Legislature Update - The Hardest Question “We have a child with a disability and want to move to Texas to be closer to family. What are services like in Texas?”

Laura J. Warren,

T

xP2P staff get this phone call about every other week. So, we explain to these families that if they move closer to family and into Texas, they will have to wait 8 to 10 years to get on a Medi- caid Waiver Program and that’s currently – this will probably change after this Legislature Ses- sion is over. They might be able to get some funding from their local MRL centers; maybe from school districts and Education Service Centers. We now have Medicaid Buy-In for Children so if their income fits the criteria, they can pay for Medicaid for their child. Or if they have no income, they can access Medicaid through that route. There are pockets of really great school programs that are inclusive and cutting-edge but that target is constantly moving so we cannot recommend a school district either. And then we hear about the services they currently get from their state, which de- pending on where they live, is almost always better than Texas services. Many express good luck to us as they hang up as they decide to stay put or con- tinue their search for the right place to live. I find these conversations to be very sad but would much rather have them before a family moves here than after. I’m embarrassed that our state cannot do better for families that have the responsibil- ity of 24-hour-care for their children with autism or chronic health care needs. I’m saddened that very capable young adults with disabilities cannot find jobs and are sitting at home watching television. I’m ashamed that families cannot move from state to state in this country and find the same level of services to help raise our children to become productive members of society. TxP2P can help families with questions and resources, moral and emotional support, and

Continued on Page 2
maybe families so they don’t feel all alone in the world but we cannot offer families the things that they need desperately: time off from care giving, time to try and plan and not just react to everything that happens to them, help paying outrageous medical and therapy bills, and relief from the battles we all endure to get adequate services for our children.

While I watch the daily news from the Capitol during this horridous Legislature Budget debate, I am fearful what the next two years will bring for families and people with disabilities. It seems that life in Texas will be harder for all of us. What can we do about this? Watch for alerts on the TxP2P Advocacy Listserv (call or email Susan Prior – 866-896-6001 or local 512-458-8600 or Susan.Prior @txp2p.org to join this listserv) and call your legislators. Or join our newest effort to have our issues heard – join us as a volunteer for our TxP2P Advocacy Network grant from the Texas Council for Developmental Disabilities – we will train families – parents, siblings, and young self-advocates – about the legislative process and how to build relationships with their legislators. Families will become resources for the legislators rather than just another hand out wanting more funding. We need to make our lives with our children and young adults real to the legislators. They need to remember the faces and lives of our children and young adults every time they vote on a measure that will change their lives. As ADAPT says, “Nothing about us without us!” If you have not seen the “Nightlight Report” yet, I recommend that you visit the website and add your comment: http://nightlightreport.blogspot.com. Our good friend, Dr. Lesa Walker, former Medical Director of the CSHCN Program at DSHS, created this report to highlight the personal ideas and proposed actions from legislators for the 82nd Legislative Session around children and adults with disabilities. She then presented their comments in blog format and asked families and self-advocates to comment on their statements. 37 legislators responded and over 200 families and self-advocates commented. It’s a great forum to get your opinions read!

**TxP2P Update**

for the month of February into March. By that evening, the carpets were ripped out and thrown out the window of our upstairs offices. The next day the sheetrock came down and we were all searching through boxes and stacks of papers for our stuff.

We’re still sorting through our things – we had to move our boxes 5 or 6 times and it was harder and harder to locate things as the 6 weeks of remodeling drug on. I want to thank the staff for laughing much more than complaining while living in very tight quarters, with double the furniture and equipment in our one remaining office and trying to do business as usual. And there are our favorite “flood” moments: the water brigade with people throwing water out of the upstairs windows as trash cans filled with water in the office, the staff evaluations done on the front porch of our building for lack of privacy anywhere else, someone stating “we just need more space!” and everyone then laughing for 10 minutes at the under-statement. We do have pictures of the aftermath of the flood on our Facebook Page if you want to see it.

**7th Annual Parent Conference, June 24-25:** As for business as usual, we somehow managed to get the conference speakers lined up and the registration packet mailed in March and on-line registration is in full swing. We will have everything we had last year as well as a new 2-day session on transition – the Pathways to Adulthood Transition Institute – an intensive planning session for parents with teenagers who are close to transitioning out of high school. We’ll have the 2-day Teen Transition Summit again as well as a one-day SibShop, child care, 60+ break-out sessions, exhibitors and our Family Gathering on Friday night with Sara Hickman.

We did run out of hotel rooms last year so if you are coming to the conference you might want to get your room early (Embassy Suites: 512-392-6450 or http://embassy.suites.hilton.com/en/ex/groups/personalized/SNMESES-PTP-20110623/index.html?WT.mc_id=POG). We now have a waiting list for hotel stipends but you still must register first and then call the office to request the hotel stipend - we usually can squeeze in most of the waiting list as well so don’t give up yet. If you have received a stipend two years in a row, you are not eligible for one this year - if you are unsure if you are eligible, we can check for you. Call 866-896-6001 or local in Austin, 512-458-8600.

**Resource Directory:** Did you know that you can search for services by county on our website? You can look up all the services (parent groups, child care, therapy centers, counseling, etc.) in your county or pick a category to search for. You can then search your neighboring counties to see what they have. And if you don’t have access to the Internet, you can call us to look it up for you or print it and mail it to you. Check it out: www.txp2p.org/resources or call us at the number listed above.
Medicaid Buy-in for Children – Another Opportunity to Get Medicaid for Your Child

Medicaid Buy-in for children became available for Texas families in January of this year. The program helps families who earn more than the typical Medicaid income limits by allowing them to "buy into" Medicaid coverage. There might be a month premium but it is based on your income, number of people in your family, and if you get insurance through work. Families with a child who meet SSI disability criteria and whose adjusted gross income is up to 300% of the federal poverty level (approximately $66,700 for a family of four) may access the program. Benefits offered through Medicaid Buy-in are the same as those available to any child with Medicaid coverage. These include doctor & hospital visits (including emergency care), prescriptions, dental care, mental health care, glasses, care in the home, OT, PT, and speech, therapies, case management, and regular check-ups.

The child must be age 18 or younger and a U.S. citizen or legal resident. If the parent’s employer pays at least half of the annual cost of health insurance, the parent must sign up and keep that insurance but the HIPP Program can help pay the premiums and Medicaid will become the secondary coverage. HIPP info: www.GetHIPPTexas.org or call 800-440-0493. There are 3 ways to apply:

1. Visit the website: www.hhsc.state.tx.us/Help/HealthCare/Children/MBIC.html and download an application (the application link is under “How to Apply”). Fill it out and mail it in,
2. Call 211 and ask them to mail you a Medicaid Buy-in for Children application,
3. Go to an HHSC benefits office. Call 211 to find one near you.

You can also contact TxP2P and we can help you access the application or email you one.

In Memoriam

One thing we learned a long time ago is that among children with disabilities and special health care needs, some leave us way too early. It’s a sad reality we all hope will not happen but some of us will grieve our child’s death. All of us here at Texas Parent to Parent are deeply saddened when we hear of a family’s loss and grieve with you. We want to share our condolences to our Txp2P families who have lost a child recently:

*Annette Reina, Annette Oseguera & family
*Brittany, Gertrud Medrano & family
*Cooper, Sarah & Kevin Knight & family
*Shane, Shelley Summers & family
*Raigen Lily, Sunshine & James Sullivan & family
*Elen Hernandez, Claudia Lopez & family

We have some resources available for bereavement and there are groups in many areas which we are always willing to find for you. You may continue to receive the newsletter for as long as you like. We do have trained volunteers whose children have passed away and are willing to be matched as needed.

With deepest sympathy,
TxP2P Staff, Volunteers, & Board

Have You Heard about the Texas Task Force for Children with Special Needs? Well, They want to Hear from You!

The Task Force was created by the Legislature during the last session and tasked with creating a 5-year Strategic Plan to improve the coordination, quality, and efficiency of services for children with disabilities or special health care needs for 9 agencies: TX Health and Human Services Commission (HHSC), TX Department of State Health Services (DSHS), TX Department of Aging and Disability Services (DADS), TX Department of Aging and Rehabilitative Services (includes ECI) (DARS), TX Education Agency (TEA), TX Department of Family & Protective Services (DFPS), Texas Youth Commission (TYC), TX Juvenile Probation Commission, and TX Correctional Office on Offenders with Medical or Mental Impairments.

TxP2P was asked by the Task Force for their help in gathering information from families to learn what agencies’ policies are in conflict, which ones make getting services for your child difficult, and how you think they can be changed to help make it easier. I will take this information to the Task Force for discussion with the agencies involved. This is not just a way to complain about services or lack thereof - this is to identify policies or procedures that aren’t working or make things so hard that you quit trying. So if you have run up against a policy that does this, please email me at Laura@txp2p.org (preferred way to receive information) but you can call me at 866-896-6001 or 512-458-8600 (Austin area) and I’ll get the information to the Task Force.

Laura J. Warren, TxP2P

Volume 10, Issue 1
When Amber Collier gave birth to her twin girls, Eden and Priscilla, at 33 weeks she was able to be with the babies in the hospital for 4 days. Then she was discharged. For the next month she drove 20 minutes everyday to be with them in the Neonatal Intensive Care Unit (NICU), but returned home at night. To help her stay connected and to bond with the babies she turned to something she had been doing all her life, photography. Amber has always loved taking pictures. In her family she was the one documenting family celebrations and events. Although she is not a professional photographer, in her work as a graphic designer she has studied the art of taking photos. Photographs are very much a part of her career and personal life.

Because of Amber’s history with photography it was natural for her to pick up her camera (a regular digital camera not a professional one, Amber emphasizes) to document her babies from the moment of their birth. Her husband, Brian, also got in on capturing images of his new daughters. Immediately after the twins were born she asked him to start taking pictures of the girls. “Thankfully, I’ve taken pictures my entire life to document happy and hard times like this. In the midst of a traumatizing experience like giving birth to a premature baby or having a full term baby hospitalized, showing photographs to family and friends can be a normalizing experience.” Sheppard noted that professionals are always looking for ways to help families feel closer to their babies. The days and weeks after a normal birth are usually a time for nesting and settling in to new baby routines. This natural bonding and attachment period between babies and families can be interrupted or inhibited with an NICU stay unless particular attention is given to that process. Professionals are tuned into the medical needs of the baby but they are also very aware of the emotional needs of the family. It is important that they support the family taking photos, bring things from home, playing soft music or reading to the baby.

During the stressful month the girls were hospitalized, Amber found the photographs comforted her, helped her deal with stress and facilitated her breast milk production. Amber was pumping for milk every three hours around the clock. She found it difficult when she was away from the babies. Looking at and holding her photos during her pumping sessions helped. It was the closest thing to being with them. She and her husband established a routine of almost every day stopping at Walgreens to print the most recent photographs and Amber would make booklets to look at and keep close to her. She believes the photos helped during the stay in the hospital and later, as well. Amber feels they empowered her, helped her remember and gave her courage. She attributes the photographs to leading her to help others going through an NICU experience.

“Mothers who go through the whole [NICU] experience . . . it empowers you, if you don’t have something to remember it by it can kind of fade away. And so for me to have those pictures throughout this whole year and after going through the whole experience I was drawn to doing something with premature babies,” said Amber.

Because of her experience Amber started a non-profit organization, Preemie Prints, to offer information, support, complimentary photography, gift bags, and prayers to families who have a premature or ill baby in a NICU. Preemie Prints serves the Bryan College Station, Waco, Houston and Temple areas.

Amber’s Tips for Photographing Babies in the NICU

- Get up close and personal; take close-up photos of hospital bracelets, hats or bands, feet and hands etc.
- Take photos of parents holding the baby
- Be sensitive to over stimulating the baby with flash photography. Turn off the flash if needed.
- Put something next to the baby for scale purposes, e.g. a hand or stuffed animal

In addition they offer complimentary photography to families with children who have:
- health conditions due to being born prematurely,
- childhood illnesses or diseases,

Continued on Page 5
Photographs Helped Mom Cope

On the other hand Amber acknowledges sometimes it is difficult, or photography might not be secondhand to some people. Amber is working with a mom right now who wasn’t able to photograph her baby born at 24 weeks until 3 weeks after the birth. She notes everyone’s comfort level is different.

Have you had a similar experience to Amber’s? What are your thoughts about using photography to help cope with the stress of an NICU stay? Join the TxP2P listserv for families with children who begin life in the Neonatal Intensive Care Unit (NICU). You must have a Yahoo account to join the listserv.

The Texas Council for Developmental Disabilities (TCDD) is developing its federal State Plan for Fiscal Years 2012 – 2016 (Oct. 1, 2011 - Sept. 30, 2016). The Plan will include goals that:

1) describe how TCDD will use federal money to support the purpose of the Developmental Disabilities Act of 2000; and,

2) support the areas listed below. You can help TCDD plan activities for the next five years by participating in surveys about Your Community and/or Leadership Development.

Promote health and improve healthcare

The DD Act requires TCDD to:

• Develop goals based on relevant data
• Support leadership activities by self-advocates
• Reach out to people who are from ethnic minority cultures, live in rural areas, or belong to other groups that may have unique needs
• Focus on advocacy, capacity-building (helping groups to be able to do more), and systems change (improving the way programs or services work)

Note: TCDD cannot fund services that government agencies should provide. TCDD does not fund direct services. Funding for projects is generally limited to 3-5 years. This survey is not a solicitation for project proposals.
At Texas ECI, we know that parents are the most important people in their child’s life and they know their child better than anyone. Parents are their child’s first and best teacher. If a family chooses ECI for services, we encourage parents to participate in every step of the process, from deciding what kind of help their child and family may need to working daily with their child to help him grow and learn.

We’re glad to have the opportunity to share information with Texas parents about ECI. Here is an overview of steps a parent and child will take in an ECI program.

**STEP 1**

**Referral**

A referral is made to ECI by someone who is concerned about a child’s development or because a child has a medically diagnosed condition that may result in a developmental delay.

Who makes referrals to ECI?

- Medical/Health Services - 35%
- Parent/Family/Friend - 26%
- Social Services - 29%
- Other - 10%

**STEP 2**

**Getting Started**

A visit with the family is scheduled to determine if ECI services are needed and if the child is eligible for services. An assessment and evaluation are either performed during that visit or scheduled for a future time. If the child is determined eligible an IFSP (see description below) will be completed within 45 days. ECI does not have a waiting list.

**STEP 3**

**Individualized Family Service Plan (IFSP)**

An IFSP is a written plan for a child’s and family’s services, based on their individual needs. Along with the child’s family and ECI staff, the IFSP team may include others, such as, the child’s physician or caregiver. The team decides:

- What services are needed
- How often and where the services will be provided
- Who will provide the service
- Goals for the child and family
- Daily activities family and caregivers will do to help the child reach identified goals

**STEP 4**

**Service Delivery**

ECI services occur in familiar surroundings and places that are convenient for families such as the family’s home, child care center or the local grocery store.

*Services are individualized and may include the following:

- Developmental Services
- Family Education and Training
- Counseling
- Occupational Therapy
- Physical Therapy
- Speech Language Therapy
- Nutrition Services
- Nursing Services
- Assistive Technology
- Behavioral Intervention
- Psychological Services
- Services for Children with Auditory and Visual Impairment
- Service Coordination
- Social Work

**STEP 5**

**Transition**

Transition is when a child leaves an ECI program. All children must leave by their 3rd birthday, or when they are no longer eligible. Transition is a process to help families decide what their child may need after leaving ECI. A child may transition to a public school program, Head Start, a private school, or other community services based on the child’s needs.

**Procedural Safeguards**

- Families and their children have rights that are designed to protect the family and child from the moment the family contacts ECI about their child’s possible need for services. All families working with ECI receive a ‘Parent Handbook’ that fully explains these procedural safeguards.

*Rights include:

- Right to Know and Understand: ECI must provide information in a way that can be understood before a family has to make a decision about services.
- Right to Consent: ECI must get permission (consent) from the family for almost any action that they take that affects the child.

---

**Thanks to Global Printing & Copying for printing this newsletter at a reduced cost for TXP2P!**

5114 Balcones Woods Dr., Ste. 309, Austin, TX 78759
512-794-8000, www.gpsaustin.com
ECI Says Hello

- **Right to Adequate Notice:** “Prior written notice” must be given to a family to ensure they have enough time to plan to participate.
- **Right to Confidentiality:** Information that ECI learns about the child or family is confidential. With few exceptions, ECI cannot give this information to anyone without written consent.

**Cost of Services**

A common question is “What is the cost for ECI services?” Families enrolled in ECI participate in the Family Cost Share system which is designed so family’s with the ability to pay share in the cost of services. It is based on family income and size, and reimbursement from public and private insurance. No family is turned away because of an inability to pay. Please visit [http://www.dars.state.tx.us/ecis/publications/index.shtml#familycost](http://www.dars.state.tx.us/ecis/publications/index.shtml#familycost) for further information about the ECI Family Cost Share system.

If you want more information about ECI go to [www.dars.state.stx.us/ecis/](http://www.dars.state.stx.us/ecis/). To find an ECI program in your community, call the DARS Inquiries Line at 1-800-628-5115.

**Early Childhood Intervention (ECI)** is a division within the Department of Assistive and Rehabilitative Services (DARS). ECI programs provide services to families with children birth to 36 months with developmental delays or disabilities.

**Personal Care Services (PCS)**

Personal Care Services (PCS) is a program for children/young adults with Medicaid who are under the age of 21 years and have physical, cognitive, and/or behavioral limitations related to a disability or special health care need that inhibits the individual’s ability to accomplish activities of daily living. Remember most young adults with disabilities are eligible for Medicaid at age 18 so keep reading if you child is about to turn 18.

Many programs have very long waiting lists but PCS does not; it gets you the help you might need now. Examples of the tasks that PCS can provide is help with bathing, dressing, feeding, grooming, positioning, transferring, toileting, light housekeeping, meal preparation, etc.

For eligibility and more information, call the PCS Client Line 1-888-276-0702.

Thank you to Mary Souhrada, Program Director/PHC Manager, with Disability Services of the Southwest, (CLASS and PHC), and Life Span (PCS and Star Plus) for her help with this article. She can be reached at Msouhrada@dsswtx.org or 512-419-1962, ext. 3015.

Life Span serves PCS clients in the Bastrop, Blanco, Brazos, Burleson, Burnet, Caldwell, Fayette, Grimes, Hays, Lampas, Lee, Llano, Mills, San Saba, Travis, Washington, and Williamson counties. You can call Life Span at 1-877-434-3153 to get more information on the PCS program for these counties.

**2011 Supporting Parent Volunteer Trainings**

You can help families like yours by becoming a Txp2P Parent Volunteer! Listed below is the schedule for 2010. Please let Susan or Patty know if you are interested in attending a training in your area.

<table>
<thead>
<tr>
<th>July</th>
<th>August</th>
<th>November</th>
</tr>
</thead>
<tbody>
<tr>
<td>Corpus Christi</td>
<td>Abilene</td>
<td>El Paso</td>
</tr>
<tr>
<td>September</td>
<td>Dallas</td>
<td>October</td>
</tr>
</tbody>
</table>

The Txp2P Newsletter is not copyrighted. Please feel free to use any of our articles in your newsletter, parent group meeting, or any other venue but remember to credit the author & Txp2P. If you would like an electronic copy, we can email it to you; please email the date of the newsletter & the article name to Susan.Prior@txp2p.org and we’ll email you the article.

Please remember to sign up for Txp2P Listservs. Contact Susan.Prior@txp2p.org if you want to join the Advocacy, ADD/ADHD, Autism, Bipolar, Dad’s, Homeschoolers, Medical Home, NICU, Transition, or local area Listservs (Austin, Bryan/College Station, Coastal Bend/Corpus Christi, Dallas/Ft. Worth, Houston, San Antonio, San Marcos, Rio Grande Valley, & Waco/Temple). If you want to moderate a local listserv for your area, we’d love to set up more of these local groups. Contact Laura at Laura@txp2p.org to discuss moderating one for us.

Save our trees and a little money - get the newsletter via email! It prints out well or is easy to read as an email. If you are currently getting this by mail but would read it as an email or print it out, please contact Susan Prior (512-458-8600 or 866-896-6001 or susan.prior@txp2p.org) and ask to receive the Txp2P Newsletter via email. If you leave a voice mail, please remember to give us your email address. Thanks!!

Make a donation to Txp2P - we’ve added an envelope to make it easy for you! Our annual direct mail campaign will be out in November but you don’t have to wait until then. Or become a monthly donor - no amount is too small!
Texas Parent to Parent is committed to improving the lives of Texas children who have disabilities, chronic conditions, and/or special health care needs. We accomplish this by empowering families to be strong advocates through parent to parent support, resource referral and education, and by educating professionals about the unique needs of our children.

Happy Mother’s & Father’s Days!

<table>
<thead>
<tr>
<th>Date</th>
<th>Conference Title</th>
<th>Location</th>
<th>Registration Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thursday, May 19 - Friday, May 20, 2011</td>
<td>Texas Guardianship Association Conference</td>
<td>Austin</td>
<td>For more information, go to: <a href="http://www.texasguardianship.org">www.texasguardianship.org</a></td>
</tr>
<tr>
<td>Thursday, June 9 - Saturday, June 11, 2011</td>
<td>Texas Council for Exceptional Children Annual Conference</td>
<td>San Antonio</td>
<td>For more information, go to: <a href="http://www.tcecweb.org/conference.htm">http://www.tcecweb.org/conference.htm</a></td>
</tr>
<tr>
<td>Tuesday, June 14 - Thursday, June 16, 2011</td>
<td>Statewide Texas Assistive Technology Conference</td>
<td>Houston</td>
<td>For more information, go to: <a href="http://www.texasatconference.net">http://www.texasatconference.net</a> or contact Kirk Behnke at <a href="mailto:kbehnke@esc4.net">kbehnke@esc4.net</a> or 713-744-6559</td>
</tr>
<tr>
<td>Wednesday, June 15 - Thursday, June 16, 2011</td>
<td>Annual Autism Conference, hosted by Texas Tech University College of Education</td>
<td>Lubbock</td>
<td>For more information, contact Barbara Stephens at 806-281-5715 or go to: <a href="http://escite2.esc17.net/default.aspx?name=wmsworkshop&amp;c=53">http://escite2.esc17.net/default.aspx?name=wmsworkshop&amp;c=53</a></td>
</tr>
<tr>
<td>Tuesday, June 21 - Thursday, June 23, 2011</td>
<td>2011 Texas Behavior Support Conference</td>
<td>Houston</td>
<td>For more information, contact Clynita Grafenreed at <a href="mailto:cgrafenreed@esc4.net">cgrafenreed@esc4.net</a> or 713-744-6345 or go to <a href="http://www.tbsconference.net">http://www.tbsconference.net</a></td>
</tr>
</tbody>
</table>