilitator will help plan and run the first and second official network meetings, at which point the network will be fully launched and able to function on its own.

As stated before, there is also a do-it-yourself manual (available here: <https://www.txp2p.org/Media/Transition/how-to-for-personal-network-rev-110117.pdf>) which can guide you through the process.

In our experience, the hardest part of network formation is just getting started. Many people are reluctant to ask friends and family to join a network. Some also feel that they

don't know enough people well enough to ask them to be part of a network.

These are legitimate concerns that are easily overcome. Many people seek meaning and belonging in their lives: an invitation to participate in a network is an opportunity to join with others in this quest. Asking tells people that one is interested in them and values them. Also, having a network gives others an opportunity to share the benefits of knowing your child. As to not knowing enough people - there is no critical number who must be assembled to form a network. There can be as few as five network members and up to thirty or more. Each network is unique.

Whatever your situation, establishing a fully functional network takes a long time (2+ years) and the sooner you get started, the better. 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 to envision a positive future for your child even if you are not there or are unable to care for your loved one. Starting a network will help in preparing the next generation of caregivers. It is a necessary step in sharing what you know so that others can follow in your footsteps.

Ultimately, Texas Network Connections is about creating a movement that changes strangers into friends; it is about changing society to be kinder and gentler for all because in the end, each and every one of us needs a network.

If you are interested in starting a network for your son or daughter (or yourself!) and/or in being a facilitator for a personal network, please contact Linda Jones at 512-659-8682, or at [lindamary555@gmail.com](mailto:lindamary555@gmail.com).

### Quotes to use as you desire!

♥"Taking these first steps of starting a network leaves me feeling hopeful that we can build a strong community of support for my daughter."

♥"It's a great way to put our minds together and think about someone we all care about."

♥"Having the network is like a big hug of support!"

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Conference Schedule

Date	Conference Title	Location	Registration Information
August 11, 2018	A Look Ahead Conference	Arlington	<a href="http://www.alookaheadseries.com/schedule">www.alookaheadseries.com/schedule</a>
September 8, 2018	Making Connections– 2nd Annual Pediatric Brain Injury Resource Fair & Conference	Austin	<a href="http://www.teamlukehopeforminds.org/">http://www.teamlukehopeforminds.org/</a>
October 20, 2018	TxP2P South Texas Parent Conference	San Juan	<a href="http://www.txp2p.org">www.txp2p.org</a>
October 25-26, 2018	19th Annual Chronic Illness and Disability Conference—Transition from Pediatric to Adult-based Care	Houston	<a href="https://www.baylorcme.org/">https://www.baylorcme.org/</a>
February 10-12, 2018	2019 Inclusion Works Conference— "Rock the Boat"	Denton	<a href="http://www.thearcoftexas.org/inclusion-works">www.thearcoftexas.org/inclusion-works</a>