



A Parent’s Perspective

TxP2P Quarterly Newsletter

TxP2P Needs Your Help

Laura J. Warren, TxP2P Staff

It’s that time again - when we ask for your financial help for TxP2P. And here’s the disclaimer: when my son came home from the hospital, we brought home about \$200 less each month than we needed. We lived on credit cards for about 2 years. It took another 4 years to pay them off with an oath never to do that again! If you are anywhere close to this situation, we don’t want you to read any further - our mantra is “take care of your family first!” However, if you have family or friends who are in a position to donate, pass the enclosed envelope to them and ask them to consider making a donation to TxP2P this year as a favor to you!

In these hard economic times, nonprofits have especially been hard hit. We have had funders tell us that they are only giving to those nonprofits who have an emergency situation - well, that’s just about all the nonprofits I know! Contributions are down and the need is great. We have tried unsuccessfully to get funding for new computers and printers. Some of our computers are 5 years old and we have lost two printers in the last 2 months. One is held together with duct tape but it works. It keeps us smiling!

In addition to our funding through grants and contracts for specific programs, we still rely heavily on private donations from individuals to fund a large portion of our family support program and our operating expenses. We have a small staff doing a gigantic job; some of them are voluntarily not being paid their full salary due to budget constraints. In addition, positions such as Program Secretary, Administrative Assistant, or Fundraising Coordinator would work miracles for our organization but there is no funding for these positions.

- ♥ \$10 from everyone who receives this newsletter would help us finally pay our administrative staff a full salary!
- ♥ \$20 from everyone who receives this letter could help us realize our dream of hiring a Fundraising Coordinator.
- ♥ Or become a monthly donor at \$10 or \$20 or whatever you can afford - the information is on the envelope.

So if you can take care of your family AND help us out this year, please do! The rent and phone bill just keep coming and I’d rather not be forced to use those credit cards again . . .

Volume 8, Issue 3
Holiday 2009
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Help TxP2P by using our Randall’s Good Neighbor Remarkable Card Number 10043!



Mark Your Calendars! TxP2P 2010 Events

3rd Annual Central Texas
Walk N Roll
Supporting TxP2P and OIF
April 24, 2010
Old Settlers Park
Round Rock, Texas

6th Annual TxP2P
Parent Conference
June 25-26, 2010
Embassy Suites San Marcos
San Marcos, Texas

Trivial Pursuit...Only It's Not Trivial

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

At the Center for Disability Studies, we receive a lot of questions from families who are struggling to get accurate answers to their questions. Here are a few of the recent ones. We're hopeful that the info may be helpful to others.

Did you know...

Case management/service coordination offered in the Home and Community-based Services waiver (HCS) will be transitioned from the HCS provider to the local Mental Retardation Authority (MHMR Center) beginning June 1st, 2010. Rules for the new service coordination/case management system are being developed. For more information, visit <http://www.dads.state.tx.us/providers/hcs/faqs/July232009MtgQAs.pdf>

All Home and Community Based Services (HCS) 3-4 bed group homes and foster/companion care residences will be visited once a year by DADS residential reviewers. This is separate and apart from the certification process. This is a new requirement included in Rider 48 of Senate Bill 1 passed during the 81st legislative session. These visits will be *unannounced* and will last approximately 45 minutes. To get more detailed information go to <http://www.dads.state.tx.us/providers/hcs/faqs/July232009MtgQAs.pdf>

If a child/adult is on a Medicaid waiver waiting list and he or she is offered services only to find out they aren't eligible and should have been on a different waiver program waiting list, you don't have to go to the bottom of the "other" waiting list. The individual's name should be placed on the second waiting list as of the date his/her name was entered on the original waiting list. For example, a child is put on the HCS waiting list on September 6th, 2000. His name comes up on the waiting list, only to find out that his IQ is a few points too high for HCS eligibility so he does not qualify. However, he likely would be eligible for the CLASS waiver due to related conditions. His name would then go on the CLASS waiting list as of the date he was put on the original list. In this example, that would be September 6th, 2000.

The Texas Legislature passed legislation that directs the state to develop a Medicaid buy-in program for children with disabilities in families up to 300% of the federal poverty level. This will provide some much needed services to a number of children until they are offered waiver services (when they automatically become eligible for Medicaid). For some children, this may eliminate the need for waiver services. The premiums for the buy-in will be determined on a sliding fee basis. This program will be implemented on September 1st, 2010.

You can receive nursing services in the CLASS waiver. Many families have been told that this is not a service available in the CLASS waiver, but it is.

The Consumer Directed Services (CDS) service delivery option provides an opportunity to pay attendants, respite providers, and others a higher wage than if they were working through the standard agency provider model. If you are on the HCS waiver, using the CDS delivery option, you have \$29 per hour for wages, taxes, and benefits that can be used to pay your attendant (providing supported home living services). CLASS, Primary Home Care, Medically Dependent Children's Program, and other rates aren't nearly as high, but you can still pay more than what is typically paid through the agency model.

Individuals using the Consumer Directed Services (CDS) delivery option can now self-direct a number of new services in addition to respite and attendant care. A list of the allowable CDS services can be found at <http://www.dads.state.tx.us>.

According to the Department on Aging and Disability Services, due to increased "acuity costs" (higher costs per person), the money appropriated for new waiver slots in the Community Based Alternatives (CBA) waiver will be used to fund the increased acuity costs and will not be used for new waiver slots as expected. This has occurred due to the fact that the legislature did not fund the exceptional item request to cover these higher costs. The number of new

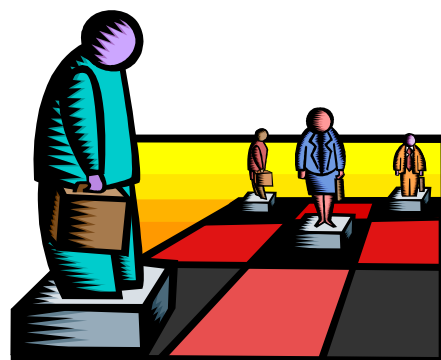
CLASS (Community Living Assistance Supports and Services) waiver slots will also be reduced. The HCS waiver will not be affected even though the HCS waiver currently has one of the highest per person costs.

So here's some food for thought. As costs for services and supports rise for those currently in the program, fewer individuals will be offered new waiver services. As individuals, families, and advocates we expend a lot of energy asking for program changes, higher quality, increased access, and increased funding. I know that most individuals and families only use the services they need. However, it may be a good time to step back and ask the question, "am I using what I need, or am I using all that is offered?"

Think about this...

- ✦ Amount budgeted for HCS waiver for 2010—\$704,444,465
 - ✦ 3% of total budgeted for 2010\$ 21,133,333
 - ✦ HCS average cost per individual, per month—\$ 3,450
- Additional number of people that could possibly receive services if costs were reduced by 3% - 6,125

Granted, this is a very generalized example and not everyone could manage with reduced services (in fact some may be receiving less than what is needed). But it is worth thinking about when doing service planning. If a person is receiving 30 hours a week of attendant care, a 3% decrease would be less than one hour per week -- .9 hours to be exact. With close to 100,000 individuals waiting for services, it is something to think about.



Jake empowered

Hays High School student promotes self-advocacy

Ryan Sachetta, Special to the Hays Free Press

Jake Pinner, 18, carries himself with an unmistakable aura of pride. It goes beyond the navy t-shirt emblazoned with the American flag across his chest or even the Rebel Pride award he won as a sophomore in 2007 at Hays High School.

Simply put, the soon-to-be senior just loves to be part of the team, especially the fandom associated with rooting for football. Jake speaks confidently of his Rebels' chances of returning to the playoffs this season. He believes in Colt McCoy's ability to lead the Longhorns down the road toward redemption in response to last season's title game snub. And his confidence in the Cowboys is weathered, but he admires the risk of parting ways with Terrell Owens.

If football is Jake's dessert, then the game's statistics stand as the maraschino cherry on top. Don't let the innocent, glistening smile and the vibrant red hair fool you, Jake is an animal when it comes to statistics. He can chew you up and spit you out with a full-on blitz of football figures and trends that could leave even John Madden in complete awe.

It's delayed, but if you keep drilling Jake will speak of his own individual accomplishments. It's a list that includes the Mighty Mustang Award, Rebel Spirit Award, and accomplished High School choir competitor with perfect pitch and the ability to sing in English and German.

Recently and most notably, Jake won the "Empowerment Award for Excellence in Promotion of Self-Advocacy" at the 34th Annual State Convention of the American Association for Intellec-

tual and Developmental Disabilities, Texas Chapter in Corpus Christi. Jake was presented the award in response to his work as a self-advocate with Asperger's disorder, a high-functioning form of autism.

"This baby was riding home with me all the way back to Buda, Texas," said Jake as he admired his hefty trophy. As he brings the award over he walks with swagger in his step, confident but never cocky.

According to the Autism Society of America, Asperger's disorder was discovered by Austrian pediatrician, Hans Asperger in 1944. Both autism and Asperger's are considered "spectrum disorders" because they can affect the diagnosed individual in various forms and degrees of severity.

Individuals with Asperger's generally possess normal intelligence and language development. But they lack social and communication skills like empathy and the ability to share excitement in other's accomplishments. People with Asperger's also demonstrate extremely high levels of fascination for certain topics.

"Asperger's is a part of my life, but it does not define me," said Jake. He subscribes to and has advocated People First Language, which can best be summarized by describing someone as the preferred "person with autism" as opposed to an "autistic person."

As we sit over dessert at Cherry Creek Catfish Restaurant, Jake has two of his favorite things within an arm's reach: Chocolate Lover's pie served up by his sister, Laney, who manages the restaurant, and copies of the Maple Street Dallas Cow-

boys and Texas Longhorns press guides.

Jake approaches his dessert with the same intensity he analyzes the glossy pages lined with team schedules and projected records. "Son, slow down," said Jeanine Pinner.



Jake and his dog Reagan relax on the couch. Jake recently won an award for his work as a self-advocate with Asperger's disorder.

Mrs. Pinner serves as training and outreach coordinator for Texas Parent to Parent, an organization that aims to provide information and support to families of children with disabilities, chronic illness and other special health care needs across Texas

"I truly believe that Jake is living proof of what can be accomplished when the self-advocate, family, friends, teachers, therapists and community members work together toward a common goal," Mrs. Pinner said.

Jake and his mother have a strong visible bond. There's the obvious mutual love and respect, but then there's the shared interests. Both are admitted lovers of technology, with Jake constantly playing flight simulator on his computer or college football on his Sony PlayStation 2, and mom glued to her Kindle wireless reading device. Both have their iPhones on hand, especially when needing to check whether or not

Continued on Page 4

Wish for This Season!

Tom & Susan Prior, TxP2P Volunteers

Happy Holidays everyone! At the advent of this very special time of year, a time of sharing, giving, and re-focusing our hearts, I thought I might share a few observations with you to include something that may be as close to your heart as it is with mine.

It seems that it's a normal human behavior, whether learned or inherited, of comparing how our child appears, ability wise, next to "that other child." I honestly believe it starts at the early ages of our child's life when the doctors, sociologists and whomever else give us charts to see where our child stands next to the "norm" in weight, height, walking, talking and on and on. Pretty soon and into the child's early years, you see that comparison growing, not from the children's mouths but from the parents. "Well, my Johnny did this today...." Or "...he just can't seem to keep up like the others..." Do you know what I mean? It's like it's necessary for us to "compare" to justify some lacking or over achieving, but most of the time it is the lacking. And what I've observed is that when we vocalize this "comparison" and people are around us, we forget that we may cause some hurt in others who are dealing with some lacking in their own child. Truth be told, it seems even magnified more so within the community of children with special health care needs. It's as if we've all forgotten that no matter the degree of disability, greater or faintly obvious, the hurt, frustration, fears for the future, grief felt by us all is just that! Still felt by us all!

My child has Down syndrome and appears very active and vocal, very social and most people enjoy her company. I should be happy and proud right? Well yes, in most cases I am. But, you know what; in the back of my and my husband's mind's is the constant reminders, "she'll still never live a 'normal' life. Will she ever know what true love is, have a child, drive a car or hold her own in society?" Our grief and hurt for her sets in on a daily basis just as much as it does with those parents whose child is many times more affected by their condition.

So why do we still hear those comparisons?

Or other thoughts like "...oh my child couldn't enjoy that; she/he just wouldn't get it..." Why? Because others can? Haven't you just limited the possibilities, however small they may be, for your child because you just compared him/her to "the other kids." We've always felt that every time there's an opportunity to expose our kids to something fun, challenging, or exciting is an opportunity to see another light go on in their lives. Whatever accomplishments are met from the very small to the giant leaps, are still successes no matter the degree of disability your child has to work through and those "wins" (and losses) like with us are rungs of a ladder, building blocks. To paraphrase a saying, "that first mile's journey begins with the first step..."

Now, if you may excuse me a moment's reflection here, there is another facet of this "comparison" that I've observed and felt the brunt of too. Yes, there are those families whose lives' have been totally turned 180 degrees by the severity of their child's condition. Some live life 24/7, 365 days of the year in total focus of their child's health and well being and my heart hurts so much for them!! If there were a Purple Heart medal, and it would make any difference, those folks deserve a footlocker full of them. But sometimes it slips. Certainly not from everyone, but every now and then I'll be in the company of those with severe disabilities of all sorts and even within the community of Down syndrome and I'll hear the comparisons but this one is of a different sort. Almost like reverse discrimination that's been the topic of news articles within ethnic groups.

Sometimes quite imperceptible at first, a look, a turning of the back, a small comment. All of a sudden you feel yourself alone in a group you used to feel at ease with sharing about your child. Then it dawns on you, I've just been compared to!! I don't fit in because my child doesn't have as severe a condition. As if my membership in some club doesn't

count because I haven't paid the dues like some others have. I suppose because we "...haven't walked a mile in their shoes..." there is no comparison. Though this is partially true, we haven't been up 24 hours a day making sure our child is still breathing, medications still flowing, and on and on. What's forgotten, what's missing from that train of thought is the compassion all should feel for our fellow parents. Least we forget...no one asked us to choose any more than the question was posed to others. There was no "column A or column B" We've all been dealt a hand, though comparatively different I admit, it is still our hand and we must play it the best we can. We are all travelling the same road.

My wish this season and hopefully for the rest of our lives, is that we watch and observe and become more sensitive. Become more sensitive to the needs of others, even though you may feel their situation is worse or better than your own. We all say, "You need to walk in someone else's shoes to know what it feels like to have a child with a disability." But doesn't that statement also apply to how you respond to other parents of children with disabilities You don't know how they feel or have you forgotten how they feel? Try not to forget how they feel, what is going on in their lives or how they are able to cope. We are all very different, unique, special, yet we all share in the same loss, grief, frustrations, don't we?

Final thought! In this season of caring and giving, remember to be non-judgmental and embrace everyone, no matter their degree of ability.



I had parenthood all figured out until . . .

Kathryn Whitaker, Austin, TX

I had parenthood all figured out until September 18, 2009 when we welcomed our fifth child, Luke Timothy, at 3lbs. 9oz. and 36 weeks gestation. By all accounts, a 36-weeker is “old” in the Neonatal Intensive Care Unit (NICU), but Luke was an IUGR baby (intrauterine growth retardation) and did not grow well in my belly.

Our first week in the NICU was spent increasing feeds, working on nursing and tanning under the “billy” light. My husband and I were feeling confident about his progress and hopeful that our stay would be a short one. On day seven, we had a small intestinal infection scare – necrotizing enterocolitis (NEC for short) but it passed after 24 hours. On day nine it came back with a vengeance. Luke was transferred to Dell Children’s Medical Center and underwent emergency surgery where he lost 16 cm of his small intestine, part of his colon and his appendix. His health was so dire, our priest performed an emergency baptism in Bay 2 in the NICU before his transfer.

Worst 24 hours of my life. Hands down.

We endured two weeks of healing and when reintroducing feeds, the

NEC came back. We were devastated. Progress was painfully slow. Then, it was bad news about the heart, then the testicles, the kidneys, the brain and the spinal cord. Our hearts couldn’t take much more. My husband joked that we needed to be discharged soon before the doctors found anything else.

After 44 days in the NICU, we were sent home, along with our nine-page discharge sheet. It was full of a litany of procedures, patient history, medications, follow-up appointments and “unresolved diagnoses” including various major organs.
















While we have a fantastic support system at our children’s school and our church, the process of navigating the waters of specialist appointments, developmental assessments and the like is daunting. By nature, I’m not a wallflower mom, but this was dizzying. We have well-meaning friends and lovely family members, but it has been those parents who have walked the NICU road before us that have been our greatest source of support, advice, reality checks and laughter.

As we left on Day 44, I kept looking over my shoulder for my guardian angel to guide my hus-

band and me down this new path of parenthood. Unfortunately, that wasn’t in our going home bag from the staff. Oh, if only. If only we had a hand to hold, a reassuring voice, a shoulder to rest our weary heads, then we could walk this path with confidence. As fate would have it we were sent a family, by way of the “A Hand to Hold” program, that endured the NICU road twice before. But, we shouldn’t leave other families’ post-NICU roads to fate. They too, need a reassuring hand to hold.

Kathryn and her husband, Scott, reside in Austin and are the parents of five children: Will (8), John Paul (5), Anna-Laura (4), Clare (2) and Luke (2 months).


















































Alleviating Stress Over the Holidays
















Tips for stress relief:
















- **Pick one night a week and do a family movie night or board games. Don’t do anything related to the holidays. Enjoy each other’s company.**
- **Have pizza for Christmas eve. Make them homemade individual pizzas so you can personalize them.**
- **Take a long walk with a friend.**













































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.

January	Austin
February	Edinburg
March	Houston
April	Dallas
July	Corpus Christi
August	Abilene
September	Dallas
October	College Station
November	El Paso

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Stay Tuned!

We are starting a new Dad's Group Listserv. Please contact Susan Prior (866-896-6001, 512-458-8600 or Susan.Prior@txp2p.org) if you are interested in joining this listserv. Spread the word!

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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.



***Happy Holidays from
the TxP2P Staff!***