Hello, my name is Linda Litzinger and I am a new Public Policy Specialist at Texas Parent to Parent. Also working in our Advocacy Network are Amy Litzinger (training teens and youth) and Jan DiMare, helping with all ages. The TxP2P Advocacy Network is funded through the Texas Council for Developmental Disabilities. During this past legislative session, many parents became involved in the legislative advocacy process by writing, phoning, visiting, rallying, speaking to media, and testifying in bill hearings at our Capitol. Each and every action, whether initiated from near or far, was helpful in reducing collateral damages to Health and Human Services and to Public Education programs.

The end result was that General Revenue was reduced by $18 billion. Medicaid alone lost $4.8 billion. So while the Rainy Day Fund is expected to grow to $9.7 billion, it is not being used for this $18 billion gap. It is expected that at the current rate of spending, Health and Human Services funding will be exhausted by March 2013, leaving a six-month gap. To spread 18 months of spending into a 24 month budget, deep reductions will be made, not in number of clients but in each person’s services. There are federal maintenance of effort (MOE) requirements related to the Affordable Care Act that prevent Texas from reducing the number of clients served. Therefore, any budget reductions must be in the amount, scope, or duration of services. The Early Childhood Intervention program received significant reductions which will result in eligibility criteria changes and fewer children being eligible for services.

How will this affect you and other parents of children with disabilities? The Department of Aging and Disability Services (DADS) is still finalizing details on how the reductions will be implemented. Rate reductions and utilization management will be the primary mechanisms for lowering costs.
Sibings play a unique role in the lives of their brothers and sisters with developmental disabilities. Many sibings wish to better understand the supports and services received and available to their families and become better advocates.

A new organization called SIBscape was recently formed to connect and empower siblings through support, education and advocacy. Programs and events will be held throughout the state, with regional groups forming to allow sibings to connect with others in their area. Peer groups are also forming to allow sibings to connect with others their age, from age 14 through adulthood.

Please visit the SIBscape website to learn more at www.sibscape.org. You can contact Stacey Mather at (512) 635-1854 or stacey@sibscape.org or Joe Tate at joe@sibscape.org with questions or to learn how to get involved.

Legislative Update - 82nd Legislative Session

Continued from Page 1

Our TxP2P Advocacy Network team is preparing formal training so that parents, young self-advocates, siblings and other interested parties may learn how to best interface with their legislators during this period between sessions. Our first training will be in Austin at the Capitol on Saturday, Oct. 15th from 9:30 a.m. to 4:00 p.m. We have funding to help with travel and hotel accommodations for the trip to Austin. For an application or more information, contact Linda Litzinger @txp2p.org or Amy Litzinger @txp2p.org or call 866-896-6001. We will also be offering online training, Skype training, in-person training, and assistance to anyone who wishes to create a town hall meeting in their area, which would help a legislator become familiar with various local disability advocacy groups. Please do not hesitate to contact us, should you wish to become more involved.
Welcome to Monarch Academy at Morgan’s Wonderland! Our mission is to students with special needs a unique learning environment so they may reach their maximum individual potential. Monarch Academy welcomes students who are entering 6th grade through age 18 as of September 1, 2011, and possess the skills and willingness to participate in the kind of unique educational program we offer. A little about our students:

Most of our students have developmental disabilities.
- About half of our students have an autism spectrum disorder (autism, PDD, Asperger Syndrome).
- About half of our students have a diagnosis of ADD/ADHD.
- Several of our students have learning disabilities.
- Some of our students have emotional impairments (anxiety, OCD).
- Some of our students have physical health diagnoses, such as cerebral palsy and epilepsy.
- Most of our students are working at an academic level below their same-age peers; some of our students are working at or above age level.

Admission to Monarch Academy is not determined by diagnosis; rather it is based upon the student’s willingness to learn, ability to work towards employment and/or service to the community, and ability to function in a classroom setting. We often hear the question: “Is Monarch Academy a good fit for my child?” Monarch Academy is not a box. Students do not “fit” into Monarch Academy. Rather, the instruction and experiences each child receives at Monarch Academy are specifically designed to fit the student. Monarch Academy provides an alternative to traditional special education programs and services because we have the ability to implement an individualized education program for each student, operating outside the constraints of programs and curriculum guidelines designed for the typically developing student. We recognize that by improving lives of individuals with special needs through equipping them with the skills they need, they will be more productive and passionate contributors to society.

Monarch Academy strives for a general student-teacher ratio for a third of the students to be 2:1, a third to be 4:1 and a third to be 6:1, meaning our overall ratio is 3.5 to 1. In addition to providing a strong academic background, Monarch Academy will help prepare its students for life and meaningful employment in the world beyond the school system. Students at Monarch Academy will gain required skills to bolster self esteem while also insuring that his or her unique abilities are developed and encouraged through the development of:
- Skills for life
- Academic skills
- Communication skills
- Social skills
- Work readiness skills
- Vocational skills

Each student’s individualized instructional plan will be based on his/her unique strengths, interests, and abilities. Parents, students and staff work together to create a blend of research-based academic curricula, work readiness and vocational skills, and social, communication, and skills for life as needed for each learner. We will have multiple reading and math curriculums to ensure the best fit for each student and learning style. All students will receive academic, social, communication, and life skills instruction. Older students will be involved in vocational training that matches their interests and abilities.

At Monarch Academy, students will be educated with same-age peers. All subject areas will be integrated throughout the day as opposed to separate classes for separate subjects. Instruction will be based on each student’s individualized goals and objectives. In addition to the classroom instruction, all students will have direct reading instruction in either an individual or small group setting. The students will have an hour each day for lunch and recreation, where they will have the opportunity to play games, cards, puzzles, read, etc. with the entire student population in order to work on communication, social, and leisure skills. Physical activity will also be a part of our daily routine, as we have access to Morgan’s Wonderland right next door.

For more information, please visit our website at www.monarchacademy.net or 210-479-3311.

2011 Supporting Parent Volunteer Trainings
You can help families like yours by becoming a TxP2P Parent Volunteer! Listed below is the schedule for 2011. Please let Susan or Patty know if you are interested in attending a training in your area.

October - Dallas  November - El Paso
Mom Shares Story of 28 Week Preemie Triplets

Tyra Kendall Daniels, TxP2P Family

Our now two-year-old triplets were born at the gestational age of twenty-eight weeks. My husband, James, and I knew that a multiple pregnancy carried certain risks and we did everything within our power to keep me and the children healthy in their “incubator” for as long as possible. Laurence, Avery and Cairo were all born in the St. David’s level three Neonatal Intensive Care Unit (NICU), weighing 2.9 lbs., 1.12 lbs., and 2.8 lbs. and according to the health professionals the two pounders were big for their age! Nevertheless, we knew that they had come entirely too early.

Our stay in the NICU was nothing like what I had expected. Not only did the staff make it a priority to address all of our concerns, but they gave us regular updates, even if it was just to say “the crew are eating, sleeping and growing today.” The commitment of the doctors and staff to care for our newborns abated so many of our fears. I realized that although I felt helpless on some levels and there was very little I could physically do for our children, I quickly discovered that the best thing I could do was rest up, visit often and remain hopeful. I even bonded with another mother facing our same challenge, who I remain in contact with to this day.

She and I would trade glances across the room at one another as doctors and nurses surrounded our little ones and cared for them; I believe we knew the others’ heart, which made it easier for us to openly express our joys, fears, successes and setbacks; who said talk therapy does not work? I also had the opportunity of connecting with mothers in hallways, nursing facilities, and waiting rooms. We shared the challenges of driving long distances to visit our children, changes in their growth and renewed hope and energy at good doctor reports. These connections served to further repel the lie that, all our family needed was each other, which could not have been further from the truth.

After two months time our children were released to go home. When we were given instructions on how to care for our young ones our confidence level soared and because of the support we received while in the NICU, we continued successfully at home.

Having said that, we began partnering with the Early Childhood Intervention program when our children were about eight months old to ensure they got the best possible start in their development. It was through our partnership with the program that I came to learn of the Texas Parent to Parent program. What an amazing resource of encouragement for families of children in the NICU!
Going to Camp: A Conversation about Letting Go

Rosemary Alexander, PhD, TXP2P Transition Coordinator

I believe in the process of letting go of our children with disabilities, and I think that sending them to summer camp is a great way to start!

When my son Will (now age 29) was 6 or 7, I learned about Camp CAMP from another parent and thought, Will would like that—swimming, archery, canoeing, horseback riding, other kids, and lots of support to do these activities. So we signed him up for a week the next summer. It was tough to leave him that first time, wondering if they would be able to keep him from falling down, if he’d sleep and eat normally, if he’d have fun, if he’d have a seizure. I didn’t get a call from camp that week and when we picked him up on Friday, I learned that it had gone well. He had a skinned knee but otherwise seemed happy and healthy. He is not verbal but his camp counselors had written about each day in a little notebook. And he won an award for having the biggest smile!

That was the start of a long tradition of Will going each summer to camp—an adult session was added so he still goes. He always has fun and wins an award—this year it was for having the best sense of humor on his adventures! Oh, sure, goofy things have happened, like the year he came home in another kid’s shoes instead of his own!

We’ve lost sheets and towels, shorts and swim suits; he’s had skinned elbows, gotten a bit pink, and come home tuckered out. But truly these mishaps have been a small price to pay for the fun he’s had and the people he’s gotten to know.

And I started looking forward to that one week per year to spend on my own stuff—that first year I cleaned out closets! We’ve taken trips, devoted time to our other son, renewed out marriage, and just loafed. It feels like a miracle, after spending your life caring for another person, to finally have some time for yourself.

Will’s going to camp gave both him and us the chance to learn that he could spend time having fun and being safe away from us. Other people can provide his care and do it well—maybe not the way I would do it, but in a way that works. Also we discovered that other people can provide experiences for him that his family cannot. And camp and other similar experiences paved the way for his eventual move into another household when he turned 20.

Letting go doesn’t mean shirking our responsibilities of advocacy, care, and providing for our children’s needs. Letting go does mean adopting an attitude that conveys to your child his or her right to make choices, become someone outside of your expectations, and step into adulthood without fear. It is also an attitude that gives yourself, as parent, the right to your own life, placing yourself first sometimes and pursuing your own goals.

I love Will and take great delight in our time spent together, and I am proud of the skills he has acquired through maturity. I also relish the time and energy I now have to spend on my own interests and pursuits. I have learned to trust others for his care.

Letting go is best done GRADUALLY! Start early and keep at it, for it takes a long time. It may be hard to take that first step and trust your child to go somewhere without you, but you can start with something shorter than a week at camp—maybe just an overnight in a camp respite program. Let your child start to make choices, take small risks, and spend time with people outside your home. That first step starts the process, so that when your child arrives at adulthood, you are both ready!

NOTE: Rosemary has worked with TxP2P since its inception but has now joined us in developing our Pathways to Adulthood Transition Program and will be writing article for our newsletter on transition issues.

A Blue Rose

Having four visiting family members, my wife was very busy, so I offered to go to the store for her to get some needed items, which included light bulbs, paper towels, trash bags, detergent and Clorox. So off I went.

I scurried around the store, gathered up my goodies and headed for the checkout counter, only to be blocked in the narrow aisle by a young man who appeared to be about sixteen-years-old. I wasn’t in a hurry, so I patiently waited for the boy to realize that I was there. This was when he waved his hands excitedly in the air and declared in a loud voice, “Mommy, I’m over here.”

It was obvious now, he was mentally challenged and also startled as he turned and saw me standing so close to him, waiting to squeeze by. His eyes widened and surprise exploded on his face as I said, “Hey Buddy, what’s your name?” “My name is Denny and I’m shopping with my mother,” he responded proudly. “Wow,” I said, “that’s a cool name; I wish my name was Denny, but my name is Steve.” “Steve, like Stevarino?” he asked. “Yes,” I answered. “How old are you, Denny?”

“How old am I now, Mommy?” he asked his mother as she slowly came over from the next aisle.

Continued on Page 6
A Blue Rose

"You're fifteen-years-old Denny; now let the man pass by." I acknowledged her and continued to talk to Denny for several more minutes about summer, bicycles and school. I watched his brown eyes dance with excitement, because he was the center of someone’s attention. He then abruptly turned and headed toward the toy section.

Denny’s mom had a puzzled look on her face and thanked me for taking the time to talk with her son. She told me that most people wouldn't even look at him, much less talk to him. I told her that it was my pleasure and then I said something I have no idea where it came from, other than by the prompting of the Holy Spirit. I told her that there are plenty of red, yellow, and pink roses in God’s Garden; however, “Blue Roses” are very rare and should be appreciated for their beauty and distinctiveness. You see, Denny is a Blue Rose and if someone doesn’t stop and smell that rose with their heart and touch that rose with their kindness, then they've missed a blessing from God.

She was silent for a second, then with a tear in her eye she asked, "Who are you?" Without thinking I said, "Oh, I’m probably just a dandelion, but I sure love living in God’s garden." She reached out, squeezed my hand and said, "God bless you!" and then I had tears in my eyes.

My Story

My name is Sharon S. Galvan and I have a 15-year-old daughter, Sabrina Victoria, who has Hydrocephalus, Diabetes, visually and hearing impairments, Cerebral Palsy, Scoliosis, Autism and Spina Bifida. TxP2P has been a huge resource for our family. The support, the suggestions, advice, and opinions that are spread from one parent to the next by TxP2P has helped me get through stress from the struggles of rejection, opinionated people, and denial of access to many doors that we have tried to get through. Standing as a unit, receiving feedback, and having someone who supports you in the knowledge that we can achieve a better life and accommodations for our children with special health care needs is amazing. I never dreamed of a group that would help us find the resources, help us learn to advocate, or find those who can help us advocate for our children.

For many years, I would walk out of ARD/IEP meetings crying - I was terrified because I had no guidance as to who, what or even where to get help. Families that connected with me through this group have shared their experiences and bonded with us to teach us to be strong and know that we are on the right track. I learned after 14 years of Sabrina’s life, that I do have a voice and get help and encouragement to use it to enhance my daughter’s well being and education. And now, I am learning not to be afraid to go to other meetings and help others advocate for our children.

I was terrified about the budget cuts that the CLASS program was making and that it was rolling downhill to our families. Then TxP2P reached out and clarified all the information and made it clearer for us all. We understood what was needed to keep our services and others found things that they were not afraid to give up in order to help other families keep theirs.

Being afraid to stand up for my daughter’s rights was one of my biggest fears in front of school officials. Reading and talking with the group, parent’s connections and support of professionals, I was finally not afraid and took the necessary stand to help change the policies in my daughter’s leaning environment. They gave me the confidence and encouragement to know that the school officials are people just like me. They put their pants on one leg at time, just like me. I have a right to fight for her and my voice does count. Recently, I stood up for Sabrina and it all paid off. New educational environment, appropriate nurses, most appropriate issues addressed and continued due to the confidence I gained with the help of TxP2P. I feel GREAT!!!!!

Sharon S. Galvan, TxP2P Family

Continued from Page 5

May I suggest, the next time you see a BLUE ROSE, don’t turn your head and walk off. Take the time to smile and say Hello. Why? Because, by the grace of GOD, this mother or father could be you. This could be your child, grandchild, niece or nephew. What a difference a moment can mean to that person or their family.

From an old dandelion! Live simply. Love generously. Care deeply. Speak kindly. Leave the rest to God.

"People will forget what you said, People will forget what you did, but people will never forget how you made them feel!"

Anonymous
On Thursday, August 18, 2011, the Emergency Medical Services for Children (EMSC) State Partnership honored six children’s advocates with its first annual EMSC Champions for Children award. This award recognizes individuals who have demonstrated “unwavering dedication and commitment to improving emergency medical care for children with special health care needs and for all children across the great State of Texas.” Jeanine Pinner and her son Jake, and Debbie Wiederhold and her son Daniel, each received special acknowledgement for their outstanding work in the development and implementation of a joint EMSC-TxP2P continuing education program for EMS and nursing level emergency care providers titled Assessment and Management of Children with Special Health Care Needs. In addition to their work behind the scenes, these two families have traveled with EMSC across the State to bring a very unique, real world experience into the classroom, presenting lectures and discussions, participating in practical scenarios and communication exercises, and interweaving the concepts of patient- and family centered care into every aspect of the training. Also receiving special recognition were Texas Senator Eddie Lucio, Jr (Dem. Brownsville) and State Representative Elliott Naishat (Dem. Austin) for their ongoing support of children’s health and safety issues. Pediatric concerns supported by these champions include expanded health coverage for children with Autism, safety belts on school busses, people-first language initiatives, and pediatric preparedness in EMS.

TxP2P is pleased to announce that we have 4 new programs underway: Speaker & Outreach Network (SON), Pathways to Adulthood (PTA), NICU Network, and Advocacy Network. We are actively recruiting & training parent and family member volunteers for all 4 programs so we can get them up and running shortly. You can reach us at 866-896-6001 or email the person identified below.

Speaker and Outreach Network: TxP2P gets many requests to have booths at fairs and conferences as well as speak at some of these events. With a state the size of Texas and a small staff, we just cannot do them all. We are training parents and family members to man booths for us and do the occasional speaking engagement. To volunteer or for more information, contact Jeanine Pinner at Jeanine@txp2p.org.

Pathways to Adulthood (PTA): While families often have to search for resources, programs and activities for their children, the biggest hole right now is in Transition - after school services end at age 22. PTA will train parent volunteers who have already started transition with their child to provide information and support for parents starting the process. Trainings will also be available. If you are interested in helping with this program, contact Laura Warren @ Laura@txp2p.org

Advocacy Network: Please see description in article on pages 1 & 2.

NICU Network: Please see sidebar in article on page 4, My Family’s NICU Story for more information.

The TxP2P Newsletter is not copyrighted. Please feel free to use any of our articles in your newsletter, parent group meeting, or any other venue but remember to credit the author & TxP2P. If you would like an electronic copy, we can email it to you; please email the date of the newsletter & the article name to Susan.Prior@txp2p.org and we’ll email you the article.

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, NICU, Transition, or local area Listservs (Austin, Bryan/College Station, Coastal Bend/Corpus Christi, Dallas/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 email. If you are currently getting this by mail but would read it as an email or print it out, please contact Susan Prior (512-458-8600 or 866-896-6001 or susan.prior@txp2p.org) and ask to receive the TxP2P Newsletter via email. If you leave a voice mail, please remember to give us your email address. Thanks!!

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

### Conference Schedule

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<tr>
<th>Date</th>
<th>Conference Title</th>
<th>Location</th>
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<tr>
<td>Thursday, Oct. 13 -</td>
<td>Texas State Autism Conference</td>
<td>Houston</td>
<td>For more information, go to: <a href="http://autism.esc2.net/conference/index.asp">http://autism.esc2.net/conference/index.asp</a></td>
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<td>Thursday, Oct. 20 -</td>
<td>12th Annual Chronic Illness and Disability: Transition from Pediatric to Adult-Based Care</td>
<td>Houston</td>
<td>For more information, go to: <a href="http://www.baylorcme.org/search/detail.cfm?cme=832">http://www.baylorcme.org/search/detail.cfm?cme=832</a></td>
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<td>Monday, Oct. 24 -</td>
<td>10th Annual Texas Dyslexia Conference</td>
<td>Austin</td>
<td>For more information, go to: <a href="http://www.504idea.org/Council_Of_Educators/Dyslexia.html">http://www.504idea.org/Council_Of_Educators/Dyslexia.html</a></td>
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<td>Monday, Nov. 7 -</td>
<td>2011 Bridging the Gap Symposium, Mental Health Connection of Tarrant County</td>
<td>Fort Worth</td>
<td>For more information, go to: <a href="http://www.mentalhealthconnection.org/bridging-the-gap.php">http://www.mentalhealthconnection.org/bridging-the-gap.php</a></td>
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<td>Friday, Dec. 2 -</td>
<td>Partners Resource Network’s 2011 Statewide Parent Leadership Conference: Beyond the ARD: Parents Engaged for Positive Change</td>
<td>Austin</td>
<td>For more information, go to: <a href="http://www.partnerstx.org/LeadershipConference/index.html">http://www.partnerstx.org/LeadershipConference/index.html</a></td>
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