Texas Parent to Parent Parent to Parent to Parent Parent to Parent Institute foreith to Parent of Institution

Texas Parent to Parent

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

3710 Cedar Street, Box 12, Austin, TX 78705 866-896-6001 512-458-8600

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Website: www.txp2p.org Email: txp2p.org

2nd Annual Texas Parent to Parent Conference

Connecting Families of Children with Disabilities & Special Health Care Needs

Friday & Saturday, August 4th - 5th, 2006

Seminar Tracks will include Special Education, Transition, Medical, Therapies, Behavior, Autism, mental Health, Advocacy, Self-Determination, General Parenting Topics, and Sessions provided in Spanish

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Special Ed Law and Advocacy Seminar Thursday, August 3rd, 2006

St. Edward's University, Ragsdale Center 3001 South Congress Blvd., Austin, Texas

You can register for the Wrightslaw Seminar now on our website or call us at 866-896-6001 to register over the phone. Registration forms for the conference will be mailed out the 3rd week of April!!

Volume 5, Issue 1 Spring 200

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

Transition from Adolescence to Adulthood - What's it All About?

By Kathy Griffis-Bailey, CSHCN

Before being able to be

and do things on their

own, teens need to

develop skills for

independent living.

ransition from adolescence to adulthood is an exciting time. There is much to learn. There are many new experiences. It is common and healthy for teenagers to want to do things on their own. Teens need to be encouraged to grow and try new responsibilities.

Before being able to be and do things on their own, teens need to develop skills for independent living. They need friends and time and places to play, relax and meet with other people. They need to think about education beyond high school and employment. They need to understand about how to get around (transportation). They must determine where to live (housing).

Teens also need to learn about and understand their health care needs. They need to participate in making decisions about their health. They likely will need to make changes in the ways they get medical care. They may need to change doctors. Learning this information, developing these skills, and making these changes also is called health care transition.

Successful health care transition, like all transitions from adolescence

to adulthood, should be planned, purposegradual. and There are many lessons to be learned and skills to develop. Some of the health

care lessons that need to be learned include:

- 1. Basic knowledge and management of health condition
- 2. Health care, personal hygiene

practices and healthy life choices

- 3. Medications, tests, equipment and supplies
- 4. Doctor visits, interactions with health professionals
- 5. Health care transition goal setting
- 6. Transition and accepting responsibilities away from home
- 7. Health care systems, records,

insurance, emergencies Begin planning early:

Some sources recommend beginning the initial planning processes as early as age 12, though the certain consensus is to begin by

age 14. Some activities may occur sooner or later, depending upon the child. Beginning early is crucial for several important reasons.

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Transition from Adolescence to Adulthood - What's it All About? Continued from Page 1

- Health transition is fundamentally a learning process for the child, family and provider(s).
- Many aspects of health care information are complicated.
- Learning takes time and positive reinforcement.
- People need time to adapt and accomplish new behaviors.
- Adolescence tests a person's ability and capacity for change. Children may grow into behaviors and responsibilities that surpass expectations (or not).
- Many life changes are difficult.
- Relationships with new providers or health systems need nurturing and time to strengthen.
- Privacy, custody, confidentiality and other legal issues must not be resolved haphazardly.
- Transitioning to different health benefits systems (including publicly funded systems such as Social Security Supplemental Security Income or Medicaid long term care waiver programs) may involve lengthy application and eligibility processes, waiting periods to overcome existing condition limitations, and/or waiting lists.

Approach transition as a team:

In addition to beginning early, it's important to approach health transition as a team. The key team members are the adolescent, family member(s), and primary and specialty care pediatric and adult practitioners. In some cases, transition team members might also include other key service providers. Examples include physical or occupational therapists, speech language pathologists, mental health professionals, and durable medi-

cal equipment suppliers. All of these potential roles in successful health care transition.



If social workers, health care case managers, or care coordinators are available, they can be important also, and for clients of the Children with Special Health Care Needs (CSHCN) Services Program in Texas, regional case management staff or contractors also are able to assist.

Through the Americans with Disabilities Act (ADA) and the Individuals with Disabilities Education Act (IDEA), the public rehabilitation and education systems have legal mandates to provide employment and education transition services. These systems may not fully address the specifics of health care transition, but parents or teens may seek to include learning experiences for health care transition as part of Individual Educational or Transition

Make transition empowering:

Plans.

Finally, and fundamental to health transition is the concept that, at various times, the adolescent is beginning, continuing, or completing a change toward autonomy, selfdetermination, self-sufficiency, and independence in the management of health care, to the extent that the young person is able to achieve those outcomes.

Health care transition involves one of the most intimate aspects of life and living, and the transition team is in an exceptional position to facilitate empowerment for the child. Certainly, successful health care transition is empowering for the young adult, but it is also empowering for parents and other family members, and it can be professionally satisfying for pediatric provid-

More information about transition is available on the Transition page of the CSHCN Services Program at www.dshs.state.tx.us/cshcn. on "Transition Information" in the menu on the left side of the home page. There are web links to other resources, including websites primarily for youth and/or families.

Speaking from the Heart: Creating Holiness Through Our Words

By Ivy Goldstein, TxP2P Volunteer, Austin

he Tap2 Adult Education series at Congregation Agudas Achim recently offered a class called Standing at the Fence: Jewish Ideas about Gossip and Careless Talk (Lashon haRa). The four part course was taught by Hazzan Neil Blumofe. Literally, lashon haRa means 'evil tongue,' and is commonly translated as evil speech or gossip. Our daughter, Sophie, has become a familiar member of our community. She is outgoing, friendly, and full of energy. All of you who know her recognize that Sophie has a disabil-Many people also notice her strengths and abilities. Yet, I am surprised at how often the contribu-

Since taking the Tap2 class, I have

overlooked.

tions that Sophie and others with

disabilities bring to our world are

begun to recognize parallels between the ways people with disabilities are often spoken about, and lashon haRa. I am sharing my thoughts with the



hope that individuals with disabilities are spoken about in a way that adds to the holiness in our world. I envi-

sion a time when all of us are valued for our differences and unique gifts. Our tradition teaches nishmat chayim. That is, through speaking, God created the world. According to our mystical tradition, the tongue is where body and soul merge. Speaking in a way that is potentially harmful to another can lead to the death of one's soul. The words we choose have the power to magnify or diminish holiness in the world. Some say this impacts both the way we live

and how we are remembered. Our children learn by our example and our words impact our legacy. Being mindful of the power of words and ensuring that what we say honors the divine spirit in everyone, is a constant, ongoing struggle.

When Sophie was born, I would describe her as having 'special needs.' I soon learned to give more thought to the word, 'special'. When Sophie was 2, our son Jeremy, age 5 at the time, said to me, "I wish I had special needs." He was tired of hearing how 'special' his sister was, and I stopped using the word. We need to recognize that typical kids in a school or recreational setting probably do not enjoy hearing about another child being singled out as 'special.'

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Speaking from the Heart: Creating Holiness Through Our

Words

Continued From Page 2

Kathie Snow, a nationally known author and speaker on People First Language, points out that in the context of disabilities, the word 'special' means, 'separated' or 'segregated.' She also says she has never met an adult who wanted to be referred to as 'special.' Snow even questions the 'Special' Olympics. She wonders what the world would be like if the resources of that organization were used to create programs and provide supports so that individuals with disabilities could participate in similar activities with everyone else. In a free society, segregating an individual because of a disability is considered discrimination. As Jews, doing so violates the fundamental value we place on community as well as our teaching that we are all created in the Divine Imaae.

People First Language is a way of speaking about individuals with disabilities that focuses on the person and not their disability. Often the labels we attach to someone may be harmful or create barriers. When we speak about a person in a way that diminishes them, even when unintentional, it is lashon haRa. Negative labels that emphasize a condition a person *has*, rather than who he or she is, interfere with our ability to encounter the person as a wonderful, unique individual. Through an increased awareness of the importance of People First Language, we are able to choose words that foster inclusion and honor the sanctity of people with differences. A person is devalued when they are branded primarily by a diagnosis or a disability. For example, often we

hear someone say, "he is ADD" or "she is autistic" instead of "he has ADD' or "she has a diagnosis of autism." When a man was recently shot on a plane by a federal air marshal, we heard the media report that the man "was bipolar." Someone may have a diagnosis of ADD,

autism, or bipolar disorder, but that is not who they are. In addition, just as it is rarely relevant to mention someone's skin color, there is often no need to mention whether or not a person has a disability.

It is important to rethink how we use the word 'disabled'. To say a student is 'learning disabled' devalues them and implies that they are broken (like a disabled car.) Instead, saying a child has a learning disability distinguishes between the person and a particular characteristic. Even better would be to say the student needs instructions repeated slowly or needs extra time to finish an assignment. When a child hears herself, often repeatedly, described as 'disabled,' what impact does that have on her self-image? All kids, especially those with learning challenges, benefit from positive messages which describe their strengths and abilities.

Another way of putting people first is to eliminate using of words which, no matter how they are expressed, denigrate a person. The word, 'handicapped' tops the list. A handicap is a barrier created by people or in the environment, such as a staircase for people who use wheelchairs. When it comes to em-

bracing and including people with disabilities, often the biggest barriers come from people's attitudes. The "h" word is not an appropriate descriptor for a parking space or bathroom and has been eliminated from all federal legislation.

Another word which is degrading

Kathie Snow . . .

points out that in

the context of

disabilities, the

word 'special'

means, 'separated'

or 'segregated.'

when describing a person is 'retarded', or 'mentally retarded.' All of us have challenges learning something. Fortunately my teenage son doesn't go around saying that his mom is 'technically retarded.' Who wants to

hear that? As Sophie's mom, I find these words hurtful. They do not in any way describe the beloved child who fills our world with light and joy.

By choosing our words carefully, we help insure that people with disabilities are embraced and included. Our words express that everyone is respected for their differences and valued for their unique contributions to the community. A heightened awareness of *People First Language* helps us create holiness in the world.

Ivy Goldstein, proud mom of Jeremy and Sophie, is a participant in the current Partners in Policymaking program. Partners is a worldwide advocacy training program for parents of children with disabilities and adults with disabilities. She is especially interested in efforts that promote the full inclusion of Jewish children and adults in all aspects of Jewish life in Austin. She welcomes your comments and can be reached at ivys-gold@yahoo.com

Here are examples of how to use People First Language:

(Adapted with permission from Kathie Snow's People First Language article which can be found at www.disabilityisnatural.com)

Say:

People with disabilities instead of the handicapped or disabled He has a cognitive disability instead of he is retarded (or MR) She has a diagnosis of Down Syndrome instead of she's Downs' He has a physical disability instead of he's quadriplegic (or crippled) She has a mental health diagnosis instead of she's mentally ill/emotionally disturbed

She uses a wheelchair **instead of** she is confined (or bound) to a wheelchair

He has a seizure disorder (or dx of epilepsy) instead of he is epileptic She communicates with her eyes (or device) instead of she is nonverbal

He has schizophrenia instead of he is schizophrenic

He receives special ed services **instead of** he is in special ed She has a developmental disability **instead of** she is developmentally disabled

He has a congenital disability **instead of** he has a birth defect She has a brain injury **instead of** she is brain damaged Accessible parking, bathroom, etc... **instead of** handicapped parking, bathroom, etc...

Children (or people) without disabilities instead of normal, able-bodied, or healthy

Avoid words like: Unfortunate, lame, victim, afflicted, suffers from, stricken with, invalid, deformed, disadvantaged; these words evoke unwanted sympathy or pity

People with disabilities want to be respected, accepted and included, just like everyone else.

What's an Interim? What are Interim Charges?

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

n the world of Texas politics and Texas policy, the interim is the time between legislative sessions. The current interim began in June of 2005 and will go until the beginning of the next legislative session in January 2007. Interim periods used to be considered the quiet time after a grueling session, or the calm before the storm. Those days, however, seem to be long gone. During interim sessions, the agencies responsible for implementing legislation (i.e., Health and Human Services Commission, Dept. on Aging and Disability Services, Dept. etc.) work furiously to get programs developed, rules in place, contracts procured, and much more. The interim is anything but quiet. All of these activities provide numerous opportunities for individuals

and families to become involved in

affect both adults and children with

the development of policies that

disabilities.

In addition to the work happening at the agencies legislators work on interim charges. Each legislative committee is assigned a number of charges by the lieutenant governor or the speaker of the house. These charges require the committees to address specific issues. The committees are directed to research, analyze, and develop specific recommendations for each of the charges. This can be an incredible amount of work. Both the Senate and the House interim charges have been released and the work will begin soon. These interim charges and the subsequent studies and reports are important because they often generate legislative proposals for the next legislative session. These proposals can significantly impact children and adults with disabilities and the programs important to them. Some examples of the charges for this interim include: House Human Services Committee Charge # 2 - Study the effectiveness, efficiency and funding mechanisms of mental health and mental

retardation services. Identify and study best practices in crisis intervention, residential treatment and aftercare. Identify and study successful mental health services delivery models established by other states.

House Appropriations Committee
Charge # 6 - Analyze and compare
service coordination and other ad-



ministrative functions across waiver programs as a continuation of the health and human services system

consolidation and optimization. This analysis should include evaluation processes, procedures, outcomes and costs with the intent of ensuring quality, defining best practices and reducing costs.

Senate Education Committee

Charge #5 - Review and make recommendations, if necessary, that streamline and clarify Chapter 37 of the Education Code dealing with student discipline. Include a study of state accountability measures for disciplinary alternative education programs to evaluate academic performance and effectiveness in modifying behavior. Include a study of the effects of zero tolerance practices and other changes made by the 79th Legislature. Include a review of after school prevention programs

Senate Finance Committee

Charge #4. Review health care funding, focusing on the Medicaid program, Medicare Part D, hospital reimbursements and trauma and indigent care.

Senate Health and Human Services
Charge #1 - Study and make recommendations for improving delivery of Texas' mental health services; consider local and regional delivery systems including access to care, cost effectiveness, choice and competition, and quality of care.
Charge #2. - Monitor state and federal Medicaid reform proposals,

including their impact on the Medicaid program in Texas, as well as cost-containment measures in other states, and make recommendations for legislative action, as appropriate.

Charge #10 - Monitor the imple-

mentation of H.B. 2292, 78th Legislature, Regular Session, relating to health and human services. Focus on implementation of service coordination and consolidation efforts to assess the impact on service quality, while reducing costs. These charges and the subsequent studies are great opportunities for individuals and families to have a voice in the development of future policies that have the potential of affecting our children. Information on the committee hearings can be obtained at the website www.capitol.state.tx.us. This is an easy site to maneuver and provides a lot of information on the various committees and committee meetings. Another great way to get information on the various charges is to call the committee clerk for the committee who is assigned the charge you are interested (i.e., House Public Education Committee, Senate Health and Human Services Committee). You can call the capitol operator at 512-463-4630 and ask to be connected to a particular committee office. The staff can tell you when a particular charge may be discussed in a hearing, the scope of the analysis, pertinent timelines, and how your ideas and opinions can be included in the discussions. They are typically eager to hear from folks around the state to get a better idea of how the issues impact Texas citizens. As always, if you would like to participate but need some help or additional information please contact me at colleen.horton@mail.utexas <u>.edu</u>. And, as always, remember that if you're not willing to help with the solutions, you don't hold much ground when you're complain-



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ing about the problems.

Calling All CHARGERS in Texas

MARK YOUR CALENDARS

group in Texas is currently being formed for infants, children, and teenagers with CHARGE Syndrome along with their siblings, parents and professionals. We're

called the TEXAS CHARGERS and we are dedicated to helping give the Texas Chargers a better quality of life. The goal of the TEXAS CHARGERS is

to meet bi-annually to discuss the physical and emotional needs of our children with CHARGE through the sharing of information and the building of a support network. So, mark your calendars for the 1st **Texas**

Chargers Retreat on October 7th 2006 at Peaceable Kingdom Retreat (peace ablekingdomretreat.org) in Killeen, Texas. This retreat will pro-

vide a stress free day for the families to come out and connect with others. The day will include sharing information on raising a child with special

health care needs in Texas and activities such as a carnival with balloons, arts and crafts, face painting, cotton candy, snow cones and a train ride. We will also have lunch and enjoy the activities at Peaceable Kingdom which include an Indian campground,

miniature golf, dinosaur tracks, a theatre & game room, swimming pool and nature trails. If you would like to receive a registration package or be on the membership list, please contact Cathy Springer at dacspringer @austin.rr.com or 512-255-3176.

You won't want to miss all the fun so make sure you mark you calendars! Keep reading future newsletters for more information about the Texas CHARGERS and we look forward to seeing all of you on October 7th at Peaceable Kingdom.

A Very Elite Sorority

any of you I have never even met face to face, but I've searched you out every day. I've looked for you on the Internet, on playgrounds and in grocery stores. I've become an expert at identifying you. You are well-worn. You are stronger than you ever wanted to be. Your words ring experience, experi-

ence you culled with your very heart and soul. You are compassionate beyond the expectations of this world.

You're my "sisters." Yes,



you and I, my friend, are sisters in a sorority. A very elite sorority. Just like any other sorority, we were chosen to be members. Some of us were invited to join immediately, some not for months or even years. Some of us even tried to refuse membership, but to no avail. We were initiated in neurologist's offices and NICU units, in obstetrician's offices, in emergency rooms and during ultrasounds. We were initiated with somber telephone calls, consultations, evaluations, blood tests, x-rays, MRI films and heart surgeries.

All of us have one thing in common. One day things were fine. We were pregnant, or we had just given birth, or we were nursing our newborn, or we were playing with our toddler. Yes, one minute everything was fine. Then, whether it happened in an instant, as it often does, or over the course of a few weeks or months, our entire lives change. Something wasn't quite right. Then we found ourselves mothers of

children with disabilities or other health care needs.

We are united, we sisters, regardless of the diversity of our children's needs. Some of our children undergo chemotherapy. Some need respirators and ventilators. Some are unable to talk, some are unable to walk. Some eat through feeding tubes. Some live in a different world. We do not discriminate against those mothers whose children's needs are not as "special" as our child's. We have mutual respect and empathy for all the women who walk in our shoes.

We are knowledgeable. We have educated ourselves with whatever materials we could find. We know "the" specialists in the field. We know "the" neurologists, "the" hospitals, "the" wonder drugs, "the" treatments. We know "the" tests that need to be done, we know "the" degenerative and progressive diseases and we hold our breath while our children are tested for them. Without formal education, we could become board certified in neurology, endocrinology and psychiatry.

We have taken on our insurance companies and school boards to get what our children need to survive and to flourish. We have prevailed upon the State to include augmentative communication devices in special education classes and mainstream schools for our children with cerebral palsy. We have labored to prove to the insurance companies the medical necessity of gait trainers and other adaptive equipment for our children with spinal cord defects. We have sued municipalities to have our children properly classified so they could receive edu-

cation and evaluation commensurate with their diagnosis.

We have learned to deal with the rest of the world, even if it means walking away from it. We have tolerated scorn in supermarkets during "tantrums" and gritted our teeth while discipline was advocated by the person behind us in line. We have tolerated inane suggestions and home remedies from well-meaning strangers

We have tolerated mothers of children without disabilities, complaining about chicken pox and ear infections. We have learned that many of our closest friends can't understand what it's like to be in our sorority, and don't even want to try.

We have our own personal copies of Emily Perl Kingsley's "A trip to Holland" and Erma Bombeck's "The Special Mother". We keep them by our bedside and read and re-read them

Then, whether it

during our toughest hours.

happened in an We have coped instant ... or over with holidays. We the course of a have found ways few weeks or to get our chilmonths, our dren to the entire lives neighbors' front change. door on Hallow-

een, and we have found ways to help our children who are deaf form words, "trick or treat". We have accepted that our children with sensory dysfunction will never wear velvet or lace on Christmas. We have painted a canvas of lights and a blazing Yule log with our words for our children who are blind. We have pureed turkey on Thanksgiving. We have bought white Continued on Page 6

chocolate bunnies for Easter. And all the while, we have tried to create a festive atmosphere for the rest of our family.

We've gotten up every morning since our journey began wondering how we'd make it through another day, and gone to bed every evening not sure how we did it.

We've mourned the fact that we never got to relax and sip red wine in Italy. We've mourned the fact that our trip to Holland has required much more baggage than we ever imagined when we first visited the travel agent. And we've mourned because we left the airport without most of the things we needed for the trip. But we, sisters, we keep the faith always. We never stop believing. Our love for our children and our belief in all that they will achieve in life knows no bounds. We dream of them scoring touchdowns and extra points and home runs. We visualize them running sprints and marathons. We dream of them planting vegetable seeds, riding horses and chopping

down trees. We hear their angelic voices singing Christmas carols. We see their palettes smeared with watercolors, and their fingers flying over ivory keys in a concert hall. We are amazed at the grace of their pirouettes. We never, never stop believing in all they will accomplish as they pass through this world. But in the meantime, my sisters, the most important thing we do, is hold

tight to their little hands and to-

gether, we reach for the stars.

Author Unknown

P.A.S.S. It On!

any of us have heard of "No Pass, No Play" and "Pass Go and Collect \$200," but how many of us know about "P.A.S.S. - Plan for Achieving Self-Support"?

P.A.S.S. allows persons with a disability to set aside money for a specified work goal. Why is this important? Any person who receives SSI benefits (or who *might* qualify for SSI), or any person who receives SSDI (or a similar benefit) and could qualify for SSI, may be able to have a P.A.S.S. (www.passplan.org/Learn/default_htm)

A Plan can help you keep or get your SSI or could mean a higher payment. (www.ssa.gov/pubs/11017.html)

Remember: a person who is eligible for SSI is automatically eligible for Medicaid! (www.dhs.state.tx.us/publications/refquide/2000/LTCMedicaid.html)

You can have a Plan if:

- You want to work,
- You get SSI (or can qualify for SSI by having this Plan) because you have a disability or are blind, and
- You have other income and/or resources to use to get a job or start a business.

(www.ssa.gov/pubs/11017.html)

Some examples of possible P.A.S.S. expenditures:

- Attendant care
- · Child care
- Transportation to and from work
- Tuition, books, fees and supplies needed for school or training
- Employment services such as job coaching and resume writing
- Modifications to buildings or vehicles to accommodate disability and make work possible
- Equipment, supplies, operating capital, and inventory required to establish a business

Any cost associated with an educational or occupational training facility, including tutoring, counseling, etc. (www.passplan.org/Learn/default.htm

 <u>www.ssa.gov/pubs/11017.html</u>)

The SSI P.A.S.S. Work Incentive can fund any goods/services that will enable a person to achieve their work goal and reduce their reliance on Supported employment benefits. services may be funded using a P.A.S.S. because supported employment increases the potential for "Increased self-support. support" in most P.A.S.S. Plans implies an increase in earnings, but in Employment Supported P.A.S.S. Plans, the vocational goal may be to maintain a supported employment position, including increasing hours worked and reducing hours of job coaching. (www.passplan.org/Learn/ default.htm)

Who can help write or set up a P.A.S.S. Plan? Anyone! Some examples include vocational counselors, social workers, case managers, employment specialists or employers. (www.ssa.gov/pubs/11017.html) There are also a few nonprofit organizations that can help you write the P.A.S.S. A fee may be charged - be sure to ask.

Studies show that very few transition-age students use P.A.S.S. (less than 3% of working-age P.A.S.S. participants were under 30 years of age) and the total number of P.A.S.S. Plans has declined by 40% in recent years due to administrative changes. Other findings indicated that persons with mental illness were more likely to use P.A.S.S. Plans, that work goals focusing on professional specialty occupations were most common, that education and transportation were the most frequently re-

By Jeanine Pinner, TxP2P

guested items and services, and that P.A.S.S. Plans were most often prepared by SSI participants themselves. (Hugh Berry: PASS and School-to-Work Transition (www.edstudies.net/ papers/conference_1099/paper-berry.html) Interested? I hope so, because although writing a successful P.A.S.S. is not the easiest thing you may do, it can be one of the most beneficial for your family member with a disability. Although the information contained in this short article does not tell you everything you need to know about P.A.S.S., it is a place to begin. Listed below are the websites I used to compile this informa-

www.passplan.org/ (check out web resources at www.passplan.org/ resources/default.htm)
www.ssa.gov/pubs/11017.html
www.passonline.org/
www.disabilitybenefits101.org/ca/pr
ograms/income_support/pass/faqs.h
tm (remember that this is a website about P.A.S.S. in California, so not all of the information will be pertinent to Texas. However, it is still an

www.workworld.org/wwwebhelp/pass.htm

excellent source of info.)

www.passplan.org/PASSdb/Listall.as p (Here you will find many examples of successful P.A.S.S.)

www.kff.org/medicare/7241/ssi.cfm www.dads.state.tx.us/handbooks/Te xasWorks/A/1300/1326.8.htm (As P.A.S.S. applies to food stamps in Texas.)

http://benefitsblog.typepad.com/ www.arcil.com/arcilsitefiles/ctbps.h tml

I would love to hear from those of you that choose to become involved in writing a P.A.S.S. You can email me at jeanine@txp2p.org.

The Medicaid Buy-In (a portion of the Family Opportunity Act) - "Getting it in Texas"

ow that the FOA has passed, the action shifts to the state-level. The Medicaid Buy-In is a state option. In most cases, the legislature will have to adopt it. Family Voices Network Members can begin the discussion by talking with your State Medicaid Director, the Governor's Office, State Medicaid Advisory Board, and state legislators. Here are some points to mention during your discussions:

Middle-income families of children and youth with special health care needs often face difficult choices in order to provide health care for their family. These choices can include: bankruptcy, surrendering custody to the state to ensure Medicaid coverage for their child/youth, or spending

down their resources/turning down raises to stay eligible for Medicaid.

- The Medicaid buy-in allows working families of children and youth with special health care needs to purchase Medicaid. This allows Medicaid to act as a wrap-around for medically necessary services denied them by their private insurance plan.
- The Medicaid Buy-In is not an entitlement program. Families must maintain their own private insurance if they have it. The state will be expanding services to working families, many who already have private insurance but must pay high out-of-pocket costs for services not covered by their health plan. The Medicaid wraparound prevents rising uncompensated care costs.

Talking Points from Family Voices

- The Medicaid Buy-In is not an entitlement program because families must use a significant portion of their income to pay for it. However, in most cases, these costs will be significantly cheaper than the out-ofpocket costs they are paying for the actual services.
- Families previously considering bankruptcy or surrendering custody of their child/youth to the state will now have the option to purchase Medicaid for their children. This state option keeps families working and participating in the state income/property tax structure. It also prevents them from having to join the ranks of the uninsured which leaves the full burden of their cost of care on the state.

Thank You to All Who Donated to our 2005 Mail Campaign!!

New Donors:

All Star Medical Vickie & Richard Black In honor of Jeffrey Wesley Patty Bradley Jeffrey T. & Elisabeth S. DeLargy Kathy Falor In memory of Sara Zimmerman

Rosalyn Fisher Alma & Christophe Harle Dr. Mary Marvin Johnson Kathleen & Joe Monaco Angela & Randy Philley In honor of the Ates Family and the Mayes Family Javier Salinas In honor of Milla Burt John Worrel, M.D.

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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
Monday, May 1 st to Tuesday, May 2 nd , 2006	What Works! Community Options Employment	Omni Austin Hotel Downtown Austin, TX	For more information, contact Morgan Castagna at Community Options, Inc. at (609) 951-9900 or E-mail: morgan.castagna@ comop.org or www.comop.org
Wednesday, May 31 st to Friday, June 2 nd ,	5 th Annual Bridges to Employment Conference	Holiday Inn Riverwalk San Antonio, TX	For more information, contact Robin Savinar at the World In- stitute on Disability at (510) 251 -4325 or robin@wid.org or www.proyectovision.net/
Wednesday, June 7 th to Thursday, June 8, 2006	1 st Bi-Annual Autism Conference	Lubbock, TX	For more information, contact Region 17 ESC at 806-792-5468 x855 or <u>www.esc17.net</u> - <u>david.jenkins@esc17.net</u> -
Wednesday, July 12 th to Friday, July 13 th ,	Texas Association on Mental Retardation 31 st Annual Convention	Omni Hotel Corpus Christi, TX	For more information, contact TAMR at 512-349-7470 or www.tamr-web.com or Email: pat-holder@tamr-web.com
Thursday, Sept. 7 th to Saturday,	Texas State Conference on Autism	Adam's Mark Hotel Dallas, TX	For more information, contact ESC Region 2 at 361-561-8400 or www.esc2.net/autism/