



# A Parent's Perspective

TxP2P Quarterly Newsletter



## TxP2P Conference Almost Here

# Unbreakable Spirits!

### June 25 & 26, 2010

**Embassy Suites San Marcos ★ 1001 McCarty Lane ★ San Marcos, TX 78666**

Once again, we'll have hundreds of parents connecting with each other through this two-day conference, learning from each other and the speakers, introducing their families to each other at our Family Gathering on Friday night, and meeting in the swimming pool and maybe even the spa. Sara Hickman, 2010-11 Texas Musician of the Year will entertain us at this event as well. Late registration starts June 4th at 5:00 p.m. so don't delay - go to [www.txp2p.org](http://www.txp2p.org) to register.

This year our Teen Summit has grown to 2 full days and we'll have SibShop for the siblings all day on Saturday. Although the price of the child care and Teen Summit has gone up, we do have some additional options to help get you to the conference. The **statewide Early Childhood Intervention (ECI)** has provided us with funding to help with registrations for families that have children receiving ECI services. We have also received additional funding from **Partners Resource Network** that will help defray the cost for some families. Call us at 866-896-6001 for more information.

Our new conference hotel, the Embassy Suites, Conference Center & Spa should be a wonderful treat. Each room has a small refrigerator, microwave, with a bedroom and living room with a sleeper sofa. The pool isn't quite what we had at the Omni but it's outside and large. And then there's the spa!

### Hope to see lots of you there!

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Spring 2010

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**Help TxP2P by using our Randall's Good Neighbor Remarkable Card Number 10043!**

## Budget Woes Threaten Valuable Programs

**Colleen Horton, Program Officer,  
Hogg Foundation for Mental Health, University of Texas at Austin**

The end of school is looming and so is the next Texas Legislative Session.

It's hard to believe, but the process for developing the state budget for 2012/2013 is in full swing. During the first part of the year, agencies held public hearings to learn from stakeholders what is important to people with disabilities and their families, what needs to be improved, what needs to be developed, and what needs to go away. Agencies will use the information to develop their legislative appropriations requests (LARs). Included in the agency LARs will be the "exceptional items" list. This is

basically a wish list of new programs, services, or administrative increases needed. This "wish list" will be combined with the current budget (referred to as the baseline budget) and forwarded to the Legislative Budget Board (LBB) and the governor for consideration. The LBB will hold public hearings in the fall before forwarding their recommendations to the Senate Finance Committee and the House Appropriations Committee. Once the session starts in January, 2011, marathon negotiations begin and will con-

tinue until the final days of the session in late May.

Believe it or not, that's the good news. The bad news is the state's anticipated financial condition. In December, Governor Perry sent a directive to each state agency to identify 5% reductions in their current budgets. More recently, the agencies were told

to implement most of the budget cuts identified earlier . . . and this isn't the last of it. With the state facing the possibility of an \$18 billion deficit, there is likely much more to come. HHSC has delayed

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the implementation of the Medicaid Buy-In Program, passed and funded during the last session. This Medicaid Buy-In program would allow families with income up to three times the federal poverty level to purchase Medicaid coverage for their children with significant disabilities. Many of you fought hard to get this program passed and funded during the last legislative session. HHSC Executive Commissioner Tom Suehs stated at a recent

public hearing that the delayed implementation is due to the complexity of the program and it is not his intent to eliminate the program. However, with the state facing such a significant deficit, it is at risk as is everything else.

It is important for families to watch the budget deliberations closely and participate in the debate as much as possible. At the Texas capitol, the “squeaky wheel” often does get the grease,

and there will be significant competition for far less money.

As always, feel free to contact me with any questions you may have. Although I have recently changed jobs and am now at the Hogg Foundation for Mental Health, I’m always happy to help with your advocacy efforts. I can be contacted by email (new email address) at

[Colleen.Horton@austin.utexas.edu](mailto:Colleen.Horton@austin.utexas.edu)

## Summer Camp and Community Opportunities for Children with Disabilities: The Do’s and Don’ts of Requesting Reasonable Accommodations

Caroline Nelson, Special Education Family Liaison, Eanes ISD

**Will the camp or summer program will be sensitive to my child's special needs?**

**Will it be willing and able to accommodate my child's differences?**

**How flexible is the camp's programming, staffing and culture?**

**Does the camp have to accommodate my child?**

**What kinds of accommodations am I allowed to ask for?**

**How do I find out the answers to these questions?**

It’s time to look for fun things for the kids to do during the summer, but parents of children with disabilities or learning or behavioral differences often wonder whether a traditional camp will be inclusive enough for their child.

Many camps specifically serve children with disabilities. But what if you or your child is interested in a summer program that is geared for the mainstream? How will you know if your child with special needs will be able to participate in a fun, safe and successful way? Most providers of summer and community opportunities for children are motivated to include kids with disabilities – the catch is that they often don’t know how. As a parent of a camper with special needs, your job is to educate the camp about your child’s needs and be creative in the process to find a way for your child to be able to participate.

Because each child, disability and camp situation is unique, this is *always* a case-by-case process. Federal and State laws prohibit discrimination on the basis of disability, but this does not mean that *all* campers must be fully accommodated

in every case. The camp’s obligation in most cases is to engage in a meaningful dialogue initiated by the parent about making reasonable accommodations. Reasonable accommodations are those that won’t cause a fundamental alteration of the program, either financially or in terms of content. Accommodations that would cause such an impact would be considered unreasonable, and would not be required.

So what does the process look like? First, it is your job as a parent to initiate a conversation with the camp about your child’s needs. This triggers the camp’s responsibility to engage in the conversation with you. At that point, it is up to you and the camp together to figure out whether your child’s disability is one that can be reasonably accommodated in the specific camp situation you are contemplating. In other words, if your child could still participate in the camp with some accommodations that do not create a fundamental alteration of the camp program or at an overly burdensome cost to the camp, then you have a set of reasonable accommodations that will work. Bear in mind that this is a joint effort: the camp may be able to accommodate but often will need your help.

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All rights reserved. Caroline Nelson is the Special Education Family Liaison for the Eanes Independent School District. She can be contacted at [cnelson@eanesisd.net](mailto:cnelson@eanesisd.net) or (512) 732-9000, ext. 20423. This article is for general guidance only and is not intended as legal advice. For more information on the laws addressing reasonable accommodations for children with disabilities, or for advice pertaining to your specific situation, please consult an attorney.

## DO...

**...start with a camp that seems likely to be a good fit.**

If your child has an interest in the camp content, the camp seems age-appropriate, and you can picture a way your child can participate in a meaningful way with some accommodations, you're off to a good start. If you're not sure, ask around – friends and neighbors may be able to give you good information.

**...initiate the conversation with the program about your child's needs.**

Remember, it is your responsibility to inform the camp about your child's



special needs to trigger an interactive conversation about whether reasonable accommodations are possible.

**...listen carefully to the camp's description of the fundamental nature of its program, its experience with accommodating kids with disabilities and its willingness to work with you.**

Although most camps should indicate a willingness to discuss accommodations, some programs lend themselves better than others to modifications. This is the part of the discussion that is unique to the camp situation and your child's particular needs, and results may differ from one situation to another. Pay attention to your instincts when deciding how much

experience you're comfortable with, as well as the tone of the conversation.

**...be flexible in considering options the camp may propose, while putting options of your own out for discussion.**

Try to start the discussion at the level of what your child needs, rather than specifically how you want the accommodation accomplished. Sometimes a camp will have a different solution from yours that might still address the need in question; be open to alternative suggestions, since those might be easier or more effective for the camp to implement. Your flexibility at this stage will pave the way for a good working relationship throughout the camp process, which you will need until the last day of camp.

## DON'T...

**...sign your kid up, say nothing about his disability and hope for the best.**

Nothing will put the camp and your child at a bigger disadvantage than if camp is missing critical information about your child. Set your child up for success by being up front about his needs.

**...downplay a legitimate need that your child has in order to make him seem more like a fit for the camp.**

Ditto!

**...assume the camp representative understands from a label or diagnosis what accommodations might be appropriate for your child.**

Camp representatives are busi-

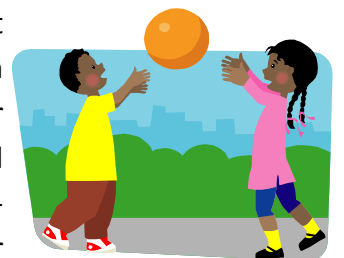
ness people with an interest in kids and whatever their camp theme is. Unless they have personal experience, they likely do not know many details about specific diagnoses or disabilities. Be prepared to describe your child's strengths and weaknesses – both related to his disability and in general -- to help the camp understand how he will fit into the program and what may need to be modified for his success.

**...assume that accommodations your child receives at school through Special Education automatically carry over to a community setting.**

The goals of Special Education and community activities, as well as the legal framework behind them, are different. Accommodations that work at school may be good examples for discussion with a camp, but use that as a starting place and be open to alternative ideas.

**...wait till the last minute. An effective, meaningful dialogue leading to a plan takes time. You or the camp may need time after an initial conversation to do some research and get back together.**

By the end of this process, you will have found some camp opportunities that will be fun for your child and which inspire your confidence. The key is to remember that it IS a process; it is neither something to which your child is entitled nor from which he is automatically excluded.



## I Saw A Child

I saw a child who  
couldn't walk, sit  
on a horse, laugh or talk.  
Then ride it through a field of daisies  
And yet he could now walk unaided.

I saw a child, no legs below,  
Sit on a horse, and make it go

Through woods of green  
And places he had never been  
To sit and stare.  
Except from a chair.

I saw a child who could only crawl  
Mount a horse and sit up tall.  
Put it through degrees of paces

Author Unknown

And laugh at the wonder in our  
faces.

I saw a child born into strife,  
Take up and hold the reins of life  
And that same child was heard to  
say,  
"Thank God for showing me the  
way...."



## TxP2P Update

### NICU Support – not just in Austin Any More!

Laura J. Warren, TxP2P

In our Winter 2009 newsletter, we announced the creation of a new TxP2P pilot program in the Austin area called “A Hand to Hold” which will provide support for families whose babies stayed in the Neonatal Intensive Care Unit (NICU). Over the course of a year while developing this program, we were able to see the very positive reaction families had to this new type of support. Many families don’t find any family support until years after the trauma of the NICU but when reminded of that time of confusion and fear, all the volunteers we trained for A Hand to Hold indicated that they wish they had the support when they really needed it – in the NICU.

In March, Kelli Kelley, Program Director for “A Hand to Hold”, announced her decision to leave TxP2P and start her own nonprofit

around this program in Austin. While we were taken by surprise and disappointed by this decision, we took the opportunity to rethink what we had planned for this program. The ultimate decision was to return to our roots and do a more traditional parent-to-parent model with one-on-one matching across the state for families who have babies in the NICU or who have just come home. But of course, we need your help – if your child started in the NICU and you would be willing to support another family in that situation or still have a connection to that NICU, please let us know – contact Erika, Kim, or Debbie at the office (512-458-

8600 or 866-896-6001) or [Erika@txp2p.org](mailto:Erika@txp2p.org), [Kim.Johnson@txp2p.org](mailto:Kim.Johnson@txp2p.org) or [Debbie@txp2p.org](mailto:Debbie@txp2p.org). We are busy getting information packets ready to get out to NICUs across the state about this new program and gearing up for our new Volunteer



Training Extravaganzas! We’re coming to certain areas of Texas and will train parent volunteers

As Support Parents, NICU Support, MEd. (Medical Education) Family Faculty, and Speaker and Outreach Network volunteers – more on this below!

### An Exciting NEW Opportunity...TxP2P Speaker & Outreach Network

Jeanine Pinner, TxP2P

Since I became TxP2P’s Training & Outreach Coordinator almost 5 years ago, I’ve logged a lot of miles across Texas, speaking to parent groups, special education personnel, insurance companies, community groups, etc. Since we started our Family to Family Health Information Center (F2FHIC) program in 2005, the requests for outreach (exhibiting at resource fairs/events), trainings (presentations on advocacy, forming parent groups, Medicaid waiver programs, resources, and so much more) and parent panels have grown to numbers we can’t always accommodate.

While discussing the incredible contributions of TxP2P Volunteers and our difficulty in being able to participate in many of the outreach and/or training events across our great state, we came up with a terrific idea . . . (drum roll, please) . . . the TxP2P Speaker & Outreach Network! This network will be comprised of trained TxP2P

Volunteers – YOU!

As parents of children with disabilities, chronic illness or other special health care needs, we’ve learned a LOT along the way! We’ve learned how to advocate for our children, intricate details about different disabilities, how to locate and obtain critical resources, and how to “keep it together” through the ups and downs of our lives. We hope that we can capitalize on some of the knowledge and experience you’ve obtained over the years to help other parents and families.

The willingness of our Volunteers has made all the difference in the ability of TxP2P to connect families with each other and the information/resources critical to helping our children and families. TxP2P Volunteers play a huge role in our Supporting Parent Volunteer program, our Medical Education Program, and our CSHCN Parent

Leader Teams in Dallas-Fort Worth, the Coastal Bend, and the Rio Grande Valley.

So, we’re coming to you again with a request for your help: please help us reach more families and professionals across Texas by becoming a volunteer for our new Speaker & Outreach Network. We have already begun our search and are asking you to volunteer for this exciting new Network!

Training, materials and support will be provided to each Speaker & Outreach Network Volunteer. We will begin Speaker & Outreach Network training sessions in the fall of 2010, so don’t wait to let us know you’re interested – please do it today! For additional information or questions, email [Jeanine@txp2p.org](mailto:Jeanine@txp2p.org) or call 866-896-6001 (ext. 104) or 512-217-3558 (cell). I can’t wait to hear from you!



**Family Voices** is a grassroots family-led, family-driven membership national nonprofit. It was established to improve family-centered care and health care coverage for all children and youth with special health care needs and/or disabilities through legislative change. Through the national network, we provide tools for families so they can make informed decisions, advocate for improved public and private policies, build partnerships among professionals and families.

As an individual member, you will receive the following benefits:

- Membership to FV-Talk, a membership-based listserv to share information and resources among family leaders,

- Advance notice for training opportunities
- 10% discount off all National Family Voice publications
- Legislative Alerts via email to learn critical and timely news on issues and legislation important to families of children and youth with special health care needs/disabilities
- Timely information on issues related to children and youth with special health care needs/disabilities and those you care for them through the e-newsletters Friday's Child and Family Matters, and KASA (Kids as Self Advocates) News
- State-level connection, support and resources from the National

Family Voices' State Affiliate Organization (SAO)

- Representation and advocacy at the state and federal levels around issues you care about

For more information, go to: <http://www.familyvoices.org/FVMembershipForm%20FINAL3.4.10.pdf>

TxP2P was named the Family Voices Texas State Affiliate Organization earlier this year. TxP2P helps carry out the mission of Family Voices through opportunities for trainings, webinars, information and collaboration on legislative issues. Family Voices provided the training in January 2009 on Medicaid Buy-In that prepared TxP2P families to work with legislators on the proposed bill.

## **What is a Care Notebook?**

### **National Center for Medical Home Implementation**

#### **What is a Care Notebook?**

The Care Notebook has multiple uses. A major role of this notebook is to help parents/caregivers maintain an ongoing record of their child's care, services, providers, and notes. This notebook is a great tool in empowering families to become the experts on their child's care. It is also a way to maintain the lines of communication between the many providers and services that help care for a child and their family.

Health professionals recommend that parents/caregivers bring this notebook to all medical appointments, therapies, care conferences, on vacations, etc. Health professionals can encourage the use of these notebook by either

having them available at the first office visit, upon discharge from the hospital or in the waiting room on a resource table. This notebook should be a team responsibility. Office staff should offer families assistance in filling out the various forms. Medical offices can copy visits, check ups, immunization records, specialist reports, clinical pathways, and give them to families to insert into the notebook.

#### **Why build your own Care Notebook?**

The Care Notebook is an organizing tool for families and will help you keep track of important information. Care Notebooks are very personal to your child and ideally should be customized to

reflect your child's medical history and current information. For this reason, this Web site has been developed to allow you to build a Care Notebook that best meets the need of your child.

#### **How do I build my own Care Notebook?**

Go to the National Center for Medical Home Implementation Website, [www.medicalhomeinfo.com](http://www.medicalhomeinfo.com), and look under "For Families" and click on "Building Your Own Care Notebook" or follow this link: [www.medicalhomeinfo.org/for\\_families/care\\_notebook/care\\_notebook](http://www.medicalhomeinfo.org/for_families/care_notebook/care_notebook)

It is recommended to view the online examples before building your own care notebook.



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# TxP2P Update

## 2010 Supporting Parent Volunteer Trainings

You can help families like yours by becoming a TxP2P Parent Volunteer! Listed below is the schedule for 2010. Please let Erika, Susan or Patty know if you are interested in attending a training in your area.

July - Corpus Christi

August - Abilene

November - El Paso

September - Dallas

October - College Station

## Loss of Federal Funding through Appropriations Glitch – Almost

Laura J. Warren, TxP2P

**A**lthough our Family to Family Health Information Center funding has been secured with the passing of the Health Reform Bill, I wanted you to know how close TxP2P came to losing a major source of funding this spring. It made all of us at TxP2P, from staff to Board of Directors, realize we have a lot of work ahead of us in order not to find ourselves in this situation ever again. So, we still need your help – please forward us any new fundraiser ideas, new grant or foundation opportunities, new corporate donors, etc. All ideas are welcome! Please send to Laura Warren at [Laura@txp2p.org](mailto:Laura@txp2p.org) Here's what happened:

March 2010: We received confirmation the first part of the month that funding for Texas Parent to Parent's Family to Family Health Information Center (F2FHIC) along with the other 50 F2FHICs across the country, funded through the federal Maternal Child Health Bureau, would not be accessible starting June 1<sup>st</sup>, 2010. Texas Parent to Parent did not lose the grant for this funding – the parties responsible at the federal level failed to submit the request for the funding to be included in the MCHB FY 10 (Fiscal Year 2010) budget year.

To complicate resolution of the problem, it was not possible to include funds in the FY11 budget appropriations process that were not in the FY10 budget. At this point, the only way to get the FY11 funding back into the MCHB budget was through a bill. The funding was attached to both the Health Reform Bill and the new Jobs Bill but it is unlikely that these processes will get the funding back

into budget appropriations by June 1, 2010.

So, what would this mean to TxP2P? This funding represents one-fourth of our budget but nearly one-half of funds available to pay staff. We already have 2 "volunteer" staff who do not request a salary and our Co-Directors voluntarily give up part of their salary in order to use funding for program staff. We can make minimal cuts to travel and training funds, but there are no excess funds to cut without directly affecting our program staff's ability to provide much needed support and information to families throughout Texas.

Then miraculously the Health Reform Bill was passed on March 20<sup>th</sup> and our funding was restored. We still don't know if we will get it by June 1<sup>st</sup>, but we know we should have it by September. We learned a lot from this experience and hope for all our sakes', we never have to repeat it.

So, now what? We need to make sure this never happens again so we need all your help. Our job will be developing a more diverse funding plan, developing additional fundraisers, pursuing corporate donors, and writing grants. A very important part of every funding process is being able to document that the work we do is making a difference in the lives of TxP2P

families -- this is where you come in . . . if TxP2P has helped:

- connect you to a resource your child or family needed,
  - connect you with another parent that really made a difference in your life,
  - increase your knowledge of an issue or a system,
  - enhance your advocacy skills,
  - improve your ability to work with professionals -- school, community, medical, etc., or
  - boost your confidence,
- we need your stories and photos! Here's how we will use the stories and photos you send us:
- in our reports, presentations, conference documents, TxP2P flyers and on our website,
  - sharing with potential funders to document the powerful experience of parent-to-parent
  - how getting a family-friendly explanation of the service delivery system and resources available helps families to obtain needed resources/services
  - how support and information about working with professionals helps to improve relationships between families and the professionals in their lives.

Please send documents and photos to Jeanine Pinner at [Jeanine@txp2p.org](mailto:Jeanine@txp2p.org). It is our understanding that your submission of personal stories and photos conveys your permission to Texas Parent to Parent to utilize them for the purposes stated. Please feel free to contact us with any questions you may have.



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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.



Congratulations to TxP2P staff's graduating High School Seniors:  
 Brenna Prior, Jake Pinner, and Elsa Sanchez

Conference Schedule

Date	Conference Title	Location	Registration Information
Tuesday, June 15 - Friday, June 18, 2010	The Texas Assistive Technology Regional Conference	San Antonio	For more information, go to: <a href="http://www.texasatconference.net/">http://www.texasatconference.net/</a> or call 713-744-6559
Monday, June 21 - Wednesday, June 23, 2010	Positive Behavioral Support Quest 2010, A Texas Journey	Dallas	For more information, go to: <a href="http://www.txbsi.org/docs/PBS_Training_Conference_Flyer.pdf">http://www.txbsi.org/docs/PBS_Training_Conference_Flyer.pdf</a> or call 713-744-6365
Wednesday, July 7 - Sunday, July 10, 2010	41st Annual Autism Society National Conference and Exposition	Dallas	For more information, go to: <a href="http://www.autism-society.org/site/PageServer?pagename=research_conference">http://www.autism-society.org/site/PageServer?pagename=research_conference</a> or call 301-657-0881, ext. 9010
Friday, July 16 - Saturday, July 17, 2010	1st Annual Texas Microboard Conference	The Woodlands	For more information, contact Jennifer Mathews at <a href="mailto:jmathews@thearcoftexas.org">jmathews@thearcoftexas.org</a> or call 1-800-252-9729, ext. 123 or go to: <a href="http://www.thearcoftexas.org/programs/realife.asp">http://www.thearcoftexas.org/programs/realife.asp</a>
Monday, July 26 - Friday, July 30, 2010	The Texas Statewide Youth Leadership Forum	Austin	For more information, go to <a href="http://txylf.tamu.edu">http://txylf.tamu.edu</a> or call 979-458-4168
Friday, August 6 - Sunday, August 8, 2010	Texas Advocates Conference	Corpus Christi	For more information, contact Tanya Winters at <a href="mailto:twinters@thearcoftexas.org">twinters@thearcoftexas.org</a> or 800-252-9729, ext 120