



# A Parent's Perspective

TxP2P Quarterly Newsletter

## TxP2P Update

Laura J. Warren, TxP2P Staff

Our 9<sup>th</sup> Annual TxP2P Parent Conference is over. It was our biggest ever, almost 750 people total: almost 450 participants including the young people in Teen Summit, 100 kids in child care, and almost 200 staff, volunteers, speakers, and exhibitors. Things went very smoothly and again, we had a lot of fun and great networking opportunities! We are almost done with the clean-up, reports, and evaluations and will start planning 2014 in October! We have also added two one-day conferences to our schedule – we did a smaller one in Port Isabel in June and one in North Richland Hills in August. We will repeat them in January (North Richland Hills) and April (Port Isabel) in 2014.

We are very pleased to announce that we received a grant in collaboration with Region 13 Education Service Center from TEA (Texas Education Agency) to create a website for families of children with disabilities or special health care needs age 0-5. We plan to use numerous videos of parents talking about their experiences to help support families who are new to this world of ours so they will have part of the parent-to-parent experience even if they don't immediately meet other parents. We'll also be able to address some of the emotional aspects that parent's experience and will include training tools on things like building relationships with providers, potty training, and becoming an advocate for your child on the website. Watch for news and opportunities for input from us over the next year – it goes live in September of 2014. Mary Jo Miller and Sherry Santa will be the staff working on this project.

Volume 12, Issue 3

Fall 2013

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## Advocacy Trends in Texas

Linda Litzinger, TxP2P Advocacy Network, Staff

As many of you know, I teach Legislative Advocacy to families, legislators, as well as to the state agencies. So after participating in six legislative sessions, **I've slowly realized a trend that calls us to action:**

- 1) Each group who proposes a bill has thought extensively of their own needs, but not so much about other groups of people.
- 2) There is little time for legislators to evaluate what is missing from the picture, with 3,000 bills and working 18-hour days.
- 3) A few citizens come and testify, but they don't hit all of the angles.
- 4) We should get to know more legislative staff before the next session, to become their experts. Now is the time to make this connection!

**What led me to think this way? Here are some examples:**

- 1) When my daughter was ready to graduate from high school, she learned she was not eligible for her diploma because she hadn't taken regular-

education PE. Texas had passed a law that ALL courses for graduation must be in regular ed, not recognizing that students with quadriplegia do the academic work, yet cannot take PE. How was this law passed? Most probably, someone was trying to make the diploma represent a standard (to colleges and employers), but in their haste they threw a group of academically-sound students 'under the bus.' (A dozen years later this was corrected).

2) A recent law strengthens the rights of service animal owners when they are out in public. Concurrently, it becomes criminal for non-disabled pet owners to fake a disability (to fly with Fido on their lap). However, the bill didn't cover the dog trainer who must be in public places during training and they could get in trouble due to this bill.



- 3) In May, 2013, a bill was passed (SB7: a 90-page bill that implements man-

aged care for Medicaid users, among other things). It also created four Advisory Committees who will help to redesign Medicaid services. Travel expenses are reimbursable for members appointed to three of the four committees, but for the Star Kids committee, the legislature forgot to make travel expenses reimbursable. It was an oversight; most legislators realize that young parents have the least means to pay for flights and hotel. As a result, families outside of Austin have fewer opportunities for input into this process. Recently we asked for the meetings to be filmed or for public testimony to be allowed over Skype. This is not resolved yet.

So, let me encourage you to step up, to help broaden the picture as bills are considered. If you are interested, we can determine the most convenient way for you to be trained. I hope you will join me. You can contact me at [Linda.litzinger@txp2p.org](mailto:Linda.litzinger@txp2p.org) or 512-922-3810 cell/text.

# Medical Transition - Opportunity to Learn More about the Transition from Pediatric to Adult-based Care

Rosemary Alexander, PhD, Transition Coordinator, Pathways to Adulthood, TxP2P

For years, my awareness of the issues related to medical transition was low to non-existent. My son, Will, moved from pediatric to adult services rather casually, keeping pediatric providers where possible and moving on where required.

However, a recent experience reminded me of the importance of this aspect of transition. My son's seizure disorder had been under control for about 10 years, from age 20 to 30, so we continued with the pediatric neurologist, just someone to maintain the current meds that were working, someone who was very kind, and easy to talk to.

Then, out of the blue, Will had a major seizure and had to be hospitalized. Our pedi neurologist had no privileges at this hospital, so I walked our new, adult neurologist, the doctor on call that day. We didn't choose this person—he just arrived. As it has turned out, we really like this adult neurologist and have found that we can partner with him very well in our efforts to work on meds and side effects but wouldn't it have been better to have made an informed choice before the crisis point?

Texas parents and professionals have a unique opportunity to learn about medical transition at the Texas Medical Transition Conference, held in Houston on October 17-18, 2013, the 14<sup>th</sup> year of this event. It is sponsored by Baylor College of Medicine, Texas Children's Hospital, the Robbins Institute for Health Policy and Leadership,

and the Health Resource Services Administration Maternal and Child Health Bureau.

This conference focuses on medical transition for children and young adults with chronic illness and disabilities. I attended it last year as part of my work for TxP2P's Pathways to Adulthood and expanded my knowledge and experience quite actively in two days. The conference is aimed at physicians, other health-care providers, primary care providers, and youth and young adults with chronic illness and their parents/guardians.

According to conference information, less than 50% of families nationwide indicate that their children and youth with special health care needs have received the services necessary to

make appropriate transitions to adult health care, work, and independence. One of the major problems is that physicians are not trained to provide health care transition services. This conference, attended by medical professionals from across the country, offers information and tools to remedy that problem.

Some topics for the upcoming conference on Thursday will be the current state of health care transition in the U.S., legal issues in transition, service models, planning tools, parent advocacy, and parents as case managers;

and on Friday, youth, young adult and family perspectives on medical transition, and financial aspects of medical transition.

To register, go to <http://www.baylorcme.org/search/detail.cfm?cme=894>

**Scholarships are available to adolescents and young adults age 15-25 with disabilities and/or their parents/caregivers** to attend the conference. Scholarships are limited but applications will be accepted as long as spots are available. Please contact Valerie Bowman at [tracs@texaschildrens.org](mailto:tracs@texaschildrens.org) for more information.

Additionally, the conference will be broadcast live at sites across Texas for anyone who is unable to attend the conference in person. There will be 9 **satellite broadcasts across Texas:**

**Amarillo**, Anna Shores, 806-337-1700 x210

**Austin**, Vanessa O'Dell, 512-324-9999 x86340

**El Paso**, Tania Alvarez-Soltero, 915-544-8484 x 201

**Fort Worth**, Carol Brant, 817-740-7537

**Kilgore**, Liz Adams, 903-988-6905

**San Angelo**, Gina Wilkes, 325-658-6571

**San Benito**, Santos Castaneda, 956-427-8000

**Temple**, Maria Blazo, MD, 254-724-3375

**Waco**, Sharron Stephenson, 254-297-1152

Or call us, 866-896-6001.



## ECI Supports Your Child's Participation in Community Activities

Early Childhood Intervention (ECI) provides services to families who have infants or toddlers with qualifying disabilities or developmental delays. Most ECI services are provided at home, however, services can be provided in other settings. An important outcome of ECI is that families receiving services feel they know how to support their children's development both at home and in their communities. Community settings can include day care, early education programs, library activities or simply playing in the neighborhood park/playground.

ECI services are intended to support

children and families, along with community providers, so children can fully participate in the community experience. The type of support that is provided is individualized to meet the needs of the child and the expectations of the family. Discussions about any community activities your child is involved in should occur on a regular basis.

It is important to consider community activities when planning for your child. Learning new skills in other settings helps children:

- learn skills that are useful for everyday life,

- interact with other children, who model the desired skills,
- practice new skills,
- experience a sense of belonging,
- develop social skills,
- be motivated to try new things, and gain confidence in his/her abilities.

Parents may ask that some of their ECI services be provided in their child's day care or early education class. ECI services in this setting are focused on coordinating learning activities with the child care provider or teacher in order to support the ECI child's active participation in activities.

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# ECI Supports Your Child's Participation in Community Activities

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This may mean adapting the activity, changing the physical environment to meet the needs of the child, or supporting peer relationships in the classroom.

ECI may also work with the child care provider or teacher to demonstrate how to structure tasks in smaller developmental steps to show learning. This allows parents and care givers to set realistic expectations. As a result, they are better able to recognize and applaud all accomplishments. The ECI provider's role is not to replace communication between the family and the child care provider, but to offer strategies that support the child's development both at home and in the child care setting.

Some families may want their child to participate in other community activities such as story time at the library, a parent/child class, or nursery/child care activities at their place of worship. In some cases, families may not be sure what is available to them in their communities. ECI and the family can work together to explore options and identify what will meet their needs.

## What can you do to help the ECI provider find ways for your child to participate in the community?

1. Identify what experiences you think will benefit your child. If you are not sure, be open to exploring ideas.
2. Identify activities your child likes. This list will help the ECI provider know what might be a natural fit.
3. Identify your child's strengths. An activity that focuses on your child's strengths is more likely to be successful.
4. Think about some of the challenges that may come up. What ideas do you have about minimizing the challenges to participation?
5. Be honest about what you worry about if your child participates in community activities.
6. Be confident in your ability to know your child and to share that information with others.

## What should you be prepared to share with the community provider?

1. Your goals and expectations for your child.
2. Your knowledge and expertise about your child.
3. Strategies that work best for your child.
4. How best to communicate with you.
5. If the community activity is a child care class, provide the staff with a copy of the Individual Family Service Plan (IFSP) - enlist them in supporting your child's goals.
6. Issues that you observe and ideas about what would be better.
7. Your child's specific needs. What is it you expect from this experience?

Early Childhood Intervention (ECI) is a division of the Department of Assistive and Rehabilitative Services (DARS). ECI programs provide services to families with children, birth to 36 months with developmental delays and disabilities. For more information about DARS/ECI, call 1-800-628-5115 or visit [www.dars.state.tx.us/ecis](http://www.dars.state.tx.us/ecis)

## Affordable Care Act: Marketplace Exchanges

Laura J. Warren, TxP2P Staff

As I said in our last newsletter, TxP2P has the Family to Family Health Information Center grant for Texas and because of that, I have slowly learned more and more about the Affordable Care Act (ACA). However, information on the Marketplace Exchanges is just coming out and grants for Navigators (those who will help us in person to find the right insurance policy) were just announced. Here's what I have learned so far:

√ The Marketplace simplifies your search for health coverage by gathering the options available in your area in one place. You can compare plans based on price, benefits, and other

features important to you before you make a choice. Plans will be [presented in four categories](#) – bronze, silver, gold, and platinum – to make comparing them easier. The category you choose affects how much you pay each month and what portion of the bill you pay for things like hospital visits or prescription medications. It also affects your total out-of-pocket costs (deductibles, co-pays, etc.) - the total amount you'll spend for the year if you need lots of care. For more information on the categories, go to <https://www.healthcare.gov/how-do-i-choose-marketplace-insurance/>.

√ The Marketplace also offers "catastrophic" plans to people under

30 years old and to some people with very low incomes. To [learn more about catastrophic plans](#), go to <https://www.healthcare.gov/can-i-buy-a-catastrophic-plan/>.

√ Insurance plans in the Marketplace are offered by private companies. They cover the same core set of benefits called [essential health benefits](#) (<https://www.healthcare.gov/what-does-marketplace-health-insurance-cover/>). Essential health benefits must include items and services within at least the following 10 categories: ambulatory patient services; health treatment; prescription drugs; rehabilitative and facilitative

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# Affordable Care Act: Marketplace Exchanges

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services and devices; laboratory services; preventive and wellness services and chronic disease management; and pediatric services, including oral and vision care.

✓ **No plan can turn you away or charge you more because you have an illness or medical condition. They must cover treatments for these conditions.** Plans can't charge women more than men for the same plan. Many [preventive services](#) are covered at no cost to you. Go to <https://www.healthcare.gov/what-are-my-preventive-care-benefits/> for a list of preventive services.

✓ While all insurance plans are offered by private companies, the Marketplace is run by the federal government in Texas.



✓ You can apply for Marketplace coverage three ways: online, by mail, or in-person with the help of a Navigator or other qualified helper. Telephone help and online chat are available 24/7 to [help](#) you complete your application at <https://www.healthcare.gov/contact-us/>. Downloadable and paper applications will be available October 1.

✓ Open enrollment starts October 1, 2013. Plans and prices will be available then. Coverage starts as soon as January 1, 2014. Open enrollment ends March 31, 2014.

If someone who can afford health insurance doesn't have coverage in 2014, they may have to pay a [fee](#). They also have to pay for all of their health care. The fee in 2014 is 1% of

your yearly income or \$95 per person for the year, whichever is higher. The fee increases every year. In 2016, it is 2.5% of income or \$695 per person, whichever is higher. In 2014 the fee for uninsured children is \$47.50 per child. The most a family would have to pay in 2014 is \$285. It's important to remember that someone who pays the fee won't get any health insurance coverage. They still will be responsible for 100% of the cost of their medical care. To avoid the fee in 2014 you need insurance that qualifies as [minimum essential coverage](#). **If you're covered by any of the following in 2014, you're considered covered** and don't have to pay a penalty:

- Any Marketplace plan, or any individual insurance plan you already have
  - Any employer plan (including [COBRA](#)), with or without "[grandfathered](#)" status. This includes retiree plans.
  - [Medicare](#)
  - [Medicaid](#)
  - [The Children's Health Insurance Program \(CHIP\)](#)
  - TRICARE (for current service members and military retirees, their families, and survivors)
  - Veterans health care programs (including the Veterans Health Care Program, VA Civilian Health and Medical Program (CHAMPVA), and Spina Bifida Health Care Benefits Program)
  - Peace Corps Volunteer plans
- ✓ Uninsured people won't have to pay a fee if they:
- are uninsured for less than 3 months of the year
  - are determined to have very low

income and coverage is considered unaffordable

- are not required to file a tax return because their income is too low
- would qualify under the new income limits for Medicaid, but their state has [chosen not to expand Medicaid eligibility](#)
- are a member of a [federally recognized Indian tribe](#)
- participate in a health care sharing ministry
- are a member of a recognized religious sect with religious objections to health insurance

If you don't qualify for these situations, you can apply for an exemption asking not to pay a fee. You do this in the Marketplace.

✓ After open enrollment ends on March 31, 2014, you won't be able to get health coverage through the Marketplace until the next annual enrollment period, unless they have a [qualifying life event](#) (this includes moving to another state, certain changes in your income, and changes in your family size (for example, if you marry, divorce, or have a baby)).



Learn more about the Marketplace, and visit [the page where the application will start](#) on October 1, 2013. To apply for insurance in Texas, you will go to <https://www.healthcare.gov/marketplace/individual/#state=texas> or call 800-318-2596.

## 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:

- ♥ Joshua, son of Myra Vidal
- ♥ Giuliana, daughter of Vanessa Ven Huizen
- ♥ Nicholas, son of Michelle Calabro
- ♥ Sophia Bella, daughter of Marisol Garcia, granddaughter of Sandra Rios
- ♥ Mason, son of Sarah Bird & Chris Purkiss
- ♥ Martie Dieppa, Supporting Parent Volunteer, TxP2P

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,  
The Staff, Volunteers, & Board of  
Texas Parent to Parent



# Promoting Change in Health Care through Advocacy: Will You Answer the Call and “Be the Change?”

Sandi Reese, TxP2P Volunteer

“Be the change you wish to see...”

Ghandi

When my son was born 12 years ago, like many parents of children with complex health care needs, I had no idea what lay before me. I was naïve and most definitely unprepared for the challenges ahead. In fact, it was not until my son was 15 months old that we received a definitive diagnosis and a broader explanation of what was to come. That being said, even with a proper diagnosis, there were many unknowns. And, as we began our health care journey, Brandon and I experienced both compassionate



family-centered care and indifference from numerous doctors, nurses and therapists in a myriad of health care settings.

## Identifying the Problem

As the parent of a child with special needs, you probably spend a large part of your life in clinics, doctors' offices, and hospitals, and have seen opportunities to improve these interactions for your child and others. I think it is safe to say we have all experienced the good, the bad and sometimes the ugly when it comes to health care.

Perhaps you wish doctors, specialists, and other medical professionals would take the time to explain your child's condition and recommend treatments in easy to understand terms rather than using complicated medical jargon. Or, you feel as though the concerns you have about your child's health and well-being are not being heard and too easily dismissed. Maybe you have developed a list of ways to improve processes at your local clinic or hospital so that your child and other patients feel more empowered and welcomed. And, some of you are praying

this will be the year your child clears a Medicaid waiver waitlist and wish there was something you could do to change the health care system.

So, what do you do with these burning ideas and frustrations? How can YOU make a difference?

First of all, I want to ENCOURAGE and remind you that because of your life's journey, you are developing skills and competencies in areas of expertise that are unique and valuable. As parents, we may not have medical training or political connections, but that does not minimize our knowledge or ability to effect positive change in the world of health care. We offer a perspective that cannot be found in medical textbooks, taught by a college professor, or assumed by our local legislator. It can only be learned through the on-the-job training of parenting a child with special health care needs.

I realize not all of us have the time, desire or ability to step into the ring of health care advocacy. The day-to-day demands of caring for our children can be overwhelming in and of itself. However, when we share our unique perspective with medical providers, decision makers in the health care industry, and legislators, we give them an opportunity to improve practices, services and policies for the benefit of others. If we don't tell them, how will they know and why would they change?

## Types of Health Care Advocacy

For those of you who have felt the call and are ready to take that first step, you are probably wondering where to begin. The best place to start is to decide which area of health care advocacy you want to focus on: legislative advocacy or patient advocacy.

Legislative advocacy involves sharing your concerns relating to health care legislation, and how it affects your family, with your local legislator. This can be done through in-person visits, letters, email, or phone calls. You can also participate by testifying at your state capitol during a public hearing on health care.

Click below for some Legislative Advocacy Tips:

<http://tcdd.texas.gov/public-policy/>

[legislative-advocacy-tips/](http://tcdd.texas.gov/public-policy/legislative-advocacy-tips/)  
<http://tcdd.texas.gov/public-policy/public-testimony-tips/>

Patient Advocacy is the process of working collaboratively (together) with medical professionals toward the common goal of improving the patient experience within a health care facility or system. This movement within health care is often referred to as Patient or Family-Centered Care.

My first patient advocacy opportunity came a few years ago when a nurse asked me to participate in a Family-Centered Care committee at my local children's hospital. I was excited but also somewhat skeptical. Would my thoughts and ideas be taken seriously? After all, I don't have medical credentials, I am just a parent.

Walking into that first meeting, I carried my skepticism with me, but it faded quickly as I was welcomed with open arms and immediately asked for my opinion on a surgical services policy. Due to the hard work of this committee, which is comprised of various hospital personnel and parent volunteers (advisors), incredible changes have occurred for the benefit of ALL patients--not just my own child.

Did you know that many hospitals either now have or are forming Patient and Family-Centered Care committees, and need patient and parent volunteers to serve as advisors? These committees review hospital policies and communications, develop patient education materials, consult with administrators on hospital design and services, and may be asked for input on specific issues brought to the committee by various departments within the facility. Often there is an application process and a background check involved in order to participate. If you are interested in serving in this capacity, I would suggest you search your hospital's website for their Patient Advocate or Family Liaison contact information.

Larger hospitals sometimes have departments dedicated to patient advocacy. Typically, these staff members either coordinate Family-Centered

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# Promoting Change in Health Care through Advocacy: Will You Answer the Call and “Be the Change?”

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Care activities or would know who to put you in touch with.

A few patient advocacy tips:

- Be committed and attend meetings regularly
  - Be positive
  - Communicate objectively and clearly
  - Respect the privacy of patients
  - Respect the diversity of the team
- Work well with others

## Other Forms of Advocacy

I also volunteer as a Parent Faculty member for a local medical resident training program run by a parent-driven organization called [Texas Parent to Parent](#). This program, MEd, is currently available in Austin and

Temple, Texas. Its primary focus is to improve health care practices for our children by educating the next generation of health care providers on the complexities of raising children with complex health care needs.

I encourage you to check with teaching hospitals and medical schools in your area to see if they have similar training for their residents and students, and are in need of family volunteers. This area of health care advocacy is the most exciting to me! The medical residents are so anxious to learn how they can help families in meaningful and practical ways. I find it to be incredibly rewarding and worthy of my efforts and time.

For those of you who accept the call

into this realm of advocacy, I wish you much success in your endeavors as you “become the change!” For those who feel called into other areas of advocacy, I wish you the same. My hope and prayer for all is that you stay strong, live boldly and be encouraged by knowing you are not alone.

*Sandi Reese, a fifth-generation Texan, lives near Austin with her husband and five of their 10 children. She has served as a special needs champion for over a decade. She currently holds advocacy positions in the Leander Independent School District, Texas Parent-to-Parent, ARC of Texas, at Dell Children's Medical Center and the City of Leander.*



I know that a lot of you are through having babies but not all. And those of you who are, might have daughters, daughter-in-laws, or nieces who could use this information! Check out what the State of Texas is doing to help families have healthy babies!

Laura J. Warren, TxP2P Staff

## Someday Starts Now

If there's a baby in your future, even if it's months or years from now, today matters. Take control. Stop smoking, eat right and exercise and do something about your stress. Whether you are a man or a woman, your health today is important - and even more important to the baby you might have someday.

**Someday Starts Now** is the public awareness campaign of Healthy Texas Babies. The campaign's centerpiece is a bilingual website – [www.SomedayStartsNow.com](http://www.SomedayStartsNow.com) and [www.AlgunDiaEmpiezaAhora.com](http://www.AlgunDiaEmpiezaAhora.com). The website features tools for Life Planning and Birth Planning Tools, videos on the importance of breastfeeding, partner involvement, and preconception health as well as information for men and women of childbearing age for before, during and between pregnancies.

To have healthy babies, moms have to be healthy. The decisions a woman makes today can affect the health and well-being of their child for the rest of his or her life. This site is designed to provide the information and resources you and your partner need to start your healthy future.

## Text4Baby

Text4baby (<https://www.text4baby.org/>) provides timely health and safety tips by text message based on where you are in your pregnancy. When you sign up, you can expect 3 free text messages per week throughout your pregnancy and until your baby is one year old. Go to <https://www.text4baby.org/index.php/about/message-content> for examples of text4baby messages.

One of our staff used the Text4Baby when she was expecting her 2nd child and reported that she really liked the messages she received. Pass it on!

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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.



**Thank You**

**Thank you to all the sponsors & partners of our 9th Annual TxP2P Annual Conference!**

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**Partners**

- TX Council for Developmental Disabilities
- Statewide ECI
- Education Service Center Region 13
- DSHS CSHCN

**Conference Schedule**

Date	Conference Title	Location	Registration Information
Oct. 17-18, 2013	22nd Annual Texas Autism Conference	Corpus Christi	<a href="http://txautism.esc2.net/default.htm">http://txautism.esc2.net/default.htm</a>
Oct. 24-26, 2013	27th Annual National MPS Society Family Conference	San Antonio	<a href="http://www.mpssociety.org">http://www.mpssociety.org</a>
October 26, 2013	7th Annual Texas Fragile X Fall Festival	Carrollton	<a href="http://txfx.org">http://txfx.org</a>
Nov. 1, 2013	Gulf Coast African American Family Support Conference	Houston	<a href="http://gcaafsc.net/events">http://gcaafsc.net/events</a>