



# A Parent's Perspective TxP2P Quarterly Newsletter



## TxP2P Upcoming Events:

**2nd Annual Walk-n-Roll**  
 April 4th, 9 a.m. - noon  
 Old Settler's Park  
 Rock Round, TX

Find more info on our website  
[www.txp2p.org](http://www.txp2p.org)



## 5th Annual TxP2P Parent Conference

June 26-27th - Omni Austin Hotel at Southpark, Austin, TX  
 Registration info will be mailed out and on the website in March

## 5th Annual TxP2P Vine to Wine

October 8th, Bob Bullock Texas History, Austin, TX

Volume 8, Issue 1

Winter 2009

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## They're Back Again...Let the 81<sup>st</sup> Begin

Colleen Horton, Public Policy Director,  
 Texas Center for Disability Studies, University of Texas at Austin

If you read the newspaper at all, it's hard to escape all the recent articles regarding services for adults and children with disabilities. They include references to: state schools, waiting lists, Department of Justice investigations, abuse and neglect, community services, long term services and supports reform, vouchers . . . and much more. I'm hoping in this short article to try and put some of this in perspective for the coming legislative session. Most of the issues are in some way connected and few are determined singularly, so it helps to start with the big picture. First, Texas currently has 13 state run institutions for those with intellectual and developmental disabilities (11 state schools/2 state centers). These institutions house approximately 4,843 individuals at a cost of around \$125,507 per person, per year compared to the \$63,529 cost to provide community services. (Legislative Budget Board, Nov., 2008) At the same time, more than 80,000 individuals (unduplicated number) with physical and developmental disabilities are on the various



Medicaid waiver waiting lists - waiting for community services. Last year, the Department of Justice issued a report on their investigation of the Lubbock State School and more recently a report on the remaining 12 facilities. The reports indicated significant abuse, lack of treatment, neglect, excessive use of medication and other restraints, preventable deaths, and much more. A House of Representatives Select Committee chaired by Rep. Larry Phillips has performed an interim study in order to make recommendations on the future of Texas state institutions. The Committee's report was released just before the holidays and can be found at <http://www.telicon.com/www/tx/topnav1.htm> Additionally, earlier in the year the State Auditor's Office released a report on the state institutions, and more recently, the Legislative Budget Board issued an analysis of Texas state institutions. These reports can be found at <http://www.sao.state.tx.us/Reports/report.cfm/report/08-039> and <http://www.lbb.state.tx.us/>

[Health Services / State Schools Report1108.pdf](#) respectively. Some legislation will most likely be derived from the recommendations of these various reports. Chairman, Patrick Rose (House Human Services Committee) announced on December 11<sup>th</sup> his intent to file legislation requiring the HHSC to develop a long term plan for reform of services for individuals with cognitive and developmental disabilities, including a plan for the closure of some state schools. The goal is to clearly identify a vision for the future of long term services and supports, improve access to services, and improve the quality of services. The intent of future facility closure is to reduce state school spiraling costs and reinvest money saved from closures into community services for people with disabilities. Many stakeholders are hopeful that this legislation will be expanded to include all disability populations.

As mentioned in the last newsletter, developing a Medicaid Buy-In for children with disability has again

# They're Back Again...Let the 81<sup>st</sup> Begin

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been proposed. Additionally, Senator Robert Deuell (the author of the children's Medicaid Buy-In legislation) has filed SB 336, giving the HHSC authority to plan and implement state institution closure activities. The objective is to remove the decision-making from the political arena and give it to the health and human services executives who know the system and can determine the most efficient and effective way to use scarce resources.

But that is not all...as with every session, ending or at least significantly reducing waiting lists for Medicaid community services waivers will be a top priority for many disability advocates. Provider rates will also be debated and decided. There will be proposals to

develop opportunities for individuals with cognitive disabilities to have access to volunteer advocates to help them with major life decisions. Additionally, following the national trend, Senator Zaffirini is developing legislation that will begin the process of transitioning state language away from use of the "R" words (retard, retarded, etc.), to using more respectful language such as intellectual disabilities. There will also be voucher bills and professional development bills in the special education arena. And of course, there will be much, much more. This is only a taste of things to come in the next five months.

The session officially begins on January 13<sup>th</sup>. After the House speaker election, committee chairs and members will be assigned, and

then the work begins. You can influence the decisions affecting people with disabilities and their families by knowing the issues and responding with your experiences and your voices. Your votes mean a lot to legislators, so let them know what you expect them to do. During the session I will be sending out (via email) notices when priority issues affecting people with disabilities are on the agenda (coming up in a committee hearing or for a vote). These notices are for educational purposes only, intended to inform individuals and families regarding the issues being discussed and how you can influence the outcomes. If you'd like to be added to the distribution list for these notices, please send an email to: [colleen.horton@mail.utexas.edu](mailto:colleen.horton@mail.utexas.edu).

## Activities to Help Prepare for Independence

Kentucky Cabinet for Health and Family Services

<http://chfs.ky.gov/ccshcn/ccshcntransition.htm>

I was on the Healthy & Ready to Work website (<http://www.hrtw.org>) and found the next two articles about transition. I hope you find them useful with your child. Don't worry too much about the age recommendations - just use them as a guideline!

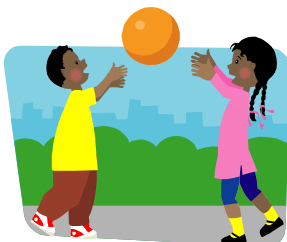
\*From ages birth to 3, encourage self-help with simple activities of daily living, seldom doing for children what they can do for themselves. Connect with Early Intervention programs in the community for help in assessing development and treating delays.

\*By age 3-5, assign children developmentally appropriate household chores and give children opportunities to interact with others in a variety of situations. Enroll in preschool programs such as Head Start.

\*By age 6-8, begin asking "what will you be when you grow up?"

\*By age 8-10, begin helping the child interact directly with health care providers and take responsibility for their own health care.

\*By age 10-12, provide career guidance including focus on abilities and



interests and how the disabilities might affect career choices. Connect with the school system's school-to-work program, if available.

\*By age 12, provide adolescents with transition workbooks or other activities which can help them focus on their talents, likes, personality traits, supports, challenges, and develop self-awareness. Young people can then look to the future and develop the vision, goals, skill development expectations, resources, and supports needed to be successful in adulthood.

\*By age 12-13, consider helping young teens find small paying or volunteer jobs.

\*By age 13-14 obtain written information about their state's vocational rehabilitation program and school-based transition programs.

\*By age 14, develop a transition plan to adult living including health services.

\*Between ages 14 and 18, ask the teen what he or she wants to do as an adult and how he or she hopes

to make it happen. Determine the need for assistance with development of marketable skills and other transition issues. If the teen wants help, facilitate referral to Vocational Rehabilitation services as appropriate and ensure that medical information is sent to the agency with proper signed releases. This may be the time for a teaching physical exam in which the young person and physician/nurse practitioner discuss normal concerns of all adolescents, pubertal changes and sexuality, the effects of the disability on future health, vocational choices, marriage and family (Johnson 1995).

\*One year prior to discharge from the pediatric health care system, assist the adolescent to identify an appropriate adult health care provider, if needed, and plan for release and transfer of information to that provider. Seeing both the pediatric and adult health care provider within this last year of pediatric service would be ideal.



# Competencies for Young People Transitioning to Post-Secondary School and/or Work

Here are some great things to work on with your teen to help him/her prepare for life. I found this one at Commission for Children with Special Health Care Needs *KY TEACH Project*. Funded by *MCHB Healthy and Ready to Work Projects & Shriners Hospitals for Children 7/2002*. <http://chfs.ky.gov/ccshcn/ccshcntransition.htm>

## **Independent Living**

- Has plans for transportation and knows how to use public and private options
- Has a driver's license or state identification card
- Can budget money; has opened and uses a bank account
- Has found housing that has accommodations needed so will have nutritional, safety, & rest needs met.
- Has cooking, meal planning/nutrition, housekeeping, laundry, and clothing care skills, and has a plan for housekeeping help if needed
- Has a personal attendant or plans to hire one if needed for personal care

## **Jobs and Post-Secondary Education and Training**

- Can use a computer: search the internet, word process, use various software
- Can advocate for self regarding accommodations needed in school, work, community, or home and can determine their effectiveness
- Has a resume and model letter requesting recommendations
- Can complete a job application and interview for a job
- Has obtained vocational training in the community through volunteer work, visiting employment sites and "shadowing" employees, part-time and/or summer jobs
- Has developed the interpersonal skills necessary to maintain employment
- Can identify people and agencies

- to assist in job searches
- Identifies activities of interest and can find community education courses
- Identifies personal learning styles, career interests and opportunities
- Knows how to register to take college entrance exams (ACT/SAT)



- Knows how to apply to post secondary institutions and for financial aid, scholarships, loans, work-study, etc.
- Knows how to access disability support and counseling services

## **Recreation and Leisure**

- Has plans for having fun in health promoting way
- Has developed a variety of specific recreation and leisure skills
- Has spectator or audience member skills
- Identifies affordable recreation and leisure activities
- Can arrange social activities
- Has identified social supports through family, peer group, mentors, and community resources.

## **Other General Skills**

- Knows strengths and limitations
- Knows laws, policies, rights, and responsibilities for adults with disabilities (has participated in transition planning meetings, identified and contacted community agencies); knows rights regarding physical accessibility
- Is aware of community resources and options
- Identifies acceptable dress behavior for a variety of situations
- Has shopping skills
- Can order and dine in restaurants, pay for service, and tip
- Has personal safety skills (such as navigating streets, reading maps, using phone, wearing seatbelts)
- Has developed communication



skills so can interact with peers, authority figures, and community members

- Has registered to vote and for military selective service (if appropriate)
- Has explored guardianship issues (if appropriate)

## **Health Condition**

- Understands body systems involved and how condition affects them and can describe condition to others
- Able to determine when condition is worsening, when secondary disabilities are occurring (decubiti, urinary tract infection, constipation, contractures, etc.) and how to take preventive actions
- Knows what equipment does and how to fix minor problems
- Knows names of medications, their actions, and side effects, and takes medications independently (or can instruct attendant)
- Able to do self care and treatments or instruct attendant
- Has someone to talk with for coping/mental health issues/problem solving
- Knows how condition affects sexuality; has considered birth control, safe sex, reproductive concerns (genetics, pregnancy); girls can care for menstrual needs
- Knows how tobacco/drugs/alcohol/foods affect body and mind and illness/disability and how they interact with medications; knows how to read labels
- Maintains physical fitness with exercise

## **Providers**

- Knows who primary care provider, dentist, and specialists are (name, address, phone, how to contact); has had experience talking with these people by him/her self - makes own appointments, asks questions.

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# Competencies for Young People Transitioning

Continued from Page 3

## Provider (Continued):

- Has a plan for getting help in an emergency
- Knows how to contact pharmacies and equipment and other health-related providers
- Has plans for finding or has found new providers in new location, and adult providers if still seeing pediatricians; knows personality factors and expertise wanted in medical and

dental care providers

- Has started process to transfer records to providers in the community of new school/work setting
- Keeps summary medical file

## Insurance

- Knows insurance plans name, address, case manager contact information; responsible for health insurance ID card
- Knows what benefits are covered

and not covered and is prepared to make co-payments; knows how to do benefits inquiries; knows codes for counseling

- Knows how to submit bills for payment and follow up disputes
- Talks with someone in "benefits" at the school/work if covered by the group insurance

## People First Language

Jake Pinner, TxP2P Volunteer and son of Jeanine Pinner, TxP2P Staff

**M**y name is Jake Pinner and I am a junior (in high school). One of the things that makes me slightly different is that I have an autism spectrum disorder.

I do believe that any person is capable of anything and if that person believes they can succeed, then they will achieve.

There are some people in this world who are alike in many ways, but there are also some people who are different in a way. One difference is that some people have disabilities.

They are people just like us and they still contribute to society despite having some obstacles. There is a way to refer to people with disabilities as people first.



Sometimes people with disabilities are looked at for weaknesses rather than strengths. For example, a person with an autism spectrum disorder may be seen as someone whose membership on a staff or team may be stressful because of work constraints, but that person may have a good memory that helps him accomplish the given task. Or someone having perfect pitch, the ability to tell what note they just heard, or calendar calculation (telling what day of the week a certain date was) is one strength people with autism have. Sometimes these strengths and talents are overlooked and those people are seen just for the disabilities. On occasion people are ridiculed behind their back and not given the same advantages anyone else has which is isolating. Everyone has a role in society. There have also been several people who had disabilities that were really successful in society.

### Current Usage

Normal/healthy/typical people  
Handicapped/Crippled/Disabled  
A mentally retarded girl  
John is wheelchair bound/confined to wheelchair  
An autistic girl/boy  
Roger suffers from Cerebral palsy  
Fred is in special ed, is a sp ed kid  
Brain damage  
Birth defect  
Julius is quadraplegic/paraplegic

### Preferred

People without disabilities  
Having a physical disability  
A girl with mental retardation  
John uses a wheelchair  
  
A girl/boy with autism  
Roger has cerebral palsy  
Fred receives special ed services  
Brain injury  
Congenital abnormality  
Julius has quadraplegia/parapalegia

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**Please remember to sign up for TxP2P Listservs.** Contact [Susan.Prior@txp2p.org](mailto:Susan.Prior@txp2p.org) if you want to join the Advocacy, Autism, Bipolar, Homeschoolers, Transition, or local area Listservs (Austin, Bryan/College Station, Dallas/Ft. Worth, Houston, San Antonio, San Marcos, Rio Grande Valley & Waco/Temple). **We have one new Listserv - Medical Home.** If you want to moderate a local listserv for your area, we'd love to set up more of these local groups. Contact Laura at [Laura@txp2p.org](mailto:Laura@txp2p.org) to discuss moderating one for us.

**Save our trees and a little money - get the newsletter via email!** It prints out well or is easy to read as an email. If you are currently getting this by mail but would read it as an email or print it out, please contact Susan Prior (512-458-8600 or 866-896-6001 or [susan.prior@txp2p.org](mailto:susan.prior@txp2p.org)) and ask to receive the TxP2P Newsletter via email. If you leave a voice mail, please remember to give us your email address. Thanks!!

**Make a donation to TxP2P - we've added an envelope to make it easy for you!** Our annual direct mail campaign will be out in November but you don't have to wait until then. Or become a monthly donor - no amount is too small.

## Tips to Help Families Build Effective Partnerships with their Child's Health Care Providers

**A**s your child's most consistent caregiver, you know your child with special health care needs (CYSHCN) in ways that no one else does. You want to be sure that your child's health care needs are met. Your perspective when something is wrong with your child, or how he/she is responding to a treatment or medication are critical pieces of information that you want to effectively share with the providers who treat your child. Through clear communication between you and your child's doctors and other providers, you can develop partnerships that will help your child receive the best kind of health care. The following tips about preparing for an office visit, talking with your child's provider, learning more after the visit, and partnering in other ways will help you work with your child's health care providers to ensure that your child and perhaps others, as well, receive the highest quality health care.



### **Preparing For an Office Visit:**

**Trust your instincts** - When you first suspect that something is not right with your child's health, or when your child is first diagnosed with a special health care need, you may not realize how valuable your instincts and intimate knowledge of your child are to his/her medical care. What you know and see about your child is critical to share with health care providers. Rely on your own good sense to know when to seek more information. Never be reluctant to check with your child's provider when you have a question about how your child is doing, how a medicine is working, or what to expect during a treatment.

**Seek all the information that you can** - Your child's providers will be your important first source of information about his/her health care needs and care. There are also many additional sources of information about specific diagnoses, medicines, and potential treatments that your child's providers and others can help you find. You may find helpful information from national and local diagnosis-specific organizations, on the web, through

other parents, in the library, and through books. Share what you learn with your child's providers to find out more about how this information might apply to your child.

**Maintain a file of important information about your child** - Ask to read your child's medical records. Keep copies of important records in your own files. Ask for a copy of the report after your child visits a specialist. Make your own notes on how your child responds to treatments or medications and what medications/doses they take, and be prepared to share this information with providers. Along with health records, it can be helpful to save other information such as appointment dates, school information, emergency contacts, and other information in a single notebook. This information will then be in one handy place and can be of vital importance to share with providers, particularly in the case of an emergency. Many providers and health systems are now using electronic records, some of which allow families to include their own notes in the record. There are also special computer programs to help you track your child's medical information.

**Ask for second opinions and referrals when you think you need them** - You may want to seek out more than one doctor's opinion before proceeding with a specific treatment that has been suggested or when you are not comfortable with a provider's approach or suggested treatment. Most providers are happy to provide such a referral to a "second opinion."

**Change providers if you cannot work out a way to feel satisfied** - Many times differences of style or other difficulties between families and providers can be worked out over time. However, if you have not been successful in building a helpful partnership with a provider, seek out another provider that better fits your needs. Tell the provider that you are leaving why you want to change. Your input may help the provider work with other families in the future.

**Look for ways that other family members can participate** - If only one family member builds a relationship with a provider, the other parent or family members will miss important opportunities to understand the child's health care needs. Try to have more than one parent or important family member participate in key appointments, at least some of the time. If this isn't possible, try to bring a close friend or neighbor. Two people will likely remember different information from the appointment and can talk over what they heard after the appointment.

### **Talking w/ Your Child's Provider:**

**Communicate openly with your child's providers** - Communication is critical in your relationship with your child's providers. Be open and honest. Speak up if you do not understand enough about a specific treatment or need further information. Make a list of questions that you'd like to ask your child's providers at visits or over the phone or e-mail. Put the most pressing questions at the top of the list. Find out what times and what ways work best to communicate with the provider. Be direct when sharing your perceptions, observations or concerns. Think about when you need to speak privately with the provider and ask for that opportunity. Be sure that your child also has the opportunity to speak privately with his/her providers.

**Help your child build a relationship with his/her providers** - Your child with special health care needs will likely have a great deal of experience over time with health care providers. It will help your child to receive the highest quality care and to become as independent and healthy as possible if you help them take a role in their own health care as early as possible. Help them write down their questions for their providers. Encourage them to speak for themselves to the best of their ability. Choose providers who listen to, understand and respect your child.

**Ask every question that you wonder about** - If you aren't satisfied with the response, ask

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again, or ask someone else. You can ask the same question of a number of providers in order to learn more about your child's needs. It may help you understand if you hear the information more than once. Every question that you have is important. Don't be afraid to ask. And don't be afraid to ask again.

**Don't be intimidated** - Sometimes family members feel hesitant when talking with health care providers because of a provider's medical credentials or experience. Providers do indeed have specialized expertise. That is why we seek their medical care. As your child's parent, you too, and your child, have special expertise. You and your child have critical pieces of the information needed to help your child receive the best health care.

**Ask your child's providers to recommend articles or books** - If you find it helpful to learn more information by reading, ask your child's providers to help you find helpful written materials. Ask if there are conferences or meetings where information about your child's diagnosis is going to be discussed. In turn, share with your child's providers the information and resources that you find. Ask questions about what you've read.

**Ask if you may tape a conversation with a provider** - Some visits to providers can be very stressful, especially if you are seeing a specialist for the first time or if you are seeking a diagnosis. It may be difficult later to remember what you've heard. If the provider has no objections, tape the conversation. This can help you remember and review at a later time what was said. If taping is not an option, take notes.

**Recognize that it may take time to get a diagnosis** - Every child is an individual, and in some cases his/her special needs may be hard to identify and name. Many children have multiple special needs or symptoms that are not easily categorized. Your provider may be reluctant to provide a specific diagnosis or may provide you with too many possible diagnoses. Discuss your concerns about diagnosis with your child's providers and seek more information if you do not understand the responses you receive.

**Ask your provider for a written care plan** - Ask your provider to write down his/her recommendations in a written care plan. Such a plan can help you to understand your child's needs and the provider's suggested treatments. It can help you plan for your child's future and help you share information with others such as home care, day care or school providers.

**Ask for help in financing your child's care** - One of the critical issues that families face is finding ways to pay for their child's medical care. A good partnership with your child's provider can help. Find out as much as you can about your child's health coverage plan/s, and give this information to your child's providers. Getting appropriate documentation and paperwork from your provider may avoid delays in processing insurance payments. If the suggested treatment or equipment is unusual, ask the provider's staff to help find out how the medical necessity for this treatment has been documented in other cases. Ask for help in getting information about and applying for public programs that might help your child.

**Learning More:**

**Make contact with another parent or parent group** - Many parents find that speaking to other parents provides them with a great deal of helpful information, comfort and support. Another parent may have useful information about how they have handled various situations or special needs, may recommend questions to ask of your providers, or recommend specific providers or programs. Seek out a parent organization such as a Family-to-Family Health Information Center (Texas Parent to Parent) in your state to find another parent to speak to, or a parent group that can offer resources, information and support.

**Search for providers that meet your needs** - While some providers enter a family's life suddenly in an emergency, most of the time parents are able to choose their child's providers, within the limits of their health plans and provider availability. Most health plans and systems now require that a child have a primary care provider who is responsible for overseeing all of his/her care,

including well care, referral to specialists and coordination of care and services, including community based services. This approach is called a "Medical Home." In order to find providers that meet your own and your child's needs, ask other families for their recommendations. Check out a provider's knowledge and experience with your child's specific needs. Ask providers about their views on parents being present for treatments and taking a shared role in decision making. Seek providers with whom you and your child feel comfortable and who you feel will understand your family's customs and culture.

**Ask for special consideration if needed** - Let your provider know what works best for your child. If specific things help your child cope or particularly frighten your child, tell your provider. This information can help the provider relate to your child. A provider might be able to make an exam or treatment easier for your child by knowing his/her special interests, activities and family events. If your child is particularly vulnerable to other children's infections, you might want to ask to wait in a special area for your appointment rather than a general waiting area. Tell your provider about your customs and beliefs that may effect recommended treatments. Speak up if a schedule is recommended that conflicts with your special plans or holidays. It might be possible to reschedule.

**Don't give up** - If you have not found what you think your child needs, either in a provider or in seeking financing for a specific treatment or equipment, don't give up. Recognize that many times "no" is the first response, but on further investigation, "no" can be turned to "yes" with the right documentation, gathering more information or speaking or working with another individual.

**Help Your Provider Help Other Families:**

**Provide feedback to your child's providers** - Let your child's providers know both when you appreciate their efforts and when you are not satisfied. Write a note, or tell

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them in person. Be as specific as possible so that the information can help improve your child's care as well as the care of other children.

**Share information and resources** - Your provider may have a bulletin board or other method for sharing information with parents. Offer to share notices about meetings, parent groups or community resources. Let your provider know that they can share your contact information if you are willing to

provide feedback about how policies meet the needs of families and children. If such a group exists, you might become a participant. If an Advisory Group does not yet exist in your provider's setting, you might suggest starting one.

**Offer to provide input beyond your child's specific needs** - Many providers routinely seek the input of families in their practice to help them improve the services they provide. Ask if there is a Family Advisory Group in the clinic, doctor's office, or hospital setting where your child is treated. Such groups of families meet together with providers and staff and

provide feedback about how policies meet the needs of families and children. If such a group exists, you might become a participant. If an Advisory Group does not yet exist in your provider's setting, you might suggest starting one.

This publication has been developed through the National Center for Family Professional Partnerships project, a cooperative agreement with the Division of Services for Children with Special Health Care Needs, Maternal and Child Health Bureau (HRSA 5-U40-06-002).

## A Grandfather's Story

**W**e were about to take Ariana home after spending 24 hours overnight with her in the hospital learning about the intricacies of her care when a doctor asked us to step into a side room with him. He mentioned his experience of 24 years in Neonatal care and said in his opinion Ariana suffered from a "Bulbar Palsy." He didn't want to see us take Ariana home out of a sense of guilt or obligation. She would probably never recover any of her functionality as we would know for a child. He said, "Let me make this crude analogy . . . Ariana is like an expensive Rolex, a beautiful time piece. However, she's been dropped and although still beautiful, will probably never keep time again."

I told him as I was reminded how I had experienced the winning of a \$1,000 Seiko LaSalle watch in a company contest. It was a beautiful glittering gold watch with an intricate solitary band. The entire band fit into the extremely thin watch face. I explained I had taken the



watch to Sears to have the band adjusted. Because of its unique design, the clerk couldn't understand how to adjust the band. He took hold of the band with a pair of large scissors and amidst my horror, he put the band in these large shears on the floor and began to step on the watch. Damage to the watch was significant - the band had large gouges from the shears. I negotiated with Sears' management and they agreed to send the watch back to Seiko for repair. After about 8 weeks of nervous calls to the Sears outlet, I was told the watch was in the store for pickup in their jewelry department. I went in and met with the Manager. He said, "Charles, here is your watch. Well, not your actual watch, but a replacement. See your watch was repaired at the factory, but in the process of shipping it back, it was run over by a UPS truck. The manufacturer and the shipper have provided this brand new watch."

I then replied, "Doctor, I understand what you are saying, but God has shown me that it's not what we

**Charles Clack, TxP2P Volunteer**

see but can't see which is real. I don't know how exactly but Ariana is in the hands of the watch maker who made her. We will not only have a beautiful timepiece soon but one who keeps perfect time. As we wait on God, He's promised us in His time Ariana will be restored to perfection. Her name and her condition are not an accident. This temporary condition is for HIS Glory. Our token to remind us of His truth that by His stripes we ARE healed." This is demonstrated in the choice of Ariana's name. Her father, talking with a fellow AA member, said, "I have to name this little girl and I have no idea what to name her." His friend said, "Well, I always liked the name 'Ariana.'" Her mother chose her middle name, "Sky." Ariana means "Silvery or Holy (Ari)" and "One" (Ana) - with Sky being Heavenly, Ariana has been named a "Heavenly Holy One." So, it is with great anticipation we await the new and the beautiful, God has blessed us and others who have met Ariana Sky with his unfathomable Glory and Grace."

## Wanted: A Grief Helped!!

**C**alling all interested Parents!! TxP2P needs more trained Supporting Parent Volunteers. We have many new parents calling for a parent-to-parent match, so we really need your help! Please join us at one of our trainings and explore how to help parents whose children are newly diagnosed. Our free volunteer trainings are from 9 a.m. - 4 p.m. on Saturdays. We offer child care, feed everyone and have a really good time getting to know

each other while we learn about stages parents may experience, emotional support, resources and communication skills. Does this appeal to you?? If so, please email Erika, Susan or Patty and we will add you to the invitation list. Here are the cities we will be visiting this year!!

**February** Rio Grande Valley,  
**April** Houston  
**May** San Antonio  
**July** Corpus Christi

**Patty Geisinger, TxP2P Staff**

**August** Dallas/Fort Worth  
**September** Austin  
**October** El Paso (West Texas)  
**November** Tyler/Longview

We need you all but are especially in need of parents of older children with the diagnoses of Autism, Bipolar, ADD/ADHD, and Learning Disabilities!

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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 these children.



## Conference Schedule

Date	Conference Title	Location	Registration Information
Friday, Feb. 20 <sup>th</sup> to Sat., Feb. 21 <sup>st</sup> , 2009	<b>2009 Attention Deficit Disorder Association Southern Region Conference</b>	The Wyndham DFW Airport North Hotel Irving, TX	For more information, contact: ADDA-SR Office at 281-897-0982 or Melissa Petty in Dallas at 972-458-9226 or check on their website: <a href="http://www.adda-sr.org">http://www.adda-sr.org</a>
Monday, Feb. 23 <sup>rd</sup> to Wed., Feb. 25 <sup>th</sup> , 2009	<b>"Blazing a Trail with Transition" Texas Transition Conference 2009</b>	Doubletree Hotel Austin, TX	For more information, contact: Cheryl Grenwelge at 979.458.1593 or <a href="mailto:cgrenwelge@tamu.edu">cgrenwelge@tamu.edu</a> or go to their website: <a href="http://ttc.tamu.edu/">http://ttc.tamu.edu/</a>
Wednesday, Feb. 25 <sup>th</sup> to Sat., Feb. 28 <sup>th</sup> , 2009	<b>The Arc of Texas 16<sup>th</sup> Annual Inclusion Works Conference</b>	Renaissance Austin Hotel Austin, TX	For more information contact: The Arc of Texas, 800-252-9729 or 512-454-6694 or go to their website: <a href="http://www.thearcoftexas.org">http://www.thearcoftexas.org</a>
Saturday, March 7 <sup>th</sup> , 2009	<b>4<sup>th</sup> Annual Special Education Parent Conference &amp; Resource Fair</b>	Morton Ranch High School Katy, TX	For more information, contact: Family to Family Network, 713-466-6304 or <a href="http://www.familytofamilynetwork.org/SpecialEvents.html">http://www.familytofamilynetwork.org/SpecialEvents.html</a>
Monday, March 9 <sup>th</sup> to Tues., March 10 <sup>th</sup> , 2009	<b>The 2009 Texas Statewide Independent Living Conference "Relay Independence: No Challenge Too Great!"</b>	Courtyard Marriott Downtown Austin, TX	For more information: Regina Blye at the Texas State Independent Living Conference, 877-371-7353 or email at <a href="mailto:admin@txsilc.org">admin@txsilc.org</a>
Sunday, April 5 <sup>th</sup> to Monday, April 6 <sup>th</sup> , 2009	<b>BRAIN STORM '09 Coalition of Texans w/ Disabilities 31<sup>st</sup> Annual Convention</b>	AT&T Executive Education & Conf. Center Austin, TX	For more information, contact: Coalition of Texans with Disabilities 512-478-3366 or register on-line at <a href="http://www.cotwd.org/convention.html">www.cotwd.org/convention.html</a>