

HAPPY HOLIDAYS!

Laura J. Warren, TxP2P

We know for some the holidays can just add stress to our already stressful lives but we hope you all find ways to enjoy the holiday season - even if it is just not getting up quite so early to get the kids to school. Try to take a little time for yourself this year!

The end of the year is also when TxP2P reaches out to our friends and family to ask for a donation to help us serve more families in 2014 but only from those of you who can afford to make a donation. We know that raising a child with a disability costs a lot because we are all doing it as well and know there are times you have no extra money and times you are doing okay.


For many families, Texas Parent to Parent is a lifeline that connects parents to other parents who walk in their shoes. Yes, it's sometimes hard to raise a child who has a disability, but TxP2P facilitates a community where parents can share their lives with each other and be joyful about their families.

Our staff presently serves over 5,000 families around the State, but there are as many as 500,000 children in Texas who could benefit from our family support services. We cannot serve many more families without additional funding.

If you are able to make a donation this year, please support Texas Parent to Parent. The money we raise will support our programs and empower us to reach out to more families throughout the state. In addition to funding through grants and contracts, TxP2P relies heavily on private donations to support our programs and operating expenses. Thanks to the generosity of individual donors, TxP2P has grown over the last 12 years and has built a solid foundation of support for families raising a child who has a disability. In 2014, we are on a trajectory toward incredible growth as an organization with the ability to impact even more families.

On behalf of Texas Parent of Parent’s staff and board of directors, I wish you and yours the very best this holiday season.

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Child Relinquishment

Linda Litzinger, TxP2P Advocacy Network, Staff

Colleen Horton from the Hogg Foundation for Mental Health was a recent guest speaker for our weekly advocacy calls. Colleen and other call participants discussed the critical issue of child relinquishment - parents relinquishing custody of their child solely for the purpose of obtaining vitally needed mental health services. The following is a summary of the discussion:

Intensive mental health services and treatment for children with serious emotional disturbance (SED) or significant behavior challenges are often not accessible to the children and families who need them. A very real consequence of not having access to these services is that in some cases the parents’ only option after

exhausting insurance, family re- sources and their own emotional health is to make the heart- wrenching decision to place their child in the custody of Child Protective Services (CPS) so that their child can get the mental health services he or she needs.

Adding insult to injury, when parents relinquish custody of their child to CPS, they are deemed as having “refused to ac- cept parental responsibility,” re- ferred to as “RAPR.” This is consid- ered a form of neglect which re- sults in the names of these parents being added to the central abuse and neglect registry. This can have horrible ramifications for both the



child and the family that can affect them for the rest of their lives. These parents have typically done everything possible to obtain services for their child, and are “relinquishing custody” solely to obtain intensive mental health treatment their child needs. They are not refusing to accept parental responsibility; they are doing what they need to do as parents, often at great personal costs.

In the past, the Department of Family and Protective Services has not been able to tell us how many of these children are in the system. They can tell us how many “RAPR” kids are in conservatorship, but cannot tell us how many entered

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the system to receive mental health services. As a result of SB 44 (Zaffirini/Burkett), this data collection is now required.

Unfortunately, our state systems treat parents very differently depending on the type of disability a child has. In the parallel system serving children with intellectual/developmental disabilities (IDD), both children and families are treated much more compassionately. In the IDD systems there is an entitlement for institutional care for children with IDD meeting certain functional criteria. If parents choose to place their child with IDD in a long term care facility, the state pays for the placement and does not require relinquishment to obtain these services. The parents retain parental rights, are encouraged to visit their child regularly, and retain decision making authority. While we don't recommend these institutional options, the contrast in how we treat families of children with SED is startling. Families of children with IDD are not labeled as neglectful and abusive parents even though their actions are no different than parents seeking treatment for children with SED.

As a state, there are times we

empathize with parents of children with IDD, yet we strongly penalize parents of children with serious emotional disturbance.

Systems changes are needed to ensure that these children and youth get the intensive services they need without requiring parental relinquishment and without "criminalizing" the child or the parent. Policy changes are needed to prevent the designation of the parents as "refusing to accept parental responsibility" when the sole reason for relinquishment is to obtain mental health services. More importantly, our state needs to find better ways to support these children and families to prevent relinquishment.

Senate Bill 44 (Zaffirini/Burkett) passed in the 83rd Texas legislative session begins to address the problem. The bill requires the Department of State Health Services and the Department of Family and Protective Services to jointly study ways to prevent relinquishment and develop recommendations for review by the Executive Commissioner. The Commissioner has discretion to implement recommendations that do not require additional resources. Actions that require additional funding will need to be

taken to the legislature for approval.

SB 44 also requires the state to discuss the option of joint conservatorship when children are relinquished to the state solely to obtain intensive mental health services. This is critically important as it allows the family to remain engaged in the child's life and contribute to the decisions made that impact the child. It also increases the likelihood of reunification with the family which should in most cases be the primary objective. The recent legislation keeps child relinquishment in the forefront and forces continued efforts to fix the problems.

It was suggested during the call that families present their experiences and stories to commissioners, legislators, the Children's Policy Council, the Council on Children and Families, and the Sunset Commission. I can help make introductions between parents should you wish to coordinate efforts. I can also help with setting up meetings at state agencies or with legislative staff. You can contact me at 866-896-6001 (toll free) or 512-458-8600 or Linda.Litzinger@txp2p.org.



One of the services provided by an Early Childhood Intervention (ECI) program is Specialized Skills Training (SST). This service is intended to address the "design of learning environments and activities that promote an infant and toddler's acquisition of skills in a variety of developmental areas, including cognitive processes and social interaction" (IDEA Part C, 34 CFR §303.13 (b)(14)(i)). 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 supports development across domains with an emphasis on strengthening cognitive skills, positive behaviors and social interactions.

There are four components within the cognitive domain that describe how young children develop and demonstrate abilities: exploring the world around them, solving

problems, remembering and retaining information, and pretending and using their imagination. Cognitive development is reflected by growth in thinking, reasoning, and understanding.

The four components of the cognitive domain are part of the cognitive process called **Executive Function**.

Executive function "refers to a group of skills that helps us to focus on multiple streams of information at the same time, monitor errors, make decisions

Specialized Skills Training

Give a Little Time to the NICU Network

Mary Jo Miller, TxP2P Staff

Are you a parent of a baby (or babies) who started life in the NICU? Are you willing to connect with another parent to share experiences and provide support? The TxP2P NICU Network needs you! Most of the connecting happens on the phone or email.

TxP2P plans to hold a NICU Network training day in Austin in January. We are also planning a training day in Houston, San Antonio, San Marcos or Temple later in 2014.

If you live in any of these areas and would be willing to:

- join us for a training day,
- help us find parents in your area, or
- work with an organization or hospital in your area to partner with us.



Please contact Sherry Santa at 512-458-8600 or toll free at 866-896-6001 or email at Sherry.Santa@txp2p.org and let her know that you want to join us or help!

Living After the NICU

On January 16, 2013 my life changed forever with the birth of my twins, Mason and Nevaeh.

I was distressed after the birth of my premature twins, followed by the death of my baby, Mason. I experienced many emotions including sorrow, guilt, anger and regret. Love and joy are there, too, but sometimes the pain can overpower these good feelings.

One of the hardest things about being blessed with twins is seeing one and not the other. I went through a harrowing birth experience and the fragility of my babies', then straight into "The NICU!" Needless to say, I'm grateful and very humbled by our experience in the NICU. Having a baby in the Neonatal Intensive Care Unit (NICU) can be a heart-wrenching, overwhelming, and potentially traumatic experience. The NICU itself is full of sights, sounds, and smells that are unfamiliar and anxiety provoking.

My baby girl and I are trying to learn to live without her twin

brother. I've followed my precious baby girl, Nevaeh, through the most difficult time in her life, the long journey through the NICU, and she has proved that she is a very strong baby girl who isn't just surviving but also thriving! As I face and learn to cope with my painful feelings, it takes time to be able to get to know and love my baby and experience the new joys of being a mother.

The NICU stay was like a rollercoaster ride, with ups and downs, triumphs and setbacks. I was along for the ride. The experience is one that no parent should ever have to go through. Especially losing one baby then watching the other one fight for her life!

Tragedies such as these are even more heart breaking when friends and family members, who should have been there by my side, were not. This is a double smack in the face. I was able to get through it all by the grace of GOD and organizations like Texas Parent to Parent.

Thanks for the continuous support for myself and my precious babies.

Tina Coleman, TxP2P Parent

"By remembering, we keep what is precious and most special, as treasures in our heart forever."

When someone comes into our lives and they are too quietly and quickly gone,

They leave footprints on our hearts.

And their memory stays with us forever.

Mason Artez Coleman Jr.



Our baby boy, you will be truly missed but never forgotten! We Love you so much and miss you every day. Your life forever changed ours.

Love you baby boy,
Mommy, Daddy, and Siblings

Does Your Child have a Care Notebook?

Source: Oklahoma Family Network Care Notebook Task Force

Jeanine Pinner, TxP2P Staff

A Care Notebook is an organizing tool for families who have children with disabilities, chronic illness or special health care needs. It assists families with recording and organizing important information about the child's health, educational and social issues such as medical information, appointments, etc. It also provides the child an area to record his or her interests and participation in various activities. This notebook is a reflection of them, medically, educationally and socially and gives the child an opportunity to express him or herself openly.

A Care Notebook makes it easier for you to find and share information with others who may provide care for your child or who are involved with your child at school, work, or in the community. In actuality, persons of all ages and health statuses could benefit from having their very own Care Notebook!

You can use your Care Notebook to:

- List phone numbers for health care providers and community resources
- File information about the child's health history
- Prepare for appointments

- Share new information with the primary doctor, specialists, emergency MD, public health or school nurse, daycare, educators, and others caring for your child
- Track changes in your child's medications or treatments
- Take with you when you take your child out of town or on vacation, or in the event of an emergency

Helpful Hints for Your Care Notebook

- Store it where it is easy to find
- Add new information as you/your child have a new evaluation, ARD, surgery, medication change, diagnosis, etc.
- Take it with you to appointments, hospital visits and ARD meetings.

Setting Up Your Notebook

- Gather information you already have
- Look through the pages provided
- Decide which information is most important to include
- Put the notebook together
- Review and update it as needed
- Don't forget to take it with you!

The greatest challenge to this



project is getting everything together. Just gather what you can and continually add new information. Be sure to take it to each physician visit, hospitalization and ARD meeting.

You just never know when you will need the information you have carefully stored here.

Texas Parent to Parent also offers the Transition Care Notebook component, which supplements the Care Notebook. This component includes issues such as financial goal setting, writing college scholarship essays, how to apply and interview for a job, resume' writing, developmental skills checklists, and more.

Texas Parent to Parent's Care Notebook/Transition Care Notebook is well underway and will be posted on our website (www.txp2p.org) soon. Our Care Notebook/Transition Care Notebook documents are in PDF format and can be filled-in, saved and printed by the user (requires the latest version of Adobe Reader [free]). Please contact Jeanine Pinner, Training & Outreach Coordinator, at Jeanine@txp2p.org with any questions about TxP2P's Care Notebook.

Austin Diaper Bank - Could Be in Your Area as Well

Beverly Hamilton saw a need in the Austin community and jumped in to help fill that need. In Central Texas, there are very few options to help low income families buy diapers for the adults and children (especially those really expensive diapers for kids over 4 years old) in their family. She quickly realized that we



did not have an organization that helped with this very expensive necessity here in Austin. So she founded the Austin Diaper Bank.

Since July 2013 the Diaper Bank has given away over 20,000 diapers to Austin families who need them. To learn more about this new local nonprofit, visit their web page at www.austindiapers.org. Learn how they got it started and maybe start one in your area!

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Charting Your Course to Financial Security

Pathways to Adulthood: Thinking About Going to College

Rosemary Alexander, TxP2P Staff

Many of you may wonder if your child might go to college some day, whether 2-year or 4-year schools or some other post-secondary college experience.

And if so, how do you prepare for this big decision? I've discovered several excellent websites with useful information on this subject.

One website is www.going-to-college.org. Below is a summary of the major topics taken from the website with advice on each topic:

Here's a quick glimpse of My Place:

- **My learning style** – Find out how you learn best. This knowledge will be very helpful when you are picking out your college classes, learning new information and studying for your tests.
- **Knowing my strengths** – Figure out your strengths. Everyone has strengths, but sometimes it can be hard to discover them. Knowing what your strengths are will help you choose the classes that are right for you and help you find a major and career in which you can excel.
- **Exploring my interests** – Investigate your interests. Determine what you like to do, what holds your attention and areas in which you have a passion. These interests will play a role in choosing a major, your college experience and eventual satisfaction with your job.
- **Accepting my disability** – Learn more about disability, how to make sense of your documentation and to accept differences in yourself and others. Read about famous people with disabilities and find out how they use their strengths in their careers.
- **Setting my goals** – Make a plan to accomplish your goals. Sometimes large goals can seem overwhelming. Learn how to take a goal, break it into smaller steps and achieve your objectives.
- **My advocacy plan** – Learn how to speak up for what you want in an effective way. This skill is important to have in college

because you are ultimately in charge of your education and will need to communicate with faculty, advisers and college personnel.

Here's a quick glimpse of Campus Life:

- **Discovering college life** – Find out the differences between high school and college.
- **Faculty expectations** – Discover what faculty members will expect from you and what you can expect from them.
- **Getting accommodations** – Learn the process for getting accommodations in college.
- **Sharing my disability** – Find out what you have to tell your professors. Also learn some tips for communicating effectively with your professors.
- **Getting good grades** – Learn some tips and tricks for getting good grades in college such as what to do before the semester starts, during the first week of your classes and throughout the semester.
- **Exploring technology** – Investigate some technology options that could help you succeed in college.
- **Finding resources** – Learn about resources both on and off campus that can support you while you are in college.

Here's a quick glimpse of Planning for College:

- **Choosing a college** – Find a good match for you. By considering key features, you can increase your likelihood for success in college.
- **Deciding on a major** – Learn what steps you can take to choose a major. To do this you need to find a major that will use your strengths, minimize the areas in which you have difficulty and capitalize on the areas about which you are passionate.
- **Applying for college** – Figure out what you need to do when applying for college. Each college has its own application requirements, form, fees, due dates and acceptance procedures. You'll learn the process for applying, tips for writ-

ing your essay, how to get your recommendation letters and how to keep it all organized.

- **Getting financial aid** – Investigate your financial aid options so you are prepared to cover college expenses. You'll learn how to get financial aid, what aid is available for students with disabilities, how to get scholarships and how to budget your money while in college.
- **Taking admission tests** – Learn about the SAT and ACT and learn how to prepare for these tests. It's important to understand how eligible students with disabilities can get accommodations on these tests.
- **High school "To Do" list** – Learn the steps you need to take in high school to get into college. All of these "To Do" items can seem overwhelming, but by having a plan, you will be better able to get it all done.

Another great website is www.thinkcollege.net; information there includes Find a College, Find a Resource, and Information for Students. It also has a list of colleges that offer courses and programs for students with disabilities. Here is the list for Texas:

Austin Community College:
STEPS - Skills, Training and Education for Personal Success—Austin, TX

St. Edward's University Austin, TX
GO Project at St. Edward's University—Austin, TX

West Texas A&M University
Where the Learning Continues (WTLC) - Canyon, TX

Texas A&M University
Postsecondary Access and Training in Human Services (PATHS) - College Station, TX

Lone Star College-CyFair
CCDEL—Cypress, TX

Houston Community College - Central
VAST Academy—Houston, TX

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Pathways to Adulthood: Thinking about going to college

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Midwestern State University

Autism Support Program—Wichita Falls, TX

Also at www.thinkcollege.net is this statement about the differences between high school and college:

High School

The law is the Individuals with Disabilities Education Act (IDEA) -- an "entitlement" law intended to guarantee persons with disabilities a free and appropriate primary and secondary education. IDEA is about success. Funding is mandated to identify children with significant problems and provide them with appropriate services that facilitate successful learning, including course modifications. Education is a RIGHT and must be provided in an appropriate environment to all individuals. The Family Educational Rights and Privacy Act (FERPA) give parents certain rights with respect to their children's education records. Student and parent advocates for student, and family input is actively sought.

College

Laws are Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act - "non-discrimination" statutes that are based on a civil rights model. They aren't entitlement laws, and they don't guarantee successful learning or mandate the creation of special programs for persons with disabilities. ADA is about access. The goal of Section 504 and the ADA is to remove barriers and to guarantee reasonable accommodations so that persons with disabilities have an opportunity to participate. FERPA transfers privacy rights to the student when he or she reaches the age of 18 or attends a school beyond the high school level. Parents do not have the right to review their child's college records without the written permission of the student.

Impact on Students with Intellectual Disabilities [ID](#)

This important and far-reaching change in legal protections has implications for all students with disabilities as they move to

college. Because a college education is not a RIGHT, participation in college courses is often a negotiation between the college and the student. Students with intellectual disabilities are taking college classes, but that participation is often negotiated on a case by case basis, as they are not legally required to allow participation of students that are not deemed "otherwise qualified" to take a course. On campuses where there is an established program for students with intellectual disabilities, the staff of the program may assist with those negotiations. It is important to note that with appropriate supports in place, students with labels of intellectual disability are finding success in college courses of all types.



In the next newsletter I'll report on websites and information for other post-secondary options for students with disabilities.

Bookshare Library & Accessible Books for Texas

Each year, thousands of students miss school due to chronic illness, extended stays in the hospital, or the need for daily home health care. This is the case for ten-year-old Hailey Bopp, who is blind with cognitive delays. Hailey's challenges often make it impossible to attend school regularly. Ann Bopp, her mom, says that whenever Hailey misses school, "She gets sad and depressed because she doesn't get to read the books her teacher and classmates are reading." To mitigate Hailey's frustration, Ann signed her daughter up for an

individual membership to Bookshare, an accessible online library for people with print disabilities. "School life is better because Hailey can keep up with reading assignments," says Ann.

As she observed how Hailey reacted to reading accessible books, Ann knew she was on the right track. "I want more families to know about this educational resource," she said. "I like to pass it on to parents with children who have qualifying print disabilities so that they might experience a quality reading experience, like

Hailey."

You can learn more about Bookshare at www.bookshare.org/. Membership is free for qualified K-12 students. Another resource is Accessible Books for Texas, www.accessiblebooks4tx.org/, which features Bookshare, and is funded by TEA (Texas Education Agency).

Thank you to Valerie Chernek, a writer for Bookshare, for sharing her article about Hailey and her mom with us. You can reach Valerie at info@valeriechernek.com.

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Texas Parent to Parent is committed to improving the lives of Texas children who have disabilities, chronic conditions, and/or special health care needs. We accomplish this by empowering families to be strong advocates through parent to parent support, resource referral and education, and by educating professionals about the unique needs of our children.



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- Texas Orthopedics & Dr. Pete Garcia
- United Healthcare Community Plan
- Epic Health Services
- Wood, Johnson, Heath, P.C.
- Alamo Consumer Direct

Conference Schedule

Date	Conference Title	Location	Registration Information
Sunday, Feb. 9 - Tuesday, Feb. 11, 2014	The ARC of Texas 21st Annual Inclusion Works! Conference	Arlington	http://www.thearcoftexas.org/site/ PageServer? pagename=events_inclusion_conference
Saturday, February 22, 2014	2014 TAPPEstry Conference	San Antonio	http://www.esc20.net/tappestry
Thursday, Feb. 27- Friday, Feb. 28, 2014	2014 Texas Transition Conference	Austin	http://ttc.tamu.edu
Sunday, March 30—Tuesday, April 1, 2014	2014 Texas Statewide Independent Living Conference	Corpus Christi	http://www.txsilc.org/conference