

id you think we might have

dropped you off our mailing

list? Or that we went away? We are

so sorry that we have not been in

touch. We have just been so busy

that the newsletter had to take a

backseat until we could get caught

• we held our 2nd Annual Walk-n-

Roll which raised twice the funds

from last year (see page 6 for pho-

· we had our 5th Annual Parent Con-

tendance (see page 7 for photos),

we received additional funding so

we could start our Parent Support

Teams in the Dallas area as well as

ference with a 50% increase in at-

up. Here's what we've been doing:

tos),



A Parent's Perspective

TxP2P Quarterly Newsletter

Have You Missed Us? TxP2P Update

Laura J. Warren, TxP2P Staff

in South Texas,

- we expanded our office space and worked on a new logo & updated website (see page 7 for info),
- 453 new parents have registered with us so far this year,
- we have hired two new bilingual staff this year, Mary Jane Ledesma and Rosalba Calleros,
- we worked with Sara Hickman on a new song called Unbreakable Spirit in honor of our kids that was debuted at our annual fundraiser, the 5th Annual Vine to Wine Reception, and finally
- we started a new program for the Austin area - A Hand to Hold (see page 6 for more information).

Volume 8, Issue 2

Fall 2009
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Help TxP2P by using our Randall's Good Neighbor Remarkable Card Number 10043!

The Need for Reform

Colleen Horton, Public Policy Director, Texas Center for Disability Studies, University of Texas at Austin

hile the Texas Health and Human Services system serves hundreds of thousands of people, it is fragmented, confusing, and in many ways, outdated. Our system has been built in silos primarily based on the lobbying and advocacy efforts of the various

stakeholders and populations that the system serves. This has developed into a system of inefficiencies and often ineffectiveness. I get calls from parents on a regular basis who

say they have waited for 5, 6, up to 10 years for waiver services yet once they get a "slot," they still can't get the services they need.

The problems are numerous. Some of the existing major issues/ problems that need to be addressed in a comprehensive strategic plan for reform include:

- Long waiting time for services,
- Fragmentation and confusion in knowing where or how to access services,

- Lack of choice of services and service settings,
- Services based on labels and diagnoses rather than actual support needs,
- Continued institutionalization of children in large state institutions,
 - Inability to access appropriate or needed services,
 - Inequity in services offered across waivers,
 - Inequity in program cost caps across waivers,
- Inequity in reimbursement rates across programs,
- Direct care provider capacity crisis,
- Lack of coordinated system access points regardless of disability,
- Continuing abuse and neglect,
- Insufficient quality monitoring,
- Lack of self determination, self direction, and client dignity,
- Multiple administrative units providing similar services, and
- Costly impact of continuing op-

eration of 13 state institutions.

In some states, the human service agencies set the policy and the direction for the delivery of services. In Texas, the system has been primarily designed by legislative directives made during legislative sessions. Every two years various stakeholders, lobbyists, and advocates ask the Legislature to do the impossible – fix the system. Consequently, decisions are made and legislative direction is given on issues in isolation, without a vision for the future of the system or a plan on how to get us there. We have a system built on piecemeal fixes. The systems are too complex and the issues are too critical to continue to operate this

In an attempt to address this problem, several pieces of legislation were filed during the 81st session that would require the development of a *comprehensive* strategic plan for long term services and supports.

Continued on Page 2

The Need for Reform

Continued from Page 1

The legislation would require Texas to design a system based on self-determination and person centered planning with service provision based on the actual functional needs of the individuals rather than their diagnosis or label. This legislation also strongly emphasizes the need to address quality assurance, monitoring, and accountability regardless of the setting in which individuals receive services.

Unfortunately, this legislation did not pass. Pass or fail, the need for reforming the system is clear. The need to address the inequities and lack of flexibility is evident.

We have to question whether the current system is sustainable. Over the past 15 years, the waiting lists for community services have grown exponentially while we continue to pour hundreds of millions of dollars into an outdated institutional system. Additionally, under the current system, many individu-

als and families who are fortunate enough to have access to services through waivers & other programs don't have access to the services they actually need. We're wasting time, we're wasting resources, and we're wasting lives.

Regardless of whether the legislation passes or not, it is time to invest the resources needed to map out a more efficient and effective system of services for the future. Continuing to operate as we have is like treating a heart attack with an aspirin. It may help you make it through the next few hours or the next few days, but it isn't going to solve the real problems. That would require significant life-style changes. Solving the problems in our system of long term services and supports requires a strong vision for the future, significant systems changes, and a comprehensive plan for reform.

Albert Hawkins, Executive Com-

missioner of the Texas Health and Human Services Commission recently retired. Commissioner Hawkins has been an effective leader and a friend to families caring for children with disabilities. He has done much to move the system forward with the limited resources allocated and the limited legislative direction provided. We wish him well in his well deserved retirement. It is important, however, that we continue to stress the need for improvement and reform to the new Ex-Commissioner, ecutive Suehs. We should start to visualize the future we want for our children, the services that they will need to attain that future, and then continue to press the new human services administration, from the governor on down, to make that vision a reality.

As always, please feel free to contact me at:

<u>colleen.horton@mail.utexas.edu</u> if I can answer any questions.

Medicaid Buy-In

Medicaid Buy-In for Children and Their Families

Due in part to the efforts of many parents, the 81st Legislature passed, and Governor Perry signed, Senate Bill 187 which directs the Health and Human Services Commission to develop and implement a Medicaid Buy-In Program for children with disabilities. This program will benefit families of children who meet the

SSI definition of disability and have incomes up to 300% of the federal poverty level which is approximately \$66,000 for a family of four. This will provide an opportunity for families to purchase, on a sliding fee basis, Medicaid health care services for their children with disabilities. Our deepest gratitude goes to Rep. Eddie Lucio,

III and Senator Robert Deuell for sponsoring and fighting for both the legislation and the funding needed to make this a reality. The Health and Human Services Commission reports that this program will begin in September 2010. Watch for more information soon.

How to Work & Maintain Medicaid Eligibility - Medicaid Buy-In for Young Adults

ew people are aware that the State of Texas authorized Medicaid Buy-In back in 2005, modernizing the employment services system for people with disabilities. In other words, Texans with disabilities are no longer forced to choose between taking a job and having health Medicaid Buy-In allows people of any age who have a disability and are working to receive Medicaid by paying a small premium (\$20-\$40/ monthly month) based on earned income.

The premiums for unearned income can be higher, depending on the amount of unearned income. If your child is about to turn 18 and is working or looking for a job, Medicaid Buy-In can help him/her to maintain Medicaid coverage. After age 18, Medicaid eligibility is based on the young adult's income.

The Department of Assistive and Rehabilitative Services (DARS), a program of the Health and Human Services Commission, is offering the new work incentive program. This program offers the same services that you get through Medicaid which includes office visits, hospital stays, x-rays, vision services, hearing services and prescriptions. To find out the eligibility requirements for your child and to apply call 211, visit your local HHSC benefits office, or visit www.YourTexasBenefits.com to request an application. For more information on this program, visit the State Employment & Disability Connections website at: www.dars.state.tx.us/edc

Assistive Technology Short-Term Device Loan Program

Updated **New Inventory Items**

John Morris, Texas Technology Access Program

The Texas Technology Access Program at The Center for Disability Studies, University of Texas at Austin, has an assistive technology device loan program designed to meet the needs of persons not served by existing agency loan programs. This program will allow persons with disabilities, their families, edu-

cators, service providers and employers to borrow AT devices **FREE** for up to six weeks, with opportunities to extend the time if the device has not been requested by another borrower. This service is **FREE** and is available to anyone in Texas that meets the qualifications.

The program will give individuals and agencies an opportunity to

borrow an AT device (examples of some of the devices available are listed below), and use it in the individual's normal environments. They are then better able to determine if the device meets their needs or the needs of individuals with disabilities they're serving. This will allow them to make an

informed choice about which device to purchase or whether to purchase a device at all.

For more information on available devices or to download a Device Loan Request Form, please visit our website at

http://techaccess.edb.utexas.edu or call **1-800-828-7839** and a Loan Request Form will be mailed to you.

Examples of some of the devices available:

- Communication devices such as Dynavox, Vanguard, chat PC
- Vision and hearing scanners/ readers
- Switches
- Early childhood learning equipment such as AlphaSmart, Kidz-Mouse
- Computer access equipment keyboard, mouse, joystick,
- Palm devices
- ADLs (Activities of Daily Living)

Additional equipment is available. New Inventory List Online!! http://techaccess.edb.utexas.edu

Call for more information! John Morris, Assistive Technology Coordinator, Texas Technology Access Program, 512-232-0753

DARS Autism Program

Serving Children Ages 3 through 8 Who Have Autism Spectrum Disorder

n August 2007, the Legislative Budget Board, in conjunction with the Office of the Governor, instructed the Health and Human Services Commission to transfer \$5 million in general revenue for the biennium to DARS to fund services, such as applied behavior analysis (ABA), for children ages

three through eight with an autism spectrum disorder (ASD).

Given the time-limited nature of the funds, as well as the lengthy process of developing program rules, DARS chose to award up to five grants for autism services to be administered as contracts. The grant model allowed DARS to implement services more quickly to children with ASD and to choose different service models that will allow for comparative analysis at the end of the project.

The program has received a 2year extension. See below for the current contractors.

Contractor	Contact Information	Counties Served*	Service Type
Any Baby Can	210.227.0170	Bexar and contiguous counties	Applied Behavior Analysis
Center for Autism and Related Disorders	886.833.3898 x104 (toll-free)	Travis and surrounding counties	Applied Behavior Analysis
Child Study Center	817.390.2880	Tarrant	Applied Behavior Analysis
Easter Seals North Texas	Jennifer Friesen 888.617.7171 (toll free)	Dallas and Denton	Applied Behavior Analysis
MHMRA of Harris County	Melinda Benjumea 713.970.8241	Harris	Applied Behavior Analysis
Texana Center	Ellen Catoe 281.239.1497	Matagorda, Wharton, Austin, Colorado, Waller, Fort Bend, Harris, Galveston, Montgomery	Applied Behavior Analysis

*Any Texas resident can apply for services at any of these providers' offices. You do not need to live in the service area to qualify for services; however, transportation and lodging costs are not covered by this program. For detailed information about financial expectations and eligibility requirements, please contact the individual service provider directly.

Young Lady with Down Syndrome in Miss Teen Austin Beauty Pageant

Susan Prior, TxP2P Staff

ho would have thought that a 17-year-old girl with Down syndrome who loves fashion, clothes and modeling would be invited to participate in a Well, some beauty pageant? dreams do come true after all. It happened to our daughter Brenna. It was actually quite an unusual set of circumstances that led Brenna to be in the Miss Teen Austin Beauty Pageant on March 1st in Austin. The Executive Director of TxP2P, Laura Warren, had received letter addressed to her mother (deceased) from the National Miss Teen Austin inviting her daughter to try out for the pageant. Laura, not being a teenager, offered the invitation to Brenna.

We called the National office to see if we could use Laura's invitation and they said yes. Brenna had to attend a training session where she filled out an application and had to go into a room with judges and answer one question. The pageant coordinator would then decide if she could participate in the pageant.

Brenna was one of 900 girls that attended the training. We thought she didn't have a chance at all. But within 2 days, we received a call from the National office stating that Brenna had been accepted to be in the Miss Teen Austin Pag-Our She was so excited. wonderful friends and family helped us to raise the entry fee monies we needed to participate. This pageant was based on interviewing skills and modeling casual and formal wear. Brenna attended the training class and rehearsal and was so confident it brought tears to our eyes. She practiced the "walk" every day in preparation for the pageant. The day before the pageant was the personal interview with the judges. She had to go into a room by herself and answer questions. We had also practiced possible questions they She was pretty could ask her. nervous but when she left the room she shouted, "I did it." She was so happy!

The day of the pageant she was so confident, excited and nervous. I

think her mom and dad were more nervous for her though. She modeled her casual and formal wear as practiced and even answered her question on stage with the other 45 girls in her age group. We were so proud of her!

Brenna did not place in the finals nor did she win a prize at the National level. She did meet many nice young ladies and was included in every aspect of the pageant. We think she won the biggest prize of all - she built her self esteem and proved that she could do something she had only dreamed of by having the confidence and determination to just

try. She was thrilled with being a part of it all and will remember it for the rest of her life. As will her mom and dad.



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Please remember to sign up for TxP2P Listservs. Contact Susan.Prior@txp2p.org if you want to join the Advocacy, Autism, Bipolar, Homeschoolers, Transition, or local area Listservs (Austin, Bryan/College Station, Dallas/Ft. Worth, Houston, San Antonio, San Marcos, Rio Grande Valley & Waco/Temple). We have two new Listservs - Medical Home & Coastal Bend/Corpus Christi. 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 ampaign will be out in November but you don't have to wait until then. Or become a monthly donor - no amount is too small!



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Velocardiofacial syndrome

elocardiofacial syndrome or VCFS (often called DiGeorge or 22q11.2 deletion syndrome) is the second most common genetic abnormality, after Down syndrome, and occurs in 1 of 2,000 births. VCFS has a great variation in the features of the syndrome. The list of anomalies include: cleft palate, usually of the soft palate (the roof of the mouth nearest the throat which is behind the bony palate); heart problems; similar faces (elongated face, almondshaped eyes, wide nose, small ears); learning difficulties; eye problems; feeding problems that include food coming through the nose (nasal regurgitation) because of the cleft palate; middle-ear hypoparathyroidism infections; (low levels of the parathyroid hormone that can result in seizures); immune system problems which make it difficult for the body to fight infections; weak muscles;

short height; curvature of the spine (scoliosis); and tapered fingers. Not all of the problems occur in all cases.

Despite its relative frequency, unlike more commonly recognized disorders, the condition is largely undiagnosed and most members of the medical, educational, public sector and disability communities in Texas are unfamiliar with it.

This year, a group of parents from Central Texas, the Dallas area, and the Houston area have formed a non-profit called **VCFS Texas** to increase awareness in Texas (and beyond) about VCFS and to help families and professionals.

VCFS Texas initiated Senate Bill 1612 in the past legislative session to provide information on Velo Cardiofacial Syndrome to medical professionals and parents when a child exhibits two indicators of VCFS. With help from Coalition of

Texans with Disabilities, SB1612 moved to the House floor and passed in a close call.

The group is working to address the development of children with VCFS in their earliest years by getting the Early Childhood Intervention (ECI) agency to provide information about VCFS to its staff, therapists and parents. Furthermore, they want to increase awareness among doctors, therapists, educators, and disability advocates. people in Texas were more aware of the disorder, children with VCFS would be more likely to receive the important therapy and treatment they need early, resulting in tremendous cost savings to families and the State, and to improved outcomes for people with the disorder.

You can learn more about VCFS and the new parent group at: www.vcfstexas.com

What is the Youth Empowerment Services (YES) Waiver?

he YES Waiver is a new 1915(c) Medicaid program that allows for more flexibility in the funding of intensive community-based services for children and adolescents severe emotional disturbances and their families. The YES waiver will initially be piloted in Bexar and Travis counties and will serve up to 300 youth. The tentative waiver start date is December 2009 however this date is dependent on the availability of waiver Harris and Tarrant providers. Counties will begin serving as pilot sites as early as 2011 if the waiver is determined to be cost effective in its first two years of operation.

Who is Eligible for YES Waiver Services?

To participate, the child or adolescent must meet the following eligibility criteria:

- Be between ages 3 to 18 years;
- Reside in Travis or Bexar County;
- •Reside in a non-institutional setting with the child's or adolescent's Legally Authorized Representative (LAR); or in their own home or apartment, if legally emancipated;
- Be eligible for Medicaid, under a

Medicaid Eligibility Group included in the approved waiver;

- Choose, or have the LAR choose, the waiver program services as an alternative to care in an inpatient psychiatric facility;
- Meets DSHS clinical criteria (including, but not limited to risk of self-harm, risk of severe disruptive or aggressive behavior, family resources, and risk of school behavior); and
- There must be a reasonable expectation that, without waiver services, the child or adolescent would qualify for inpatient care under the Texas Medicaid Inpatient Psychiatric Admission Guidelines.

What are the YES Waiver services? The services provided are:

Respite

- Community Living Supports
- Family Supports
- Specialized Psychiatric Observation
- Transitional Services
- Adaptive Aids & Supports
- Minor Home Modifications
- Non-Medical Transportation
- Paraprofessional ServicesProfessional Services

Supportive Family Based Alternatives

When can I access YES Waiver services?

At this time, client enrollment has not begun as DSHS is establishing a Waiver Provider network. Once client enrollment has begun each provider will perform the eligibility and enrollment process. Visit the YES Waiver website www.dshs.state.tx.us/mhsa/yes for notification of client enroll-

ment into Waiver services. Will there be a wait list?

The providers will maintain an interest list for individuals who meet age and residency eligibility The YES Waiver has a criteria. limit on the number of people who can be served in each county. There is a first come first served policy for YES Waiver services. This policy is based on the chronological date of registration on the Providers are not interest list. currently accepting names for the interest list. Visit the YES Waiver webpage www.dshs.state.tx.us/ mhsa/yes for further notification on the interest list.

A Hand to Hold

Texas Parent to Parent is very proud and excited to announce our newest program, A Hand to Hold. It is a community-based support pro-

gram for parents of infants after a Neonatal Intensive Care Unit (NICU) stay or the loss of a baby while in the NICU. The new program will be launched in 2010 in the Austin area with plans to replicate across the state in three to five years.

"We were in the hospital with our son for 14 months. He was born at 26 weeks with several medical conditions. We felt extremely isolated when we arrived home, because we couldn't take him out in the public due to the risk of illness.

One out of every eight births is preterm: before 37 weeks gestation. It's the leading cause of newborn death and often results in lifelong disabilities including mental retardation, chronic lung disease, learning difficulties, cerebral palsy, blindness and deafness. While fertility drugs and advanced maternal age have increased the number of preterm births, in nearly half of the cases, the causes are unknown.

Researchers have found that parents of preterm infants and babies born with special health care needs often struggle with depression, anxiety and post-traumatic stress disorder. Left to handle these issues alone, the prolonged stress can have a profound impact on the entire family unit, often resulting in depression, separation, divorce, and child abuse.

In addition, parents must navigate complicated insurance and health care systems to advocate for their children. Oftentimes they are faced

with complex medical equipment, detailed medication schedules, numerous specialists, and complicated medical bills.

A Hand to Hold fills an existing gap which directly helps parents post-NICU, thereby improving outcomes for infants and families. A Hand to Hold

matches parents, post NICU, with a trained parent volunteer who has experienced a similar journey and can quickly help them connect with needed resources and services. Planned programs include a peer support network, parent support groups, bereavement support, an online resource guide, newsletter, quarterly lecture series, online social network, family outings, baby play dates, and a track in our annual parent conference.

This is a great blend of what TxP2P already does for parents but brings it to additional parents who are also at risk of isolation after coming home with their baby from the NICU or for families who are coping with the loss of a baby.

A New Program for TxP2P

TxP2P is honored that the following friends of TxP2P are willing to serve as "Champions for Families." Their voices will help advance the mission of A Hand to Hold and position the program for success: Kristin Armstrong, mother, author, and runner; Dr. Ari Brown, M.D., FAAP, pediatrician, author, and mother; Sara Hickman, singer, songwriter, and activist; Luci Baines Johnson, mother of 5 and grandmother of 11; and Kim Wedel, Assistant Commissioner for Early Childhood Intervention Services.

A special thank you goes out to St. David's Medical Center, who is our first title sponsor.

TxP2P is actively recruiting parents of children who started their life in the NICU to be trained to support parents new to this experience. Please contact TxP2P staff at 512-458-8600 or 866-896-6001 for more information.



2nd Annual Central Texas Walk-n-Roll

This walk benefits both Texas Parent to Parent and the National Osteogenesis Imperfecta Foundation and raised over \$9,000 for the two organizations in 2009.

It started out a bit cold but turned into a beautiful day full of fun!

Texas Parent to Parent
Unevasale Syr

We had a 1-mile walk, with people on foot, skates, & bicycles, in wagons and wheelchairs, and a few staying behind at the pavilion. We also had games for the kids, pizza, cake and ice cream, and a raffle for some great donated prizes.



3rd Annual Walk-n-Roll Saturday, April 24 Old Settler's Park, Round Rock, TX Please join us!!



As Executive Director, I have been told many times that our logo needed to be redesigned. However, I still remember the months it took us the first time to come up with our logo in 2002. I did know that they were right. Our logo was created in a way that it couldn't be resized easily but I still wasn't actively pursuing a logo change. Then one of our dads, David Rockwood, who just happens to work for GSD&M Idea City, presented me with the logo shown here. At first, I just saw the butterfly but then slowly the two intertwined "P's" became visible, one forward and one backward. Then I read the description that they had written about TxP2P being like butterflies,

spreading information from family to family instead of pollen to flowers. And of course, there is also the metamorphosis that we watch families go through, from confused or scared to confident and capable parents. So, we have a new logo! And soon we'll have a redesigned website so watch for more changes!

5th Annual TxP2P Conference

The 5th Annual TxP2P Parent Conference was another huge success with almost 400 attendees and over 600 people involved. Although the theme was "Many Hearts, Shared Dreams: One Voice," the unofficial theme was "crowded."

Registration



Breakfast



Exhibitors



We had 61 break-out sessions



Entertainment for the kids



Relaxation and networking time



Teen Expo & Family Gathering



& Joe McDermott!



Next year, June 25 & 26, 2010, San Marcos Embassy Suites. Hope to see you there!

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Email: txp2p.org

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.



You may remember an email we sent out a couple of months ago asking for stories about your experiences with EMS and your children. Well, here's why we asked for your help.

TxP2P was very flattered to be asked to be part of a collaborative partnership with EMSC (Emergency Medical Services for Children) State Partnership to help find common goals and establish statewide priorities for emergency care for Texas children. Along with TxP2P, other organizations who are also members of

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TxP2P Partnership with EMSC Jeanine Pinner & Debbie Wiederhold, TxP2P Staff

this partnership include: Texas Department of Public Safety (Teenage Drinking & Driving programs), National Association of EMS Educators (NAEMSE), Children's Hospital Association of Texas, Committee on Accreditation of Educational Programs for the EMS Professional (CoAEMSP), and the Texas Ambulance Association. Stories about your experiences, positive <u>and</u> negative, provide valuable information that will help us accomplish these goals. If you haven't sent us your "EMS story," please send it now to jeanine@txp2p.org.

In the coming months, we expect to participate in some of the conferences or trainings that EMSC is planning around the state and to assist in developing a training module for how to use equipment for children with special health care needs. We may be calling upon you to ask for your participation and support in these trainings as they occur.

Conference Schedule

Contenting Schedule					
Date	Conference Title	Location	Registration Information		
Wednesday - Friday, Nov. 18-20, 2009	Texas Guardianship Association Fall Conference	Waco	For more information, call 888-399-9115 or at http://www.texasguardianship.org		
Thursday - Saturday, Dec. 3 - 5, 2009	2009 Texas State Conference on Autism	Corpus Christi	For more information, call 361-561-8518 or at http://www.autism.esc2.net/conference/index.asp		
Thursday, January 28, 2010	The Texas Mental Health Juvenile Justice Summit	Austin	For more information, call 512-473-2274 or at http://www.texanscareforchildren.org/calendar.php?month=10&year=2009		
Wednesday - Saturday, February 10 - 13, 2010	17th Annual Inclusion Works! Conference	Austin	For more information, call 800-252-9729 or at http://www.thearcoftexas.org		
Monday - Wednesday, Feb. 15-17, 2010	Texas Transition Conference	Austin	For more information, call 979-458-1593 or at http://ttc.tamu.edu/		