

## TxP2P Update

Laura J. Warren, Executive Director, TxP2P

Hope you are enjoying the spring and have not seen any of the tornados that have been visiting our state in the past month or so. I want to share a great **emergency preparedness website** brought to us by the State of Texas: *Ready or Not, Have a Plan* at [www.texasprepares.org](http://www.texasprepares.org). It covers all types of disasters and gives us great tips for preparing as well. When you have a child with a disability, relocating overnight can be a nightmare but might happen due to hurricanes, tornados, or wildfires. We also have an article in this newsletter about emergency preparedness.

I also want to introduce you to what I think are some wonderful family-written articles on a variety of topics available on two different websites:

**Texas Parent to Parent** – We have compiled a long list of articles from our newsletters on our website (<http://www.txp2p.org/resources/articles.html>) for you to use when needed. The topics include becoming an advocate, taking care of yourself, family stories, family-centered health care, special education, care notebooks, and many more. We are in the process of rebuilding our website to make searches and navigation easier. For now, these articles are difficult to find (we jokingly call them our best kept secret) so just use the link.

**Navigate Life Texas** – TxP2P has parent contractors across the state that research and update all the resources on this website. They also write a blog each month so we have **20 new blogs** each month on this webpage: <https://www.navigatelifetexas.org/en/blog>. The stories include emotional topics, tips for parents from parents on a variety of subjects, how to teach independence, mental health issues in children, self-care for parents including how to maintain a relationship with your spouse, and much more. You can search by region of the state or topic or author.

And don't forget, we have our Statewide Conference ([www.txp2p.org/training/conference.html](http://www.txp2p.org/training/conference.html)) coming up on June 16<sup>th</sup>-17<sup>th</sup> in San Marcos. Hope you will join us.

Volume 17, Issue 1
Spring 2017
Inside this Issue:
♥ TxP2P Update: pg. 1
♥ Around the State: Tx Network Connections, pg. 1
♥ Around the State: Emergency Preparedness, pg. 2
♥ From our Families: Kayleigh's Story, pg. 3-4
♥ Around the State: Zika Prevention, pg. 4
♥ Around the State: Beyond ECI, pg. 5
♥ Transition: Finding and Keeping Attendant Care, pg. 6-7
♥ Advocacy: Legislative Update, pg. 7
♥ Conference Schedule, pg. 8

## Tx Network Connections (TxNC), a New TxP2P Program

Linda Jones, Texas Parent to Parent

Welcome to the **Texas Network Connections (TxNC)** Update Section of the newsletter! From now on, in each newsletter, we will endeavor to keep you up-to-date with the latest developments with TxNC. In case you have not yet heard, TxP2P has created a program, called Texas Network Connections, where parents and people with disabilities can hire a trained facilitator to help them establish a personal support network.

A network is a group of committed individuals who meet 2-4 times a year to be the intentional community of caring that we all need throughout our lives and that a person with a disability especially needs as they live in their community. Parents can have peace of mind knowing that if anything happens to them, the network members will step in to insure the safety and continuity of care/support for their family member.

To date, we have launched **ten** networks! One has been meeting for



over ten years and others are just getting started. Consider starting a network if you, as a parent, want to:

- increase your child's social opportunities,
- give caring friends and family an opportunity to have a meaningful relationship with your child,
- help you and your child make decisions,
- support your child's increasing independence,
- wonder how to make sure that

your child with a disability will have a good life after you are no longer there to care for them, and

- wish for a group to increase your connections to the community, energy, ideas and hope, for now and the future.

In future updates, we will talk about how TxP2P can help get your network started or how you can start your own network. We will share stories and experiences of those participating in networks. And we will talk about the benefits of networks and how they evolve.

If you are interested in exploring more information about networks, please refer to our section on the TxP2P website (<http://www.txp2p.org/parents/TexasNetworkConnections.html>) and/or call Linda Jones, our consultant who works on networks, at 512-659-8682.

# Emergency Preparedness

Liz Hong, TxP2P Staff

When I was nine, my mom left me home with my 13 and eight-year-old brothers, to run another child to practice. My 18-year-old brother came home with his girlfriend unexpectedly and had only been there a few moments when disaster struck. Literally. The ground began shaking and I experienced the most intense earthquake I have ever felt: the 1989 Loma Prieta Earthquake.

We were left without power for two days, and many of the neighbors went for weeks without gas. Meanwhile, another brother was away at college in one of the areas that was hit the hardest, and we had no way of knowing if he was okay for days! Even though we had heard for years about how we had to be ready for “the next big one,” when it came, we were decidedly unprepared and learned some big lessons that day! When I spoke with my mom many years later, she offered advice to me and my family based on what we experienced that day.

The most important lesson my mom learned was to have an out-of-town and out-of-state contact. She agonized for two days about whether or not my brother was okay. When she finally got hold of him, she discovered that the university was fine and the students were taking advantage of time off from school by having after-quake parties!

While phone lines in the neighborhood may be busy, it is often easier to get hold of someone outside of your area. Also, there are apps and webpages that can help let your family members know you are safe after a disaster. Facebook will automatically prompt you to mark yourself safe, if you have an account. It will also send a push notification to your Facebook friends letting you know you are safe as well. The Red Cross runs a website called Safe and

Well, where you can check in and let people know you are okay and leave notes. Unfortunately, this site does not send push notifications, so you will have to tell your family ahead of time to look for you there. Make sure they know the exact address and/or phone number you will register yourself under, as they will have to know one to find you.



Another lesson we learned is to know what to do in any type of possible disaster. After the quake, many people in the neighborhood debated about what they needed to do. Some people thought they needed to shut off their gas lines, just in case they were broken. In reality, the gas company recommended only shutting the gas off when you smell gas. As a result, they were flooded with people needing to get their gas turned on; some people had to wait two weeks.

In Texas, we most often see storms and flooding, tornadoes, hurricanes, and fire. Do you know what to do if one of these comes to your neighborhood or community? Have you thought about how you can help meet the needs of your child with a disability or special healthcare needs if you had to go for an extended time without electricity or fresh water? You can find out more about what preparation to expect in your community at Texas Prepares (<http://www.texasprepares.org/>). This site has a variety of videos, checklists, tools,

and information about what to do when disaster strikes.

When I asked my mom about that day, she ended on one final note. She wished that she had prepared for things to keep us kids busy! After the earthquake hit, we were not able to go many places outside of our neighborhood. What’s more, we kids were scared and so we tended to cling to my mom all in one room. We were all in one small place and bored, scared, and grumpy.

Now that I have children, she suggested that I pack into our disaster kit some new, interesting activities for us to do with our kids in an emergency setting. Even a fun pack of cards or a new coloring book can help ease the tension and make the time pass a little more quickly. One thing to consider is what you will do if you have no power and cannot charge phones, tablets, and other devices. Plan ahead to have other activities that your kids can do that do not need electricity.

As May rolls in, we will soon begin seeing more storms. The season can bring damaging thunderstorms, floods, and tornadoes. Take time before the disaster to plan ahead and be prepared. That way, should you experience a natural disaster or other emergency, you will be ready for what comes.

Log on to Texas Prepares ([www.texasprepares.org](http://www.texasprepares.org)) to find out more about what to expect in a disaster and how you can be ready. Also, check out the video on Navigate Life Texas that has tips for preparing families with children with disabilities for a disaster. Go to [www.navigatelifetexas.org](http://www.navigatelifetexas.org) and type *emergency preparedness* into the search bar.



**superior  
healthplan**™



**Amerigroup  
RealSolutions**  
in healthcare

**Thank you to our Sponsor  
Circle of 2017!!**



**Driscoll  
HEALTH PLAN**  
*A friend of the family*



**UnitedHealthcare**  
Community Plan



# Kayleigh's Story

Sandy Williamson, Parent

Being the parent of a daughter who has Down syndrome has been filled with many ups and downs. Like most parents, I wanted my daughter to have many of the same opportunities that other parents have for their daughters. Dance lessons, birthday parties, swim lessons, sleepovers, prom dates...you know, those fun things that would make her have happy memories. Those wishes never included struggles with her health. I was aware of her higher risk of developing sleep apnea and leukemia, but she always seemed so healthy along with those dance recitals or swim lessons that I never worried other than a passing thought occasionally.

By age 16, Kayleigh began to start putting on the same amount of weight that I was putting on. Then, she was diagnosed with sleep apnea. Trying to get her to use a c-pap machine would result in a battle each night when it was time to go to bed. Because of the apnea, she would fall asleep at the drop of a hat during the day. We could be driving for only 5 minutes and she would fall asleep or if she were just sitting at a desk at school, she would fall asleep.

Our biggest scare came in August 2008. Every two years, I always had a complete blood work analysis done on her. I wanted the doctors to check everything including her vitamin levels. That month, the doctor called me to tell me there were some abnormalities in her blood work. He said he did not think it was leukemia, but he could not rule it out and he wanted me to take Kayleigh for more testing.

For two days, the tears just did not seem to stop. I would watch my daughter sleeping and just could not seem to wrap my brain around the thought of a health issue. A few days later to my relief, I learned that Kayleigh did not have leukemia, but instead she had a blood platelet disorder called Idiopathic Thrombocytopenic Purpura (ITP).

This began our journey with autoimmune disorders. After two years of her platelets not going higher than 100, her hematologist at Texas Oncology tried steroids. That added a few more pounds but did not help her count.

By 2011, she was diagnosed with hypothyroidism. I was told this was common for individuals with Down syndrome and medication was started.

By 2012, Kayleigh and I both were over 200 pounds each and her sleep apnea was even worse. We joined Weight Watchers early that year. I saw the direction we both were headed with



our health: my mother had had two major strokes.

At this same time, the doctor told me Kayleigh was pre-diabetic and I had early signs of hyper-tension. After joining Weight Watchers, the pounds started disappearing from both of us and Kayleigh went from a diagnosis of hypothyroidism to hyperthyroidism. In 2014, she was diagnosed with Graves' Disease. The medication to treat the disease had one side effect – it caused the blood platelets to drop. That is when I pulled all artificial sweeteners from our diet.

I took the position that Kayleigh's diet changes would also be my diet changes. We started eating more lean meats like fish, chicken and turkey. We stopped eating and drinking any foods that contained high fructose corn syrup and I started cooking our meals at home as opposed to eating out all the time.

It was then that I started reading and listening to anything I could find on individuals with Down syndrome and their autoimmune disorders. I learned that the autoimmune gene is in the 21<sup>st</sup> chromosome. The 21<sup>st</sup> chromosome has the fewest genes at around 480, where other genes have 600 or more. However, the 21<sup>st</sup> chromosome is where the gene associated with Alzheimer's, autoimmune disorders, and leukemia is located. I began to realize just how important healthy eating, sleeping and exercise were to us in general, but it seemed magnified when it came to my daughter. I learned that she had a

higher risk of developing celiac disease. She was tested and does not currently have celiac, but she does have a sensitivity to gluten--thus we are on a low gluten diet.

At the beginning of 2016, Kayleigh's platelets continued to fall to 30 and by April they had dropped to 15. The doctor decided that the only thing we could do was remove her spleen. It was at this same time that my mother was diagnosed with Alzheimer's – I then began my journey of researching the effects of this disease on individuals with Down syndrome. The risk is 90% due to the Amyloid Precursor Protein (APP) gene located in the 21<sup>st</sup> chromosome. This made my drive to keep Kayleigh on a healthy diet and exercise my number one priority.

Kayleigh wanted to participate in more races with me, so we started training for her first 8K in June – just 4 weeks after her spleen had been removed. The success of her splenectomy left all of us, including her surgeon, amazed.

By August of 2016, her Graves' Disease was in full remission. She was taken off her medication and no longer had to get bloodwork every month. Her sleep apnea was no longer an issue as well.

By the first of October, she was able to swim a mile and on November the 4<sup>th</sup>, she completed her first 10-mile race (Run For The Water). After that race, I took Kayleigh to a doctor who specializes in running to help Kayleigh reach her goal – a half marathon. She continued to train for races thru Run-Lab and as of February 19<sup>th</sup>, she became the first individual with Down syndrome to complete the Austin Half Marathon. I continue to read medical information on the genes located in the 21<sup>st</sup> chromosome. I have learned that I have to keep myself informed not just of the effects of healthy living for Kayleigh but myself as well.

We follow more of a Mediterranean diet full of fresh fruits and vegetables along with lean meats. We have turned it into a fun time of learning new recipes and cooking together. We participate in races together and she has been named as a "true inspiration" by [www.People.com](http://www.People.com). Her finish of the Austin Half Marathon has been seen all over the world.

*Continued on page 4*

All the attention is nice, but what is amazing is the effect of our life style changes on our health today and what it means for our future. Through all the reading I have done about Alzheimer's, I have learned that it is now considered type 3 diabetes. There are four major contributors: sleep, eating habits, aerobic exercising and socializing. We still do Weight Watchers and we continue to train for more races. We are doing the Cap10K in April; Run for

the Water in November and Austin Marathon has already offered her free entrance for her race next year. Run For The Water has asked if she will not only return to participate in the race this year but also be an ambassador. The idea that changes in our diet and exercise would have such a powerful impact is mind blowing. Yes, the changes were difficult and there were many arguments over our healthy eating but it was worth it. I never want to lie in a hospital bed

crying with my daughter for the pain she would have to suffer if I had not taken care of myself. I would not have been able to live with myself if my daughter was the one lying in a hospital bed because I did not to make these changes a necessity – a necessity that is now a way of life. No, we can't prevent everything, but we can try to keep the things that are preventable from having such a devastating impact on our future.

## Information about the Zika Virus

Elizabeth Hong, TxP2P Staff

Headlines about Zika are everywhere! With [microcephaly](https://www.cdc.gov/media/releases/2016/s0413-zika-microcephaly.html) (<https://www.cdc.gov/media/releases/2016/s0413-zika-microcephaly.html>) and related health conditions, it is no wonder why. Despite this, though, many of us are left wondering what that means for our families and us. In November 2016, the Texas Department of State Health Services announced local transmission of Zika virus had occurred in Texas. Several other cases of transmission were reported and so the CDC determined that [Brownsville](https://www.cdc.gov/zika/intheus/texas-update.html) (<https://www.cdc.gov/zika/intheus/texas-update.html>) is now a cautionary area (yellow area) as there may be a risk of infection. At this time, prevention is the only way to combat Zika.

Due to the nature of the [Zika virus](https://www.cdc.gov/zika/transmission/) (<https://www.cdc.gov/zika/transmission/>), anyone who does not live in an area with active Zika transmission is unlikely to get the Zika Virus unless they travel to an area with active transmission or engage in unprotected sex with someone who has been in an area with active transmission.

Zika is primarily spread through the bite of the Aedes Aegypti mosquito. This particular mosquito breeds in very small amounts of water. There is enough water in a bottle cap or leaf for it to breed. Also, this mosquito stays close to home and will bite where he breeds. These mosquitoes can also carry Dengue, Chikungunya, and West Nile so there is ample reason to prevent them. However, because of the seriousness of [mother to fetus transmission](http://www.medscape.com/viewarticle/871391) (<http://www.medscape.com/viewarticle/871391>) of Congenital Zika Virus Syndrome (CZVS)

including microcephaly, central nervous system abnormalities, vision and/or hearing issues, and more, it is imperative to do our best to prevent widespread infection of Zika virus in our communities.

The same [tips](http://www.texaszika.org/docs/ZikaPushCardGeneralEnglish.pdf) (<http://www.texaszika.org/docs/ZikaPushCardGeneralEnglish.pdf>) that we hear from [preventing mosquitoes](http://www.texaszika.org/prevention.htm) (<http://www.texaszika.org/prevention.htm>), removing standing water, clearing rain gutters, and checking your property for sources of water, can help prevent the spread of Zika.

Also wearing long sleeves and pants, using an EPA approved mosquito repellent, and using air conditioning, screens, or mosquito nets can help prevent the bites themselves. While Zika may not be in your community, preventing mosquitoes helps to prevent Zika from spreading in our neighborhoods and cities. While it may not seem as important to prevent bites if you have no intention to become pregnant, it is an important step in prevention for others in our community.

The [CDC recommends](https://www.cdc.gov/zika/hc-providers/reproductive-age/desire-pregnancy.html) (<https://www.cdc.gov/zika/hc-providers/reproductive-age/desire-pregnancy.html>) that women wait at least 8 weeks after exposure to try to get pregnant, that men wait 6 months, and that partners use a barrier method of birth control to prevent transmission. Medicaid has announced that women and girls between the ages of 10 and 45 may be eligible to receive free EPA-approved mosquito repellent. More information can be found [here](https://hhs.texas.gov/about-hhs/communications-events/news-releases/2016/11/texas-medicaid-brings-back-mosquito-repellent-benefit) (<https://hhs.texas.gov/about-hhs/communications-events/news-releases/2016/11/texas-medicaid-brings-back-mosquito-repellent-benefit>).

[brings-back-mosquito-repellent-benefit](https://hhs.texas.gov/about-hhs/communications-events/news-releases/2016/11/texas-medicaid-brings-back-mosquito-repellent-benefit)).

Anyone who has been exposed to Zika and has symptoms can be tested for the virus by the local health department and CDC. Also, pregnant women who have been exposed either through sexual transmission or exposure in an area with mosquito transmission occurring should be tested regardless of whether or not they have symptoms. You should see your doctor to coordinate testing. However, at this time, the CDC has a backlog of Zika tests and will only process the tests for those who have been exposed AND are experiencing symptoms, or pregnant women who had been exposed with or without symptoms. Those who are interested in becoming pregnant and are concerned about the Zika virus can be tested through private labs like QuestDiagnostics, LabCorps, or Viracor. These tests can cost anywhere from \$165-\$700. You can read more about Zika testing [here](https://www.cdc.gov/zika/hc-providers/types-of-tests.html) (<https://www.cdc.gov/zika/hc-providers/types-of-tests.html>).

Due to the nature of the mosquitoes who carry Zika virus, it is possible for this virus to spread through large parts of the country. While most of us do not live in areas where there is current widespread transmission, we can all do our part to help prevent further spread. To find out more about Zika, you can click on any of the underlined links in this article. You can also log on to [www.Texaszika.org](http://www.Texaszika.org) where you can read more about transmission and prevention.



Does 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)

*\*Head Start is a federal program that promotes the school readiness of young children. Head Start and Early Head Start programs support the comprehensive development of children from birth to age five, in centers, child care partner locations, and in the children's homes.*

*Parent involvement is a large component of the Head Start program. Children are eligible for Head Start based on income requirements. Head Start also has slots specifically reserved for children with disabilities. The Program Locator can help you find the program nearest you: <https://eclkc.ohs.acf.hhs.gov/hslc/>*

## HeadStartOffices

### Questions to help you decide which option to consider:

- 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 and activities, and enroll in 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 friends, relatives, and child care staff who may have useful information to the conference
- 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, contact your ECI service coordinator.



# Finding and keeping positive care-givers for your child

Rosemary Alexander, TxP2P Staff

Sooner or later, many parents of children and young adults with disabilities need to find a care provider. It might be a babysitter for a Saturday night out, a respite provider to stay a weekend with your child while you go to your high school reunion, an after-school childcare provider, or an attendant to assist your young person with his or her daily activities. It's not easy to find someone you like and trust, then train them and keep them as your employee. You probably think of yourself as a parent, not an employer—but you are about to become an employer now! Here are some ideas for carrying out this new job.

You may be paying out of your own pocket or through a program; if through a program, you'll need to understand the hiring process and requirements. You may be using the CDS model (Consumer Directed Services) where you are the employer of record.

## The Hiring Process

Assuming you are ready and eager to find someone to help you out, how do you get started?

1. You have to locate people who would be interested in a part-time job and have the skills, experience and heart for working with someone with a disability. Think about what skills are required to care for your child or young adult, but remember that the willingness to learn might serve as well as previous experience. I have found several very able attendants for my son who had no experience with disabilities but were eager to learn.

Where to find people:

- your own network of friends, relatives and acquaintances; tell everyone you know that you are looking for someone and you might find someone's cousin, sister, daughter, son, or friend who is interested
- staff in special education programs in public schools
- students at local universities and junior colleges, particularly students majoring in education, social work, nursing, health and human services, OT, PT, etc.
- through the web; [www.care.com](http://www.care.com) is the current favorite among many parents I know

- local agencies or service organizations or non-profits
- neighborhood or parent listservs
- newsletters and bulletins for neighborhoods, churches, parent organizations, or community organizations

You will often need an ad of some kind to recruit potential employees. Try to be realistic about the job requirements yet also make the job attractive. Start with the necessities, such as the hours and days of the week, a basic job description, the pay rate, if the person must drive, etc. But if there is room, perhaps you can also mention the benefits of the job, such as what's fun about it or how the job will provide new opportunities to grow and learn.

Don't include your name or address or other private information, just how to respond through a phone number or email address. One friend of mine has a website about her son where a potential employee can read a bit about the job and her son's disability and decide at that point whether to pursue the job.

2. Let's suppose that you have gone through the search process and have found someone that you might hire. What's next? You might start with a phone interview that will screen out those that just won't work out. What are the deal breakers? Ask if the person is free when you need them, has reliable transportation, smokes, is allergic to pets, whatever is crucial to you. Give more detail about the job (including the less pleasant aspects!) and see if they are still interested. If things seem promising, set up an interview.

3. Your next step depends on what you know about the possible employee. If the person is your best friend's daughter, the process can be more informal. If this is a stranger you located through the web, you should proceed with caution. The interview can occur in a public place, such as Starbucks.

Prepare for the interview by writing down the questions you want to be sure to ask. Try to make the person feel comfortable and get to know them a bit. Ask the person to tell you about himself or herself, what experience she has had, why he wants the job. Tell them about the

job and about your child. Give the person time to ask questions. Know what you are looking for and ask yourself if this person fits your needs.

Be sure you deal with the business end of the job. Talk about money: what the rate is, how often he will be paid, if you will reimburse for mileage and food or other expenses, how to reach her and other basic facts, such as references. Get permission to do a criminal background check; for a background check you'll need her full name and date of birth.

4. Be sure to do the follow-up: call references and do a criminal background check. To do the check, go to <https://records.txdps.state.tx.us/DpsWebsite/Index.aspx>.

You will need to create a new account or sign in with your user id and password. Each search costs \$3.00. You enter the name and date of birth and then the results will appear. What you want to see is NO Matching Records; that means the person does not show up in the criminal database. If you are working with an agency or funding source, they will be able to access more in-depth databases.

5. If you and the potential employee are still mutually interested, it's time for this person to meet your child. The meeting can be in a public place or in your home. You need to observe the potential employee interacting with your child and see how your child responds.

## Training

Once you've hired someone, you have to get him or her ready to work. Here are some ideas for orientation and training:

- Make sure this person has CPR and First Aid training. You might even encourage her to take defensive driving if she will be driving your child places.
- Spend time with the new employee; give him or her a written schedule, procedures, and contact information.
- Be sure he understands your expectations and how to communicate with you.
- Be sure she knows techniques for handling your child's behavior, communication methods and other essentials for your child's care.

*Continued on page 7*

# Finding and Keeping Positive Care-givers for Your Child

Continued from page 6

- Link him with another person already doing the job so the new person can gain on-the-job training.
- Observe him or her interacting with your child and share what works or is to be avoided.
- Define the first month as a trial period and then talk at the end of the month about whether the job is working out for each of you.
- Check in often to make sure the new employee understands the job and has a chance to ask questions and get further training.

If you feel uncomfortable leaving your child alone with a new person, at first stay at home but remain in another room and leave the new employee nearby with your child. Then leave home but stay close so you could return quickly; stay away only for an hour or so. Gradually extend the length of time you are gone and how far away you go. Build trust over time.

## Managing and Retaining Employees

If you like the new person and she is doing the job well, you will probably want to encourage her to work for you as long as possible. You will need to nurture and monitor the working relationship. Here are some guidelines:

- Be sure the employee knows what's important to you.
- Encourage the employee to bring up concerns early on, before they get worse.
- Do an occasional evaluation or assessment where both you and your employee talk about what's going on, what's working well and

not working well; give the employee a chance to talk.

- If you are in a program that requires a formal evaluation, tell the employee several months ahead of time what the evaluation will be based on.
- Praise when he or she does something well.
- Give a bonus or gift at holiday time.
- Give a bonus for staying and /or doing a good job.
- Have occasional gatherings for your employees (if you have more than one) to talk, work on schedules, eat and enjoy time together. Work to build a team.
- Provide your employee with the expertise and equipment to do a good job.
- Use some form of record keeping so that each employee can note what went on during his or her time with your child and can share it with the team and family.

Your attitude toward the employee makes a big difference. To retain an employee, you must always be

respectful of this person. Never yell at him, berate her, or be overly critical. If you have to confront the employee with negative feedback, think first about how to present it. Communicate your thoughts privately, never in public; don't attack the person but rather comment on the behavior; tell her how to remedy the problem and what you want her to do instead of what she is currently doing.

We as parent-employers are sometimes in a tough spot, because this is not an ordinary working relationship. This employee may be in your home and may bathe your child, dress and feed him, entertain him. The employee gets to know your child, home and family in a close way. You may end up developing a strong relationship with the employee, even a real friendship. Yet you are also the employer. It's sometimes hard in such a relationship to point out what's going wrong.

Somehow you have to maintain a balance between being positive, approachable, concerned, respectful, yet still being able to discuss the job requirements objectively; you have to be able to talk about money, performance, and issues that come up. It's a delicate balance and takes practice. You learn the skills as you go to be an effective employer. Putting the time and energy into being a good employer is worth it: you will get the help you need to provide quality care for your child or young adult. Learn to share with another person the joys and challenges of parenting your son or daughter!



## 85<sup>th</sup> Legislative Session Update

Linda Litzinger, TxP2P Staff

We have an amazing number of parents participating in this 85<sup>th</sup> Legislative Session and a record number of *Special Education* bills filed! Among them: new curriculum at the college level to prepare regular educators for inclusion, elimination of the 8.5% cap on special education, re-testing of students turned away, Response to Intervention strategies, high stakes testing, safety cameras implementation intervals, legal fees, to name a few.

Some *health issues* that are being debated are the managed care drug

formularies, pharmaceutical step therapy, frequency of changing providers, and cannabis for additional medical diagnoses.

*Long Term Care* issues being considered are CDS attendant wages (involving cuts so deep that entire staff may quit), registration and oversight of day habilitation sites, employment support, elimination of sub-minimum wages, guardianship reform, and deaf-blind supporters and interveners.

One way to watch for bill hearings is

by monitoring by committee. *Education*: [House](#) and [Senate](#). *Health and Human Services*: [Senate](#), [House Health](#) or [House Human Services](#). You can also sign up for [bill alerts](#) for specific bills.

Far or near, if you wish to participate, please let me know! [linda.litzinger@txp2p.org](mailto:linda.litzinger@txp2p.org) or cell 512-922-3810.



Texas Parent to Parent  
1805 Rutherford Ln., Suite 201  
Austin, TX 78754  
Toll Free: 866-896-6001  
Local: 512-458-8600  
Website: [www.txp2p.org](http://www.txp2p.org)  
Email: [txp2p.org](mailto:txp2p.org)

Address Service Requested

NONPROFIT ORG  
US POSTAGE  
PAID  
AUSTIN, TX  
PERMIT NO. 657



5114 Balcones Woods Dr., Austin, TX 78759  
512-794-9000, [www.gpsaustin.com](http://www.gpsaustin.com)

Thanks to Global  
Printing Solutions for  
Printing This newsletter  
at a reduced cost for TxP2P!

Conference Schedule

Date	Conference Title	Location	Registration Information
May 11-12, 2017	5th Annual Texas Primary Care & Health Home Summit	San Antonio	<a href="http://www.texashealthhomesummit.org">www.texashealthhomesummit.org</a>
May 13, 2017	A Look Ahead Conference	Arlington	<a href="http://www.alookaheadseries.com/registration">www.alookaheadseries.com/registration</a>
June 16-17, 2017	13th Annual Texas Parent to Parent Conference	San Marcos	<a href="http://www.txp2p.org">www.txp2p.org</a>
August 3-4, 2017	25th Annual Texas Autism Conference	San Antonio	<a href="http://www.txautism.esc2.net">www.txautism.esc2.net</a>
August 4-6, 2017	Abilities Expo	Houston	<a href="http://www.abilities.com/Houston">www.abilities.com/Houston</a>