Parent to Parent

Texas Parent to Parent

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

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How I Survive the Holidays!

Compiled by Laura J. Warren, Texas Parent to Parent

et's face it - if
you have a child
with a disability,
mild or severe, visible or
hidden, your
life is
stressful.
So, if the
holidays are
a stressful
time for the
general pub-

lic, they will be doubly stressful for us. I've watched a lot of people go through the holidays, some more successfully than others, and decided to ask them for their best tips on surviving the holidays. Here's what they said:

 I make sure I take a little time for myself.
 . without my children, dear husband and pet dogs. I enjoy walking - just 30 minutes can make a world of difference.

• Give yourself freedom to JUST SAY NO to something you really don't want to do. Whether it is a fundraising meeting, a PTA meeting, whatever task you really just don't want to do or have run out of mental or physical energy for, JUST SAY NO. True, this is not something you can "get away with" on a regular basis with whatever your responsibilities are, but if you own up to being just too tired or overwhelmed, 100 chances are your honesty will be appreciated. And if it's NOT, well, what were you pressing yourself to do it for if there wasn't going to be any appreciation?

- Something I do for myself when we've got a large group over (large for us is more than the 5 in our family!) is escape to our bedroom for a quick respite from the excitement. Entertaining exhausts me but I do enjoy family gatherings. I've just recognized that a five-minute break from the group can keep me going longer.
- Everyday, take ten minutes in a quiet room, lying down, with or without music/ headphones,

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A Great Beginning—Texas Parent to Parent's First Year!

By Laura J. Warren, Texas Parent to Parent

What hat a year!! started with a dream and a few people discussing the idea of a statewide parent to parent program in Texas is now a reality. Finding our talented grant writer, Nancy Post, who agreed to help us write grants in December 2001, we were off and running. Our first Board of Directors meeting was in January, we were incorporated in February, designated a nonprofit organization in March, received our first grant in April, and moved into an office in June. We have over 170 parents on our database and we have not really advertised yet. We are still scrambling to keep up with writing grants, matching par-

ents, running a Federal grant, and keeping up with all the Board, State, and Federal requirements of a nonprofit organization, but we are very pleased with where we stand at the end of 2002.

We want to thank our Board of Directors for all their hard work! To Sarah Barnes, Nancy Swiderski Brach, Margaret Bruch, and Madeline Sutherland - thank you and you will be missed! To our new members, we thank you for the time commitment to help us move TxP2P forward in the years to come - Raymond Turner, Denise Brady, Maria Garcia, Leticia Padilla, and Bryan Sperry. To those members who saw us through this year and will continue

helping us in the years to come, a very special thank you - Debbie Burt, Jan and Charlie DiMare, Susan Prior, and Leah Rummel. And to our Board Chair, Val Sutorius - you are amazing - one of the hardest-working, everlearning, dedicated women we have met. To Nancy Post, your willingness to zip down to Austin to work with us or attend a seminar is so appreciated - thanks for all you have done for us! To our dedicated volunteers who have helped us with new parents! We could not have come so far so fast without all of you. So, Sue, Tammy, Patty, and I would say a

heartfelt THANK YOU!!!

and FREE your MIND! Really focus on an absence of thought, and see where your mind goes. Whatever thoughts DO come in must be tossed away if they are stressful or negative. Just BE. No role, no problem, nothing to solve. Ten minutes. JUST TAKE IT. Take twenty if possible.

• Delegate whatever you can to others; give up traditions you don't

"My key to surviving the holidays is to lower expectations." enjoy; and most of all be careful to eat right, exercise, and get plenty of sleep. Holidays are to be enjoyed and if the one who is 90% re-

sponsible for the work of them isn't enjoying herself, then she can't make them enjoyable for the rest of the family. As my husband says, if Momma ain't happy, ain't nobody happy.

• My key to surviving the holidays is to lower expectations. I have worked hard at establishing new traditions for our family that are nothing like what we did when I was a child or what the Norman Rockwell America is pictured as doing. Our traditions are much more informal, flexible, small scale, workable. That way we aren't disappointed by not conforming to the perfect picture. An example: the Christmas Day when my son was having a really bad day--maybe he was getting sick or something but he was terrible--crying, not cooperating, getting into one thing and being unable to switch to something else, including sitting down to Christmas lunch. Finally, we found the only thing that calmed him down was sitting in our car parked in the garage. And that's where he ended up eating Christmas lunch! No silver, no china, no demands on anyone. If he didn't want to open gifts, we would let him do something else and come back to gifts when things were quiet. The only quests we invite on holidays are people who know us well and can put up with his unconventional behavior. Is that giving in to my son or being healthy, realistic and flexible? I don't know--but I do know that this approach has really helped us with holidays.

- To get through the holidays, we try to keep the number of people visiting to a minimum as well as preparing our 8-year-old son with PDD for company through the use of pictures from the previous holidays, social stories, telling him stories about "the little boy whose cousins, aunts, etc. came to visit" for the holidays. We actually get respite from the various people who are available and offer to take care of him while we shop, go to the movies, etc.
- We're always the first to leave group gatherings. We've just learned from experience that pushing the kids (even when they beg to stay longer) ends up with disaster when we get home (they get cranky, fight with each other, and become impossible to reason with). We all enjoy the holiday events more when we set limits, not only to how many invitations we accept, but also to how long we'll stay before we ever leave the house for the event.
- When we're going to be with a big group of family, I plan and get the supplies together for a kids' activity. It's usually some kind of holiday decoration or food. That way I know it's something my

daughter can participate in safely and not feel left out of the activities. Of course, the kids can choose to participate or not but at least I know that the only options available won't be just rollerblading, football, etc.

- We stock up on bubbles, play dough, and other activities that can by shared by the children. Because my son is possessive of HIS toys, these are presented as separate from his, i.e. community property.
- As for the kids, I recommend taking a sitter along on those Christmas shopping trips. I recently hired a student sitter, and for every paid four hours, he "gives" us a break time hour where he comes along on little planned trips, so I can focus on what I am trying to/want to do. Plus, I have made a point of getting time via this same sitter every week to spend time with just my husband.
- To help with behavior issues of having to "work" again once school starts, we enlist the help of teachers in providing practice sheets of work he is struggling with and set aside time every day,

at least every other day, to "work".

When we travel, my kids each have backpack that they fill



with puzzles, books, crayons, etc. that they can take to entertain themselves. We also play guessing games of items we see along the road or goofy alphabet games.

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Opportunities to Write About You and Your Child

ere are two opportunities to get a story by you or your child published:

The Exisle Publishing Company is looking for stories written by parents who have children with special The stories need to be needs about you, not your child or their medical history, just about you. The story needs to reflect how you feel about the life you now have since your child was born. The stories will be used for an international book. For more information, con-Benny Thomas benny@exisle.co.nz or Exisle Publishing, P.O. Box 60 490, Titirangi, Auckland, New Zealand.

Guidelines For A Different Journey: Personal Stories for Parents by Adults with Disabilities is a new book that Stan Klein and John Kemp are co-editing. For this book, adults who have grown up with disabilities and/or special health care needs are invited to write short essays for parents of children with disabilities and/or special health care needs. The authors are asked to write an essay that they wish their own parents had read or been told while they were growing up. For more information, email stan@disabilitiesbooks.com

Book Review: From Emotions to Advocacy by Pete & Pam Wright

Review by Rosemary Alexander, PhD, Austin

rom Emotions to Advocacy is the latest publication by Pete and Pam Wright, the special education gurus known across the country for their family friendly advocacy. Through publications, a web site, and public appearances, they assist families across the country with their special education issues.

The title tells us that parents must work our way through the strong emotions that accompany having a child with disabilities before we can become strong advocates. He says, "Accept your emotions as normal. Understand that if you do not control your emotions, you may damage or destroy your child. Use your emotions to motivate you to learn new information and skills."

Even though Pete Wright is a bigtime lawyer who has argued many special education cases in court, he encourages parents to build a positive relationship with your child's school without sacrificing what you believe your child needs. The book instructs the reader about special education law but also provides strategies, such as letter writing, interpreting test scores, creating a paper trail, and setting meeting

agendas that help parents to negotiate with school staff. He helps us understand the parent-school conflict and how to resolve it. He provides ways to organize your child's records

"As your child's advocate, your goal is not to litigate. Your goal is to use tactics and strategies to secure quality services for your child."

and how to write measurable goals and objectives. He urges parents to use these strategies while maintaining respectful and cordial interactions with school staff.

"As your child's advocate, your goal is not to litigate. Your goal is to use tactics and strategies to secure

quality services for your child. When you negotiate with school personnel, you market win-win solutions to problems. In the end, you and school personnel should be able to sit down together and break bread. When you do this, you have successfully completed your journey from emotions to advocacy."

I have been assisting other families through the ARD process for the past 10 years. This is the first book I have read that confirms many ideas and experiences I have had about helping families and gives me many ideas for new ways to help. It also confirms my feelings about how to work with my own son's school, giving me new confidence to work through my emotions and emerge as a strong, caring advocate.

You can order this book from www.feta.com.

How I Survive the Holidays!

- One thing that I have been doing, it's not really related to coping, but I guess integrating an additional something worthwhile into gift-giving, is give people gifts that benefit the International Rett Syndrome Association. You should have seen the looks on her therapists' faces last year when they all got a BIG roll of plastic wrap and NuSkin body lotion. (The plastic wrap was a fund raiser for IRSA, and I sell NuSkin products and donate the profits to IRSA.) It was really funny because they joked that they could do body wraps with them and lose some weight! This year, I ordered "Heavenly Chocolates" for gifts from a family in Florida that makes homemade candies and the profits are going to fund the future of their daughter with Rett Syndrome. She is now a young adult and they started the company when she was a toddler. The adults in our family are not giving gifts this year but donating to the charity of our choice, which means mostly to the IRSA. When parents of children with disabilities are asked by friends and family
- what they could get their child (or them) for Christmas, they could respond by asking for a donation to the appropriate organization (in the child's name) to be made to the local or national Down syndrome Association, etc.
- •I try to buy gifts all year long whenever I see something that's just right for a person on my list and try to stay away from the malls at Christmas. Instead of individual gifts for kids in a family I usually get something they can all do--board games, boxes of art supplies, boxes of "let's pretend" stuff (thrift stores are a good source)--or give an IOU for an activity in the future like a trip to the zoo or lunch at McDonalds. Outdoor activity "kits" are fun, too--like a bird feeder and a bag
- Sam's Club has become my favorite friend around the holidays. They have huge pecan pies without the huge price and my family loves them. They are a hit at my house and they did not take all the time I don't have to make.
- I do as much cookie baking ahead as possible and freeze them.

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Slice and bake ones are great for kids to do--from scratch with little ones is just too much of a mess. Make get-togethers pot-luck.

- Decorations--if it's just for Christmas, it's work to unpack, then pack up again after the holidays, and find some place to store. I like to use arrangements with fresh fruits and vegetables and greenery from the garden what doesn't get eaten afterwards can be pitched in the compost heap. Also, lots of candles.
- Give a party for another holiday-Valentine's, 4th of July--rather than Christmas. And make it potluck. Send cards for another holiday - people are just as happy to hear from you any time of the year. Start a new tradition!

So, I guess it all boils down to four things: keep it simple, don't try for perfection, make new traditions if necessary, and try to take care of yourself. I'm sorry I missed half of the holiday season but look at this after the holidays and see if it helps you plan for next year. I hope the experiences of others helps you have a fun holiday!

Give Yourself a Break for Just Five Minutes By Patty Geisinger, Austin

sn't it funny that we have all these silly parties to attend just so we can pamper ourselves? Pampered Chef, Southern Living, Creative Memories, Tupperware, Mary Kay, Avon, Partylite you name it; we have a party in our homes for it. Why? "I have to go to so and so's party because they came to mine." "I got invited, so I really ought to go!" "I've said I would order because she ordered from the PTA fundraiser." Perhaps we are using all these parties and cookie exchanges, volunteer opportunities or fundraisers to actually pamper ourselves in a very overwhelming fashion. We want to spend some time with other women, to talk and commiserate, yet wouldn't it be easier on our schedule and headaches to just admit that we need a break from our lives, our children and our heartaches? And instead of over scheduling the commitments, we would take a little time for ourselves?

Laura Warren, with Texas Parent to Parent, used to tell our support groups that the only way for her to find some respite was to read in the bathroom for five minutes. true this is for all of us, because we all need a break from time to time. Respite resources are at an all time low, the economy is still in a dot.com dip, gas prices are higher every day, menopause is coming, airport screeners are searching old ladies and making us drink the breast milk out of baby bottles, terrorists, wars, famine, the apocalypse...

Okay, maybe our lives aren't quite so dramatic, but to a mother of a

one-year old with cerebral palsy, or a 4-year-old with autism—a break is just what the doctor ordered (or he would check us into the nearest available institution). With little or no respite programs in most areas of the state, it is up to us to find a way to take care of ourselves, pamper ourselves and

our bodies/souls so that our families remain intact, out of traction, emotionally stable so that we don't have to be on Dr. Phil because our relationships are messed up!

So what to do? Too many of us just struggle on trying to please everyone or being angry with everyone or plunging into a

about myself is a daily task. Unfortunately, it is like losing weight; calories in, calories out if you take in less and expend more—then voila, you lose weight. If you constantly expend more of yourself than you take in—then voila, you have lost yourself!!"

"Caring for and

depression. It is exhausting. The answer to our dilemma might be the easiest and yet the hardest thing in the world to do. Say "NO" and Ask for help! I'm sure my friends are now thinking, "Physician, heal thyself!" And yet, if I go for that pedicure today, and think, "Okay, I've taken care of myself, that's all done!" then I have missed the point. Caring for and about myself is a daily task. Unfortunately, it is like losing weight; calories in, calories out—if you take in less and expend more—then voila, you lose weight. If you constantly expend more of

yourself than you take in—then voila, you have lost yourself!! Our families cannot operate if we are not rested and cared for. Our children with disabilities, the siblings, our parents and significant others are all affected by our emotional health. So, we don't need a Pampered Chef party to pamper ourselves. What we need is to give ourselves permission for that five minutes (or longer - but start with just five minutes) in the bathroom by ourselves with our magazine. Then maybe we can find those 30 minutes to go to the gym. We need to go see that movie, get the manicure, listen to the favorite CD, go to yoga or go to church for our own health and well-being. We need to say no when asked to serve on the 10th committee, no to make treats for the class party, no to the organization of the block party. Ask for help from that neighbor who has offered so many times, say yes to help from the church, say yes to the family member who wants to come and help and LET THEM! It is so easy to feel guilty or selfish for not filling every moment caring for our child, family, community, and church, but the long-term debt on your soul for ignoring the care of yourself is larger than any deficit our children may have physically, intellectually or socially. So, here is your excuse for just five minutes; "I must do it, I can do it, I will do it!" But only you can choose to do it for yourself. Choose today to do it for yourself. Just five minutes to start and the future looks brighter already!

Places to Go, Things to See

ne of the biggest joys in my life is my seven-yearold son with autism; but finding the right public setting for us can sometimes be less than a joy. Although our family lives in a world of autism, this IS our society and we must go out among them and interact successfully on some level. "We came, we saw, we conquered" is more like "We came and went, saw and were ogled, and conquered more often than not."

Our last five years of integrating with the rest of the world has in-

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cluded a number of most helpful and highly recommended personal inclusion attendants. Trained to boldly go out into everyday social situation together with this boy, they did and we now do seek peer interaction for him. "Go forth and see normal" with the aim of (perhaps later) "go forth and be normal."

Let's get started. This is Places to Go, Things to See. First, nothing beats physical activity for these kids, and no activity beats swimming. Or moving in that water although you may not even be "really

By Nancy S. Brach, Austin

swimming" yet. Great exercise, lots of social opportunity, and unbeatable sensory input of particular value to people with autism.

"Big pools," like some of Parks our and Recreation spots i.e. Dick



Nichols

Southwest Austin, which may seem more intimidating, can actually offer more opportunity for private Continued on page 5

"space" when the child's mood becomes over-stimulated, rather than being a smaller more confined area. The first time and each time you and your child visit a public pool, you will both have a chance to relax if you communicate to the friendly lifeguard on duty about your child's particular behaviors, such as their apparent disregard for a lifeguard's instruction. Explain to the guard that persons with autism tend to have difficulties with "processing" what the ears hear; that they need more time to think about a simple request. A few helpful clues to "Get the child's attention first, and then use only a few words" can go a long way towards a successful experience. If the child is not independent in using the pool restroom for changing and showering without incident, a same-sex companion is good planning. Potential problems can be minimized by having it be appropriate to be in the men / women's changing area with the child. By going to the pool lots of times, and getting that repetition in, just like other things that the child becomes familiar with, and learns the rules of and how to enjoy, swimming will yield a great payoff.

I have learned it is good to go where you are expected/accepted to have some exuberant behavior, maybe some verbal outbursts of joyful noise or even sporadic blasts of high energy. And for this, there is the toy store! Terra Toys right there on main street Congress Avenue, just south of the Capitol. Nice area for exploring the cool little stores with their many offerings, like a real barbershop with a guy who looks like a real barber, and a fire station to look over at across

the street that has never yet, cross your fingers, "startled" us with sirens and stimuli. The stores there have a small town feel. My 4 $\frac{1}{2}$ foot 90-pound son and I have moseyed into some of these places, darted around a few times, while displaying some obviously autistic stuff, and behold! -- no adverse social (or retail snobby nose) reaction! And I have to say, in these situations in Everyday USA for us as their caregivers and defenders, it is welcome, this gift of a stressless everyday everyman experience. Like, yeah, we're weird, but we are fitting right in kind of thing. (Mind you, fellow parent/gentle reader, "situation" at those times is NOT out of control, but generally speaking, yes, we are WEIRD. And not ashamed to say so, thank you.)

And so we come to where I tell you about why Terra Toys is a top-pick. Scene: Any child, just has the mind *set*, firmly, in his or her own uniquely occasionally puzzling way, on having to look at and touch personally the tin toys which are on display in a tall wood and a bitdelicate-looking-glass case. And it's locked. Hmmmm. Could be a problem. . . Now, if you are at all like this mom, right there you think there has got to be an easier place to manage than this enticing (to your kid) but delicate (potential disaster to YOU) scenario. The Kid in Story does have a bit of the Bull in a China Shop thing. Sigh.... if only.... But lo! The beaming toy store guy appears, armed with the key and an almost unbelievable excitement about handling every last thing in that case, too! Plus he's equipped with an unbeatable set of play skills and useful toy knowledge. And so he interacts, unbelievably (I already said that) incredibly, beautiful, coexistingly with Kid in Story, right there on the rug on the hard floor. The two of them looking, and laughing, and winding and playing! The minutes or hours there are almost dreamlike, Willie-Wonka-quality stuff, and I have stood by and watched in utter calm delight at their fascination and fun.

Intangible and remarkable, experience the magic quality of your own benevolent guided tour of toys at Terra Toys without fail. A fourstar experience time and again! And Be Happy to know that you can

choose some new for home, toy every time you check out this toy place, because you can get something cool for as little as 50 cents if you



want to! Also on our list for a free spirit experience is ToysRUs at Brodie Oaks. And Toy Joy there close to UT on Guadalupe. Toy stores are just a natural for solace, acceptance, and comfort level, plus lots of things to hold the interest and other wacky people to go be amongst. I hope you have found this to be of information or interest to you and your Special Family, and will hope to see you around, playing on planet earth, sometime soon!

[For more on sensory integration/ life skills and abilities, ask an "OT," or <u>occupational therapist!</u> Independence and happiness are skills for the job of being a person, and kids are special people. Writer Nancy Brach is certified in occupational therapy assistance, practices OT in the Austin community, and is vice-chairperson of the board of



$P_{ m ARTNERS\,IN}$ oxdots Leadership and Advocacy Training Sponsored by The Texas Council for Developmental Disabilities

esigned to prepare individuals to be effective leaders and advocates, Partners in Policymaking is a training program for adults with disabilities and parents of young children with developmental disabilities. It explores disability issues and builds skills that individuals need to influence legislation and policy effectively to obtain the most appropriate state-of-the-art services for

themselves and others.

Participants represent a variety of ethnic backgrounds and geographic regions of the state and types of disabilities. The "Partners" attend eight monthly, 2-day training sessions. They also complete assignments between sessions and commit to one major assignment such as serving an internship with a public official, organizing a letter writing campaign, or doing other forms of

local advocacy and education.

The Texas Council for Developmental Disabilities began its first Partners in Policymaking class in August 1990, with additional classes beginning each fall. Participants explore current developmental disabilities issues, best practices, and the policymaking and legislative processes at the local, state and federal levels in order to Continued on Page 6



Texas Council for Developmental Disabilities

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strengthen self-advocacy skills and increase personal empowerment. The overall goal is to achieve a productive partnership between people needing and using services and those in a position to make policy and law.

Session topics include: History of the Disability Movement, Inclusive Education and Effective Communication, Supported Living, Person-Centered Planning, Inclusive Communities, Supported Employment, Assistive Technology, Seating and Positioning, Positive Behavior Supports, Federal Policy and Legislative Issues, State Legislative Issues, State Policy/Service System, Parliamentary Procedure, and Community Organization.

The current class of Partners is in Applications for the progress. next class will be available mid-February. Call Laura Buckner toll free at 866-291-1990 for more information.

Support Through the School System!

By Rosemary Alexander, PhD, Austin

he Parent and School Support Team of Austin Independent School District works with families and schools to promote better educational opportunities for children in special education. The team can be called on to help where the relationship between school staff and a family has broken down. By listening to both sides, looking at paper work, and

offering support and compromise, the team hopes to heal the break and further a working better relationship. We families assist one-to-one by linking them with resources, meeting to look at IEPs and other

"We are excited to be part of the movement to make education family-centered and supportive for children in education."

school paperwork, and listening with empathy to family stories. We also

provide training to school staff on family issues and communication techniques.

One big effort of our team is working with two other local agencies to provide weekly support and informational meetings for families in our district and the surrounding Called The Family Support Cooperative, the meetings take place at a school and help families attend by providing free pizza, childcare, transportation and sibling Each evening offers an groups. emotional support group plus seminars on topics such as behavior management, special education law and advocacy, resource information, and the knowledge needed when kids approach the transition to adulthood

Our team also attends the face-toface meetings required by law when a child moves from an ECI program into the school district at age 3. We attempt to welcome families

into AISD, reduce their fear about entering a large system, and provide them with vital information about the special education process and resources.

Our team, which has been in the district for 10 years, is currently made up of a parent, a speech pathologist who is bilingual, and a bilingual teaching assistant, with half -time support from a bilingual secretary. All of us have worked over many years to support families in a wide variety of ways. Our office is at a school but we serve the whole district. Our salary is paid for by AISD special ed funds. Paying our salaries represents the commitment our school district has made to support families and school staff so that fruitful and positive relationships are routine. We are excited to be part of the movement to make education familycentered and supportive for children in special education.

Look Out Families...Here They Come...The 78th Legislature

By Colleen Horton, Texas Center for Disability Studies

ou can't pick up the newspaper these days without the words "budget crisis" attacking your senses. For months, the legislature and the media have been warning about the massive budget shortfalls and the need for the tightening of agency belts. There are already some strong indications of how difficult it will be this session to maintain and expand the services for people with disabilities and their families. Some clear signs include:

The directive from the governor's office for state agencies to indicate how they would reduce their budget by 3% and 5%.

Forceful and continuing statements by state leadership that they will stay within the budget and not create new tax revenues.

Many of the potential budget cuts could significantly affect families caring for children with disabilities. Did you know...

that the proposed rules for the Children with Special Health Care Needs (Texas Department of Health) already contain contingency plans for how they will implement budget reductions? Unfortunately, this gives legislators an invitation to slash the

CSHCN budget.

that the proposed "baseline" agency budgets for both the Department of Human Services and the Department of Mental Health/Mental Retardation do not include sufficient funding to maintain services to all those currently in waiver programs? A portion of the funding needed to continue to provide services to those already in the waiver programs is being requested through "Exceptional Items" requests. Most believe there is little chance that Exceptional Items will be funded.

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- Medicaid community waiver programs are optional and that in tough budget times the state the state could decide to eliminate or greatly reduce waiver services? Co-payments or other types of cost sharing in the waiver programs are also a possibility.
- Co-pays are already being established in the Children's Health Insurance Program and additional cost savings and cost sharing initiatives will likely be proposed?
- The new Texas Home Living Waiver being established at MHMR will "deem" family income when determining eligibility for children, making many children with disabilities ineligible? This is a drastic change from all of the current waiver programs that base eligibility on

the child's income (which is usually little or none). Children who are not Medicaid eligible will not be offered these waiver services. If it works for this waiver, could amendments to existing waivers include similar changes? The answer is yes...in tight budget times, anything is possible.

The message is, as Bob Kafka from ADAPT would say, "don't mourn...

organize."
Family support and support for children with disabilities seems to be a likely target for budget



reductions. The *only* way to slow the train is a loud, unified voice. We must continue to send the message that families of kids with disabilities need services and supports and they want those services in their communities.

So, get ready, learn the issues. Get set, find out who your legislators are and which legislators are on the committees that affect our issues. And, go...speak loud and speak often. It's our only chance.

Colleen is a Children's Policy Specialist at the Texas Center for Disability Studies. She is also the parent of a child with developmental disabilities. If you would like to be added to her legislative email alert list, please contact her at colleen.horton@mail.utexas.edu. This list will provide information on issues before the legislature and announcements on important opportunities for families to influence policymakers.

Proposed Rule Changes Could Limit Child Care for Working Poor Families and the Parents of Disabled Children

Center for Public Policy Priorities

roposed amendments to the Texas Workforce Commission's (TWC) childcare rules require that low-income parents and the parent's of disabled children work at least 36 hours per week to be eligible for a childcare subsidy. This major policy change does not reflect the realities facing many working poor Texans who are unable to find a full-time job in a period of economic downturn and places an undue burden on parents of disabled children. Additionally, TWC is proposing a lifetime limit of 12 months of Transitional Child Care benefits for welfare recipients transitioning into the workforce. Both proposals are out of synch with the realities confronted by working poor Texas families and those struggling to stay off welfare.

The Texas Workforce Commission is currently discussing policy concepts and seeking preliminary guidance on childcare rule changes. This comes at the same time that the agency faces serious financial challenges in providing child care assistance to those leaving public assistance (current clients of the TANF program who are in job preparation activities and those who

have found work and are transitioning off) and working poor families who need child care assistance to stay employed. Public input is needed to ensure that the Commission moves ahead with rule changes that accurately reflect the realities of working poor families.

Not only do current resources leave hundreds of thousands of potentially eligible children unserved, but TWC's own budget request for 2004-2005 includes dramatic reductions in child care subsidies for working poor families as it anticipates increased numbers of TANF families who will be required to work and thus also require child care assistance.

Unfortunately, possible childcare rule changes currently under discussion may even further tighten the squeeze on working poor families. The rule changes under consideration also add new limitations to the local control of childcare services by local workforce development boards. The crisis in funding for childcare for working poor families cannot be "solved" by merely making it more difficult for hardworking Texas families to receive childcare subsidies. Moreover,

TWC has offered little evidence that current policies are creating any significant fiscal pressure on the childcare system.

In addition, TWC is also considering possible changes to several other child care rules affecting local child care matching fund requirements, self-arranged child care, child care for teen parents, other eligibility for Transitional Child Care, the Train Our Teachers (TOT) child care worker incentive program, and child care for parents during an appeal of service discontinuation. TWC's discussion document of all the proposed changes can be viewed at: http:// www.cppp.org/products/testimony/ testimony/tst12-5-02.html

To communicate your concerns about the proposed changes to the TWC child care rules you can make them via electronic mail to: ruleandpolicy.comments@twc.state.tx.us; or by fax to (512) 463-1426; or, mail written comments to: John Moore, Asst. General Counsel Texas Workforce Commission 101 East 15th Street, Room 608 Austin, Texas 78778-0001 For more information, contact: Jason Sabo, sabo@cppp.org

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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.



Date	Conference Title	Location	Registration Information
02/03/03 to 02/04/03	Spring 2003 504 Conference Behavior/Discipline Emphasis	DoubleTree Hotel Austin, TX	Phone: 512-219-5043 Fax: 512-918-3013 www.504idea.org
02/05/03 12:30 pm	Capitol Day 2003 Theme: A Texas Tragedy	North Steps Texas State Capitol Austin	Contact your local Arc or The Arc of Texas at 800-252-9729
02/07/03 to 02/08/03	2003 Texas Symposium on Deafblindness	Radisson Hotel Austin, TX	Beth Rees TX School for the Blind and Visually Impaired 1100 West 45th Street Austin, TX 78756 Phone: 512-454-8631 TDD: 512-206-09451 www.tsbvi.edu/Outreach/vi Email: BethRees@tsbvi.edu
02/09/03 to 02/11/03	Creating Community Connections: Best Practices Conference For Texans with Disabilities	Texas Council for Developmental Disabilities and The Enterprise Foundation www.txddc.state.tx.us/ menus/fset_cncl_event. asp	Eric Samuels The Enterprise Foundation 2800 South IH 35, Ste. 170 Austin, TX 78704 Toll Free: 800-533-2244 Phone: 512-458-3200 esamuels@ enterprisefoundation.org
02/27/03 to 03/01/03	Inclusion Works! Conference 2003		Mike Burnett/Rona Statman The Arc of Texas 1600 West 38 th St. #200 Austin, TX 78731 Toll Free: 800-252-9729 Phone: 512-454-6694 mburnett@thearcoftexas.org OR rstat- man@thearcoftexas.org