



# A Parent's Perspective

**TxP2P Quarterly Newsletter** 

# Celebrate TxP2P's 10<sup>th</sup> Birthday with a Gift!

Laura J. Warren, TxP2P

e are coming to the close of our 10<sup>th</sup> year and it's that time where I ask you to help support us with a donation. And then I clarify - we are parents just like you so we know the cost of raising a child with a disability or special health care needs and know that sometimes, there is just no money to give. We understand and the last thing we want is for you to give us money you need for your family. However, if you do have funds that you can donate, please help us help other families.

In addition to our funding through grants and contracts for specific programs, we still rely on private donations from individuals to fund a large portion of our family support program and our operating expenses. Your donation will help us continue our current efforts across the state of Texas.

#### 2012 TxP2P Successes include:

- Encouraged, informed, & served almost 4,300 families and 850 professionals through 29 listservs, trainings across the state, & our quarterly newsletter,
- Matched over 125 families with trained parent volunteers for peer support,
- Held our 2-day annual parent conference with almost 400 parents & professionals and 52 youth & young adults with disabilities attending sessions a 15% increase in attendance from 2011, and
- Received a grant in collaboration with Texas Children's Hospital for transition.

With your help we will do even more! We have a small staff doing a gigantic job of running our statewide program; some of them are voluntarily not being paid their full salary due to budget constraints. In addition, funding positions such as Program Secretary or Fundraising Coordinator would work miracles for our organization. Please see enclosed envelope for more information.

Thank you for helping us continue to provide support to families across the state for another year. **We wish you and yours the very best this holiday season!** 

TxP2P Staff & Board of Directors

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Winter 2012

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#### Dear Families,

As we approach the 2013 Legislative Session, there is shared concern of further cuts to Public Education or Health and Human Services (Medicaid). Our advocacy team is available to train you in a formal class, electronically, or as you visit the capitol or testify in a bill hearing. We also train 18+ programs in schools. We train on how to advocate, not what to say! Please contact us at <a href="mailto:linda.litzinger@txp2p.org">linda.litzinger@txp2p.org</a> or at 512-922-3810 cell/text.

Sincerely, Linda Litzinger, Amy Litzinger, and Jan DiMare

Financial support for TxP2P Advocacy Network is provided in part by the Texas Council for Developmental Disabilities, with Federal funds\* made available by the United States Department of Health and Human Services, Administration on Developmental Disabilities. \*\$61,780 (60%) DD funds; \$41,473 (40%) non-federal resources.

# The 83<sup>rd</sup> Legislative Session in Football Terms! (January 8 – May 27, 2013)

Linda Litzinger, TxP2P

**lirst Quarter** (Prior to November elections): Texans approach Legislators to develop a relationship before the session begins and to write specific bills. Meet legislators

in their local offices or meet policy staff working year round at the Capitol (we can escort you); both relationships are important.

Second Quarter (November and

December): Meet new legislators still in their own districts. File bills starting on Nov 12. Advocates begin to promote them, to create momentum.

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# **Legislative Update**

Halftime (January, 2013): All is on 'pause' while legislators claim office space and await committee assignments. At some point everything will gel so you should go visit! We are happy to escort you.

Third Quarter (Feb and March): Busiest quarter of the game; stay active and block your spring break for advocacy. There are many ways to make contact, speak to the press, or attend committee meetings where Texans testify on bills (even youth). On March 5<sup>th</sup>,

there is a family press conference, followed by families making visits or testifying to a committee (see below for more information).

**Fourth Quarter** (April and May): Bills come out of committee. Advocates contact legislators as bills are scheduled for general

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Funding proposed last

spring will be finalized. The 83<sup>rd</sup>
session ends May 27<sup>th</sup>
and Governor Perry signs
bills by June 16<sup>th</sup> which
will carry August 26<sup>th</sup>
effective dates, unless
specified. It is a bien-

nium calendar; anything not passed (or funded) will wait two more years.

voting.

## Ways to Track the 83<sup>rd</sup> Legislative Session

## **Bookmark these sites:**

Texas Legislature Online: <a href="http://www.capitol.state.tx.us">http://www.capitol.state.tx.us</a>

Coalition of Texans with Disabilities' policy page: http://www.txdisabilities.org

Organizations emailing frequent news during the session:

Texas Council for Developmental Disabilities: <a href="http://www.txddc.state.tx.us/connect">http://www.txddc.state.tx.us/connect</a>, Governor's Committee on People with Disabilities: email <a href="mailto:gcpd@governor.state.tx.us">gcpd@governor.state.tx.us</a>

Arc of Texas: email kbrock@thearcoftexas.org.



<u>National issues including funding of state programs</u> (a Policy Collaboration between agencies): <a href="http://affnet.ucp.org/ucp\_generalsub.cfm/1/8/11981">http://affnet.ucp.org/ucp\_generalsub.cfm/1/8/11981</a> or <a href="http://capwiz.com/thearc/mlm/signup">http://capwiz.com/thearc/mlm/signup</a>.

#### **Ways to Track Policy Implementation**

HHSC: <a href="http://www.hhsc.state.tx.us">http://www.hhsc.state.tx.us</a>
DSHS: <a href="http://www.dads.state.tx.us">http://www.dads.state.tx.us</a>
DARS: <a href="http://www.dars.state.tx.us">http://www.dars.state.tx.us</a>

#### **My Medicaid Matters - Texas**

Nationally, the talk is urgent to protect Medicare, but will Medicaid be thrown under the bus? 'My Medicaid Matters (MMM)' is a nationwide effort to educate legislators and the public about the value of Medicaid, explaining who uses it, how many are minors who cannot earn a living, how many have developmental disabilities, etc. MMM branches host press events and circulate petitions in an effort to protect basic health care, plus Long Term Supports for persons with disabilities. Save March 5<sup>th</sup> for a rally/media event at the Capitol followed by calling on legislators. MMM info and petition: <a href="http://www.mmmtx.org/">http://www.mmmtx.org/</a>, Photos: <a href="http://www.facebook.com/mmmtexas">http://www.facebook.com/mmmtexas</a> For more information, including the 150 organizations who have partnered for this effort: <a href="http://www.thearcoftexas.org/site/PageServer?pagename=ARCTX">http://www.thearcoftexas.org/site/PageServer?pagename=ARCTX</a> mymedicaidmatterstx

# 2-1-1 Finding Help in Texas

ave you visited the 2-1-1 website lately? As with all of the resources in Texas & beyond, numbers are constantly changing, new resources are popping up and families are finding things they need. When I visited the 2-1-1 website recently, an "Alert!" button is the first thing I noticed. It is linked to the "Transportation Assistance Registry." By clicking on this Registry, it leads you to a window that includes the following information: "To register for the Transportation Assistance Registry, dial 2-1-1, select a language and then press Option 4. By signing up for this registry, you are helping your local emergency responders and officials plan for disasters. Your information will be used to help them know the type of services that might be needed during a disaster. Each community uses the information on this registry in different ways. Having your information in the registry does not guarantee that you will receive a specific service during an emergency. You must develop and maintain your own family disaster plan."

The bolded print is something to consider if you have not done so.

### Debbie Wiederhold, TxP2P

Have you contacted your local EMS or Fire Department? Do you know where they are? Why not find out — BEFORE it's needed, and we all hope their services are never needed, but if they are, won't it help everyone involved to know you and your household? It just takes a phone call to get things started, consider doing so today!



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# My Job with SMU Mustang Football Program

Davis Hecksel, son of David Hecksel, TxP2P Volunteer

My name is Davis Hecksel and I am 23 years old. For the past four years, I have volunteered with the SMU Mustang Football program at the Southern Methodist University (SMU) Campus in Dallas, Texas. I volunteer helping Dean 'Flash' Saul, the team's Equipment Manager. It's a lot of fun!

Each week day during the season, I arrive bright and early at 6:30 a.m. for practice. Between 6:30 and 8:30 a.m., I am on the sidelines observing the team's daily practice session and talking with the Assistant Coaches. I have learned each and every of the team's defensive call schemes! Between 8:30 and 9:00 a.m., I eat with the team in the athletic cafeteria. Between 9:00 and 10:30 a.m., I work in the equipment room. My volunteer work involves picking up jerseys after practice and putting them in the wash. During home games, I get to stand on the sideline with the team and watch the game. My first year no one knew who I was, but now I Everyone recognizes me.

I really enjoy working with the

team because I get to know the coaches and players. I get to be a part of what happens behind the scenes at a college program football though even for many years they have been mediocre. It's true! However, since Coach June Jones became head coach,

have been to three consecutive bowl games. I don't want that streak to end. I get to share my passion for sports with other people who have just as much passion for it as I do. Those who know me well call me "The Sports Savant." I am frequently in the top 10 percent of the ESPN "College Football Pick-em" online contest. I am thankful for the

don't even need a sideline pass. coaches and staff, particularly Director of Operations Coach, Randy Ross, for letting me volun-



teer and assist their football program.

I live in Dallas, Texas. While I do have a disability (Autism and mild CP), the SMU Coaching staff looks past my differences and accepts me for who I am - a member of the SMU Football program team and a friend.

# Time Management During the Holidays

Excerpt from Better Homes & Gardens Magazine - Aby Garvey, Organizing Expert

**SET YOUR PRIORITIES:** Before you start enjoying myself. launch into holiday planning, ask What do I love most? What do I dread? This exercise will help you decide what belongs on your to-do list and what needs to be simplified or deleted altogether.

is a priority, put it on the calendar up time for making new traditions. just like you would any other important activity. Pick an evening to munch cookies, sip cocoa, watch a favorite holiday film.

PUT IT IN WRITING: Jot down your cooking and baking; entertaining; personal holiday mission statement religious celebrations; cleaning; and post it in a prominent spot. and decorating. Set a deadline for Mine is the joy is in the journey, each task, ask family members how which reminds me not to wait until they can help, and then delegate everything is checked off my list to like crazy!

JUST SAY NO: Don't get caught in the trap of doing something just because it's what you've always done. Only commit to activities that really matter to you and your family. You'll enjoy a little breath- KEEP IT CLEAN: Before you open MAKE FAMILY TIME: If quality time ing room in your schedule and free gifts, give everybody a bin for their

> SHARE THE LOAD: With your pri- and trash nearby. Cleaning as you orities set, compile a master to-do list that covers these categories: and relaxing and makes tidying for gift giving and wrapping; cards;

HOLD YOUR CARDS: Defer sending greetings until another holiday such as New Year's or Valentine's Day, when both you and your recipients have more time to enjoy the sentiment.

loot and have bags for recycling go keeps the environment neat guests a snap.



Thank you to our 2012 Corporate Sponsors!!









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# A Look at the Social/Emotional Development of Infants and Toddlers

Early Childhood Intervention (ECI) is a division of the Department of Assistive & Rehabilitative Services (DARS). ECI programs provide services to families with children, birth to 36 months with developmental delays and disabilities. For more information about DARS/ECI, call 1-800-628-5115 or visit www.dars.state.tx.us/ecis.

ealthy social and emotional development begins at the beginning! This developmental area, perhaps more than any other, occurs early, when parents and other important caregivers in the baby's life welcome him/her into their lives. This is the time that the relationship between parent and child unfolds, and helps to establish the foundation for lifelong learning.

An infant or toddler's mental health or social and emotional wellness describes his/her ability to demonstrate developmentally appropriate social behavior and emotions based on individual characteristics, i.e. family culture, environmental circumstances and the quality of close relationships. Infant Mental Health has been well defined by several professional organizations.

**ZERO TO THREE** defines infant mental health as, "...the developing capacity of the child from birth to age 3 to: experience, regulate, and express emotions; form close and secure interpersonal relationships; and explore the environment and learn -- all in the context of family, community, and cultural expectations for young children. Infant mental health is synonymous with healthy social and emotional development."

The National Scientific Council on the Developing Child recognizes that "young children experience their world as an environment of relationships, and these relationships affect virtually all aspects of their development — intellectual, social, emotional, physical, behavioral, and moral."

# The Role of Relationships and Development

Infants rely on their parents and other primary caregivers to help them regulate and, over time, learn culturally acceptable ways to respond to and express emotions. Infant development begins and continues within the context of an emotional relationship.

Why is social and emotional development so important? infant and toddler's social and emotional development is critical to developmental progress across all domains. The desire to engage with others, curiosity & willingness to explore, enjoyment and pleasure from social encounters, & the ability to adapt to challenges are all characteristics of an infanttoddler's emotional competence. These skills are learned through experiences shared within relationships. Early intervention services that support a child's development recognize the importance of promoting healthy social and emotional development.

Infants and toddlers who have delays in development or who often have disabilities need additional support to enjoy the same quality of developmental experiences as children who do not have to manage those challenges. A relationship with a parent or caregiver who is able to put the child's needs first is likely to be the most important influence the child's development. Infants and toddlers who attachments experience secure have an increased capacity to adapt to stressful circumstances that could negatively impact development (Zeanah, Zeanah, 2001).

ECI service providers promote social and emotional development of infants and toddlers by providing a relationship-based approach to intervention. Services focus on addressing the developmental needs of the infant and toddler but also value listening to families to help them identify what they need to help their child develop. The

relationship of the early intervention provider to the family is as important as the early intervention provider's skill in addressing the child's development. intent of early intervention is to implement strategies that will support the child's development but to do so keeping in mind that the strength of the parent child relationship is the foundation for all learning. Strategies are embedded in the family's typical routines and therefore offer opportunities throughout the day for the family to help their child grow and learn. If a family feels stress around a specific developmental task, the ECI provider and family will work together to determine what strategies will be the most effective in moving forward. This approach is an integral part of routine service delivery.

Zero to Three provides more information on how to promote social and emotional development;



how to manage challenging behaviors, or information about early childhood mental health. To learn more visit the Zero to Three website:

- Promoting Social and Emotional Development <a href="http://www.zerotothree.org/child-development/social-emotional-development/">http://www.zerotothree.org/child-development/social-emotional-development/</a>
- 2. <u>Challenging Behaviors</u> <u>http://www.zerotothree.org/child-development/challenging-behavior/</u>
- 3. <u>Early Childhood Mental Health</u>
  <a href="http://www.zerotothree.org/child-development/challenging-behavior/">http://www.zerotothree.org/child-development/challenging-behavior/</a>

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# Medical Transition—Getting Your Child Ready to Move from

# **Pediatric to Adult Medical Services**

edical transition is an important piece of the overall move for teens with disabilities to adulthood. Three major issues arise in this process: the legal implications of a person's turning 18, the need for adult medical services, and funding for adult medical services.

#### Legal Issues at Age 18

Preparing for your child's 18<sup>th</sup> birthday is often when parents start thinking about medical transition. Eighteen is the age of majority in Texas, when a child assumes the rights & responsibilities of adulthood. At that age, health care professionals may not share information with parents, unless provisions are made to allow parent access.

# How can parents guarantee that they can continue to be part of the medical decision-making process?

In some cases, parents become the legal guardians of their children, guaranteeing that they are the decision makers for all medical issues; they then have the right to sign permission forms for medical procedures, be present at appointments, and have access to medical records. A guardian is authorized to speak for the child. There are several different kinds of guardianship and the process can be lengthy and costly. If you plan to pursue guardianship, begin the process a year before your child will be 18 years old.

In other cases, when parents do not become their child's guardian, the child can invite the parent into medical appointments & to assist with decision making. Also the child can sign a form giving the parent access to medical information. "Children age 18 and older have complete control over their medical care & records, and parents require authorization to access their records. This is true even if the child's care is paid for by the parents' insurance." (Quote from http:// journal.ahima. org/2012/03/01/howto-request-your-medical-records/).

Another approach is to prepare your child to assume his or her health care responsibilities. You can actually start this as soon as your child can understand simple medical ideas, but no later than 14. At that age, you can begin to give your child the opportunity to make her own appointments, learn what medications he takes, interact with and ask questions of her health care provider, and be able to state what his medical issues are. You can help your child to compile a written

statement to help her present her medical information to others. There is a great Medical Summary form to fill out, available at <u>Journey to Adulthood</u> <u>- A Transition Travel Guide</u>, pp.28-30, found at <a href="http://www.gottransition.org/youth-resources">http://www.gottransition.org/youth-resources</a>.

Being able to advocate for oneself and participating in medical decision making, even if in small ways, is very empowering for young adults and sets an example for self-advocacy in other areas of life experience. There are several excellent internet tools to help youth develop their expertise in advocating for themselves in the medical arena. For example, http://www.got transition.org/youth-resources has an amazing list of guides for youth transitioning to adulthood, such as a transition toolkit, guide for talking to your doctor, & heading for college with special health care needs. Check it out!

At this same website (Got Transition?), several helpful 1-page checklists are available for both the youth and the family. To access them, go to: <a href="http://www.gottransition.org/6-core-">http://www.gottransition.org/6-core-</a>

<u>Elements-Table</u> and then go to: **3. Transition Preparation,** Use the Transition Readiness Assessment (youth, family) to address gaps in preparation, knowledge, & skills.

This transition time may also be an opportunity for your son or daughter to learn what their disability or chronic illness is called (if they haven't already) and be able to describe its main characteristics, as well as important complications that could occur as they move into adulthood. You and your child might look together at webbased directories that list disabilities & define them, such as http://www. cdc.gov/ncbddddisabilityandhealth/ types.html. At this site, you can print out a 1-page fact sheet on a specific disability, something a person could use in other settings. You might pair this activity with a look at the following site, listing famous people with different disabilities: http://en.wiki pedia.org/wiki/Category: Lists\_ of\_ people with disabilities.

#### Moving to Adult Services

Many pediatric professionals will no longer see a youth after age 18, thus pushing families to seek medical providers for adults rather than pediatricians. "Without planning for transition, teens & families may be surprised when they are refused care at a doc-

Rosemary Alexander, Ph.D., TxP2P

tor's office or a children's hospital because they have 'aged out.' You don't want to find this out when you are sick and need help really fast. Plan ahead! Start planning at age 16 for your transfer to doctors or nurse practitioners who care for adults. Actual transition is usually between ages 18 and 21." (From Journey to Adulthood - A Transition Travel Guide, p. 26, found at <a href="http://www.gottransition.org/youth-resources">http://www.gottransition.org/youth-resources</a>)

### Here are some tips for finding adult health care professionals (from the same source, above, p. 27):

- Ask your current doctors, nurse practitioners or care coordinators who they recommend.
- Ask adults who have health needs like yours who they see.
- Look at your health insurance company booklet or website for approved providers.
- Call and interview doctors or nurse practitioners. Find out if they have experience with your health condition, how long it takes to get an appointment, and how quickly you can be seen if you are sick.
- Use the internet. Look at websites of the American Academy of Family Physicians, American College of Physicians-Internal Medicine, American Academy of Physical Medicine & Rehabilitation, American Academy of Orthopedic Surgeons or other specialists needed for your care.

And I would add, ask other parents for advice about adult providers through the Texas Parent to Parent listserv for your area. Parents are often a great resource for other parents! Request to get on a listserv at by emailing Susan Prior at TxP2P at Susan. Prior@txp2p.org.

Remember, to the extent that your child is able to do so, include him or her in the process. For most young people with special needs, this is the beginning of an important and long-term relationship.

# Finding Medical Insurance for your adult child

Youth and families often need to find new sources of funding for adult health care services. Health care insurance can be obtained through any of the following:

1. Employer-based coverage through a family member's work. Children may now stay on their parent's insurance through age 26.

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### **Medical Transition**

Even after age 26, a parent may petition to keep a child on his or her plan through many company plans if your child is: "(1) incapable of selfsustaining employment because of intellectual or physical disability; and (2) chiefly dependent on the insured or group member for support and maintenance." (TX Insurance Code, Section 1201.059). Be sure to check well before the 26<sup>th</sup> birthday, as sometimes there is a limited time during which you can make this request and it may have to be renewed each year. You may also be able to extend coverage through COBRA for up to 36 months for your child through your employer-based insurance.

- 2. Government-sponsored health plan: a. Medicaid: a government program which pays for an array of health care services for individuals with disabilities with low incomes. You child may eligible for Medicaid become through: getting SSI (Supplemental Security Income - Medicaid is automatically granted after your child becomes eligible for SSI at age 18, when family income is no longer counted toward eligibility) or getting on a Medicaid Waiver program. See http://www.hhsc.state.tx.us/ medicaid/med\_info.html and http:// www.ssa.gov/disability/. If your child has Medicaid, he may be eligible for:
- PCS (Personal Care Services for Children)-up to age 21
- PHC (Personal Home Care for Adults)--over 21
- See <u>Dads.state.tx.us/services/list of services.html</u> for a list of Medicaid-based services in Texas.

**Important:** Even if right now you don't think you will need or want

eligibility for Medicaid Waiver services, go ahead and place your child's name on the interest lists. Most Waiver programs have many years' waiting time, and you will want to have all possible options available.

- b. **Medicaid Buy-In**: a program available for working people with disabilities aged 16-65 who are not on SSI and earn income less than 250% of poverty level; for more info, go to <a href="http://www.hhsc.state.tx.us/bi.html">http://www.hhsc.state.tx.us/bi.html</a>
- c. **Medicare:** young people may qualify for Medicare through Social Security Disability Income (SSDI) if:
- they are "adult disabled children" of adult workers who have become disabled, retired, or deceased; Medicare starts 24 months after getting SSDI; see <a href="http://www.ssa.gov/disability/">http://www.ssa.gov/disability/</a>
- they have worked & paid into Social Security for 2 or more years and then become disabled. After receiving disability benefits for 24 months, they are eligible for Medicare.

Insurance for people who can't get coverage because of a pre-existing condition:

**Texas High Risk Pool:** provides health insurance to Texans who cannot obtain coverage because of a medical condition; go to <a href="http://www.txhealth.pool.org/">http://www.txhealth.pool.org/</a> for more information.

**Pre-Existing Condition Insurance Plan** (**PCIP**): created in 2010 under the Affordable Care Act and offers uninsured people with pre-existing conditions coverage; the person must have been without coverage for at least 6 months. See <a href="https://www.pcip.gov">www.pcip.gov</a>

HIPP (Health Insurance Premium Payment): for families in which one

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member has Medicaid and another family member gets work-place health insurance; Medicaid may pay your family's private health insurance costs. Go to <a href="http://www.get">http://www.get</a> hipptexas.org/

You can fit together the 2 kinds of medical insurance, private & public. Usually Medicaid is the payer of last resort, or the "secondary" payer, which means that Medicare & workplace health insurance are "primary," and they will pay first. Most medical providers will be able to sort out who to bill first and then second.

#### Two final considerations:

- 1. Write down your child's medical history, major issues and care a how-to guide for your child's care, so that others in your child's life can be prepared to provide care when you can't. Keep the summary short, if possible, identifying the most important points and limiting it to one or two pages.
- 2. Create an emergency plan for your child's care. See <a href="http://cshcn.org/planning-record-keeping/emergency-preparedness-children-special-needs/emergency-preparedness-reference">http://cshcn.org/planning-record-keeping/emergency-preparedness-children-special-needs/emergency-preparedness-reference</a> for complete instructions and a checklist. Another emergency-preparedness form to fill out is at <a href="http://www.acep.org/content.aspxid=26276">http://www.acep.org/content.aspxid=26276</a>.

Good luck with this process, an important step for your child's growing up. If you have questions on this topic or other transition topics, please get in touch with us at TxP2P and our new Pathways to Adulthood program (<a href="https://www.txp2p.org/parents/pathway.html">www.txp2p.org/parents/pathway.html</a>).

# Our Journey through School with Megan

hen our daughter Megan, now twenty, entered Kindergarten 14 years ago I had no idea what her school career would be like. I can still remember so clearly that first kind teacher finally telling me that I could leave, that Megan would be fine and assured me they would call if anything came up. I guess it really wasn't normal for a parent to be in the classroom for several hours each day!

We've had our ups and downs with the school district but over all Megan has received the education and care she deserves. We have met countless devoted teachers, aides, and therapists whom are some of the best people and the kind of people that I respect the most, the ones who choose to work with our children. However, I also recall a contentious conversation with a regular ed art teacher who told me she didn't "sign up to be a special ed teacher," and to which I replied, "Well, Megan didn't sign up to be a special ed kid."

In primary, intermediate, and middle school, during the first week of school, the counselor or I would go into the classrooms and talk to the children about Megan and her disability - to give them an idea of what life is like for her and to show them ways to help and interact with her. I would tell the kids to sit on their hands, not use words, and tell me they were

#### Cathy Beard, TxP2P Parent

hungry or that their head itched. It was amusing to watch them moan, squirm, and look puzzled and frustrated. They got the point!



In fifth grade a fellow student wrote a paper for the PTA's "Reflections"

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competition. This mother called to get our permission to write it about Megan. The title was "A Different Kind of Hero." He won the competition and his endearing essay is something I will treasure forever.

This past year when the school district talked about consolidating the primary schools Life Skills classes onto one campus I proudly stood up and read his paper at the school board meeting. My point being, if Megan and her friend had never met due to the fact that she wasn't educated in her home school, then it would have been a loss on both sides.

Her years in high school consisted of art, choir and lunch with the regular ed kids, and several periods in the Life Skills class where it was, and still is the "hub" of many activities for all students.

Megan graduated this spring and "walked the stage" escorted by a wonderful student who has been her friend for many years. As she started making her slow methodical journey from one side to the other, all three hundred seniors started clapping and standing until they were all up and they continued standing & clapping until she was across the stage. Needless to say, it was quite moving and had our whole row in tears.

Megan is now in the 18 plus program. She spends a couple of hours at school each day, but mostly is out in the community volunteering and exploring places. She visits the local senior citizen center and the assisted

living home where she and her aide sing and entertain the residents. The daycare, local library, grocery store, and thrift shops all are getting to know Megan. We think, plan, and talk a little bit each day about what her future will be like from here on. We are exploring the idea of starting an activity center for young adults like her here in our hometown, and at this point our plan is for Megan to live with us for as long as possible. Megan's school journey may be almost over but we look forward to the future and the new possibilities it will bring for all of us. Megan was diagnosed with Rett Syndrome at 8 years of age.

## In Memoriam

ne thing we learned a long time ago is that among children with disabilities and special health care needs, some leave us way too early. It's a sad reality we all hope will not happen but some of us will grieve our child's death.

All of us here at Texas Parent to Parent are deeply saddened when we hear of a family's loss and grieve with you. We want to share our condolences to our TxP2P families who have lost a child recently:

- Anthony Hollaway
- Aden Ayer
- Annalisa Talavera
- Bryan Ho
- Jackson Sexton

We have some resources available for bereavement and there are

groups in many areas which we are always willing to find for you. You may continue to receive the newsletter for as long as you like. We do have trained volunteers whose children have passed away and are willing to be matched as needed.

With deepest sympathy, TxP2P Staff, Volunteers, & Board of Directors

The TxP2P Newsletter is not copyrighted. Please feel free to use any of our articles in your newsletter, have parent group meeting, or any other venue but remember to credit the author & TxP2P. If you would like have an electronic copy, we can email it to you; please email the date of the newsletter & the article name to have supply sup

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★ Please remember to sign up for TxP2P Listservs. Contact Susan.Prior@txp2p.org if you want to join the ★ Advocacy, ADD/ADHD, Autism, Bipolar, Dad's, Homeschoolers, Medical Home, Medicaid Waiver, NICU, ★ Spanish, Transition, or local area Listservs (Austin, Bryan/College Station, Coastal Bend/Corpus Christi, Dal- ★ las/Ft. Worth, Houston, San Antonio, San Marcos, Rio Grande Valley, & Waco/Temple). 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 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 contact contact if you are currently getting this by mail but would read it as an email or print it out, please contact contact if you c

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THANKS TO GLOBAL PRINTING SOLUTIONS FOR PRINTING THIS NEWSLETTER AT A REDUCED COST FOR TXP2P!

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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.



### ADDRESS SERVICE REQUESTED

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# Conference Schedule

Date	Conference Title	Location	Registration Information
Thursday, February 7 to Saturday, February 9, 2013	Inclusion Works The Arc of Texas	Austin	For more information, go to: <a href="http://www.thearcoftexas.org/site/">http://www.thearcoftexas.org/site/</a> <a href="PageServer?">PageServer?</a> <a href="pagename=events">pagename=events</a> inclusion conference
Thursday, February 21 to Friday, February 22, 2013	Texas Transition Conference Texas A&M University	Austin	For more information, go to:  http://ttc.tamu.edu
Saturday, February 23, 2013	TAPPestry Conference 2012	San Antonio	For more information, go to: www.esc20.net/tappestry
Sunday, March 3 to Tuesday, March 5, 2013	2013 Statewide Independent Living Conference	Austin	For more information, go to: <a href="http://www.txsilc.org/conference/">http://www.txsilc.org/conference/</a>
Thursday, March 21 to Saturday, March 23, 2013	Texas Association for Education & Rehabilitation of Blind & Visual Impaired (TAER) Annual Conference	Dallas	For more information, go to: <a href="http://www.txaer.org/conferences.html">http://www.txaer.org/conferences.html</a>