

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

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Our Children . . . Our Journey First Annual Parent Conference in Texas

By Laura J. Warren, TxP2P

The first annual Texas conference for parents and caregivers of children with disabilities, chronic illness, and special health care needs was held July 30 & 31 in Temple, Texas at the Temple Bible Church. The conference was sponsored by Children's Hospital at Scott & White and was a collaboration between Children's Special Needs Network (CSNN) in Temple and Texas Parent to Parent (TxP2P). The conference came about when Dr. Don Wilson with Scott & White Hospital saw the Parent Panel Presentation of the Temple TxP2P Medical Education Program (see page 3 for more information on this program). Dr. Wilson was impressed with the presentation and asked CSNN & TxP2P what else could be done for Texas parents. We suggested a conference directed at the parents. And we were off . . . After many date changes, a location change, and a panic over lack of hotel



rooms in Temple for the weekend we had already announced, we quickly started getting speakers. Many had to tell me the day I called them whether they could present in order for us to get the registration forms out to parents with enough time for them to get registered. There were many more problems to arise (on-line registration never got finished, child care workers were not available on Friday, getting donated food was not as easy as it was supposed to be) and Mary Klentzman with CSNN lost her mother less than two weeks before the conference. The actual conference ran much smoother than the preparation and we learned a lot from this first experience. We will start working on the next conference this fall and hope to have a college campus to use for the sessions and housing. Meanwhile, we want to give a **BIG THANK YOU** to the following people:
 Dr. Don Wilson, Scott & White
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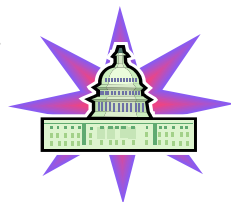
Legislative Update: What's Happening in Austin . . .

By Colleen Horton, Texas Center for Disability Studies, The University of Texas

So, what's going on in Austin you ask? I know that you didn't really ask, and probably don't want to know, but here goes anyway... The health and human services agencies are in the final stretches of consolidation, the agency budgets for the next biennium are being developed, hearings on budget priorities are being held, Medicaid managed care expansion is receiving a lot of attention, and legislators want to know what our priorities are for the next session. Many disability advocates are busy trying to determine just that. For those not in Austin or not connected to an active advocacy organization, it may be difficult to

try and figure out what's being talked about that could affect our children with disabilities. You may get email alerts or notices of public hearings but find it frustrating when trying to determine what it all means. Rest assured, you're not alone. The bureaucratic maze and the legislative process often leave the most seasoned advocates dizzy. In the current environment it's not always easy to know what issues to spend your time on, as there are so many things that need to be addressed to improve services for children. While it's important to promote issues that "push the envelope" as far as it goes, it's also important not to spend a lot of

time on the impossible. Two advisory groups have spent numerous hours over the past few months trying to do just that - identify realistic priorities that will help children. The Children's Policy Council (CPC) and the TIFI (Texas Integrated Funding Initiative) Consortium have been developing policy and funding recommendations for inclusion in their mandated reports to the legislature and the Health & Human Services Commissioner. In developing policy recommendations, these groups took a hard



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Hospital, for getting us started, getting us seed money, and grinning every time I told him what we forgot to do;

Mary Klentzman and her family, CSNN, and her entire family for pulling off the miracle of finding enough child care workers and food for the entire conference;

Laura Warren, TxP2P, for setting up the speakers;

Tammy Mann, TxP2P, for recruiting and arranging the exhibitors and helping find food;

Susan Prior, TxP2P Board Chair, TX Interagency Council on Early Childhood Intervention, for orchestrating the registration before and at the conference and creating the conference program;

Linda Thune and family for designing and facilitating the SibGroup on Saturday;

Linda Samilpa, TX Interagency Council on Early Childhood Intervention, for helping where ever we

needed her to help - registration, exhibitors, monitoring;

Edgenie Bellah, Debbie De Luna, Leticia Padilla, Debbie Wiederhold, Ali Cloth, Patty Geisinger, Tammy Mann, Susan Prior, Linda Samipla for serving as speaker monitors for each session;

Edgenie Bellah, Debbie De Luna, Leticia Padilla, Debbie Wiederhold, Ali Cloth, Patty Geisinger, Tammy Mann, Susan Prior, Linda Samipla for serving as speaker monitors for each session;

and finally, all the wonderful speakers who agreed to not only speak for free but who spent the money to get back and forth to Temple for the privilege: **Jeff Garrison-Tate, Executive Director, Brighton: The Center for Inclusive Communities, and Colleen Horton, Texas Center for Disability Studies, The University of Texas, our keynote speakers; Kelly Barr, Physical Therapist, Kidz Therapeez; Renee**

Borders, Transition Coordinator, Austin ISD; Emily Cicchini, VSA arts of Texas; Rosalyn C. Fisher, M.S., Registered Occupational Therapist; Patty Geisinger, Tammy Mann, Susan Prior, and Laura Warren, Texas Parent to Parent staff & volunteers; Joan Givens, Education Specialist, Region XIII Education Service Center; Steve Hamman, Assistant Director of Special Education, Austin ISD; Jeane Johnson, Parent Liaison, Round Rock ISD; Amy Martin, Training & Technical Assistance Coordinator, Austin-Travis County MHMR; Peggy Martin, Kid & TeenSAFE Coordinator, SafePlace; Glen A. Rives, Attorney; Kristin L. Tindell, Board Certified Associate Behavior Analyst.

And thank you to all of you who attended and entrusted us with the care of your children.

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Legislative Update: What's Happening in Austin . . .

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look at what is needed and what is doable.

The CPC and the TIFI Consortium are charged (by statute) to develop recommendations on ways to improve health and human services for children and the families who care for them. These committees are comprised not only of state agency staff, but also have strong family representation. This family participation helps to ensure that the recommendations truly focus on things important to families and not simply focus on what the professionals believe to be important.

The Children's Policy Council report contains 20 recommendations that focus on access to services, coordination and collaboration within the system, and the need to improve services for youth aging out of children's programs and entering the adult service system. These recommendations apply to children across

all disabilities. The TIFI Consortium recommendations focus on systems improvements and the unique support needs of children with mental health disabilities and their families.

I urge parents and families across Texas to become familiar with the issues by taking a look at these reports when they are published.

(Both reports should be available by early September on the Health & Human Services Commission website - www.hhsc.state.tx.us). Decide which issues pull at your heart, and then do something about it. Find out more about the issue; find out who else is working on a particular recommendation; find out how you

"Some of the most effective advocacy takes place at the local level - visits to legislator's district offices, phone calls, emails, and letters can all have an enormous impact."

can help. If you have lots of time and can jump in with both feet, that's great. If you only have a few hours a week, there's still plenty that you can do to change the way things are. Some of the most effective advocacy takes place at the local level - visits to legislator's district offices, phone calls, emails, and letters can all have an enormous impact. The decision making power lies with the legislature but local constituents are the driving force behind those policymakers.

The last legislative session was tough on family support programs and other programs for people with disabilities. This session will likely be similar. There will be a lot of competing forces vying for funding as well as policy changes. Let's make sure that kids with disabilities are not ignored. Take time to review these reports, ask ques-

TxP2P Makes Changes in Medical Education Program (MEd.)

By Tammy Mann, TxP2P

Many of you are aware that Texas Parent to Parent has been collaborating with hospitals across the state for the past two years to help educate Pediatric and Family Practice residents in effective ways of working with families that have children with disabilities and special health care needs. This program has been very successful thanks to the hard work and dedication of the parents that work the programs in each area (Austin, Temple, Dallas, & Ft. Worth for now). Previously, we have provided this education under the name of Pro-

ject DOCC. Due to the inability to expand and sustain these sites in a way that we were comfortable with under Project DOCC, we made some changes that the doctors and parents involved believe are very positive!

Our program is now simply called the "TxP2P Medical Education Program (MEd.)" and even though it is presently aimed at medical residents, we are planning to reach out to Nurses, Child Life Specialists, Social Workers, Therapists, Educators, and any



one else that is interested in learning effective ways to work with families. We are now able to offer a menu of services/sessions that can be individualized to the needs of each location. These sessions can be as simple as understanding pet peeves or as complex as learning the IEP/ARD process with the goal of creating doctors that are advocates for families and our children.

If you are interested in learning more about our MEd. or any of our other Educational Opportunities, please contact Tammy Mann at Tammy@txp2p.org or (512) 458-8600 local to the Austin area or toll free at (866) 896-6001.

The Power of Portfolios

From F2F News, Family To Family Network

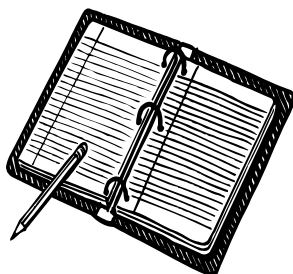
What is a student-introduction portfolio? What can it do for your child? If you don't know about portfolios, or if you always wanted to do one but haven't found the time, keep reading!

Student-introduction portfolios are designed to assist others in getting to know your child for who he or she really is, and not just for their disability. The intended readers can be teachers, administrators, related service providers, classmates, other school personnel (i.e., nurse, cafeteria manager, bus driver, etc.) and other members of the IEP team. The challenge of the portfolio is to develop a picture of the whole student using a variety of evidence and documentation. Follow these steps, and you'll be on your way to creating a great portfolio for your child.

Step One:

Decide on the intended audience for your portfolio and what you want to communicate. What is the reason you are creating this portfolio? Make sure your purpose is stated on the very first page of the portfolio.

Step Two: Decide the different areas that you will use to communicate to the portfolio's audience. Some ideas are: My Child's Favor-



ites, Medical Information About my Child, My Child's "Resume", listing past school/therapy/tutoring experiences, Family, Our Vision for our Child, Classwork, etc. You can create tabs to divide the notebook by information areas (such as family, social, educational, health). This will help busy school personnel easily access the information to them.

Step Three: Get information from people who can give insight that supports the purpose of the portfolio. You can use questionnaires, interviews, or letters done by school personnel who already know your child. Include information from a variety of sources, if possible.

Step Four: Assemble relevant photographs, work samples, etc. Each item used should have significance in that it supports the purpose of the portfolio. Date everything and explain why it has been included.

Step Five: Evaluate your portfolio. If educators don't know why they're supposed to read it, if it's too long, or if it's disorganized, no one will take the time to look at our child's portfolio.

Check for these items:

___ is there a statement of purpose?

___ is the print size and font easy to read?

___ are the pages easy to turn?

___ are there no more than five main areas?

___ is the amount of print on each

page not overwhelming?

___ is the information organized by areas?

___ is the information shared only once, without unnecessary repetition?

___ are all artifacts clearly marked with captions, including date and significance?

___ do all included visuals tell something important?

___ is the information presented in such a way that the portfolio could stand on its own?

Step Six: Share this valuable and important document with others. The best way is to make several copies and leave them with key support providers.

There is no one right way to share this portfolio, just do what works best for you and the intended audience. Older children can participate in the sharing of their own portfolio. Having the portfolio ready for the beginning of the school year will help ensure that everyone is working together right from the start to give your child the best possible educational experience.

"Student-introduction portfolios are designed to assist others in getting to know your child for who he or she really is, and not just for their disability."

Rasha's Story . . . Her Petition, Her Life, and Her

Determination

By Laila Kawar, Mother of Rasha and TxP2P Volunteer, Dallas, TX

On our flight back from Israel last summer, my daughter Rasha needed to use the bathroom, but there was no way I could fit with her in that tiny small bathroom. She needed my help because she has Cerebral Palsy and she can't stand or sit independently. We tried for a long time and when we finally managed to close the door, it was almost impossible to do anything in that cramped space. We went back to our seats frustrated, humiliated, and angry. Rasha asked me, "What can we do about this, mom?" With tears in my eyes, I replied, "I don't know." Rasha looked at me and said, "I know . . . I'm going to write a letter to the President about this. This is not fair and they need to fix the problem."

She wrote a letter to the President. Upon writing her back, she decided that his answer

wasn't really an answer to her problem, so she decided to start her own interna-



tional petition online. Rasha is going now from door to door, handing out business cards, and asking people to sign her petition and pass it on. To read and/or to sign her petition you can go to www.ucp.org

Rasha is a typical, beautiful, bright little girl. She should be considered mature, focused and energetic, by any standards. Rasha is in a regular classroom (fourth grade), but the tools she uses are different than pen and paper. She types on her laptop using a head pointer, she uses a power chair that she drives using a head switch (she taps with her head on a switch to give commands: forward, backward, left or right), and she uses a communication device to talk.

Rasha was born in November 1994 in Texas. Complications during delivery left her with Cerebral Palsy (CP) which affected her motor development. Finding out about Rasha's disability (when she was 1 year old) left me in a big shock . . . I wasn't ready for that, I never expected that, and I knew nothing about CP. After I

went through the normal stages of denial, blame, depression, grief, etc, I knew that I had to know as much as I could about CP so I could help Rasha. My wonderful mom, who came from Israel to spend 2 months with us in Texas, helped me accept my little angel, Rasha, and love her just the way she was and see actually how perfect she was.

I started attending every seminar/workshop/convention/training I heard about that had anything to do with disability. I became a parent advocate but I was overprotective of Rasha, and made **ALL** decisions for her, believing that this was my responsibility as a parent. Then, 3 years ago, I attended a wonderful conference sponsored by The Arc of Texas, "Inclusion Works," that opened my eyes to many new things and provided me with priceless tools, resources, and information. Right after that I participated in a life-changing training program called "Partners in Policymaking", a program for self advocates and parents of children with special needs, funded through the Council for Developmental Disabilities and facilitated by Family to Family Network. Attending Partners not only taught me how to be a better advocate for Rasha and other people with disabilities but it also reminded me to help Rasha become more independent. You can learn more about this program at <http://www.partnersinpolicymaking.com>

The wonderful change in my life, and my daughter's life, happened so fast. She started actually telling adults (including me!) how she wanted things done for her . . . then she submitted a resolution to the CTD (Coalition of Texans with Disabilities) conference. (Go to www.txddc.state.tx.us/menus/fset_pub_1.asp and select "November 2003")

Three months later, she was invited to speak at "Inclusion Works" Conference and then at the Parent Leadership Institute in Houston (<http://www.partnerstx.org/Institute.html>)

She also was invited to speak at different schools, talking about her abilities and how she is more "similar" to other kids than differ-

ent. Rasha designed a Power Point presentation entitled "I Am Able". Through the use of her laptop and communication device, Rasha is able to effectively communicate her message to all ages throughout the world. The responses were overwhelming, ranging from people with disabilities thanking her for being an advocate for their needs to typical everyday individuals thanking Rasha for opening their eyes to the needs of others.

The media has been a great source of continuous support. The Cable News Network (CNN) and the Associated Press (AP) provided excellent national coverage of Rasha's story. Our local affiliates added support including WFAA TV, The Dallas Morning News, The Coppel Gazette, numerous local papers, and a host of radio stations.

Most of the officials in influential positions who have the ability to assist, including Senators and Congressmen with whom Rasha corresponded, replied with willingness to participate in many different

"She started actually telling adults (including me!) how she wanted things done for her . . ."

areas to support her cause and were grateful for the opportunity to work with her and others to help make a difference. One example of how supportive many officials have been in regards to the petition came in the form of a letter from the US Department of Transportation. The Deputy Assistant General Counsel for Regulation and Enforcement notified her that because of her letter he is writing a proposed rule regarding this matter and was grateful that she brought this to his attention.

With the support of National United Cerebral Palsy (UCP), and other advocacy organizations, Rasha is determined to spread the word and gather as many signatures as possible. The next step in her mission is to travel to Washington, D.C. to meet and contact the appropriate officials and discuss options for acquiring accessible bathrooms in all airplanes.

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Rasha's Story . . . Her Petition, Her Life, and Her

Determination

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As a single mom, raising a child with special needs can be hard sometimes, but Rasha and I share so much love, joy, fun, and wonderful moments. Nothing would mean more or replace those priceless times. It's true that I had to give up my successful career to devote my full time and energy for my little angel. (In Israel, I was a partner in an advertising and marketing company and a general manager for a weekly newspaper). It's also true that I do miss my old life and being a successful business woman but I never regret what I did. I know that I'm making a difference not only for Rasha but for many people with special needs around us. Actually, my background as an advertising/marketing consultant helped me promote Rasha's petition (and it took and is still taking lots of time and hard work contacting media and ad-

vocacy organizations all over the world). I also do lots of volunteer work as a parent advocate for families of children with special need, and I'm involved in a wonderful medical training program through Texas Parent to Parent. (See article on page 3) As Family Faculty, I help residents understand what it means to have a child with special needs. Looking at Rasha, who is becoming a young advocate, makes me so proud of her. She is determined to fight for what is fair and she is really working hard to get as many signatures as she can from all over the world to support her petition. She is a beautiful mature 9 year old, who works hard with her



therapists and still lives a typical life (including having lots of friends, being a cheerleader, girl scouts, going ice skating, bowling, to the park, the zoo, the movie theatre, and McDonald's). She is also a good student and at the same time gets her intensive therapy program every afternoon and on the weekends including physical therapy, occupational therapy, speech therapy, massage therapy, and until a year ago she also had music therapy and horseback riding (Hippo therapy). Rasha is the perfect example that no matter what your abilities and disabilities are, you can achieve your dreams if you believe in yourself. Rasha's favorite sentences are "I can and I will", and "I want to be like everybody else". She believes that with God's help and hard work, she can do anything she wants.

Keeping in Touch With IDEA

Information provided by NEWSLINE from The Parent Advocate Quarterly published by Partners Resource Network

Our congress is working hard to reauthorize the Individuals with Disabilities Education Act (IDEA) Amendments of 1997. Some of these changes will be positive ones, and some may not, but whatever the outcome, it is important that you keep informed and understand how the changes might affect your child or the children you teach. Let your legislators know how important this is to you and let them know what you think!

Teacher Qualifications: The IDEA law currently allows each state to decide teacher qualifications requirements. The U.S. House of Representatives has passed their proposed change to require that all teachers of core subjects be *highly qualified* no later than 2005-06 school year. It also requires a bachelor degree and certificates in the subject that he/she teaches. The U.S. Senate version, currently proposed, extends the time for teachers to become high qualified. It also proposes alternate methods for teachers of students with severe cognitive disabilities to meet the requirement. Special education teachers who also teach core sub-

jects must have dual certification.

Individualized Education Programs: The IDEA law contains short-term objectives and benchmarks. They are reviewed and revised annually with the entire IEP team in attendance. The House of Reps version proposes to include short term objectives through the 2005-06 school year when the No Child Left Behind requirements begin. Federal model IEP forms will be developed. The Senate version would eliminate short term objectives. Positive behavior interventions would be added.

Reduction of Paperwork: The IDEA law does not contain specific language regarding this subject. The House version states that if the IEP team is in agreement, then a 3 year IEP can be written. It also provides for flexibility in attendance during IEP meetings. The Senate version proposes that 3 year IEPs be considered only for students 18-21. All others are still annual. It would also reduce the times for procedural safeguard notices to be sent.

Discipline: Under IDEA, students can be removed up to 10 consecutive days during which they are not enti-

tled to educational services. After 10 days, students will receive education services. Students who bring drugs or weapons to school may be removed for more than 45 days, as decided by the local educational agency. The House version states that each infraction is considered individually. Educational services will continue, yet from the general educational setting for up to 45 days, or as set by each state. It would eliminate manifestation determination hearings, Functional Behavioral Assessments, and BIPs. The Senate version would allow services to remain after the student is disciplined, and it retains manifestation determinations and the 45 day rule. It mandates a 20 day expedited hearing when discipline measures are disputed by the parents and includes positive behavior interventions for students with behavior problems.

"Some of these changes will be positive ones, and some may not, but whatever the outcome, it is important that you keep informed and understand how the changes might affect your child or the children

Oops! We Missed Some of Our TxP2P Donors Last Issue

By Laura J. Warren, TxP2P

I thought I had checked and rechecked but I was wrong. I'm so sorry that I missed the following donors from our 2003 Annual Cam-

paign:
Ann & Scott Sellers in honor of Max & Lily Sellers
Daniel Baird, State Farm Insurance in honor of Val Sutorius

The De Rose Foundation in honor of Frank De Rose

Again, I apologize for the oversight.

TxP2P Update:

As Texas Parent to Parent continues to grow, we continue to search for new ways to support parents. One method we have created in the Austin area is a listserv for parents interested in getting information about area resources and events. Parents are invited to join the listserv and we all share new resources as we find out about them. It is also an excellent way to share information on doctors, dentists, therapists, etc. in the area. A parent can also post a question asking for suggestions on issues such as feeding or finding a dentist and they may get six or seven ideas from different parents. I actually started this listserv by accident - I was just trying to find a quicker way to reach the parents in Austin when I had information to share - but it has turned into a very useful resource. I sometimes use it to gather suggestions for parents from other parts of the state when they

need help with an issue. I moderate the group, which simply means I read all the emails before they are posted to the group - it's just a precaution. I have a parent willing to moderate a Listserv in the Dallas area but would love to start groups in other parts of the state. If you have a little time and are interested in becoming a moderator for an area in Texas or would like to get on one of our other listservs (see below), please contact me at 866-896-6001 or email me at Laura@txp2p.org

In addition, TxP2P has several other listservs - if you are interested in joining one, just contact me with the name of the group:

- TxP2P Advocacy Listserv: This group is for parents and professionals who are interested in advocating for people with disabilities and special health care needs at the local, state, and federal levels and is a conduit for Action Alerts and other information on legislative topics

By Laura J. Warren, TxP2P

- TxP2P ECI Listserv: This group is for parents of children 0 - 5 years to discuss issues that relate to young children and the transition issues of moving from ECI to a local school district

- TxP2P Bipolar Listserv: This group is for parents of children with Bipolar Disorder.

- TxP2P Special Homeschoolers: This group is for parents who are homeschooling their child(ren) with disabilities or special needs.

Patty Geisinger and I will be at Scottish Rite Hospital in Dallas on Oct. 1st & 2nd and at the Brighton Center in San Antonio on Oct. 29th & 30th to facilitate **Supporting Parent Volunteer trainings**. If you are interested in providing information and emotional support to new parents and can attend one of these trainings, please contact Patty or me at 866-896-6001 or email me at Laura@txp2p.org

Can the Medical Transportation Program Help My Family?

By Sara Coulter, Mother of Kedrick, Austin, TX

YES IT CAN!!! Medical Transportation Program (MTP) is funded by Medicaid, but administered by Texas Department of Transportation (TxDOT). The program is designed to assist children and adults with disabilities get to and from medical appointments and therapy sessions. The program is available to any child or any adult with a disability who have Medicaid. Once established in the program it can be a great benefit. I use it a lot to take my son to see specialists out of the area. It is not a huge financial relief, but sometimes we all need just twenty extra dollars to get through some months. I usually need a lot more, but then who doesn't?



First, take a deep breath and remember who you are calling, the GOVERNMENT. The one main thing to have at all times is

paperwork. I don't mean there is an immense amount associated with this program, but if your doctors don't have to call their doctors, then the process can speed up. Faxing is a true way to achieve expedition of services. The ability to fax data ahead will expedite your issues sometimes. But, then there is always the one who just can't get with even its own program and that is why I say sometimes. **One reminder, every time your child is evaluated at a new doctor or clinic you are entitled to a copy of all the first lab, and initial evaluation report by the physician, therapist, specialist and so on.**

PAPERWORK TO INITIATE PROGRAM:

1. Medicaid ID # (9 digit number usually to the left of client's name)
2. Doctor's name, address, and FAX & phone number.
3. Time & Date of appointment

4. Principal diagnosis & and applicable secondary diagnosis (mobility, heat related, etc.)

5. Initial reports from physicians (copies)

6. Proof of Insurance (for Individual Driver Recipient)

7. Driver's License #

8. MTP 1-877-MED-TRIP (located on back of Medicaid ID form)



Call the MTP @ 1-877-MED-TRIP (1-877-633-8747), select preferred language and wait until operator answers. The number given by the one website connects you with the actual TxDOT office.

Keep searching until you find the toll free number. After giving them #1-3, they will tell you based on your Medicaid if you are indeed eligible for MTP. Once set up, the system does run pretty smoothly.

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Can the Medical Transportation Program Help My Family?

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The operator will inform you that first you must take a certain type of transportation, bus, cab or special transit. If you live on a bus line, they will offer you bus tickets. Next, if you don't live on the bus lines, they will offer "door to door" pickup by cab service or special transit. If you need a certain type of vehicle, (lift, air conditioning,) you must specify this to the operator at the appropriate time. The other option, if you have a vehicle, is to become an INDIVIDUAL DRIVER RECIPIENT (IDR) (I just love the festive names the Govt. uses to call things). The IDR must be over 18 years of age, have a valid driver's license, and liability insurance. Try to ask the operator for the IDR first, but some will still want to give you the traditional spiel and others will think out of the box and proceed to this service. This is a mileage reimbursement program so you will need to fund the visit up front and then be reimbursed. The current reimbursement rate is \$0.35 per mile. Once you turn in your paperwork, you receive your reimbursement check usually within 2-3 weeks. It depends on where you live in the state. Remember, dealing with the Govt. again here (US Postal).



Once you give the operator your Medicaid ID#, the operator will receive a code corresponding to your type of Medicaid letting them know if you are eligible for the program. Don't get discouraged if the operator denies you services. Ask for an explanation as to why your type of Medicaid is not eligible. I contacted Medicaid concerning denial and they answered that all types of Medicaid are eligible for the MT program. You can always ask to speak to a supervisor. Some operators may get testy over this, but be polite and firm in your desire to speak with a supervisor. In addition, remember you are at the mercy of which operator picks up the phone. The best I can say is that they claim to go by a case to case basis.

In entering into the IDR portion of the program, a MTP supervisor will review the application and may require more documentation concerning the severity of the child's disability. That is why it is so important to have the various doctors written diagnoses or interpretations handy. Any document you can get to them quickly (faxing) will eventually help expedite the process. After

you are accepted as an IDR, MTP will then ask you to provide your license, insurance and one document from a physician stating the disability or disabilities.

Once in the program all you need to do is call 3-5 days prior to the appointment and give them:

1. Medicaid ID # (9 digit number usually to the left of client's name)
2. Doctor's name, address, and FAX & phone number.
3. Time & Date of appointment

The operator will then fax a form to your doctor to get verification of the appointment. Once this is established then the mileage will be calculated and a pre-printed verification form will be mailed out to you. Take this form to the doctor's appointment and have it signed by a nurse or the actual doctor. If you forget to take form then just make sure you get a note verifying that you did go to the appointment. Don't try to use a prescription as proof of being at the physician's office; get a back to school/work form. This will show a date when you were there. Not all prescriptions will have a date on them. MTP stated that prescriptions can be "picked-up" and do not always confirm that you actually went to the visit. MTP also stated that once you visit the same doctor or in the vicinity a few times, then they will not send a form to every one of your doctors in the vicinity for every visit.

At the end of each month, send in your verification form and other documentation (if any). In a few weeks the reimbursement will be mailed to you.

If you have appointments out of town that require an overnight stay, MTP will provide a motel room and a daily food allowance (\$25.00). There are many types of overnight stays. I tried to use Ronald McDonald House and was put on a waiting list. MTP has to make sure you have accommodations, so they may call RMH to verify the waiting list and then proceed with the motel arrangements. I sometimes have to schedule my son's appointments on one day and again on the next day. Instead of paying you for two round trips, MTP will pay for one round trip mileage and then put you up overnight in a motel room. When this occurs you will have to make a stop at a Western Union store in the city of the appointment to pick

up the food allowance funds. You do not have to pay for the motel upfront. This will be taken care of by MTP and the motel. If you have any extra day's food allowances, these must be returned to MTP. The extra day's monies need to be sent back to MTP at the same time you send in your monthly verification form to MTP. The extra amount needs to be put into a money order and addressed to the same agency that issued it. When you get these upfront funds, they will come from an agency called EAST TEXAS SUPPORT SERVICES. It's a government thing again so I have no explanation as to why a third agency now is involved. But who cares when they are helping you.

There are instances when MTP will provide you with the mileage funds upfront. If there is enough time prior to the appointment, then MTP will send you the funds in a check in the mail. If not, then you will have to stop at a Western Union store to pick them up. This is supposed to be a "once in a lifetime" perk, but if sufficient evidence can support another "upfront funding" then MTP will provide the funds.

MTP is not an emergency service. However, if you need to take your child to a physician that same day, call MTP and they will ask you to provide verification of the appointment. This is the same type of note I mentioned previously (back to school/work note). I usually get one every time in case I lose the verification form or forget to bring it to the doctor's office. If you need to go to the physician right away and can't call MTP ahead, MTP will accept appointments up to 48 hours after the visit. But, in these instances you may have to have a supervisor at MTP approve the mileage/visit.

This system is sometimes difficult, but it is not hard. I am able to take my son to Houston to see specialists because of this program. It has benefited our family tremendously and then not at all sometimes. I rent a van to take my son to Houston and the mileage money is enough to do that, gas up the van, and have a reasonable food allotment for the trip. But, MTP doesn't help you rent the van nor give you a food allowance for every trip.

If you have any questions, please post them to Laura@txp2p.org and I will try to get you the specific answer you need. GOOD LUCK!!!!

"First, take a deep breath and remember who you are calling, the GOVERNMENT."

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 Email: txp2p.org



Serving children with disabilities, chronic illness and other special needs by providing support and information to their families through peer support, resource referral and public awareness.

Conference Schedule

Date	Conference Title	Location	Registration Information
Thursday, October 21 through Friday, October 22, 2004	Future Horizons Autism/Asperger's Conference	Hilton Austin North Austin, TX	For more information, go to www.FutureHorizons-autism.com or call 800-489-072; fax: 817-277-2270
Wednesday, November 3, through Friday, November 6, 2004	Yesterday, Today, Tomorrow 2004 LDAT Conference Learning Disabilities Association of Texas	Renaissance Hotel Austin, TX	For more information, call 800-604-7500 or 512-458-8234
Thursday, November 4 through Friday, November 5, 2004	Chronic Illness: Transitioning from Child-Based to Adult -Based Care	Baylor College of Medicine Houston, TX	For more information, contact Baylor College of Medicine at 713-798-8237 or email cme@bcm.tmc.edu
Thursday, November 18 through Sunday, November 21, 2004	Moving Forward with Music Therapy 2004 Annual Conference of American Music Therapy Association	Hilton Austin Hotel Austin, TX	May offer complimentary conference registration, contact Al Bumanis at 301-589-3300, ext. 103 or Bumanis@musictherapy.org
Wednesday, November 17 Through Saturday, November 20, 2004	2004 TASH International Conference on Inclusion Blazing the Trail	Hilton Hotel Reno, Nevada	For more information, go to http://www.tash.org/2004reno/