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Texas Parent to Parent

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

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The Budget Crisis - No Painless Cuts

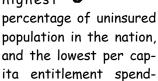
uring the 2002 campaigns, as the threat of a deficit was looming, the Governor and other government officials talked about how they would cut the fat out of the budget. Some of them now realize that they

While estimates of the deficit have gone from \$5 to \$9.9 billion, the painful reality is coming

were on a wild goose

home to roost. In a state that already has the highest

chase



ing, while there may be some fat in the budget somewhere, it is not in health or human services.

The combination of a serious budget shortfall and promises avoid raising revenues, meeting head on with rising costs for health care and other services, and increasing numbers of people needing services, means that something has got to give.

Mind-numbing statistics
There are no easy solutions to this problem.
The state government has proposed a 12.5% budget cut across the board. This cut, combined with losses in some programs of Federal matching funds, and the possibility of cuts

from the Federal government as well, means much lower revenue to the state. All state programs would be affected, but cuts in Health and Human Services would fall particularly hard on those already vulnerable.

Much of the following information comes from the excellent report by the Center for Public Pol-"What Priorities, Texas Can't Buy with \$54.1 Billion," of which this is a brief overview. For greater detail, see http://www.cppp.org/ index.html, go to Policy Areas, to State Budget & Taxes, to State Budget, to Policy Pages, for the full article. Of course, the budget situation is fluid until the final

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By Nancy Post, Texas Parent to Parent

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Texas Parent to Parent Update: Central Texas Faith in Action Respite Cooperative

By Laura J. Warren, Texas Parent to Parent

very parent at one time or another needs and expects to receive respite from daily child rearing. This brief time away provides parents with an opportunity to relieve stress and to return with a renewed capacity to enjoy and nurture their children. Respite care for families of children with disabilities or chronic illness is a truly essential piece of a very complicated life. In national studies, respite care is the need most frequently cited by families of children with special needs and one that is very hard to These families care for their child 24 hours a day, 7 days

a week, most times with very little support. Respite allows the primary caregiver and family members to step back from the consuming demands of care and take a little time for themselves. With respite, the primary caregiver is better able to continue to provide appropriate care required by the child over many months and years. Texas Parent to Parent (TxP2P) has received funding from the Justin Paul Foundation and has submitted a grant to the Robert Wood Johnson Foundation specifically targeted for faith based respite programs. While TxP2P will be integral in providing the

support and training to get the project off the ground, respite cooperatives will eventually be self-sustaining projects administered entirely by the churches/ faith communities involved. Programs will be tailored to the needs of the churches and families involved. TxP2P will continue to be involved as requested to provide technical assistance, but the intention is to build a program for and by the local faith communities to avoid creating a separate bureaucracy or unnecessary control or regulations.

Texas Parent to Parent is

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The Budget Crisis - No Painless Cuts

version is passed, but the crucial decisions are being made now.

In Medicaid and CHIP (Children's Health Insurance Program) alone, nearly 700,000 people would lose services by 2005. While CHIP is predicted to survive in some form, deep cuts are considered likely. Also under consideration is trimming benefits, such as dental care, eyeglasses, hearing aids, durable medical equipment, treatment of mental illness, speech therapy and physical therapy.

In Dallas County for example, cutting Medicaid by 12.5% would cause 38,000 low-income people, most of them children and pregnant women, to lose their health insurance. Estimates are that Parkland Health and Hospital System would be left \$60 million short, and Children's Medical Center of Dallas would be \$50 million short. However, the largest amount of money would come from a proposed 33% decreased reimbursement of Medicaid providers, doctors and hospitals, paid by the Health and Human Services Commission for providing care. Health administrators worry that at those rates of reimbursement, doctors would leave the children's health care programs, causing children to loss their doctors. The costs of these cuts are amplified by the loss of matching federal funds, about \$1.50 for every \$1.00 paid by the State. The cost to Dallas County is estimated to be about \$700 million. The overall loss to the state of Texas is expected to be \$1.6 billion in state funds, plus at least \$2.3 billion in federal dollars, for doctors, hospitals, clinics, home health care, etc.

The Texas Department of Health would reduce services for Women's Health, Children with Special Health Care Needs (CSHCN), Early Periodic Screening, Diagnosis and Testing (EPSDT), and numerous public health programs, such as vision/hearing screening. Some programs would be eliminated completely, including the Epilepsy Program and Children's Heart Outreach.

A 12.5% decrease in the Department of Human Services (DHS) budget would mean severe cuts in the Community Care programs, forcing some people from their communities into nursing homes, and

cutting cash assistance and other services to Texas' poorest children, receiving TANF (Temporary Aid to Needy Families).

The Texas Department of Mental Health and Mental Retardation (MHMR) budget, already threadbare, would face cuts that would affect services to about 33,000 people, including more crowded residential facilities and hospitals, and reduced funding for Children's Mental Health Community Centers. Texas currently ranks 46th in per capita mental health spending, and the current MHMR budget, according to the Texas Observer, can only serve a third of its present "priority population," leaving hundreds of thousands of people without services. For example, the Waco Center for Youth, the lone statewide mental health hospital for children, has a six-month waiting list for one of its 81 beds, and the other regional state hospitals are 98 percent full and nearly impossible to get into. While both the

population and the need for mental health services have continued to grow, the legislature hasn't increased fundfor chilina dren's mental health in nearly

10 years.

"The overall loss to the state of Texas is expected to be \$1.6 billion in state funds, plus at least \$2.3 billion in federal dollars, for doctors, hospitals, clinics, home health care, etc."

Because of long waiting lists for services, several state agencies are already facing a lawsuit by the Arc of Texas and Advocacy, Incorporated. The lawsuit against the state is an effort to stimulate development of Medicaid waiver services for the more than 20,000 Texans with mental retardation and other developmental disabilities who are on waiting lists for waiver services. (Medicaid waiver services waive the requirement that the overall household income meet Medicaid guidelines, and instead use the child's income, usually little or nothing, as the criterion.)

Agencies being sued for inadequate current services are:

- The Texas Health and Human Services Commission in its role as the state's Medicaid agency;
- The Texas Department of Mental Health and Mental Retardation,

which operates the Home and Community-based Services waiver (HCS) serving people with mental retardation;

• The Department of Human Services, which operates the Community Living Assistance and Support Services (C.L.A.S.S.) Medicaid waiver program serving people with developmental disabilities other than mental retardation.

What does that mean in the lives of individuals, families, and children? How does this avalanche of statistics look from the perspective of the families who depend for assistance on these services? One program, C.L.A.S.S., (Community Living Assistance Services and Supports), a Medicaid waiver program, provides funds for helping families care for a family member at home. Parents talk about what it has meant to their families.

After her daughter was injured in a car accident, one mother knew she had to be *sure* her daughter remained eligible for Medicaid to get the medical care she needed. To protect her daughter's eligibility, the parent had to do anything she could, including keeping her income within the guidelines, to keep 'qualifying'. She even refused to marry the man who had stood by her for many years. But because Medicaid did little to help her care for her daughter at home, she applied for C.L.A.S.S.

Since they became eligible for C.L.A.S.S., her daughter qualifies for assistance that makes it much more possible for her to live in her own home, including an attendant, modifications to make her home accessible, and various types of therapy, none of which are covered by Medicaid. Since eligibility for C.L.A.S.S. is determined by her child's income, the parent was freed from having to take a vow of voluntary poverty.

There are many benefits, and she finds it hard to choose the most important one. "Today, I can work almost whatever hours I want and for the best pay I can get! But is that more or less important than the fact that our attendant who comes everyday from 4-10 pm allows me the freedom to do that? How is that more important than the therapies my child receives weekly that enable her to progress

daily? Where does marrying the man who still stands by me fit in? I almost forgot the \$15,557 van modifications that almost no one other than a Medicaid waiver program pays for!" In other words, she does not have to choose between caring for her child at home and living her own life. She has seen life before and after community living assistance, and she would never want to go back.

Another parent talked about the major changes in the life of her family when her son, who has autism and requires 24-hour-a-day care, qualified for the C.L.A.S.S. program. With attendants, who could provide him with the very high level of attention he needs, the parents and siblings no longer had to focus exclusively on caring for their son, and the family could again function as a family.

She has seen some important

"He's become pottychanges. trained since the attendants started coming. He'd worn diapers for years. That was a major accomplishment!" He's learning other skills, including communication, and is more independent now. His brother likes the fact that with the help of attendants, the family can take him to baseball games, out to eat, or to the grocery store, things they could not have done before. Without that help, he would be much more isolated from his community, and even in his own family. These new skills will help him become more independent in the long term, and make him better able to care for himself as an adult, hold a job and contribute to society. His progress will be important to his siblings also, because, as his mother noted, after his parents are gone,

Having now lived with the assistance of skilled attendants, the mother would never go back to life as it was

they will have the responsibility of

supervising his care.

before, although her family would have to go into debt to do it. Although they have the option of putting their son in an institution, it is a choice they would never make. She has worked with people who were in institutions, and now are living with assistance in their own homes, and knows too much about their dread, even threats of suicide, at the thought of going back to an institution. So, although the responsibility is a large one, they are determined to keep him at home. Now, she, her husband, their other children, and her son with special needs, all have a more satisfying life as individuals, and together as a family, and a more positive future.

Another parent with a child who needs intensive, round-the-clock care, talks about how her family's Medicaid waiver program has affected their lives. "The most helpful aspect of our Medicaid waiver program is the peace of mind it brings. Our daughter is now on 9 medications, has 8 specialists, uses 3 positioning devices and seems to develop a new diagnosis every two years. She is only 12, and I have a bad feeling that if we were not on the C.L.A.S.S. program, our family situation would be very different. Either we would be bankrupt or my daughter would be living in a nursing home. Because we have C.L.A.S.S.. she is able to have all the medications she needs. She can see the pediatric specialists as needed, and is able to get the devices she must have to live in our community. Her siblings can interact with her on a daily basis and she can go to the school of our choice. We, as a family, can go on outings with her, or we are able to leave her in the care of an attendant if her health is poor. My husband can run his business and I have the opportunity to be involved in all my children's educational experiences. We can be contributing members of our neighbor-hood, schools, church and community. We volunteer and give of ourselves to worthy causes. None of this would be possible if we had to scrape by, work three jobs, or not have Jessica in our lives." Just as the parents before her did, she knows how important the benefits are to the whole family. "This Medicaid waiver program has kept our family intact and vital."

What's the bottom line for children and families?

As an administrator of Children's Medical Center in Dallas trying to cut back his budget reported, there was no fat in his budget to trim: "What we're down to now is amputation." His comments could apply to almost any program affected by the State's proposed budget allocations.

All of the programs under the knife serve real human beings. There will be no painless cuts. Every child needing Early Childhood Intervention will have a greater distance to go without it. Every child who goes without medical care, EPSDT (Early Periodic Screening and Diagnostic Testing), or eyeglasses or a hearing aid, risks having a small problem grow into a major one. Children with mental illness who do not have the care they need may end up in Child Protection Services or the mental health unit of the prison system. People deserve the support they need to succeed in living in the community. Loving families, determined to give their children the best care possible, in the nurture and security of their own home, need the services that will protect the integrity of the family and support their determination to do so. For more information on the proposed funding cuts and ways to contact your legislators, see the "Legislative Update" by Colleen Horton below.

Legislative Update

here do I begin? Anyone who reads the newspaper or watches the news on TV knows of the incredible budget crisis Texas is currently facing. Over the past 6 weeks, the House Appropriations Committee and the Senate Finance

By Colleen Horton, Texas Center for Disability Studies

Committee have been holding hearings on the vast number of state funded programs including education and health and human services programs that provide supports and services to children with disabilities.

While there are thousands of indi-

viduals with disabilities (adults and children) on various waiting lists - waiting for community-based services - there has been little talk this session of funding new slots. The discussion at the Capitol has been "where do we

Continued on Page 4

Legislative Update

cut." The following is a brief snapshot of some of the <u>proposed</u> policy changes to date. This is not by any means meant to be a complete list, nor are any of these proposals finalized. This is simply intended to give you an idea of what we may be facing.

- Eliminate eligibility for more than 16,000 individuals receiving community-based services through Primary Home Care.
- Elimination of In-Home and Family Support Programs at both Texas Department of Human Services and Texas Department of Mental Health and Mental Retardation.
- Reduce the Consolidated Waiver
 Program from 200 individuals to 125.
- Eliminate services for more than 34,000 in the Frail Elderly Program.
- Change eligibility for the Children's Health Insurance Program from 200% of federal poverty level to 150%.
- Reduce the total number of CLASS slots.
- Change Medicaid eligibility from 300% of the SSI level to 100% of the SSI level. This would make more than 41,000 individuals currently receiving long term care services ineligible. This would also affect eligibility for waiver services.
- Reduce Medicaid provider rates by 33%. This would significantly reduce (if not eliminate) access to medical professionals and other providers.
- Eliminate drug coverage for all

Medicaid recipients (including those receiving waiver services) except pregnant women and certain nursing home residents.

All agencies will be affected. All programs face possible reductions. What can you do?

It is vitally important that those families whose children currently receive waiver services and those "waiting" for services call members of the House Appropriations Committee and the Senate Finance Committee. Tell them how important community-based services are to your child. Help them understand that community services help to keep children at home, help keep families together, and help to prevent costly institutionalization of our children.

Time is truly running out. It is your responsibility to help save these programs for children and adults with disabilities. All members of the legislature can be reached by calling the Capitol Operator at 512/463-4630. Start making calls today! It is the only thing that will make a difference.



Please remember, if you're not part of the solution, then you're part of the problem!

Who to Call:

Call the Capitol Operator at (512) 463-4630 and ask for the office of each representative:

House Appropriations Subcommittee on Health and Human Services

Rep. Talmadge Heflin, Chair

Rep. Vilma Luna, Vice Chair

Rep. Arlene Wohlgemuth, Chair, Subcommittee on Health & Human Services

Rep. Craig Eiland

Rep. John Davis

Rep. Suzanna Gratia Hupp

Rep. Dawnna Dukes

Rep. Vicki Truitt

Senate Finance Committee

Senator Teel Bivins, Chair Senator Judith Zaffirini, Vice Chair

Senator Robert Duncan Senator Jane Nelson

Senator Kip Averitt

Senator Gonzalo Barrientos

Senator Kim Brimer

Senator Kyle Janek

Senator Jane Nelson

Senator Steve Ogden

Senator Florence Shapiro

Senator Eliot Shapleigh

Senator Todd Staples

Senator Royce West

Senator John Whitmire

Senator Tommy Williams

Book Review: <u>Planning Care for Children in Respite Settings</u> by Helen Laverty and Mary Reet

ritten by Helen Laverty, a registered nurse who has worked with people with learning disabilities for twenty years and Mary Reet, a pediatric nurse with similar experience, this book was developed in response to a practical need- quality respite care for children with special needs and their families. Offering a new approach, centered on the child's abilities rather than disabilities, this book employs a positive focus on emerging levels of independence in disabled children.

Laverty and Reet have developed a model, which they call "Hello, this is

me". This model provides a method of assessing and planning care for

children with a variety of needs. The authors emphasize a partnership between families and caregivers, which enables children and parents to make their voices heard when planning respite care, so that each

"Offering a new approach, centered on the child's abilities rather than disabilities, this book employs a positive focus on emerging levels of independence in disabled children."

child's unique needs can be met. This model allows caregivers to cal-

Review by Cindy Lennartson, Austin

culate the amount of support each child will need, but more importantly, it ensures that respite care is not just a break for families but also an enjoyable experience for the child.

The book demonstrates the "Hello, this is me" model with actual case studies and assessment tools. This innovative, clearly explained approach to respite planning would be invaluable to both respite providers and families in need of respite

Jessica Kingsley Publishers, London, 2001. 171 pages. \$24.95, purchase at http://www.jkp.com

2003 YOUTH LEADERSHIP PROGRAM

By Sandie Gonzalez, Children's Association for Maximum Potential (C.A.M.P.)

he Children's Association for Maximum Potential (C.A.M.P.) is looking for future community leaders to participate in an exciting new program - the 2003 Texas Youth Leadership Forum (YLF) for young persons with dis-The YLF, which will be abilities. held at a Hill Country Conference Center in San Antonio, is a fun, educational, vocational awareness program that enables young people to learn from each other and from successful adults with disabilities who are recognized leaders and role models

Modeled after a national youth leadership program that originated in California 12 years ago, the first Texas YLF will include 30 young people with disabilities, ages 16 to 22, from across Texas. Forum participants will be selected through an application and interview process and include applicants that want to

be leaders in the community who have demonstrated academic success, community involvement, leadership potential, and an ability to interact effectively with other students.

The Texas YLF participants will attend a weeklong session, from Sunday, July 27 to Friday, August 1, 2003, in which they will develop a "personal lead-

ership plan." This plan will help them identify and deal with barriers to personal and professional success. Participants will also collaborate with other young people who have leadership qualities, learn more about assistive technology, work on building self-esteem, and learn about the history of disability as a culture.

The YLF is FREE for individuals who are selected to participate. program is offered by C.A.M.P. with financial support provided through the Texas Council for Developmental Disabilities (TCDD), a 30member board dedicated to ensuring that Texans with developmental disabilities have the opportunity to be independent, productive and valued members of their communities and to improve the community's understanding of disability issues. If you know a young person who would benefit from this program, please encourage them to call for an application. For additional information and to request an application, please call Jennifer Murphy or Sandie Gonzalez at (210) 292-3566 or (210) 292-3574.

Summer Camp: To Send Your Child or Not To Send Your Child - A Very Difficult and Emotional Decision!

Compiled by Laura J. Warren, Texas Parent to Parent

sent my son who has mild cerebral palsy, speech delay and sensory issues, to a week-long day camp for the first time when he was 6 years old. It did not go well. Jason cried each morning as they pulled him up the road to camp, even though he had his best friend with him. I have never been able to get him to try it again, even though I know, once he could no longer see me, he had fun. I have talked to a lot of people about the dilemma of sending their child with disabilities to camp. For some, it is as good as it gets; for others it's a disaster. Here are a few stories I collected in the hope that they might help with this very hard decision.

**I was so apprehensive about sending Kaly to camp! She could not prevent anything bad from happening to her nor could she then tell me (or anyone else) what had happened! Besides that if I took her and dropped her off at some strange place with people she didn't know, surely she would think I had abandoned her! How would either of us have a good time! After years of almost completing an application, I finally sent Kaly off to C.A.M.P. Camp. Her camp goal was to under-

stand that she was on vacation and it is suppose to be fun! My friends lined up activities to keep me occupied during the "ordeal" and I had to admit that I had a pretty good time!

The day came to pick Kaly up and I am not sure who was happier to see whom, but we were both pretty happy! Kaly had taken a camera to camp and we put the pictures in one of her many photo albums. talked endlessly about riding the horses and her new friends. One day she was looking through the photo album and said "Mom, I want to go there - and ride the horses, too." So, off again she went to camp but I planned my own activities! That year, Kaly came home saying "Mom, vacation is fun!" This will be the 5th year she has gone to C.A.M.P. Camp and we both love it!

**I only have one story about camp for my daughter Amy, (autism, epilepsy, severe mental retardation). We took her to our local MHMR camp at an old girl scout camp. Amy was about 8 years old and it was a one-night camp. They assured us they would call if there was a problem. Amy's epilepsy level at the time was about 250 to 300

absence seizures, lasting 5 to 10 seconds apiece. This caused her to forget everything constantly. Evidently, during the night, she kept waking up to unfamiliar surroundings and people, and was completely terrified - with screaming and crying and wanting to get away. They would calm her down and she would go to sleep again, only to reawaken and go through the whole process This evidently happened again. about four times during They never did us. When we got there the next morning, she and her FOUR attendants were exhausted, practically hysterical and couldn't wait to get away from each other. After that, MHMR asked that we not bring Amy for any outings again, as they could not afford four attendants for one child! It was a completely traumatic experience for her, the MHMR people, and us. After that, we were fairly well ostracized from MHMR activities for her, ourselves, and her siblings. This made for a very bad time for our family and I would caution anyone with a child with autism and epilepsy to be careful about this kind of activity.

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Mothers' Milk Bank at Austin

By Kim Updegrove, CNM, MPH, MSN, Clinical Coordinator, Mothers' Milk Bank at Austin

he milk that you sent to my son saved his life. You would never know how you helped us, he was so sick and little and we all know the big difference that breast-milk makes. We would never

finish expressing our gratitude for all your help, please give my thanks to all the people that make this miracle possible. And never

forget that your society helped save my son's life." -Premature recipient's mom

The above testimony was sent to the Mothers' Milk Bank at Austin (MMBA), from the mother of a premature infant who received human donor milk from the MMBA. The Mothers' Milk Bank at Austin is a nonprofit organization dedicated to the provision of safe human milk for premature and sick babies. Premature infants are six to ten times more likely to acquire lifethreatening infections during the neonatal period if fed infant formula instead of human milk. Nonetheless, not all mothers are able to provide sufficient breast milk for their infants during this critical period, leaving commercial formula as the only alternative. The MMBA fills this need for human milk.

The concept of the Mothers' Milk Bank at Austin began in 1998, when two Austin-area neonatologists, Dr. Audelio Rivera and Dr. George Sharpe, gathered local health care providers and community members together to discuss the possibility of creating a bank of donor milk. The physicians described differences seen in the babies in the neonatal intensive care units depending

on whether they were fed formula or breast milk - differences in rates of infection, and, in time spent in the NICUs. As is seen in the medical literature, a link between the miracle of mothers' milk and the miraculous lives of premature infants was made.

By 2002, the MMBA had grown to serve infants in NICUs in 13 hospitals in and around Texas, as well as about 32 infants at home. Hospitalized premature and ill infants take priority, but outpatients suffering from failure to thrive or malabsorption syndromes, cardiac conditions, immune disorders, or renal disease also are served by the milk bank.

MMBA collects human milk from healthy donor mothers who have more milk than their own infant needs. Safety of the milk is provided through screening of medical and lifestyle histories, blood tests, microbiological testing of milk samples, and pasteurization of pooled milk. Staff at the milk bank work with lactation consultants, nurses, and physicians to educate both the public and health care providers about the benefits of breast milk. The milk bank also provides advice to mothers who are breastfeeding their own infants. Donating milk can be a very rewarding experience!

"It was such a blessing to find an organization such as yours. I am very happy that, through you, I can help other tiny babies on their way to a healthy, happy life. Donating my extra milk gives me such a sense of satisfaction and I am very proud to say that I do so." -Donor

Many people make the efforts of the MMBA successful! Donors voluntarily pump and store their milk according to the Milk Bank's guidelines, avoiding medications, herbs, and other dangerous behaviors. Volunteers from organizations such as the Junior League of Austin, and individuals of all ages serve to pick up milk from remote drop-off centers, call donors with reminders for paperwork, and handle filing and other paper needs in the office. Health care providers recognize when their infant patients will benefit from milk, and work with

the parents or hospitals to obtain milk for the baby. The team efforts of these groups help change the outcomes for these smallest members of our population.

"On a personal rates of infection note, we would and, in time spent like to thank all of you so very

"The physicians described differences seen in the babies in the neonatal intensive care units depending on whether they were fed formula or breast milk - differences in rates of infection, and, in time spent in the NICUs."

much for providing us with 'mommy milk'. We truly believe that she is the healthy, thriving little girl she is today because of your enabling us to provide her with what God intended and I could not produce. Our most heartfelt thanks to all the mothers" -Recipient's mom (baby was 2lbs. 6 oz. at birth)

If you would like to be screened for either donor or recipient status, call (512) 494-0800 and ask for Kim Updegrove. Volunteers can call the same number, but ask to speak with Sarah Emery. We are open daily, from 9:00 a.m. to 5:00 p.m., with the exception of Fridays when we close at 1:00 p.m.

Kid & TeenSAFE, Personal Safety for Students with Disabilities, a Program of Disabilities Services ASAP

id & TeenSAFE, located at SafePlace in Austin, can provide a 1-1/2 hour presentation for teachers, parents and family members to help them recognize and prevent against abuse against students with disabilities. The training includes discussion of incidence of abuse, risk factors for our children, signs of abuse, responding to abuse disclosures, re-

porting abuse and personal safety strategies.

Another service Kid & TeenSafe can provide is 3 to 4 customized sessions for students with disabilities. These sessions will include discussions on emotions, touches and words, medical terms for body parts, fun and hurtful secrets, harassment, bullying, personal safety rules, and healthy relationships.

Contact Peggy Martin, Kid & Teen-Safe Educator, for more information or to schedule a training, at 512-356-1568 or email her at pmartin@austin-safeplace.org The trainings are free except for travel expenses which are negotiable. Also, the website for Disability Services ASAP (A Safety Awareness Program) is austin-safeplace.org/programs/disability.

Central Texas Faith in Action Respite Cooperative

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currently working with three churches in Travis and Hays County to create respite cooperatives. We plan to expand into Williamson County soon and then to expand the number of respite cooperatives available in the three county area. Our goal is not only to create respite opportunities for families but also to encourage the inclusion of families of children with disabilities and chronic illness within faith communities.

Texas Parent to Parent will use the funding received to hire a Respite Coordinator who will help create the respite cooperatives and then provide continuing administrative and technical support. TxP2P will work with the faith communities to re-

cruit volunteers to provide respite care in cooperation with the families of children with special needs. The volunteers will receive training in caring for persons with disabilities and chronic illness and a briefing by each parent on his or her child's own particular needs and interests. Family members will take turns staying for the respite event until the volunteers and families are comfortable with volunteers caring for the children.

Each respite cooperative will be designed by the church/faith organization and parent representatives with the assistance of TxP2P. The decisions to be made will include who will be involved, how often an event is offered, how many children can be

served, location and other logistics. Each cooperative will be different. Each faith organization will decide what piece of the cooperative they want to provide: location for respite event, volunteers and/or funding as needed.

As with our Project DOCC Program (medical resident training program), TxP2P will create the respite program with the faith community in the Austin area and then replicate it across the state. If you would like more information or to help with this effort, please contact Sue Regimbal with Texas Parent to Parent at 512-458-8600 if local to Austin or our toll-free number 866-896-6001, or email her at Suetxp2p@sbcglobal.net)

Summer Camp: To Send Your Child or Not Continued from Page 5

Camp Discovery, also known by the kids as "skin camp", is safe fun every year! Tom has gone for 3 years in a row now and every time we pick him up from the airport, he says, "I wish I could live at camp. We don't focus on each other's skin. We just have great fun!!! It is the only place in the whole world where I feel normal for one glorious week!" The youth camp for Camp Discovery is held at Cross Lakes, Minnesota. Kids, ages 10 to 13 years old, go to this one. The teen camp is in Pennsylvania and has 14-17 year olds. The staff all have some type of skin disorder too. And many of the staff

are doctors, nurses, medical residents and former campers who are now young adults. There is talent night, swimming, boating, canoeing, crafts, campfire songs, horseback riding, tubing, archery, water skiing, and a boat trip to Dairy Queen. It is a 3 to 5 hour bus ride from the Minneapolis Airport but it is more than a ride. It is more like a mobile party in the bus! While waiting for the gang to arrive from many different flights, the staff tease the campers with mysteries/riddles to solve. They teach the kids cool jokes to tell their friends when they get home. They play card games, eat, and horse around and chat all while waiting at the airport. And finally Tom comes home with a ton of freebie stuff: tote bag, toys snacks, mini clocks, calendar, etc. All say Camp Discovery on them - great souvenirs! A month later the Camp Director, Dr. Julie, sends photos of all the fun had by Tom. It is a very loving environment. Tom almost hates to see his condition improve because he may not qualify for camp again this year. But he wouldn't want to bump a sicker kid out of camp fun.

If you would like to talk further with any of these moms, call us!

Someone Who Understands

farmer had some puppies he needed to sell. He painted a sign advertising the pups and set about nailing it to a post on the edge of his yard. As he was driving the last nail into the post, he felt a tug on his overalls. He looked down into the eyes of a little boy.

"Mister," he said, "I want to buy one of your puppies." "Well," said the farmer, as he rubbed the sweat off the back of his neck, "These puppies come from fine parents and cost a good deal of money."

The boy dropped his head for a moment. Then reaching deep into his pocket, he pulled out a handful of change and held it up to the farmer.

"I've got thirty-nine cents. Is that enough to take a look?"

"Sure," said the farmer. And with that he let out a whistle "Here, Dolly!" he called. Out from the doghouse and down the ramp ran Dolly followed by four little balls of fur.

The little boy pressed his face against the chain link fence. His eyes danced with delight. As the dogs made their way to the fence, the little boy noticed something else stirring inside the doghouse. Slowly another little ball appeared, this one noticeably smaller. Down the ramp it slid. Then in a somewhat awkward manner, the little pup began hobbling toward the others, doing its best to catch up.

"I want that one," the little boy said, pointing to the runt.

The farmer knelt down at the boy's side and said, "Son, you don't want that puppy. He will never be able to run and play with you like these other dogs would."

With that, the little boy stepped back from the fence, reached down, and began rolling up one leg of his trousers. In doing so he revealed a steel brace running down both sides of his leg attaching itself to a specially made shoe.

Looking back up at the farmer, he said, "You see, sir, I don't run too well myself, and he will need someone who understands."

The world is full of people who need someone who understands! Don't be

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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.

Texas Parent to Parent would like your help!

We want to get as many resources on our Website Resource Directory as possible so parents can find the services and support they need. Please take a look at the Directory for your area and/or county at http://www.main.org/txp2p/Resources.html If we are missing services that you are aware of or have the wrong info, like phone numbers, address, etc., please let us know. Either call Laura, Tammy or Sue at 866-896-6001 or 512-458-8600 or email Tammy-txp2p@sbcglobal.net You will be helping other parents by reducing their search time.

ALL PARENT GROUPS: Please register with us so parents can find you. Go to http://www.main.org/txp2p/Groups.html to register on-line or call us at the above numbers.

Date	Conference Title	Location	Registration Information
April 24 to	2003 Texas Association for the Education and	Omni Hotel Downtown	Christy Shepard (281) 897-6490
April 26, 2003	Rehabilitation of the Blind and Visually Impaired (TAER)	700 San Jacinto Blvd Austin, TX	Fax: (281) 517-2660 or cjshep@academicplanet.com www.tsbvi.edu/Outreach/taer-2003
April 30 to May 2, 2003	Asperger's SuperConference 2003	Southfork Ranch Parker, TX (Near Dallas)	Phone: 800-489-0727 or 817 -277-0727 www.futurehorizons-autism.com
June 12 to June 13, 2003	Texas Focus 2003: Tactile Learning	Historic Sheraton Gunter Hotel on the Riverwalk San Antonio, TX	Melinda Lucas (512) 206-9344 or MelindaLucas@tsbvi.edu or Jim Durkel at (512) 206-9270 or JimDurkel@tsbvi.edu
June 27 to June 28, 2003	Texas Council for Exceptional Children (CEC) 23 rd Annual Conference Changing Students: Changing Practices	Radisson Hotel Austin 111 East Cesar Chavez St. Austin, TX	Mary Ann Gustafson 512-232-5538 or Melissa Olive 512-475-6585 www.tcecweb.org/ stateconference