

# A Parent's Perspective

**TXP2P Quarterly Newsletter** 



### **Helping Your Teen Create Social Circles**

Linda & Amy Litzinger, TxP2P Staff Reprinted from Navigate Life Texas, https://www.navigatelifetexas.org/en/blog/ article/helping-your-teen-create-social-circles

"It can be really hard for a teenager to find a social circle when she can't do the slumber party because she needs a parent or caregiver with her and she can't just ride in her friend's car to the mall." – Linda

Children with disabilities or special health-care needs often need a little extra support to find their place in the tricky world of high school. Linda actively supported her daughter, Amy, who is now in her 20s, has a master's degree, and is active in her community's art, dance, and theater scene.

Starting when Amy was very little, Linda found ways to help Amy follow her interests. Amy was in art and science camps, dance classes, and the Girl Scouts. You can see some of Linda's suggestions for making these sorts of activities work in her article, "Finding Activities that Work for Your Child" on Navigate Life Texas website (www.navigatelifetexas.org).

As a freshman in high school, Amy didn't immediately know how she fit in. But then she found her place in theater. "I had a great theater teacher who got me involved in her program," Amy says. "There were all kinds of different kids in theater, with and without disabilities, and I was just part of the group."

Other students who aren't interested in theater might find their place in things like art classes, keeping score for a sports team, joining the band, working with A/V equipment, in a chess club or other school clubs, or by taking photos for the school paper.

Or they might connect with other teens and find their place in activities outside of school. Amy used Girl Scouts and her church youth group to connect with other teenagers: "For years, my friends from Girl Scouts had seen what it took to plan an activity that was accessible for me. They became my advocates and made sure other school friends would plan activities that would work for me so I could be included."

It can take some very open conversations up front to figure out how to make activities work for teens or young adults with disabilities or special health-care needs. When Amy went to Girl Scout camps, Linda would very clearly outline what Amy was going to need from the staff there. Helping any teacher or group leader understand your child's needs and abilities is important before the activity or program starts. Otherwise, the activity leader might expect the teen or young adult to do things that are outside of their abilities.

Continues on page 2

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#### Inside this Issue:

- ▼ Helping Your Teen Create Social Circles pages 1 & 2
- ▼ TxP2P Program
  Spotlight Advocacy
  Network— page 1
- ▼ Developing a Social Group for Young Adults — pages 2 & 3
- ▼ Summer Camp: Now is the Time to Sign Up—page 3
- ♥ Personal SupportNetwork Provide SocialOpportunities page 4
- ♥ Social Apps for Making Friends — page 5
- ♥ Our Book Review page 5
- ▼ The Governor'sTrophy page 6
- ▼ TxP2P Update page6
- ♥ ECI Specialized Skills
  Training page 7
- ♥ Conference Calendar— page 8

### Spotlight on a TxP2P Program: Advocacy Network

The TxP2P Advocacy Network started in 2010 as a grant from the Texas Council for Developmental Disabilities. We set out to provide the training and experience for parents of children with disabilities, siblings, family members and self-advocates (people with disabilities) in advocacy skills. TxP2P doesn't set the agenda or policy statements based on the beliefs of Texas Parent to Parent.

Instead we encourage the parents and family members to bring us an issue they want to work on or change and we help them decide: who can make the changes they are interested in, how to contact and approach that person or group, and how to discuss the issue.

This can be a local, regional, statewide or national issue. Linda and Amy Litzinger have been with this project from the beginning. They attend a variety of state meetings every month in order to stay up to date on what is happening in the state and identify some of the trending problems or issues that our families are facing. They meet with parents by phone or in person to discuss the issues they want to work on and help them plot out the steps to affect the change they want to make.

For those of you interested in state legislature advocacy, Linda and Amy coach parents and family members in a formal training at the Capitol at least once a year and have a mock legislature

#### Linda & Amy Litzinger, TxP2P Staff

This can be a local, regional, statewide or national issue. Linda and Amy also will go with them to visit their legislators to learn how to best express their views to their legislators.

You can contact Linda at Linda.Litzinger@txp2p.org or 512-922-3810 and Amy at Amy.Litzinger@txp2p.org.



### **Helping Your Teen Create Social Circles**

Continued from page 1

Linda stayed involved in and out of Amy's school. Linda says, "Volunteers run activities outside of school like scouting or church groups. They don't always want to put in extra time re-planning events so they're accessible. I made sure I was always on the planning committee so that they'd be accessible from the start. and social opportunities too."

I also got a job substitute teaching 2 or 3 days a year at Amy's school so that I could observe extracurricular and social opportunities too."

Some other places that might help a teenager or young adult find social outlets include: programs at the YMCA, 4H, or activities designed specifically for children with disabilities. See our Finding Activities That Work for Your Child blog article for some ideas that have worked for other families. You and your child could also find or start a



Meetup group at www.meetup.com/. Meetup groups offer ways for people with common interests to find each other. There are groups for just about anything your child might be interested in. But we recommend you always think about safety. Make sure groups meet in public places, and maybe have someone who you trust go with your child until you know who else will be there.

You and your child can also use Navigate Life Texas website to find services, groups, and events near you under the "Find Services, Groups and Events" tab.

### **Developing a Social Group for Young Adults**

Leah Rummel, TxP2P Volunteer

When my son, Brandon, graduated from his 19+ program at high school, we moved back to our rural community of Dripping Springs. I wanted my son in a smaller community where he could more easily meet people and develop friends. Brandon was already working at 3 part-time jobs and participated in a choir and horseback riding, basically a busy guy.

On Fridays we scheduled a more fun and social day, because having friends is important for happiness and health. Then I thought, if we are going to do fun things on Friday, we might as well invite other people. There were other young adults in Dripping Springs that needed more social opportunities and stronger friendships.

Brandon has a personal network of friends and families who help keep him active in the community. Brandon's personal network suggested that I set up a social group on Facebook and invite people from the community to meet up for social events. I set up the "Dripping Springs Friendship Club" on Facebook. It is a closed group and I approve those who want to participate. We are currently up to 123 members.

Brandon's job coach and occasional aide, Mary Buchanan, was interested in helping with the group and began posting what Brandon was doing each Friday. Mary was retired from Dripping Springs School District as

a special education teacher and knew many of the young adults in the area.

We started with 4 to 6 people showing up to the events each week and now the group has grown and can have as many as 20 especially on bowling days. The group meets for lunch and then goes on to a social event. The rule was set that each person with disabilities would need to have someone to support that individual for their events. Here are some of the benefits we have found with the group:

- Many of the young adults have become great friends; they go out to movies or to eat on their own, and many communicate with each other
- One young man is now a job coach for two others looking for work.
- Some are talking about how they can't live with one another.
- From the group, there has been a spin-off with the development of Exceptional Saturdays, a group of musicians who volunteer each week with adults with disabilities, many in our friendship club. They meet at our local bar "Hudsons on Mercer" to play and write music. Exceptional Saturdays has played out in the community and are known in Dripping Springs.
- Five of the guys that come each Friday formed a band called "The Eddie Ray Band."

They perform around town and even played for Tim Shriver at a Special Olympics event.

There are challenges, of course, which include:

- Getting everyone to respond if they are going to participate for the week.
- Developing what the group will do,
- Getting creative on transportation. Many of the young adults now will come on their own if we can find them rides. We have shared rides to the events.
- Getting more engagement from everyone in the group to suggest events for the week or post their own events.
- Communication. Some people are not on Facebook so postings have to be via email, text and Facebook, making communication harder.

It is always a work in progress but worth the benefits. Some fun ideas from our group for you to consider are:

- Bowling
- Yoga
- The movies
- Making crafts
- Cooking lessons
- Making art at the Art Garage
- Putt-Putt
- Going out to hear music
- Helping out at a local farm
- Singing Christmas Carols
- Halloween and Christmas parties, and much more.

The group has really evolved since September 2015. One of the best

Continues on page 3

### **Developing a Social Group for Young Adults**

Continued from page 2

things I have seen from this group is how supportive they have become of one another.

They really care about their friends and want to know what is going on in each other's lives. The parents have also developed relationships and don't feel as isolated, sharing information and ideas. Who knows where we will

go from here, but it has been worth the effort for my son who now has friends.

You can learn more about personal networks on the TxP2P website, <a href="www.txp2p.org">www.txp2p.org</a> and look for Texas Network Connections – <a href="www.txp2p.org/services/texas-network-connections">www.txp2p.org/services/texas-network-connections</a>. You can create your own network for your

child or have TxP2P help you.



### Now is the Time to Sign Up for Summer Camp



Early spring is the time to think about signing up your kid for summer camp, as many camps fill up during this time. So how do you take the leap, find the right camp, sign up and pay for it?

There are many benefits to your child going to camp, but here are 3:

Your child will have new experiences, learn new skills and meet new people. You will have a chance to spend 1-1 time with other family members and take a break.

And it's a chance to practice the fine art of letting go. While away, your child will learn that he can be okay without you for a few days, and you can learn that your child can survive for a few days without you -- a big transition step for both of you!

#### Learning more about camp

Start by reading this very helpful article on Navigate Life Texas under Family Support: <a href="https://www.navigatelifetexas.org/en/family-">https://www.navigatelifetexas.org/en/family-</a>

support/sending-your-child-to-camp. Here you will learn much more about the advantages, how to find the right camp, how to get ready for camp and other ideas that are super helpful.

#### Finding a camp

There are several options for camp experiences: day camps and overnight camps, where your child might spend a weekend or up to 5 days out of town. And note that some camps are for children with disabilities or chronic illness only, while others are for all children—in either case you will need to explore how a camp supports children with disabilities. You need to find a good match between your child's interests and needs and what

Take the plunge and find a way for your child to have fun while you get some respite! Apply for camp now!

supports a camp can provide.
At this link on Navigate Life Texas website, you will find a way to search

for camps: go to

www.navigatelifetexas.org and type in summer camps in the search bar. Or to find camps in your area, go to www.navigatelifetexas.org and click on Find services-groups-events, then at that page fill in summer camps, and

#### Rosemary Alexander, TxP2P staff

you'll end up at a page where you can enter your location and get a list of camps in your area.

Here is another website that helps you find a camp: <a href="http://find.acacamps.org/">http://find.acacamps.org/</a> on the American Camp Association website.

Several away-camps in Texas are for children and adults with disabilities from all over the state: Camp CAMP, Camp Summit and Texas Lions Camp. These camps provide genuine camping experiences with the supports needed by children (and adults) with all kinds of disabilities.

#### Paying for camp

Some camps have scholarships or a sliding—fee scale to help pay for the cost of summer camp. If your child is on a Medicaid Waiver like CLASS or HCS, your waiver budget can include funds for out-of-home respite for camp. Other possibilities are your Local Authority, your school district and local organizations. Please go to the <a href="https://www.navigatelifetexas.org">www.navigatelifetexas.org</a> article on sending your child to camp for more details: <a href="https://www.navigatelifetexas.org">https://www.navigatelifetexas.org</a> article on sending your child to camp for more

www.navigatelifetexas.org/en/familysupport/sending-your-child-to-camp. Or call us at TxP2P for help at 866-896 -6001.

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### **Personal Support Networks Provide Social Opportunities**

Linda Jones, TxP2P staff

Good health is more than just physical well-being. It also includes having relationships with other people.

Social health is commonly defined as your ability to form meaningful relationships with other people and interact in healthy, positive ways. The way you connect to the people around you and experience a sense of belonging all contribute to your social health.

People with disabilities are often particularly challenged when it comes to social health. When a person with a disability graduates from public school, they are suddenly left without the social opportunities that the school community has provided. A personal support network can help fill that gap and address the issue of social health. Texas Parent to Parent helps families create personal networks for their children and adults. (To learn more about networks, go to www.txp2p.org and look for Texas Network Connections www.txp2p.org/services/texasnetwork-connections.)

"People with disabilities are often particularly challenged when it comes to social health."

How can networks promote social engagement? First of all, network meetings provide a venue for people with disabilities to be around other people who care about them. Even if the individual doesn't relish being around others, the experience still gives a positive social opportunity for the number of times the group comes together each year.

Second, networks may provide a way for the focus person to develop relationships that go beyond meetings. Network members will learn what a person enjoys doing, how they communicate, and how to keep them safe while out and about. Building this knowledge can open doors to lots of social events. For example, as a result of my own participation in the Bee Hive Network, a young man named Berk and I have started volunteering once a week at the Austin Humane Society.

Third, networks provide a place where parents and family members can share their concerns freely, thus lightening the load and perhaps opening a door and encouraging participation of network members in unexpected ways. Apart from the main purpose of networks being focused on the person at the center, friendships can develop among network members, providing social opportunities and a sense of



Berk and a dog at the Austin Humane Society

community for all members of the network.

It is true that a network is not an instant fix or a magical solution; however, networks provide their own magic--social opportunities and fun for everyone in the group!

### **Social Apps for Making Friends**

I remember the first time I thought of reaching out to other moms with a child like mine. On our daily trip to the park, I was standing there watching my kids when a neighborhood mom and her rambunctious little boy showed up. We had that momentary eye contact where you realize, this mom knows the struggles of an energetic 3-year-old. We swapped stories about sensory processing disorder and she told me she was in a group on Facebook.

That group got me through the first two years of my son's diagnosis. They answered questions, soothed my concerns and helped me to understand his diagnosis and what it meant for him and our family. As we began to settle into our new normal, I began to realize that much of my support was online, and I was ready to get out of the isolation I felt in my community. If you have been left feeling like you could use a little more human connection without the device, here are some apps to find other friends in your area, for you or your child.

#### <u>Patook</u>

This app stresses that it is for making friends
ONLY! Part of the verification process includes taking a picture of yourself holding a sign that says I will not flirt on Platook! Through a questionnaire, you give all kinds of information in-

cluding the personality types you prefer. You can include key words to help connect you with people interested in the same things. This app has a high rating, and a LOT of downloads. It's easy to use. Just make sure you swipe right on people you like and left if they aren't a good match. This

app works with Android and IOs.

Elizabeth Hong, TxP2P staff

#### **Bumble BFF**

Did you know you can use Bumble to search for friends? With a handful of questions, my pro-



file was up and running. I found that in my area, Bumble

Continues on page 5

had a younger crowd that I felt did not match me as well.

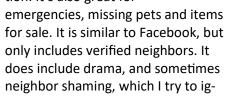
#### Meet up

This is still a great option for finding mommy groups, book clubs, support groups, you name it. Meet Up is both an app and a website, which means you can use your computer or your phone. Don't worry if you don't see the group you want, you can make your own. Joining a group might cost money, depending on that

have a fee and so many groups charge. This app works with Android and IOs.

#### Nextdoor

If you want to connect with families in your neighborhood, this may be a good option. It's also great for



group's policies. Starting a group does nore. One of the moms in my neighborhood used Nextdoor to find members for a neighborhood online moms group. It is great for asking questions or sharing info. I really find Nextdoor to be a great way to communicate with my neighbors and find out what's going on near me! This app works with Android and IOs.

> I hope you find some of these apps useful and find friends to share the challenges and successes of raising your child. Having friends and peer support is what TxP2P wants for you

### The benefits of friendship







**Helps** you cope!



### Book Review: Meredith and Me, by Sarah Barnes

Review by Rosemary Alexander, TxP2P Staff

If you are the parent of a child with a disability or chronic illness, the book Meredith and Me will send you straight back to your memory of getting the first diagnosis or news about your child's condition. The Austin-based, award-winning author, Sarah Barnes, vividly describes the joy she felt with her newborn and then the anxiety, fear and ultimately devastation of learning that her baby's brain was abnormal.

Yet this book is laced with humor and hope. Sarah takes us on her

Sara Barnes with her daughter Meredith

journey from Meredith's birth to age 18, as she graduates from high school, with details, stories, emotions and experiences that make the journey very real and thoughtful.

Sarah describes therapies, surgeries, and milestones; she and her husband encounter positive school staff and unresponsive school settings; they have painful encounters with the public and find caring, helpful family and friends; their family adds a little sister who gains skills with lightning speed;

they celebrate as Meredith gradually learns to walk and talk, doing things that doctors had said she would never do. Through it all Sarah has an eye for poignant details, honest emotions and funny scenes.

An example: Meredith has a visual

impairment and would use only one eye at a time. Sarah was told that corrective surgery might never work. "The 'never' word always made me sick to my stomach. The next several months I would sometimes walk around the house with one eye closed to see how Meredith's world looked, which made me either an incredibly sensitive mother or completely neurotic!"

Meredith and Me is truly a gift to the community of families of children with disabilities and special health care needs, and perhaps it will also touch those outside our community, helping them to understand the journey that we experience with our children. Thank you, Sarah, for your story.

Sarah's book is available at Book People in Austin or online at Amazon Kindle. For more information on buying the book, please contact Sarah directly at mydifferentroad@gmail.com

### The Governor's Trophy to Laura J. Warren

The Governor's Trophy is the Governor's Committee's highest honor and is awarded to the person who has achieved the highest success in enhancing the empowerment and employment of Texans with disabilities. The Governor's Trophy recognizes long-term commitment and outstanding efforts at both the community and

state level to a professional or volunteer in the field of disability issues.



Laura Warren, Austin

Founder (one of many) and Executive Director of Texas Parent to Parent, Laura Warren has played an instrumental role in educating and advancing peer support for parents of children with disabilities. She has demonstrated the importance of a parent's voice and believes in focusing on the abilities of children. Fifteen years ago, she initiated a 2-day conference for the whole family with an attendance today of over 800. She has touched the lives of many thousands of individuals with her strong and dedicated

leadership and her belief in the power of the parent voice.

Laura has built a robust collaborative relationships with state leadership. Laura is highly respected and has created a legacy of an unsung heroine and role model for parents. Through her dedication, Texas Parent to Parent (TxP2P) has grown the organization to a staff of 25 and a budget over half a million dollars, and a national reputation as a leader in parent advocacy. Before launching TxP2P, Laura worked for ten years for the Arc of the Capital Area's Pilot Parent program.



# **TxP2P Update**

Laura J. Warren, Executive Director, TxP2P

**H**APPY NEW YEAR! We hope you all had a little rest and relaxation over the holidays!

We have had a few changes at TxP2P. As of December 31<sup>st</sup>, 2018, Susan Prior has retired. For all of you who registered for our mailing list or conferences, Susan was the person who responded to you by email or phone about your registration. Susan has been an employee with TxP2P for 11 years, but she was actually with us since we started in 2002. She was the person who every week urged me to start a statewide parent-to-parent program after I left a local program in Austin. And once we did start TxP2P, she was on our first Board of Directors and soon became the Board Chair. It won't be the same without Susan at the office, but we are all very happy that she is finally going to be able to stay home now with her daughter and get a little rest.

Also, Patty Geisinger has been out since the first part of December after a major surgery, but after a few bumps in her progress, she is recuperating and getting stronger every day. We expect her to be back in the office soon.

Finally, the planning has started for our conferences this year: East Texas Parent Conference is in Tyler on February 23<sup>rd</sup> and our new venue, Amarillo, will be Route 66 Parent Conference on March 30<sup>th</sup>. Hope you can join us for these regional conferences, as well as our Annual Conference June 21-22 in San Antonio.



# Early Childhood Intervention

### **Specialized Skills Training**

**S**pecialized Skills Training (SST) is a service offered exclusively by Health and Human Commission Services, Early Childhood Intervention (ECI) programs. SST is designed to help parents and other caregivers identify strategies to promote their child's development, especially cognitive and social skills, through common daily activities in settings where the child and family typically spend time. This is because there is no richer learning environment than an infant and toddler's home and no better teachers than parents, extended family and siblings.

Research demonstrates that the brain is the most malleable or "plastic" during the infant and toddler years. Because of this, every interaction and every environment the child experiences is an opportunity for growth and development. SST helps parents identify opportunities for enriching interactions to enhance learning.

Cognitive development begins in infancy. For example, an infant kicks a mobile because she naturally kicks out the legs. The

mobile moves and perhaps makes sounds. She sees something happen that has captured her interest. The infant may first observe, but after several repetitions, she understands that the action causes the mobile to move.

This early learning of cause and effect is a building block for more complex tasks. In addition, family members share in her excitement about what happens when the infant kicks the mobile. The baby enjoys this interaction and attention and wants to repeat it. Positive early experiences that support cognitive development contribute to traits that support life-long learning, such as curiosity and persistence.

The SST service is provided by an Early Intervention Specialist (EIS). The EIS is credentialed by the Health and Human Services Commission ECI program. An EIS is a credentialed specialist in:

- Infant and toddler development, both typical and atypical patterns
- Early childhood cognition, motivation and learning
  - Typical infant and toddler behavior and challenging behaviors (biting, tantrums, picky eating, sleep issues)
  - Infant and toddler social interactions
  - How developmental areas are interconnected Children with delays

and disabilities often need assistance to enhance their development. Through Specialized Skills Training, EIS teaches parents to support the child's cognitive development by introducing strategies into everyday activities that promote cause and effect, attention and adjusting to changed demands.

For example, when a child is having problems with transitions, the EIS may suggest a timer or song to "cue" the child to anticipate there will be a change from one activity to another. The EIS supports the family as they implement this strategy for transition and also asks for feedback about how it is working. Sometimes this means that the EIS and family must try several strategies to find the right fit for the child and family.

There is a strong link between the development of cognitive functions and social and emotional development in young children. One of the key points about brain development is that a positive relationship with primary caregivers is essential. The focus of all early intervention services is to create positive working relationships with families that will support the parent and child relationship and promote development across domains.

For more information, please visit the HHS, <u>ECI website</u>.

(https://hhs.texas.gov/services/disability/early-childhood-intervention-services)





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#### **Conference Schedule**

Date	Conference Title	Location	Registration Information
February 10-12, 2019	2019 Inclusion Works Conference— "Rock the Boat"	Denton	www.thearcoftexas.org/ inclusion-works
February 20-22, 2019	2019 Texas Transition Conference	San Antonio	www.ttc.tamu.edu/texas- transition-conference
February 23, 2019	TxP2P East Texas Parent Conference	Tyler	www.txp2p.org
March 30, 2019	TxP2P Northeast Texas Parent Conference	Amarillo	www.txp2p.org
June 21 - 22, 2019	2019 Statewide Annual Conference	San Antonio	www.txp2p.org