



# Texas Parent to Parent

Providing support and information for families of children with disabilities, chronic illness and other health care needs

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*Wednesday, October 3, 2007*

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*6 - 9 pm*

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*For more information, call Michaelanne Richter-Kurst at*

*512-423-1748 or go to our website [www.txp2p.org](http://www.txp2p.org)*

## What Will it Take to Make Us Fighting Mad?

Colleen Horton, MPAff, Public Policy Director  
Texas Center for Disability Studies, U.T. @ Austin

Ten year waiting lists...abuse in state schools...where is the outrage? What has happened to our willingness to get fighting mad? In Michael Moore's most recent documentary "Sicko," many things stand out, but one question he poses is particularly powerful. Why don't Americans get outraged enough to do something about the injustices we know exist? What happened to our integrity and our courage? In countries in Europe, South America and other parts of the world, mass protests take place when the people believe their government is taking them in the wrong direction. Why have we become so complacent, so accepting of the status quo? What happened to our sense of re-



sponsibility for righting the wrongs? As a child in the 60's I remember the riots in Washington. I could see the smoke of the burning city from across the river where I lived in Virginia. I didn't really understand at the time how the people could be so angry that they would burn their own city. Now I do. African Americans were rightly outraged at their lack of civil rights and demanded change. They had the courage to risk it all. I also remember the campus riots, especially Kent State. The youth of our country could no longer accept a war that the elite were thrusting on them, a war they didn't believe in. They were mad enough and had the courage to fight back. They were willing to take risks for what they

believed in. Today, injustice abounds but our reactions are terribly tempered. The tax breaks for the rich, the lack of adequate health care for millions, the young soldiers dying everyday in a war most of us don't believe in, the genocide in Darfur. Closer to home, we have long waiting lists for services for both children and adults with disabilities, abuse and neglect in our state schools, lack of low income housing,, insufficient accessible transportation and the list could go on. Why are we not fighting mad? Speaking of injustice, Geraldo Rivera recently did a segment on his show, "Geraldo At Large" featuring a young man, Haseeb Chisty, who resides at the Denton State School.

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# Who's Driving the Bus?: Driver's Ed - Speaking from the Heart Makes a Difference!

Jeanine Pinner, TxP2P

**D**o you doubt that speaking up really counts for anything? Ever wonder if anyone is really listening to you? Living in a world that is frequently scary, one that sometimes doesn't make sense, times when you doubt that anyone is really listening, it can be difficult to convince your children that speaking from the heart can make a difference.

Last year, my son, Jake, and I attended the 2006 Texas State Conference on Autism in Dallas. Jake chose each of the sessions he wanted to attend and loved every minute. He was particularly inspired by the keynote address from Taylor Crowe, a 25-year-old man with Autism, and told me that if Taylor could do it, so could he!

Some months later, I was invited to participate in the Stakeholder Committee Meeting for the 2007 State Autism Conference. I knew my voice as "mom" and advocate mattered, but believed the voice of the self-advocate was the most important. I asked Jake what he'd like for me to take to this committee on his behalf - what would he say to committee members if he were there?

Here's what he gave me:

## Jake's Wish List: 2007 Texas State Autism Conference Stakeholders' Meeting—2-26-07

### 1. Self-advocacy skills

- asking for help when you need it
- explaining your disability
- knowing your modifications and how to ask for them when you need them

### 2. Managing challenging teachers

- Dealing with tough teachers (teachers that are not really experienced with Autism issues)

### 3. Understanding my disability

- understanding which behaviors are happening
- how it may affect your self-esteem

### 4. Organization

- managing your time keeping your school work (notebooks & binders) clean and organized

### 5. Social interaction

- proper ways to communicate with friends or anyone you don't know really well

### 6. Participation in ARD Committee meetings

- being able to attend meeting

• understanding what's going on  
It was a proud moment for me when I handed Jake's Wish List to Dr. Patti Huskin from ESC Region 2, the education service center responsible for the Autism Conference. Shortly after the meeting, Dr. Huskin emailed us to let us know that she would do her best to include a self-advocates' track at the conference. Jake haunted ESC Region 2's website for weeks after receiving her email and, as evidence of a self-advocates' track emerged, he became more and more excited about attending the conference. I was (and still am) absolutely knocked out by how quickly Dr. Huskin and her Team were able to add an entire track for self-advocates to the conference. Only a Team with profound passion and dedication could have pulled this off!

As the conference date approached, Jake's anxiety level rose. *Was I sure I had registered him? Would a hurricane cause the conference to be cancelled? If it rained really hard, would they be able to hear the presentations going on inside the conference center? What time would I pick him up from school to get on the road? Would we check in at the hotel or the conference center first? Should he pack right now? Which suitcase should he use? What if...???* You get the idea, right?

Our day to leave finally came (whew!). We arrived in Corpus Christi to gorgeous weather, set up the TxP2P Exhibit, and Jake proudly checked in at registration and picked up his conference materials. I waited outside in the truck while he checked in completely on his own. He wanted me to go with him to locate the rooms his sessions would be in (yes, he had already selected each of his sessions before he even arrived in Corpus), so I did. I was proud of him for being the one to suggest it -- knowing what he needed and asking for it - yea!

Thursday - another beautiful day. We were a little behind schedule, so instead of taking the shuttle, we drove over to the conference center and Jake made it into the center on his own while I found a parking place. Hundreds of people were

making their way to their own sessions while Jake was trying to locate his. When I finally caught up with him, he had already determined that his session was in a different location than we originally thought and he hadn't been able to find the correct room.

What to do???

Ask for help! The wonderful folks at the Information Desk told us exactly how to find the room for Jake's session. He just bounced right into the room like he owned the place - so excited to be there! Throughout the day, I caught reassuring glimpses of Jake here and there. I knew it wouldn't take him long to create a visual map of the center and had instructed him that he was not to leave the building without me under any circumstances. Each time we had a few minutes together, I probed for information - *"How's it going? Are you enjoying your session? What are y'all doing? What are you learning?"*

He happily shared some of what he was learning and explained the difference between *modifications* and *accommodations* to me. By day's end he was tired, but still fired up, looking forward to his sessions on Friday and Saturday.

Friday! Jake wants to ride the shuttle. I'm carrying too much stuff back and forth from the hotel to ride the shuttle, but I know it's important to him. Now *I'm* a little nervous - how to let him take the shuttle while knowing he's getting on the right one and only gets off at the conference center? Hmmm.....lurk around the corner in the truck and follow the shuttle to the center? Yes!

He knew I was there, but ignored me. The shuttle arrived and he boarded, along with other conference participants. I followed only part of the way and made my way to the parking lot on the other side of the conference center, parked and went into the building. By the time I saw Jake, he had already connected with our friend, Tracey, and had made plans to attend the keynote with her and her group. He didn't need me to tell him what to do or where to go, so back to the of

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This young man was horrifically beaten on the state school premises by an employee. The injuries and disabilities he sustained in the attack are permanent. A young man who has intellectual disabilities, but could walk and run and enjoy his life, can no longer do so. He now spends his days in a wheelchair and must be fed through a tube in his stomach as a result of the beating. Four years after the incident he remains in the facility where the crime took place. Until just recently, the state had denied Haseeb sufficient home-based community services that would allow him to leave the state school and return home to his family. In four years, no feasible offers of home services were made until Geraldo made Haseeb's case national news. Our state spends over \$111,000 per year, for each of the 5,000 residents in 13 state schools while more than 80,000 indi-

viduals with disabilities are on waiting lists for less expensive community services. Where are the voices of the 80,000 people who are waiting? Where is our outrage and what will it take to bring it back? We can't give Haseeb back the life he had, but for his sake and the sake of all our children waiting for services, we can begin to have the courage to stand up, make noise, and challenge the system. Two things you can do today! Contact Lt. Governor Dewhurst to request that he appoint a joint select committee to study the abuse at Texas state schools, as requested by Senators Deuell and Lucio. (512/463-0001) Contact *your* state senator and representative and let them know that people with disabilities are waiting far too long on the Medicaid waiver waiting lists to get the services and supports they need. For more information, you can contact me at

[colleen.horton@mail.utexas.edu](mailto:colleen.horton@mail.utexas.edu)

**Editor's Note:** There are groups who are getting ready now for the next legislative session. If you have time and/or interested in making changes for people with disabilities, I suggest you contact **Texas Parent Advocates Consortium**. They are a "virtual" group who communicate via email and have an annual rally during the legislative sessions, have about 80 members across Texas, parents of children ages birth through 30, cross disability. To join, email: [txpacs-subscribe@yahoo.com](mailto:txpacs-subscribe@yahoo.com) & explain who you are & why you wish to join. TxP2P also has an advocacy listserv which you can join - just call or email Susan Prior (512-458-8600 or 866-896-6001 or [susan.prior@txp2p.org](mailto:susan.prior@txp2p.org)) and ask to join the TxP2P Advocacy Listserv.

## Assistive Technology - Short-Term Device Loans

**T**he Texas Technology Access Program at The Center for Disability Studies, University of Texas at Austin has an Assistive Technology (AT) Device Loan Program designed to meet the needs of persons not served by existing agency loan programs. This program will allow persons with disabilities, their families, educators, service providers and employers to borrow AT devices for up to six weeks, with opportunities to extend the time if the device has not been requested by another borrower. This service is free and is available to anyone in Texas that meets the qualifications.



The program will give individuals and agencies an opportunity to borrow an AT device (examples of some of the devices available are listed below), and use it in the individual's normal environments. They are then better able to determine if the device meets their needs or the needs of individual with disabilities they're serving. This will allow them to make an informed choice about which device to purchase or whether to purchase a device at all.

For more information on available devices or to download a Device Loan Request Form, please visit our website <http://tatp.edb.utexas.edu>

or call 1-800-828-7839 and a Loan Request Form will be mailed to you. Examples of some of the devices available:

- Communication devices—such as Dynavox, Vanguard, chat PC
- Vision & hearing scanners/readers
- Switches
- Early childhood learning equipment such as AlphaSmart, Kidz-Mouse
- Computer access equipment - keyboard, mouse, joystick,
- Palm devices

Additional equipment is available. Call for more information!

## Workbook Explores if Youth Should Disclose Having a Disability

Reprinted from Texas Council for Developmental Disabilities FYI Newsletter, Feb. 2007

*"The 411 on Disability Disclosure: A Workbook for Youth with Disabilities"* is designed to help young people make informed decisions about whether or not to disclose their disability and understand how that decision may impact their education, employment, and social lives. Topics include:

- Should I disclose?

- If I decide to disclose, who is an appropriate person to tell?
- When should I disclose?
- How much should I disclose?



The 99-page workbook is available from the National Collaborative on Workforce and Dis-

ability for Youth (NCWD/Youth) at <http://www.ncwd-youth.info/resources&Publications/411.html>. A limited supply of print copies is available. If you are interested in receiving a copy, send an e-mail to [publications@ncwd-youth.info](mailto:publications@ncwd-youth.info) or call 1-877-871-0744.



me - very happily and successfully - another goal accomplished! Saturday arrives - sunny and humid, seagulls calling out to passersby. One more trek to the conference center with my cart and materials.

Exhibit Hall I went. Jake was attending the conference independently I'm by myself today - Jake has left the hotel without me, located the shuttle and arrived safely at the conference center, all on his own. His self-esteem is soaring! My anxiety is lessening - he's OK and proving he's more than capable. Jake's session today is *Introducing Me Too*, a session designed to help self-advocates create Powerpoint presentations that explain each person's disability, needs, and strengths to others. He loved it!

This entire experience reinforced my faith in Jake's ability to make good decisions and confirmed for me that he really has been listening to our years of instruction. Even though I've been teaching him many of the things that were covered in his sessions, he heard it differently, perhaps even better from someone else. We never know how much time or how

many opportunities we'll have to teach our children what they need to know to be safe, independent and productive. The window of opportunity could end tomorrow. This reminds me that not only must I make good use of every opportunity that is provided, but that I must work to create new opportunities for him for as long as he needs them or as long as I'm able.

Jake's participation in the 2007 conference was a powerful experience for him (and for me). Through the carefully organized and well-planned self-advocates' sessions, his knowledge and confidence has grown. He has his own dreams and goals for his future and every one of these learning opportunities helps him make progress toward them. He tells me that now he knows he's not alone, that there are other self-advocates out there who are experiencing some of the same difficulties and fears he is. He sees some who are where he was (his words) several years ago, and some who are where he wants to be. He feels valued, respected, and honored just being here at the conference. He tells me (a lot!) that he is

thrilled to have had some impact in making positive change in the world through Dr. Huskin's use of his Wish List to help create an entire conference track for self-advocates with Autism.

As Jake puts it, "It takes a lot of courage to say what you think. Sometimes when you speak what's in your heart to someone who cares and is really listening, things change."

**Thank you, Jake! And Thank YOU, Dr. Huskin!**

*I'd love to hear from you about what's going on in your corner of Texas in this arena. Does your favorite conference have a track for self-advocates? What is provided at your school district/community/ education service center for self-determination and self-advocacy instruction and activities? Who is traveling on this journey with you and your child? What can you and your child do to create more learning opportunities for self-advocates? Please write to me at [jeanine@txp2p.org](mailto:jeanine@txp2p.org) to share your experiences and ideas. We'll publish your contributions in an upcoming newsletter. I look forward to hearing from you soon!*

## TxP2P Request for Family Stories

### TxP2P Board of Directors

In an effort to continue to expand and strengthen the programs and services that TXP2P provides, we seek funding from a number of sources. Our funders (grantors, donors, sponsors of events, etc.) often want to know in what way we have directly impacted families. Being able to relay the personal story of a child or family with whom we have assisted is a great way to let our supports and funders know that their financial support is making a difference in people's lives. We would greatly appreciate you taking the time to tell us your story.

We have developed some questions for you to use in writing your story that will help show the benefits of parent to parent support. We need the stories to be a page or less and

would love to have a photo of your child and/or family to go with it. Here are the questions to answer:

- How long have you been connected to TxP2P?
- How did you learn of TxP2P?
- In what ways has being connected to TxP2P assisted you in dealing with the challenges of having a child with a disability, chronic illness, or other health care need in your family? Examples: emotional support, information, connection to others, etc.
- What services or supports have you accessed through TxP2P? (parent match, attended parent conference, received stipends to attend



parent conference, trainings, learned of valuable resources, listservs, web based resource referral, etc.)

- Would you recommend TXP2P to another parent and why? (Please describe)

Please also give us your contact information and your relationship to the child in your story. We would love to hear from grandparents, family members, or even professionals as well as parents. We will also need your child's name, age, and diagnosis and let us know if we can contact you about this information.

You may mail the story to us at Texas Parent to Parent, 3710 Cedar Street, Box 12, Austin, TX 78705-1449 or email it to [Laura@txp2p.org](mailto:Laura@txp2p.org). We look forward to hearing from you soon!

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## Conference Schedule

Date	Conference Title	Location	Registration Information
Thursday, Sept. 27 to Saturday, Sept. 29, 2007	<b>Fifth Annual Conference on Brain Injury</b>	The Westin Riverwalk Hotel San Antonio, Texas	NABIS Conference PO Box 1804 Alexandria, VA 22313 Phone: (703) 960-6500 E-mail: <a href="mailto:conference@nabis.org">conference@nabis.org</a> or Website: <a href="http://www.nabis.org/articles/conference.shtml">http://www.nabis.org/articles/conference.shtml</a>
Saturday, Oct. 6 to Sunday, Oct. 7, 2007	<b>2007 NAMI Texas Conference: Renewal and Recovery</b>	Hyatt Regency on Town Lake Austin, TX	NAMI Texas 2800 S. I-35, Suite 140 Austin, TX 78704 512-480-2071 <a href="http://www.namitexas.org/programs/convention.html">http://www.namitexas.org/programs/convention.html</a>
Saturday, Oct. 6 <sup>th</sup> , 2007	<b>The 3rd Annual Disability Conference &amp; Resource Fair for the Northwest Houston Community</b>	Graceview Baptist Church Tomball, TX	For more information, contact: Michelle Guppy at <a href="mailto:MichelleMGuppy@yahoo.com">MichelleMGuppy@yahoo.com</a> or 281-686-0103
Thursday, Oct. 11 <sup>th</sup> to Saturday, Oct. 13 <sup>th</sup> , 2007	<b>The Arc's 56th National Convention Lighting the Way</b>	Hyatt Regency Dallas, TX	The Arc of the United States 1010 Wayne Avenue, Suite 650 Silver Spring MD 20910 Phone: (301) 565-3842 Toll Free: 800-433-5255 <a href="http://www.thearc.org">www.thearc.org</a>
Friday, Oct. 19 <sup>th</sup> to Sunday, Oct. 21 <sup>st</sup> , 2007	<b>2007 The Arc of Texas Conference Making Dreams Reality</b>	Camp For All Burton, Texas	The Arc of Texas 8001 Centre Park Drive Austin, TX 78754 800-252-9729 or 512-454-6694 <a href="http://www.thearcoftexas.org/resources/ArcTXReg2007.pdf">http://www.thearcoftexas.org/resources/ArcTXReg2007.pdf</a>
Wednesday, Oct. 31 <sup>st</sup> , to Saturday, Nov. 3 <sup>rd</sup> , 2007	<b>43rd Annual LDAT State Conference Meeting the Challenges</b>	Renaissance Austin Hotel Austin, Texas	LDAT 1011 W. 31 <sup>st</sup> Street Austin TX 78705 512-458-8234 or 800-604-7500 (TX only) email: <a href="mailto:contact@ldat.org">contact@ldat.org</a> <a href="http://www.ldat.org/about/conference.html">www.ldat.org/about/conference.html</a>
Thursday, Nov. 8 <sup>th</sup> to Friday, Nov. 9 <sup>th</sup> , 2007	<b>8th Annual Chronic Illness and Disability: Transition from Pediatric to Adult-Based Care</b>	Texas Medical Center Houston, TX	For more information contact: Ellen Seaback 713-798-8237 <a href="mailto:cme@bcm.tmc.edu">cme@bcm.tmc.edu</a> <a href="http://www.baylorcme.org/search/detail.cfm?cme=608">http://www.baylorcme.org/search/detail.cfm?cme=608</a>



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Serving children with disabilities,  
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by providing support and information to  
their families through peer support,  
resource referral and public awareness.



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