



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

TxP2P Needs \$20 from YOU to Realize Our Dreams for Texas

Texas Parent to Parent will be 7 years old next month. Six years ago, we had 4 part-time staff members, and 128 families and a few professionals on our mailing list. Now we have 3 full-time and 7 part-time staff, and our mailing list includes 2,400 families in addition to 550 friends and professionals. We can now provide trained volunteers across the state to match with parents whose children have a new diagnosis. We provide a major parent conference annually, and we are developing our 5th Medical Education Program site for pediatric residents. Seven years ago we were just hatching the idea of a statewide parent to parent program, the only one in Texas, because we believe in the power of parent to parent support. Now we provide support and information to families all across the state. We are proud of how far we have come. But we still have a long way to go. The number of families requesting our services is constantly increasing, and our small staff needs to grow in order to keep up with these requests for help, as well as to provide new services that address the changing needs of families as their children grow from infancy through adulthood. We want to assist more families, develop more programs, hold a bigger conference, hire more

Debbie Burt, TxP2P Board Chair

staff, and better support administrative staff. While we have had success in securing grant funding to support program expenses, we are still very much in need of unrestricted funding that can be used for administrative staff and fundraising expenses. Unrestricted funding comes mainly from personal donations and fundraisers. These monies are vital to adequately fund administrative and fundraising staff, which will allow us to strengthen Texas Parent to Parent's capacity to help Texas families, while ensuring our sustainability for future generations of families who need our help. The administrative support to develop our programs is underfunded. If everyone who receives this newsletter donates \$10, we could finally pay our administrative staff a full salary! If everyone donates \$20, we could also realize our dream of hiring a professional fundraiser. We have all seen the power of many small donations coming together to make something big happen. Please help us today - look for the envelope included with this newsletter and mail us your donation - any amount you can spare will be joined with other donations to make TxP2P's dreams come true! Please do what you can to help us to build the state-wide parent to parent program that Texas deserves!

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



Happy Holidays!

TxP2P Staff - Laura, Sue, Rosemary, Patty, Debbie, Jeanine, Lisa, Erika, Susan, Lucy, & Jan



Medicaid Buy-In for Children

Colleen Horton, Texas Center for Disability Studies, The University of Texas at Austin

I know it's hard to believe, but by the time this newsletter reaches your mail box, filing of legislation for the 81st legislative session will have begun. Yes, it's not only hunting season, it's also filing season. As with every session, there is much on the agenda that will impact both adults and children with disabilities. Some of the issues that we know will be discussed include:

- Medicaid buy-in for children with disabilities
- Medicaid waiver waiting lists
- State schools
- Education vouchers
- Access to medical provider for people on Medicaid
- Reform of the long term services and supports system
- and much, much more.

I encourage everyone reading this to get involved with whatever issues



you feel passionate about. If you don't, who will? In this newsletter, I wanted to offer you

information on one issue that we know will be important to many families of children with disabilities - the proposed Medicaid buy-in program for children with disabilities. This program would allow families with income up to 300% of the federal poverty level to pay reasonable premiums for Medicaid insurance coverage for their child with disabilities. Outlined below are the basics of such a program, an explanation of the issue, and some background on why this is needed. During the last legislative session, Senator Deuell and Representative Lucio filed legislation to create a buy-in for children. While the legislation did not pass in the 80th session, they have already begun working on the initiative for the coming session. Additionally, Commissioner Albert Hawkins, Health and Human Services Commission (HHSC), has included a funding request in the Commission's pro-

posed budget for the next biennium.

The Issue:

Far too many children with disabilities or special health care needs do not have access to health care services that are so critical to their well-being and often their survival. These children may be uninsurable in the private insurance market, yet not eligible for public assistance due to their family's income.

The Recommendation:

Design, develop, and implement a Medicaid Buy-In Program for children with disabilities, as allowed in the Deficit Reduction Act of 2005.

Background:

The Deficit Reduction Act of 2005 (DRA) allows states to develop Medicaid buy-in programs for children with significant disabilities and special health care needs in families with income up to 300% of the federal poverty level.

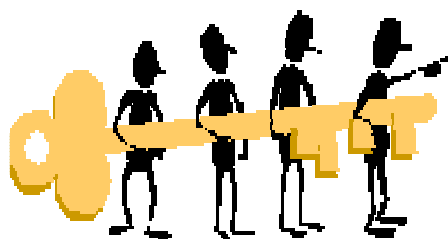
This is needed because many children with disabilities are uninsurable in the commercial insurance market primarily due to their pre-existing conditions. Even when insurance is offered, the cost to insure a child with significant disabilities or health care needs is often prohibitive. Families can be faced with difficult choices such as whether to pay insurance premiums or pay their mortgage. Numerous families have intentionally lowered their income or refused promotions in order to qualify their child for the state Medicaid program so that their child could receive needed medical care. Even more disturbing, some families resort to divorce to allow household income to drop below the financial eligibility requirements of Medicaid. These families typically have tried every other avenue available, with little or very limited assistance materializing.

The problem perpetuates itself. Not only does the inability to obtain health insurance for their child force families into poverty to qualify for Medicaid assistance, the inability to obtain health insurance also forces these families to remain in poverty. Families are unable to

acquire assets over the Medicaid limit which means they cannot save for other needs such as college for other children, retirement, or even emergencies.

Another disturbing potential outcome for families' when they can't obtain needed medical care for their child with disabilities is institutionalization of the child. Due to the entitlement for institutional services, institutionalization may be the only option families sometimes have. Child development research has shown that institutionalization of children negatively affects all areas of their development. Additionally, institutionalizing children with disabilities is fiscally inefficient when supports and services can be provided to the child in the community at a lower cost, allowing the child to remain with the family.

In 2007, the 80th Legislature considered proposed legislation that would have directed HHSC to develop and implement a Medicaid buy-in program for children with disabilities. However, funding requests for the program were not included in the Commission's appropriation requests. Without the funding, no program can be established. The fact that HHSC has requested funding already puts the initiative ahead of where it was last session.



If the opportunity to buy into the state Medicaid plan to obtain health care services for your child with disabilities is important to you, and you would like more information on this initiative, please contact me (colleen.horton@mail.utexas.edu).

As always, I'm happy to share the information I have to assist families in their efforts to change the system and improve the quality of life for their kids.

ADOPT A LEGISLATOR!

A joint project of Texas Parent Advocates Consortium (TxPacs) & TxP2P

Just in time for the upcoming January to May legislative session!

What? A plan for meeting your legislators and helping them learn of your family situation, hosted by TxPacs & TxP2P

Why? Legislators need to equate the issues to real people and their unique stories.

Who? Parents, grandparents, family members, self-advocates and

friends.

When? Each month you'll receive an email with an idea for:

-sending a holiday card with family photo

-calling a legislator's staff on how you stand on a bill

-visiting with staff to discuss an issue important to you

-inviting your legislator to an award, recital, or event involving your child.

How? To participate, join the following yahoo group by sending an email to: Adopt_a_Legislator_subscribe@yahoogroups.com In your email, let us know your name, city, and county please. That's it, and you'll receive a monthly note!

Questions? Contact Linda Litzinger by emailing: Adopt_a_Legislator-owner@yahoogroups.com Hope you all can join us!

Dealing with Ourselves While Our Children Grow Up!

Rosemary Alexander, PhD, TXP2P staff

Note to self: get started on my son's transition issues. Oh, and by the way, sort out which transition issues concern him and which concern me, and deal with mine right away!

That's the note I should have written to myself when my son Will was about 15 years old. He's now 26 and I've come a long way on both his issues and my own, but I can well remember the fear and anxiety I felt whenever I thought about Will growing up and ending his school career. And through my work with countless families over recent years, I have heard many other parents express these same emotions. What I have observed is our tendency to allow fear and anxiety to block the way toward planning for our children's adult years. That's why I have come to believe that it's important to examine our fears about our children reaching adulthood, so that we can start to plan for their future. Here's my best attempt to think about our fear of transition, based on my experience and what I hear from other parents every day.

Well, why are we so stressed about our children growing up? What about this natural fact of life sends us into a turmoil of negative

emotions? First, I suppose we feel anxiety for any of our children in their teen years, but when you add in a child who may be much less able to take care of himself, protect herself, earn a living, make wise choices, maybe not even tell us when something is wrong, then of course we feel even higher anxiety. Second, our children's teen years can throw us back into the grief of having a child with disabilities, as we see the milestones that the neighbor's kid achieves with ease. Getting a driver's license, getting a first part-time job, going out on a date, the prom - all the big steps teens usually take may not happen for our children, and that hurts. Third, growing up means leaving the public school system. When you consider all that a child gets from school - a safe place to be all day where there are opportunities to learn, exercise, meet friends, and gain job skills, then throw in free transportation, we may dread graduation: after graduating, our children may still need these same supports and opportunities but not have a system to provide them. The responsibility may fall entirely on us parents to provide these opportunities and supports - and that rightfully makes us very afraid! On the

other hand, the opposite may be true for some of us, who dread a future when we are not needed quite so much. For years, we have defined ourselves as our children's advocate, care provider, problem solver, and biggest fan. How will we see ourselves when we are no longer needed to fill this role? We may have to face changing how we see ourselves, as our children's need for us changes. Finally I think that a child growing up reminds

us of what we fear the most: the time when we are gone and our

children with disabilities do not have us to protect and advocate for them, care about their quality of life and ease the way for them. What will happen to my child when I'm gone? That's the fundamental fear we all face....and transition brings up that fear.

Oh, yeah, and while we deal with these emotions, our kids' behavior may be getting worse as THEY experience the raging hormones of the teen years!

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