

Texas Parent to Parent

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

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Help TxP2P by using our Randall's Good Neighbor' Remarkable Card Number 10043!

We hope your holidays were fun, safe, and relaxing and that your new year is FANTASTIC!!



from the Staff and Board of Directors of Texas Parent to Parent!

TxP2P Program Update: Another Amazing Year!!

Laura J. Warren, TxP2P

There are 10 of us working at TxP2P now with almost 140 trained Supporting Parent Volunteers, almost 1,000 families, and over 300 professionals on our mailing lists. We've only been open for 3-1/2 years but parent to parent support is obviously a needed service in Texas. I want to give you a brief introduction to the staff of TxP2P and then get you updated on the programs we have available, are creating, or are somewhere in between.

The TxP2P staff talks to parents on a daily basis but we also have other duties. We are:

Laura Warren, Executive Director, Founding Partner of TxP2P. She has a son, Jason, 19, who was born at 24 weeks gestation and has mild disabilities and learning difficulties. Laura works on overall coordination of TxP2P, grant management, grant writing, fundraising, the new transition program, the newsletter, the website, and provides parent support.

Sue Regimbal, Financial Director, Founding Partner of TxP2P. She has

two daughters, Ciara, 6, and Maeve, 2. Sue works on overall coordination of TxP2P, financial management, grant management, grant writing, fundraising, and evaluation analysis. Patty Geisinger, Co-Volunteer Coordinator, Founding Partner of TxP2P. She has four children, Josh, 16, Jessie, 14, Libby, 9, and Mary, 7. Jessie has multiple disabilities. Patty works on parent matching and follow-up, Supporting Parent Volunteer trainings, volunteer and parent support, the Faith-based Respite Program and our Medical Education Program.

Debbie Wiederhold, Resource Coordinator, has been with us for 1-1/2 years. She has 3 grown children and Daniel, 13, with Osteogenesis Imperfecta, Type 2. Debbie researches new resources and services for families for our Website Resource Directory, keeps our resource information up-to-date, provides parent support, and works on our Medical Education Program.

There are 10 of us working at TxP2P now with almost 140 trained Supporting Parent Volunteers, almost 1,000 families ...

Shawn Lennartson, Respite Coordinator, has been with us for about a year. He has a daughter, Anna, 14, with Osteogenesis Imperfecta, Type 1, and 9-year-old twin boys, Eric and Carl, who were preemies. Shawn works on our Faith-based Respite Program, parent matching and follow-up, and provides parent support.

Leticia Padilla, Regional Volunteer Coordinator for the Rio Grande Valley, has just been working with us since September, 2005. She has a son, Gerardo, 11, who has autism. Letie provides outreach, parent matching, parent and volunteer support, and trainings in the Valley. You can reach Leticia directly at 956-793-9543. Leticia also speaks Spanish.

Grace Garza, Administrative Assistant, also has just been with us

TxP2P Program Update: Another Amazing Year

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since September, 2005. Grace has grown children and helps with parent paperwork, mailings, parent matching and follow-up, and evaluations. Grace also speaks Spanish.

Rosemary Alexander, Transition Coordinator, also has just been with us since September, 2005, and is a Founding Partner of TxP2P. Rosemary has two sons, Will, 23, with multiple disabilities, and Randall, 21. Rosemary is helping us get our Transition Program started.

Jeanine Pinner, Outreach and Training Coordinator, has only been with us since October 31st. She has two children, Laney, 30, and Jake, 14, who has autism. Jeanine is working on the Family to Family Healthcare Education and Information Center (see article in this newsletter).

Claire Milam, Co-Volunteer Coordinator, has just started with us. She has two children, Isabel, 5, and Julio, 3, who has Down syndrome. Claire works on parent matching and follow-up, Supporting Parent Volunteer trainings, and volunteer and parent support. Claire also speaks Spanish.

We are all pleased to be working with TxP2P and watching it grow. It seems to have taken on a life of its own that we sometimes just have to follow! If you call us and get a busy signal, please be patient and leave us a message. We will get back to you as soon as we can. We get a lot of calls, many from parents who do not have children with special needs but we still try to direct them to the appropriate resources if possible.

Our basic services will remain the same and include:

- **Information and referral**, through staff experience and knowledge, Supporting Parent Volunteers, and our Resource Information Sheets and Resource Directory on the website, www.txp2p.org.

- **Parent support**, including parent-to-parent matching, through staff and Supporting Parent Volunteers: to date we have matched over 450 parents with trained, experienced parent volunteers. However, many parents are still waiting for a match. **We need your help!** If you are interested in being trained as a Supporting Parent Volunteer, we have scheduled the following trainings:

1/14/06: Rio Grande Valley
1/28/06: Austin

2/11/06: Dallas
4/8/06: San Antonio
6/24/06: Rio Grande Valley
9/16/06: Houston
11/4/06: Dallas

We will also offer a training in conjunction with our 2nd Annual Parent Conference. If you are interested in one of the trainings, please call 866-896-6001 (Austin area 458-8600) or email Patty@txp2p.org or Claire (Claire@txp2p.org) to sign up. We will contact you with more details on each training as we get closer to them.

- **TxP2P Newsletter** will continue quarterly for 2006. We recently received some help with the printing costs through Sterling's Printing and Copying in Austin which will make preparing the newsletter quite a bit shorter for us. If you would like to submit an article for the newsletter, please send it to Laura@txp2p.org

- **TxP2P Website** will undergo some changes after the holidays when we move to a different software program that will hopefully make it easier to update. Our website address has officially changed to www.txp2p.org so you will not be able to access it through the www.main.org/txp2p.org website much longer. You can email any of the staff by using their first name @txp2p.org

- **TxP2P Annual Parent Conference** is in the planning stages and we hope to get it scheduled for June in Austin. We'll announce the date and location early in January. If you would like to participate in the planning process, call 866-896-6001 (Austin area 458-8600) or email Laura at Laura@txp2p.org

- **TxP2P Medical Education Program (MEd.)**, continues to train Pediatric and Family Practice residents, as well as other health care professionals, in five sites in Texas. There is a separate article about this program in this newsletter.

- **TxP2P Faith-based Respite Program** continues in the Austin area to create several respite programs in collaboration with faith-based communities. We have one program running once a month that started this past summer that you can read more about in a separate article in this newsletter. We have several more

groups that are interested but have not started yet. After we get a few programs running, we will create a manual that will help faith communities and/or parents set up similar programs across the state. We will provide technical assistance and materials.

We received two new grants this year. The first was through the Children with Special Health Care Needs Services Program (CSHCN), Texas Department of State Health Services, to provide parent support in the Rio Grande Valley and create a transitions program for parents of teens and young adults.

The second grant was one of the Family to Family Health Care Information and Education Center (F2F Center) grants through the U.S. Department of Health and Human Services. TxP2P received state approval to apply for the grant and was awarded one of the ten grants offered through the Centers for Medicare & Medicaid Services. There is only one F2F Center per state and to date there are now 29 states with a F2F Center. We were quite honored to be the Texas recipient of this grant award. You can read more about these programs in articles in this newsletter.

We are also pleased to be involved with the creation of a national parent to parent effort, Parent to Parent USA (P2PUSA). Laura has been on the management team and is now on the Board of Directors for P2PUSA. Their purpose is to ensure that families nationwide whose children have special needs have access to quality Parent to Parent support. This mission is fulfilled by promoting best practices through an alliance of statewide Parent to Parent programs and providing technical assistance to experienced and emerging programs. If you have families or friends in other states, please direct them to this organization for support. Their website is www.p2pusa.org.

So, the staff and Board of Directors of TxP2P are quite busy planning for 2006 and looking forward to another outstanding year! We hope the same for you and your loved ones!

Our website address has officially changed to www.txp2p.org

TxP2P's Medical Education Program (MEd.)

Thanks to advances in medicine, technology and genetics over the past twenty years our children have new opportunities and hope for the future. More children with chronic illness and developmental disabilities are living at home and actively participating in their communities. Through a grant from the Texas Council for Developmental Disabilities, TxP2P has been offering educational opportunities for the past 3-1/2 years to Pediatric and Family Practice Residents and other health care professionals to provide a better understanding of what life is like within a family with a child who has a chronic illness or disabilities. Our trained Medical Education Program (MEd.) Family Faculty accomplish this by widening the residents' perspectives from the hospital and office to the child's home and community. They also show the benefit of a partnership between the physician and family to improve the quality of life for the family and the educational opportunities for the child.

To provide a glimpse of family-life, our volunteer parents invite residents into their homes to experience first-hand how they meet the challenge of raising a child with special health care needs. Simultaneously, our volunteer families learn more about how doctors develop early in their careers. Through this opportunity, we hope to foster communication skills that create collaboration and mutual respect between patients, families, and doctors.

The training for residents is based on the needs of the Residency Programs and may include the following: Family Visits: Our Site Coordinators match residents with volunteer families for in-home visits. Family visits enhance the residents' understanding of the impact a child with a chronic illness or developmental disability has on family dynamics. They will quickly understand how a physician's referral for nursing care or a feeding pump can help a family stay home together, rather than having one parent in the hospital with the child, and one at home trying to be both parents. Long term visits with one family over several years are an option.

Communication Skills: The residents interview a parent using suggested questions covering such issues as funding sources, discussing difficult topics like a DNR (do not resuscitate) order, and fostering family-centered relationships. The residents are allowed to ask any questions they have and the parents have agreed to answer. This is a unique opportunity for the residents to ask questions of a child's parent they may not be able to ask under normal circumstances. Parents provide insight from their personal experiences such as receiving a diagnosis, dealing with the emotional and financial aspects of their situation, and the struggles they have to access resources.

Parent Panel Presentations: We individualize the curriculum to benefit

To provide a glimpse of family-life, our volunteer parents invite residents into their homes...

participants from a variety of training backgrounds including medicine, nursing, education, psychology, social work, home-visiting programs and others. We offer parent panel presentations on such topics as accessing community resources, negotiating special education, delivering sensitive news, interviewing skills, understanding stages that parents experience, personal parenting experiences, the Medical Home concept, and Transition from Pediatric to Adult-Centered Health care. Topics can be presented by an individual parent or a panel of parents.

TxP2P trains pediatric residents at Children's Hospital of Austin and the family practice residents at Blackstock Family Clinic in Austin, both through the Seton Healthcare Network. We also train pediatric residents at Scott and White Hospital in Temple, Texas Scottish Rite Hospital for Children in Dallas, and family practice residents in the Osteopathic Department at the University of North Texas Health Science Center in Fort Worth.

If you are interested in becoming a MEd Volunteer Parent, contact Debbie Wiederhold at 866-896-6001 (Austin area 458-8600) or Debbie@txp2p.org. If you have a program that can benefit from the trainings we provide, contact Laura Warren at 866-896-6001 or Laura@txp2p.org.

Respite: A Blessing for our Church Community

By Patty Geisinger, TxP2P

Texas Parent to Parent received a grant this past year to help faith communities find a way to serve our diverse community by providing respite: a ministry which would benefit both families of children with disabilities and volunteers who provided the respite. Materials were adapted from a similar program in South Carolina, and after much planning, editing, preparation and worry, we kicked off our pilot respite site in May at St. John Neumann Catholic Church in Austin. It was helpful that both Colleen Jones and I attend this wonderful parish, and knew how to maneuver the ins and

outs of getting a new ministry off the ground. We handed out information, held a training, and located families in the church whose children would attend. The parents filled out an in-depth notebook about their child, the special needs, and the siblings. We had 17 willing and excited adult and teen volunteers ready for our first night of respite. The parents arrived with our children, our notebooks and our anticipation. The first night was very revealing! We introduced each of our children to the volunteers, told them about our family life and what they might expect from our

children. Most of the volunteers listened intently, but we all noticed the growing noise in the room. And then, as if drawn by an inner sense, the volunteers rose, one by one, and moved out into the room while we were still speaking, to play with the kids. The plan was for the parents to move down the hall, have snacks and get to know each other, in reach of volunteers with questions and concerns. There were four families, with a total of 12 children. More volunteers than participants led the adults to pair up in twos and take children to the playscape or on

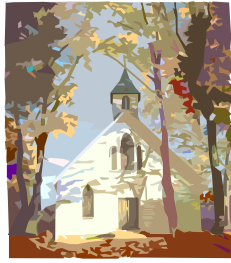
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Respite: A Blessing for our Church Community

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impromptu walks around the building. No one was alone, and everyone was having a great time!

I slipped down the hallway with the parents, almost unnoticed by everyone. A potluck of snacks, desserts and even a bottle of wine awaited us. We had a unique chance to visit, undisturbed except by the occasional laughter echoing down the hallway through our open door. We kept it open, just in case! To our surprise, we were not called, not noticed, not needed for almost 2 hours! We relaxed, laughed, chatted, and even played a short game! An unexpected blessing was the support and resources we shared in that short



amount of time. Everyone agreed to look for other families who may need some time off as well!

At the end of the night, the volunteers gave our children back, entertained us with funny stories, lessons learned and connections made. They saw us at the beginning of the night tense and unsure if this experiment would work, and now we were smiling, relaxed and ready to be with our children again. Most told us how much fun they had and what a blessing it was to have spent time with our families. But as the summer stretched on and we have all gotten to know each other better, I have to believe that it is the

added blessing of seeing the parents return more relaxed, refreshed from our short time away which is bringing our volunteers back. They do see that they have made a difference, brought us respite, and with their hearts and hands, become Christ to us in a very small way.

TxP2P has a Respite Coordinator who has the tools to help your faith community in the same way. If you are interested in learning more, call or email Laura Warren (Laura@txp2p.org) or Shawn Lennartson (Shawn@txp2p.org) at TxP2P (512-458-8600; 866-896-6001) and we can help you and your church find those unexpected blessings from respite.

TxP2P Family to Family Health Care Information and Education Center

TxP2P has recently received one of the Family to Family Health Care Information and Education Center (F2F Center) grants through the U.S. Department of Health and Human Services. The F2F Centers are part of the Real Choice Systems Change grants to help those with disabilities exercise meaningful choices regarding how and where to live through the President's New Freedom Initiative which promotes the goal of community living for individuals with disabilities and long-term illness. The F2F Center grants were created to establish family run centers that provide information, education, and training opportunities for families with children with special health care needs.

TxP2P will assist families of children with disabilities and special health care needs to ensure that their children can continue to live at home or in an integrated community setting whenever possible. We will also assist families with information

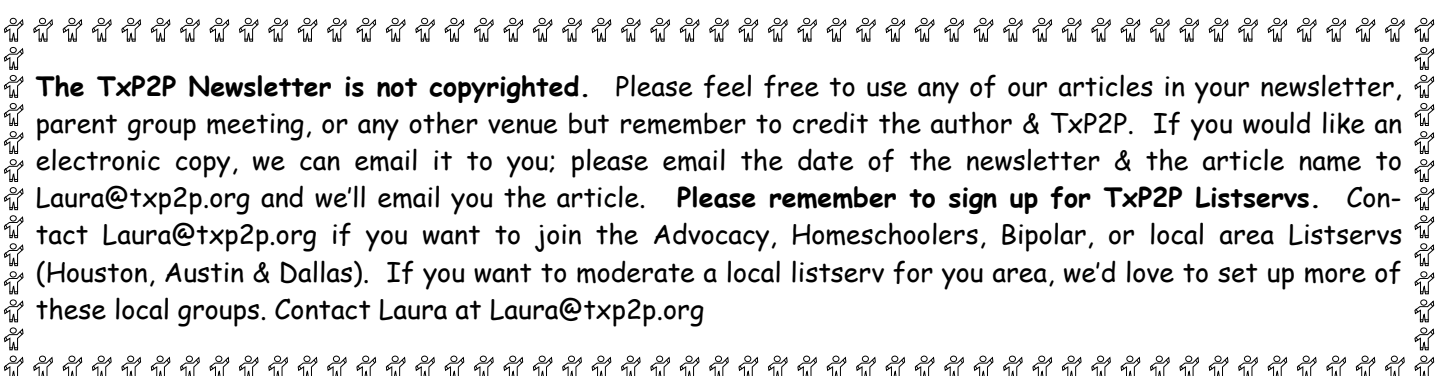
and resources so that they will be able to make informed choices about the care that their child receives; from who they choose as service providers to the manner in which services are provided. We will also assist with long-term plans and supports for when their child will leave home. We will ensure that families are aware of the philosophy of home and community based supports. We will accomplish this through:

- Providing general information and referrals to programs, services, and benefits that can help children stay in their community and progress in their development; AND providing resource directories to link families with individualized services for a child based on the family's personal situation, including where they live in Texas, income level, the age of the child and the type of health care needs and/or disabilities
- Providing education and training opportunities for parents, parent

groups, service providers and other professionals who provide health care services and resources for children with special health care needs; trainings will be in a different part of Texas each month, ensuring to cover all regions of the state

- When requested by a parent, providing a one-on-one match with a Supporting Parent Volunteer to provide information, referrals, health care information, and emotional support to new parents or parents new to the special health care need or issues
- Developing and promoting our Transition Program for parents of teens and young adults through written information, articles in the newsletter and on our Website, one-on-one support from our Transition Coordinator, and trainings to be provided in conjunction with other monthly trainings
- Providing opportunities for peer

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TxP2P Family to Family Health Care Information and Education Center

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support, discussion, and interaction through expansion of our Internet Listservs, our annual statewide parent conference, matches with Supporting Parent Volunteers, and providing technical assistance and advertising for local parent groups while continuing to identify and provide additional avenues of interaction for parents

- Collaborating with existing Family to Family Health Care Information and Education Centers in other states to

benefit families; continuing existing collaborations and pursuing additional ones with the Texas Department of State Health Services on best practices and findings from resource dissemination

- Providing opportunities for parents to become parent leaders in health care policymaking and advocacy

We are very excited about starting this new resource for families in Texas. For more information on the

grant, contact Laura Warren at 866-896-6001 (Austin area 458-8600) or Laura@txp2p.org. For training opportunities, contact Jeanine Pinner, Training and Outreach Coordinator at 512-217-3558 or Jeanine@txp2p.org. Parents can call TxP2P at 866-896-6001 (Austin area 458-8600) for more information on the trainings available through the F2F Center.

TxP2P CSHCN Grant: Parent Support and Transition Services

TxP2P recently received a grant from the Texas Department of State Health Services through Children with Special Health Care Needs Services Program (CSHCN) to provide parent support statewide, with an emphasis on families in the Rio Grande Valley, and to develop a transition program. This is our first grant specifically funding parent support and we are very pleased to have received it. It greatly increases our ability to provide services in Spanish.

We have hired a Regional Volunteer Coordinator to help us reach families in south Texas, particularly Cameron, Willacy, Starr, and Hidalgo Counties. We have a Supporting Parent Volunteer Training planned for Saturday, January 14, in order to increase the number of volunteers in that area. We hope any of you in the area that feel you are ready and able to provide emotional and informational support to another parent will attend. You can contact Leticia Padilla directly at 956-793-9543 or call the TxP2P of-

fice at 866-896-6001.

Another important piece of the grant is the development of a transition program, both for moving from Pediatric to adult health care and for families concerned with what their child will do after they age out of the school system. Rosemary Alexander will work as a consultant to help us develop this project, **Pathways to Adulthood**. We will begin by researching the programs already addressing transition issues in Texas to create a comprehensive listing of services for families available as a Resource List and on our Website Resource Directory. We also plan to provide additional training for any of our Supporting Parent Volunteers who are interested in supporting families during transition to again provide parent to parent support for this very important stage.

We are also exploring the idea of creating a center based on PLAN (Planned Lifetime Advocacy Network, www.plan.ca) that will assist families

with transition issues. We plan to work with a few families in the Austin area in 2006 to create a personal network for their child based on the book, *A Good Life*. The personal network focuses on several major aspects of a person's life who is at risk of being isolated:

- *home vs. house* to provide a choice and a sanctuary that is designed to meet the individual's needs, not the staff's needs,
- *making a contribution* to provide every person the right to make a contribution so they are not just a receiver of help,
- *ensuring choices* for independence, and
- *building relationships* to ensure that every person has relationships with people in their life that are not just service providers.

We will provide more information over the coming year and at our Annual Parent Conference on this program and other transition issues.

Rudy's Pool Adventure

This was a summer for the record for us here in Austin, TX and I'm not just talking about the heat! This will have been the summer of "Rudy's Pool Adventure"! My Rudy is 12 years old and has Down syndrome. Several years ago, I signed him up for swimming lessons at our neighborhood pool which has a city program and noted on the application that he needed extra help. He was assigned a couple of swim coaches and an extra helper, but whatever it took, my son was going to participate and learn to swim; and with some modifications, swim he did! He later perfected this

sport through Special Olympics and in fact won several medals for his excellent swimming skills!

Rudy has school pals that he meets up with at this pool and he loves to stay in the deep end. Not being a swimmer, I stay in the middle of the pool to watch him and make sure he follows the rules. There have been times when I have seen kids stare and move away from him, and though I do not like it, he does not seem to care. I have had to go over and introduce him and let



other kids (usually his age) know his name and what school he goes to. After I explain that he is non-verbal and he usually just wants to hang with them and if they just say "Hi

Rudy," he feels acknowledged and will hopefully stay out of their space. By the time we leave, kids are saying bye to him!

On a Friday afternoon in June, we had been at the pool for about an hour when a lifeguard on my side of the pool asked me to get Rudy out of the deep end and keep him with me.

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I was puzzled by it and I asked why. He informed me that only kids under 14 who could swim the length of the pool could stay there unsupervised. There were stares from other parents and I was thinking, here I go again! I don't look for situations but I don't back down either when I feel that Rudy is being treated unfairly. Of course, Rudy could not understand why he had to get out and the more I thought about it, the angrier I got. Especially when an 11-year-old girl asked the lifeguard if she could swim and after confirming that a parent was somewhere in the pool, he told her it was okay. That is when he met the real Rudy's mom . . . "Oh no," I said "why isn't she asked to swim the length of the pool? Why does Rudy have to prove himself and she doesn't?" One look at his face and I knew I had him! I mentioned that Rudy was protected under the American Disabilities Act and that he could not be treated unfairly in a public facility that receives public

money. And how did they know Rudy could not swim the length of the pool, did they test him or did they just presume incompetence because of his disability? (At this point, I really did not want Rudy tested since he was picking up on the confrontation and besides, he had already been swimming for an hour). I told the lifeguards that they would be hearing from me...talk about people staring now! I went home and e-mailed a letter to the mayor of Austin. Within days, I had a call from the supervisor of that pool and he was so surprised since there had never been any issues there before. I told him I agreed because we had been going there since it opened and I'd never had any issues either! I told him I understood the safety factor but if Rudy has to prove himself, then so does everyone else who follows under their age rules. I agreed to bring him back with his swim coach so that he could "prove himself". He had also

suggested that maybe Rudy could go with a "separate and segregated handicapped children's group" and I said, 'Oh no, we can come on our own individually any day of the week!' We returned with Rudy on a Sunday and not only did he swim the length of the pool, he did it three times! We had a cheering crowd for him too! The lifeguards were surprised and said they were very impressed. I then got a call from the supervisor who said all the lifeguards in Austin had been trained on ADA and while I told him that was good for them, I wanted them to have additional training on practice, not just policy. I have now been asked to collaborate with their staff training next spring to help give them information on how to work with our kids! Okay, I guess there was some heat after all, but sometimes we have to make some big splashes in educating the world about how competent our kids can really be!

How to Fill a Prescription for a Child on Medicaid or CHIP

What do I do when my doctor gives me a prescription for my child?

BEFORE You Leave the Office, Ask: Do any of the medications the doctor prescribed for my child need prior approval before the pharmacy will fill them?

* If NO, you should be able to get your child's prescription filled. (For Medicaid, you will have **no** co-pay; for CHIP you **will have** a co-pay.)

*If YES, ask whether your doctor or someone on the staff has already asked Medicaid for prior approval. If they have not gotten prior approval yet, ask them to:

*get permission before you leave the office, OR telephone you after they have gotten approval, OR prescribe a different medication that does not need prior approval.

What do I do if the pharmacy does not give me the prescription?

Ask the pharmacy why it was not filled. If the pharmacy says prior approval is needed, ask if the pharmacy can call the doctor, or call the doctor yourself.

If the pharmacy is out of the medication, ask them:

*to call another pharmacy to see if you can get the prescription filled there, OR to tell you how soon they can fill the prescription for you.

If the pharmacy says they can only sell you the medication at full cost, **wait before you pay!**

*Children's medications should be free in Medicaid, and in CHIP you should only pay the co-pay.

*If a prescription under Medicaid needs prior approval, ask the doctor to get permission so that you do not have to pay.

***Always** call your doctor first before you pay full price for a medication.

What happens if my child needs medications at night and/or on the weekend, and the doctor cannot ask for prior approval?

*The pharmacist can give you a 72-hour (3 day) emergency supply of the medication. It should last your child until the doctor can ask for prior approval.

Will Texas Medicaid or CHIP pay for prescription drugs for a child?

*Children and teens in both Medicaid and CHIP can get most medications that are prescribed by a doctor. There is no monthly limit on the number of prescriptions a doctor can prescribe your child. (Some adults can only get 3 prescriptions per month).

*In Medicaid, even non-prescription ("over the counter") medications can be free of charge if a doctor gives you a prescription for them.

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*There are no co-pays for prescribed medications in children's Medicaid.

*CHIP does not cover over-the-counter medications. CHIP does require co-payments for children's prescriptions.

What are the steps needed to fill a child's prescription?

*There is a list of medications that Medicaid will pay for when your doctor prescribes them. The list is called the Preferred Drug List (PDL). The medications on the list are effective, safe, and affordable.

*If your doctor wants to prescribe a medication that is not on the list, he or she will have to ask for and get permission from Medicaid BEFORE

you can fill the prescription. Your doctor or one of the staff will have to convince Medicaid to pay for a medication that is not on the list. This is called getting "prior authorization" or prior approval.

*The pharmacist cannot fill a prescription that is not on the list until your doctor has gotten prior approval. **Only** the doctor or clinic can ask for prior authorization - the pharmacist cannot.

*This is why it is safest to always ask the doctor or clinic before you leave the office whether your child's prescription needs "prior authorization" or not. If prior approval is needed, ask the office to make sure your pre-

scription is approved as soon as possible. Otherwise, you may be delayed at the pharmacy. Or you can ask your doctor to prescribe another medication that does not need to be approved.

*Right now, CHIP does not require prior approval for prescriptions.

What should I bring with me when I take my child to the doctor's office and pharmacy? Your child's Medicaid or CHIP ID card

If your child is on CHIP:

*Money for the prescription co-pay OR if you have already spent your yearly limit, bring your child's CHIP "\$0 co-pay card" to show you do not have a co-payment. (see last page)

Legislative Update: Policy Update By Colleen Horton, Tx Center for Disability Studies

I will stray somewhat from my usual legislative update to give you a human example of how policy decisions and budget policies can affect services to people with disabilities.

A recent news segment on WFAA, News 8, in Dallas exposed a horrific story of a young man living in Denton State School. According to the news segment, this young man was brutally beaten and permanently injured by one of the staff hired to care for him. The young man, Hasib Chisty, ended up in a coma and now has quadriplegia. His attacker, hired to provide direct care for the residents of the state school, all of whom have some level of cognitive disabilities, was a drug addict.

Here are the details as described in the News 8 story that resulted from a 4-month investigation. Hasib's attacker, Kevin Miller, has admitted to the assault. He has stated that there is a "culture of negligence and drug use on the job...the employees on that shift did either crack, powder cocaine, marijuana, oxycontin, hydrocodone, valium..." Miller has testified under oath of a pattern of abuse by staff who "used rubber gloves to abuse the residents." Miller also testified to the use of metal spoons as weapons to hit residents on the head. He stated in his taped testimony that this was "the tip of the iceberg of some of the examples of abuse here." According to the News 8 story, Hasib's mother was told for more than two years that the injuries were caused by a seatbelt. It's amazing how people in positions of power often

believe the rest of us are so ignorant. While the assault took place in August of 2002, the state school only recently admitted in a letter to Hasib's mother that her son's injuries were caused by abuse. If this type of abuse occurred in a private facility, the state would likely work quickly to close the facility down. Unfortunately, this state-owned and operated facility isn't held to the same consequences.

For those not familiar with the state school system, there are eleven in Texas, housing almost 5,000 individuals with varying levels of mental retardation. The daily rate for these state operated state schools was increased in September to \$308.75 per day. The math is easy. The state invests well over \$500 million dollars per year for a system that takes away personal freedoms from individuals with disabilities and violates their civil and human rights.

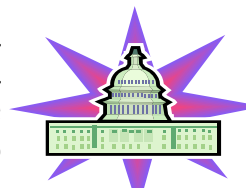
People with disabilities in Texas have long advocated for community-based services that support individuals with disabilities to remain in their homes and communities, services that prevent segregating individuals with disabilities in institutions. Community-based services, while offered in Texas, are not accessible by many who need them due to the "institutional bias" that exists. What is this bias? It's simple. For an individual with disabilities who meets the eligibility criteria for institutional care, the state will pay exorbitant amounts to segregate that person in an institution -

the individual is entitled to this care and the state must provide it. The state will not, however, give that same person an entitlement to community services even if the costs of care are much less. For those who desperately need supports and services, often the only choice available is to be forced into a facility. Currently in Texas, more than 100,000 individuals, both children and adults with disabilities, are waiting for community services - while we spend over \$100,000 per person, per year on state school "care."

This should be unacceptable to those who care about people with disabilities; it should also be unacceptable to all Texas taxpayers when tax dollars support abuse and neglect of some of Texas' most vulnerable citizens. It is time that the State of Texas takes a serious and comprehensive look at options for consolidating and closing state schools. This should not be about politics and it should not be about local economics. It should be about the rights of individuals. It should be about quality services and humane treatment. It should be about the right of these individuals to live and work and play in their communities. It's about the right to live free of abuse and neglect.

It's about human and civil rights because separate is still not equal.

To view the video of the WFAA, News 8 segment, go to http://www.wfaa.com/shared_content/VideoPlayer/videoPlayer.php?videoId=38956&cat



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Serving children with disabilities,
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 by providing support and information to
 their families through peer support,
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Conference Schedule

Date	Conference Title	Location	Registration Information
Saturday, January 28, 2006	Disability Leadership Network of Houston Resource Fair 2006	Emmanuel Episcopal Church 15015 Memorial Drive Houston, TX	For more information, contact Family to Family Network of Houston at 713-303-9993 or / www.familytofamilynetwork.org
Wednesday, February 22 to Saturday, February 25, 2006	Inclusion Works! 13 th Annual Conference	Renaissance Austin Hotel Austin, TX	For more information, call The Arc of Texas at 800-252-9729 or in Austin, 454-6694 or go to their website at www.thearcoftexas.org
Friday, March 3 to Saturday, March 4, 2006	TxABA 2006 Annual Conference & Workshops	Marriott Houston Hobby Airport Houston, TX	For more information, contact Susan Miller at (940) 891-6720 (7:00a.m.-11:00a.m.) or email her at smiller@pacs.unt.edu
Friday, March 3 to Saturday, March 4, 2006	Wright's Law Workshop Special Education Law and Advocacy Boot Camp	Will Rogers Memorial Center Ft. Worth, TX	For more information, contact the Arc of Dallas at 817-871- 7392 or at their website www.arcdallas.org/wrightslaw
Sunday, March 26, 2006	Down Syndrome Association of Central Texas Dash for Downs	Williamson County Regional Park Cedar Park, TX	For more information, contact Stefanie Martinez w/ DSACT at 512-454-8142 or www.dsact.com

Concerning the Article on page 6 "How to Fill a Prescription for a Child on Medicaid or CHIP": This information sheet has been prepared by the Houston/Harris County Covering Kids and Families Access Initiative. To learn more about the Initiative, please call the Children's Defense Fund of Texas at 713-664-4080.
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