A Parent’s Perspective

TxBP Update

Laura J. Warren, TxBP Staff

We have two conferences coming up quickly! The 2nd Annual Empowering Tools Conference in Port Isabel is Saturday, May 2, 2015 and our 11th Annual TxBP Statewide Parent Conference in San Marcos is Friday & Saturday, June 12 & 13, 2015. Registration will be open soon for the Empowering Tools conference and is already open for our Statewide Parent conference in San Marcos. Hope you can join us at one of the conferences!

TxBP has had some shifts in staff and Board of Directors that I wanted you to know about: Sherry Santa has been with us for two years in Family & NICU Support and most recently, as Coordinator for our Medical Education Program (MEd.). She has to step away from the Family Support part of her job due to some good changes for her family that will require more of her time but will continue working as the MEd. Coordinator on a part-time basis. Melissa Fox has been with us as a Program Assistant for over a year and has accepted a position in the Family Support Team. Janette Rodriguez has been working in the office as a volunteer bilingual Family Support Team member and translator for the past several months and she was happy to become our newest staff member.

We say goodbye to 2 long-time Board of Director members in 2015: Debbie Burt was at our first meetings back in 2001 when we formed TxBP and has been on the Board ever since. She has helped us in numerous ways including as a cheerleader, Support grandparent, Board Chair, Program & Services & Governance Committee member, and most recently, as the Coordinator of our Vine to Wine silent auction. Bob Tabor is stepping down as the Past Chair. Bob came to the Board with little knowledge of our world but a big desire to help. He brought with him knowledge for business and a big heart. He and his colleagues organize the Richard P. Slaughter Charity Golf Tournament each year which benefits TxBP and 2 other nonprofits each summer! Debbie & Bob – THANK YOU so much for all your support and time - you will be missed!

If you haven’t checked out the TxBP Care Notebook (http://www.txp2p.org/resources/CareNotebook.html) and Medical Home Toolkit (http://www.txp2p.org/resources/medHome.html), do it now – they are both excellent management tools that can help you keep track of your child’s medical, school and transition needs. We hope you have a lovely spring!

Paying it Forward Awards

The TxBP Paying It Forward Awards recognizes the best in Family Support for families of children with disabilities, chronic illness or special health care needs. There are two categories: Champion Parent Category (support provided by another parent or family member of a child with a disability) and Champion Professional Category (support provided from professional, service provider or anyone without disability experience). Winning stories will receive a trophy and free registrations to the TxBP Annual Parent Conference for the winner and the person who nominated them.

So, what do you need to do?

- Write a one-page story and include a photograph of your family or child (500 words or less)
- Complete Nomination Form online
- Submit your entry no later than March 20th, 2015
- You will hear from us if your story is a finalist and will be included in the on-line voting no later than March 25th, 2015
- The finalists will be posted on our website for voting by the public
- We will contact you by May 18th if you are one of the two winners
- We will announce the winners at the conference on Friday, June 12th

TxBP will use these stories after the award contest as family stories for grants, fundraising and raising the awareness of the importance of family support for our families.

Submit your nomination form, story, and photos on-line at www.txp2p.org or email to jdimare@txp2p.org
It seems as though we just said “goodbye!” as you left the 2014 TxP2P Statewide Parent Conference, and here we are on the doorstep of our 2015 conferences! Yes, that’s right – conferences ... as in more than one!

Here’s what’s ahead:

Saturday, May 2, 2015: 2nd Annual Empowering Tools Conference (Port Isabel)

Friday & Saturday, June 12 & 13, 2015: TxP2P Statewide Parent Conference (San Marcos)

The 2nd Annual Empowering Tools Conference will take place on Saturday, May 2, 2015, in Port Isabel. We are thrilled to once again partner with Port Isabel ISD and their terrific Special Education Department. And, we are excited to welcome our new partner, Education Service Center, Region 1, in providing this free conference to families and professionals in the Rio Grande Valley! The Empowering Tools Conference will again offer participants a terrific resource fair that includes nonprofits, county and state organizations and community providers. It is free to attend the conference, but registration is required. Check our website at http://www.txp2p.org/index.html for the link to register. Free child care is available to those attending the conference, but advance registration is required. CEUs for Social Workers (SW), Licensed Professional Counselors (LPC) and Early Intervention Specialists (EIS) will be available. We are also still accepting registrations from organizations that want to exhibit at the Empowering Tools Conference. Here’s the link to register: http://www.txp2p.org/training/RegionalConferenceExhibitor.html. It is free to exhibit, but registration is required. The deadline to register (to attend, for child care or to exhibit) is April 17, 2015, so don’t wait to get started! No on-site registration will be allowed.

The 11th Annual TxP2P Parent Statewide Conference is on the horizon, too, taking place at the Embassy Suites in San Marcos on Friday and Saturday, June 12 & 13, 2015. TxP2P staff is hard at work to make our 2015 conference the best yet! Registration to attend, be a sponsor, or to exhibit is now open on our website at http://www.txp2p.org/index.html. The registration packet is available for download at http://www.txp2p.org/training/conferenceReg.html. CEUs for Social Workers (SW), Licensed Professional Counselors (LPC) and Early Intervention Specialists (EIS) are available. Conference and child care registration closes May 29, 2015. Exhibitor registration closes on May 1, 2015, or when capacity is reached.

The 3rd Annual Living with Disability Conference (LWD3), a collaborative event between Texas Parent to Parent, Community Now! and the Arc of Northeast Tarrant County was held at the First Baptist Church in Hurst on Saturday, February 21st. It was a huge success, with more than 40 sponsors and exhibitors and over 200 participants attending the conference. We anticipate that the 4th Annual Living with Disability Conference (LWD4) will take place in April of 2016, so keep your calendar open and check our website often for updates!

To make sure you have the latest information about each of these events, register with TxP2P today by going to http://www.txp2p.org/contactus/join.html. We look forward to seeing you soon!

Mother-Son Team Make 150 Legislative Visits

Zachariah, and his mother, Leslie, have made over 150 appointments with legislators since August. Obviously a great amount of time and expense was involved in doing this from a few hours away. Leslie replies that she is advocating for a new medicine to save her child’s life, so that one doesn’t consider expense at that point. I asked Leslie a few questions about this experience:

What would be a few pointers that you might mention, to help parents get started on a series of legislative visits? I have five tips:

1) Advocate for an issue that is near and dear to your heart, otherwise you will encounter burn-out.
2) Create a one-page story and also print a hundred copies of a family photo. On a return visit, it is rewarding to see your photo attached to their wall.
3) Bring your child with you if you can; this helps legislators to understand what you say.
4) Be the most polite that you have ever been; legislators and their staff have lots of bills to focus on, so don’t shorten their list!
5) Work in Pairs: Everyone will be very nice to you, but it still feels better to work in pairs. A parent who is not talking can study the legislator to read their body language; also there will be someone to open the heavy doors as you push your child through them.

And what have you found to be the most rewarding about this process? Things like:

1) When you see the ‘light bulb’ go off and they understand what you mean.
2) When you meet the Speaker of the House and realize that he has studied your issue before the meeting.
3) When you receive a phone call or letter from a legislator, thanking you for your information and saying that they will sign on as a co-author or co-sponsor of your bill.

Is there anything that has been difficult, that you’d like to mention? Don’t get discouraged if someone is against your bill. You only need a majority; you don’t need everybody!

Contact Linda Litzinger if you would like help in the Texas Capitol, at 512-257-8688 or Linda.Litzinger@txp2p.org.

Jeanine Pinner, TxP2P Staff

Linda Litzinger, TxP2P Staff

Volume 14, Issue 1
My 14-yr-old son, Christopher, underwent his 27th overall surgery last week to relieve pressure behind his left eye (successful!) and as usual, he came through like a champ! But it hasn't always been that way. He was a 26-week 2 lb micro preemie at birth. Christopher spent his first four months of life in the Seton NICU, the longest 128 days of my life! Besides a multitude of preemie-related issues including bilateral ROP (Retinopathy of Prematurity), he was also born with a host of bone anomalies - craniosynostosis (three cranial reconstruction neuro-surgeries), kyphosis scoliosis, osteoporosis, and bilateral club foot which required four different surgeries in which his ankles were broken and reset, his Achilles tendons were snipped and repaired, foot/heel reconstruction, and two years ago, he had a 4 1/2” screw in each foot to reset the growth plates. After the 1st three surgeries, he woke up in thigh high casts, and thankfully, black boot casts were all he needed after the last one. Along the way, he's had several eye surgeries, tonsillectomy/adenoid removal, appendectomy, and, well, you get the picture. As you can imagine, he used to shake as we approached the hospital. That damn breathing mask scared him most. He understood once that mask went on, he'd wake up in pain and/or with thigh high casts. One of his surgeons gave us a kid-size mask to take home for exposure in a relaxed setting. Of course, all that happened was our home was no longer a relaxed setting!

Between age 3 and 4, my husband, Bob, and I began dressing him as Superman for every single hospitalization to help him find his inner strength. Around a year later, he dubbed himself the Kranio Kid & what a difference! I made him an eye mask, badge and credentials on a lanyard, and the red Superman cape. Before this latest surgery, our AWESOME 15-yr-old neighbor & friend, John, an amazing artist, made the Kranio Kid come to life in a painting! Somehow he completely understood my babbling, catching every nuance of what Christopher stands for: Bravery, Courage, Strength, and Perseverance. My son IS the Kranio Kid! A hearty thanks to everyone who sent their love, prayers, positive energy & continued support! And if someone out there is, or knows of, a good seamstress, I'm happy to provide materials for an actual Kranio Kid outfit. :)
Lessons Learned, the Hard Way!
Rosemary Alexander, PhD, TxP2P Staff

O ur son, Will, has generally been a healthy, active person, eager to go and do, be involved and engaged in life, but last winter he lost 25 pounds and became lethargic, unresponsive, and sad. We had to help him walk and started using a wheelchair for him part of the time. I dreaded seeing him come up the walk to our house from his attendant’s car, being supported and half carried. Will was eating much more than I do but dropped from 110 pounds down to 85. He was just skin and bones, and we were frantic to figure out why.

Of course, we consulted with his primary doctor (GP), then moved on to his neurologist and a GI specialist. No one seemed to have a clear answer. Then two good things happened: I found a nutritionist who had experience with epilepsy and I set up a Medical Home for Will.

First, the nutritionist: a colleague at TxP2P gave me the nutritionist’s name, and Will and I went to see her. She looked at Will and his current lab work and said, “Low Vitamin D!” It turns out that some seizure meds (which we had increased over the last year after a serious seizure) can deplete Vitamin D, which promotes absorbing nutrition from food. Will was eating like crazy but gaining no nutrition from it; he even had the sweet odor of someone in the state of Ketosis.

At this point, I was a bit skeptical—we never find easy answers for Will’s issues! But I was ready to try anything, so we started Will on Vitamin D and also other high nutrition, high protein, and high calorie foods and supplements. And gradually he gained weight. And as he gained, he started having energy, walking independently, smiling and laughing, and engaging in life again. We have been weighing him once a week for a year now, and the other night he was at 118!! It has been very gradual, but by fall he was back to normal, maybe better than normal! I keep going to Target and buying bigger pants!

Second, a Medical Home: around the time that we found the nutritionist, Will was in his GP’s office, and I asked, is there a Medical Home model available in this practice? I asked because I felt that he was slipping through the cracks: no one doctor was keeping tabs on this perilous situation and we were losing Will. The answer was “Yes,” and promptly he was enrolled in a Medical Home: a service within a doctor's office that coordinates care, is the center for various specialists, responds quickly to needs, and knows the person. Using a Medical Home meant that I could call the nurse practitioner assigned to Will, Steven, and he knew immediately who Will was and what his issues were—I didn’t have to start all over at every encounter. Steven took requests to the doctor and got back to me within a few hours. He knew who the nutritionist was and would immediately get lab work done that she requested, then share the results with her automatically. It was a home, a place where you are known, cared for and felt welcome. I felt like Steven was my new best friend. I believe the coordination and responsiveness helped to save Will’s life.

What lessons can I pass along from this experience? I can’t vouch for nutrition, Vitamin D, or supplements for any other person, but I can urge you to keep looking for an answer when you have a big problem. Reach out to other parents for resources. Be open to new paths, keep opening doors. And look into a Medical Home if your child faces complex medical issues. A medical practice that coordinates, knows your child, and responds quickly, with compassion, may make a big difference. To learn more, go to www.txp2p.org, and click on the Medical Home Toolkit on the left sidebar. Send questions & comments to rosemary.alexander@txp2p.org.

Thank you to our 2014 Corporate Sponsors!!

Volume 14, Issue 1
Did you know that vision is involved in 90% of the learning that occurs in early childhood? Babies and young children learn by looking at toys and objects, and watching what people around them are doing. They watch their own hands and feet, they look at pictures, and they imitate others. But what if a baby doesn’t see well, or doesn’t see at all? Having a visual impairment can slow a child’s acquisition of skills and understanding of the world. But with special teaching techniques and tools, children with visual impairment can largely keep up with their peers. One of the most important things you can do to help a child is to recognize they have a vision problem so she can get treatment.

As a parent, you are the most important person in your child’s life and know your child better than anyone. Watching your baby’s eyes can give you a lot of information about how the little one sees his world. Does the baby look at your eyes and face when you talk? Do the eyes look unusual? Does the baby squint or seem sensitive to light? Young children who rub their eyes, have excessive tearing, or tilt their head to look at something may have problems with their vision. Both eyes should look directly at a person or object by the time a baby is 3 or 4 months of age. When looking at something, the eyes should be still, and not drift or wiggle.

Infants and young children who have medical conditions or other health problems are at a higher risk for vision impairment. Babies who were premature or who had head injuries, strokes or other conditions that cause oxygen deprivation can lose vision or ability to cognitively process visual information. If a baby has cataracts or glaucoma, even if it has been treated, he may still have a permanent loss of vision. Albinism or lack of pigmentation of the skin usually affects the pigmentation of the eyes, causing visual impairment and light sensitivity. Genetic syndromes can cause visual impairment; these include Down syndrome and CHARGE syndrome. Other conditions such as cerebral palsy and optic nerve hypoplasia often are accompanied by vision impairment. In some cases, children can have surgery or wear glasses and have their resulting vision corrected to the normal range. For others, treatment may improve their vision but still not result in typical sight.

Here are some vision milestones that happen in typical development:

**At birth**
- Focus on objects 8-10 inches away
- Have difficulty using both eyes together

**At 3 months**
- Visually follow moving objects
- Eyes are beginning to work together
- Shows the beginning of a visually directed reach

**At 6 months**
- Turns head to see objects
- Uses an accurate reach
- Has good color vision, may have a favorite color
- Sees at greater distances
- Picks up dropped toys

**At 12 months**
- Shows interest in pictures
- Points and gestures
- Places shapes in board
- Judges distances
- Recognizes own face in mirror

**At 18 months**
- Recognizes familiar objects
- Scribbles with crayons or pens
- Shows interest in exploring

If your child looks or behaves in a way that causes you to wonder if there is a problem with vision, talk to your child’s doctor. You may need a referral for an eye examination. Even a child who wears glasses may still not see the way other children see and may benefit from special services. Early intervention is very important. In the early years, every month counts. Children with vision problems often show delays in development. A child who is not identified in the early years may later have problems paying attention in school, learning to read, and learning from what a teacher is writing on the board or screen, playing sports, and socially interacting with other children. A visual impairment is a significant disability, and accessing educational services during the earliest years can make a big difference in learning throughout childhood and later life.

If your child is suspected of or found to have a vision problem, call your local Early Childhood Intervention (ECI) program. To find a local ECI program access the DARS website at www.dars.state.tx.us/eci/searchprogram.asp or call the DARS Inquiries Line at 1-800-628-5115.

**Additional Vision Resources**
- Texas School for the Blind and Visually Impaired, Infant and Toddlers with Visual Impairment or Deafblindness http://www.tsbvi.edu/outreach/4083-infants-toddlers-preschoolers-vi
- Texas School for the Blind and Visually Impaired, Infant and Toddlers with Visual Impairment or Deafblindness http://www.tsbvi.edu/outreach/4058-infant-preschool-services-db
- Blind Babies Foundation fact sheets http://www.blindbabies.org/learn/diagnoses-and-strategies/
Congress Passes ABLE Act: Major Victory for Persons with Disabilities and Their Families

Achieving a Better Life Experience (ABLE) Act of 2014. First introduced in 2006, and subsequent sessions of Congress, the ABLE Act will allow people with disabilities (with an age of onset up to 26 years old) and their families the opportunity to create a tax-exempt savings account that can be used for maintaining health, independence and quality of life.

“Today marks a new day in our country’s understanding and support of people with disabilities and their families,” Michael Morris, National Disability Institute (NDI) Executive Director, said. “A major victory for the disability community, ABLE, for the very first time in our country’s policy on disability, recognizes that there are added costs to living with a disability.” He continued. “For far too long, federally imposed asset limits to remain eligible for critical public benefits have served as a roadblock toward greater financial independence for the millions of individuals living with a disability.”

NDI has long championed the ABLE Act as a critical strategy to providing a pathway to a better economic future for all people with disabilities. As the nation’s first nonprofit dedicated to improving the financial health and future of all people with disabilities, the organization has extensively documented and called attention to the daily reality and extra expenses associated with living with a disability, and the challenges of navigating the complex web of government rules to maintain public benefits eligibility.

In recognition of this unprecedented legislation, NDI has created a list of 10 items about ABLE accounts that individuals with disabilities and their families should know:

ABLE Accounts: 10 Things You Must Know

1. What is an ABLE account?
ABLE Accounts, which are tax-advantaged savings accounts for individuals with disabilities and their families, will be created as a result of the passage of the ABLE Act of 2014. Income earned by the accounts would not be taxed. Contributions to the account made by any person (the account beneficiary, family and friends) would not be tax deductible.

2. Why the need for ABLE accounts?
Millions of individuals with disabilities and their families depend on a wide variety of public benefits for income, health care, food and housing assistance. Eligibility for these public benefits (SSI, SNAP, Medicaid) require meeting a means or resource test that limits eligibility to individuals to report more than $2,000 in cash savings, retirement funds and other items of significant value. To remain eligible for these public benefits, an individual must remain poor. For the first time in public policy, the ABLE Act recognizes the extra and significant costs of living with a disability. These include costs, related to raising a child with significant disabilities or a working age adult with disabilities, for accessible housing and transportation, personal assistance services, assistive technology and health care not covered by insurance, Medicaid or Medicare.

For the first time, eligible individuals and families will be allowed to establish ABLE savings accounts that will not affect their eligibility for SSI, Medicaid and other public benefits. The legislation explains further that an ABLE account will, with private savings, “secure funding for disability-related expenses on behalf of designated beneficiaries with disabilities that will supplement, but not supplant, benefits provided through private insurance, Medicaid, SSI, the beneficiary’s employment and other sources.”

3. Am I eligible for an ABLE account?
Passage of legislation is a result of a series of compromises. The final version of the ABLE Act limits eligibility to individuals with significant disabilities with an age of onset of disability before turning 26 years of age. If you meet this criteria and are also receiving benefits already under SSI and/or SSDI, you are automatically eligible to establish an ABLE account. If you are not a recipient of SSI and/or SSDI, but still meet the age of onset disability requirement, you would still be eligible to open an ABLE account if you meet SSI criteria regarding significant functional limitations. The regulations to be written in 2015 by the Treasury Department will have to explain further the standard of proof and required medical documentation.

You need not be under the age of 26 to be eligible for an ABLE account. You could be over the age of 26, but must have the documentation of disability that indicates age of onset before the age of 26.

4. Are there limits to how much money can be put in an ABLE account?
The total annual contributions by all participating individuals, including family and friends, are $14,000. The amount will be adjusted annually for inflation. Under current tax law, $14,000 is the maximum amount that individuals can make as a gift to someone else and not pay taxes (gift tax exclusion). The total limit over time that could be made to an ABLE account will be subject to the individual state and their limit for education-related $29 savings accounts. Many states have set this limit at more than $300,000 per plan. However, for individuals with disabilities who are recipients of SSI and Medicaid, the ABLE Act sets some further limitations. The first $100,000 in ABLE accounts would be exempted from the SSI $2,000 individual resource limit. If and when an ABLE account exceeds $100,000, the beneficiary would be suspended from eligibility for SSI benefits and no longer receive that monthly income. However, the beneficiary would continue to be eligible for Medicaid. States would be able to recoup some expenses through Medicaid upon the death of the beneficiary.

5. Which expenses are allowed by ABLE accounts?
A “qualified disability expense” means any expense related to the designated beneficiary as a result of living a life with disabilities. These include education, housing, transportation, employment training and support, assistive technology, personal support services, health care expenses, financial management and administrative services and other expenses which will be further described in regulations to be developed in 2015 by the Treasury Department.
Continued from page 6

6. Where do I go to open an ABLE account?
Each state is responsible for establishing and operating an ABLE program. If a state should choose not to establish its own program, the state may choose to contract with another state to still offer its eligible individuals with significant disabilities the opportunity to open an ABLE account.

After President Obama signs the ABLE Act, the Secretary of the Department of Treasury will begin to develop regulations that will guide the states in terms of a) the information required to be presented to open an ABLE account; b) the documentation needed to meet the requirements of ABLE account eligibility for a person with a disability; and c) the definition details of “qualified disability expenses” and the documentation that will be needed for tax reporting.

No accounts can be established until the regulations are finalized following a public comment period on proposed rules for program implementation. States will begin to accept applications to establish ABLE accounts before the end of 2015.

7. Can I have more than one ABLE account?
No. The ABLE Act limits the opportunity to one ABLE account per eligible individual.

8. Will states offer options to invest the savings contributed to an ABLE account?
Like state 529 college savings plans, states are likely to offer qualified individuals and families multiple options to establish ABLE accounts with varied investment strategies.

In Memoriam

One 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:

Aisha Qureshi, daughter of Marty and Rashid Qureshi
Daniel “Peanut” Carbajal, son of Lori Carbajal Medeiros and Brian Medeiros
Savanna Borden, daughter of Tamara Atkinson and David Borden

With deepest sympathy,
The Staff, Volunteers, & Board of Texas Parent to Parent

National Disability Institute (NDI) is a national nonprofit organization dedicated to building a better economic future for people with disabilities. The first national organization committed exclusively to championing economic empowerment, financial education, asset development and financial stability for all persons with disabilities, NDI affects change through public education, policy development, training, technical assistance and innovative initiatives. NDI and its Real Economic Impact (REI) Network have helped more than 2.3 million people with disabilities receive nearly $2.3 billion in tax refunds and credits. To learn more, visit: www.realeconomicimpact.org. Engage with NDI on Facebook: RealEconImpact or follow NDI on Twitter: @RealEconImpact
## Conference Schedule

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<tr>
<td>Thursday, March 26</td>
<td>TXAER Annual Conference</td>
<td>Arlington</td>
<td>For more information go to <a href="http://www.txaer.org/conference">http://www.txaer.org/conference</a></td>
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<td>- Saturday, March 28</td>
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<tr>
<td>Saturday, March 28</td>
<td>DeafNation Expo</td>
<td>Austin</td>
<td>For more information go to <a href="http://www.deafnation.com">http://www.deafnation.com</a></td>
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<td>Saturday, April 25</td>
<td>Walk Now for Autism Speaks</td>
<td>Abilene</td>
<td>For more information go to <a href="http://www.walknowforautismspeaks.org">http://www.walknowforautismspeaks.org</a></td>
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<tr>
<td>Sunday, April 19</td>
<td>Waco Walk for Autism and Family Fun Day</td>
<td>Baylor University Waco</td>
<td>For more information go to <a href="http://www.hotautismnetwork.org">http://www.hotautismnetwork.org</a></td>
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<td>Saturday, May 2</td>
<td>Txp2P &amp; Port Isabel ISD presents the 2nd Annual “Empowering Tools Conference”</td>
<td>Port Isabel</td>
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