I warned you that it was coming and now the next legislative session is only a month away. In the last newsletter, I talked about the importance of getting involved, making contact with your legislators, letting your voice be heard, and making a difference. I will only repeat those sentiments by saying: if you don’t, who will? If we don’t all work together toward improving the “system”, who will? Remember, if you’re not part of the solution, then you shouldn’t complain about the problems. With that said, in the coming months there will be plenty of opportunities to help push initiatives forward (the good ones), and help stop some initiatives fast in their tracks (the bad ones). We’ll be counting on your help!

The 79th Legislative Session will officially begin on January 11th, 2005. While the session will not begin until January, legislators started filing bills on November 8th. Several issues will have a high priority and will occupy significant amounts of the legislators’ time. First, school finance will once again be addressed. There is added pressure to come up with solutions for school finance, but no one I’ve talked to believes that it will be easy. Some believe that it won’t be accomplished during the regular session. Whether a solution is found or not, this issue will obviously take a lot of time and energy from other issues.

If you have a child using special education services, public school finance should be of interest to you not simply because of the taxes you pay, but also because of how it may affect services. School districts receive funding for children in special education based on a complex system of funding weights. Any changes to the school finance system will likely include changes to the system of funding weights for special Education. It will be important for
Let the Games Begin...Again...

Advocacy, Inc., Seeks Nominations for New Board Members

Advocacy, Incorporated, the designated Protection & Advocacy (P&A) system for Texans with disabilities, is seeking applications to fill upcoming vacancies on its board of directors. The nonprofit corporation is funded by Congress to protect and advocate for the legal rights of people with disabilities in Texas. Advocacy, Inc., especially encourages individuals from rural areas, distinct language and ethnic communities, and other traditionally underserved communities to apply. A nominating committee will review all applications, select some candidates for an interview, and make recommendations to the full board.

Board members are generally elected in April, and new members officially begin their term on May 1, 2005. Appointments are for 3 years, with meetings usually held four times/year. Regular meetings are on the 4th Saturday of January, April, July, & September. Board members are also asked to serve on at least one committee. These committees usually meet by teleconference. Expenses for travel, room & board connected with the board meetings are paid by Advocacy, Inc.

Deadline for applications is March 1, 2005. An announcement and the application are on the Internet at http://advocacyinc.org/noticeVacancy.htm. Individuals also can obtain an application by calling Shirley DeBerry 512-454-4816 or 800-252-9108.
Texas Completes Rollout of 2-1-1 Information & Referral Service

To be seen as having a disability is not to be given the same chance to make mistakes and to learn and grow from them just like everybody else.

To be seen as having a disability is to be a statistic because we aren't asked what supports we need to live a normal life.

Who better than us will know what we need and want.

To be seen as being handicapped is to be seen as going around begging because the word handicap means cap in hand.

What we want is to be seen as people first, our disability second.

To be seen as having a disability is to be in a service system and have everyone telling you what's wrong with you and what you need.

When what we really need is to be shown how to do things for ourselves.

Looking for rent assistance, available nursing homes or the nearest food bank? Put down the yellow pages and just dial 2-1-1. You will be directed to a local information center where a referral specialist will answer questions about health and human services available in your community and through state agencies.

2-1-1 Texas, which has been available in parts of the state for more than two years, is now available throughout Texas. The launch of Texas now serves more than the El Paso Area Information Center 32 percent of the total 2-1-1 population in the nation. Last year, 2-1-1 deaf and hard of hearing can access state rollout.

Texas received more than 1.5 million 2-1-1 through Relay Texas and through TTY lines connected di-

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When all we want is for the system to see us as individuals and to help us with the things we need help with, not with what the system thinks we need. To be seen as having a disability is to see people not understanding us. When what we want is to be given the chance to educate people so they can learn that we're not all that different from them. To be seen as having a disability is not to be taken seriously. When what we want to do is to show people that we know how to vote, and not only do we vote, we know how to vote. We feel more competent that we know the issues because we're taught what the issues are.

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directed to an area information center, which is run by a community group and staffed with certified information referral specialists. Each center has a database of services available in the area, including state services, food pantries, career services, after-school programs, counseling services and many other nonprofit resources. The centers are constantly expanding their databases.

To reach 2-1-1 Texas, just dial 2-1-1 or logon to www.helpintexas.com for a list of area information centers and other ways to find services, hotlines and more. Callers using a cell phone may need to call an area information center directly, and the local phone numbers are available on the Internet site. New technology soon will allow all cell phone users to access 2-1-1 directly.

ARTS WITH YOUR CHILD: A HOLIDAY EXPRESSIONS

BOOK

Materials:
White cone shaped coffee filters - at least 3 per child
Heavy white cardboard
Rubber stamps with holiday symbols
Stamp pads
Hole punch
Nice thin but strong yarn, ribbon, or string
Markers

Preparation: Cut the cardboard to fit the inside of the cone filters; this will help prevent the images from bleeding through to the other side. Also have enough cone shapes to make front and back covers for the books. Depending on your child’s manual dexterity, pre-hole punch the filters and covers for stringing later on.

Talking about Art: Read books about and discuss the December holidays. Ask the children to come up with some words that describe the holidays, and what the meaning of the holidays are to them and their families.

Art Activity: Have the child pick at least 6 of their favorite holiday words, and write them each on one side of three filters; or write them for them (perhaps you will have some pre-written for them to choose from)

Using dye based ink in bold colors, allow child to stamp their chosen designs each side of the filters. They can also choose to draw designs directly on the filters.

Once the filters are decorated, have the child stack the book in order, and put it between two white cardboard covers. Show them how to string the ribbon or yarn through the holes and tie to make a binding.

REMEMBER: Art is really about choice. Even if your child has limited manual dexterity or limited language skills, use this activity to stretch their ability to communicate with you by offering them a range of choices, and honoring their preferences. If you work together and allow them to guide the activity through simple yes’s and no’s, you will become collaborators in a work of art!

Decorate the cover and back cover…you may decide to break out glitter glue and other materials for this step! Children may also wish to add a title: What the Holidays Mean to Me. This is a great idea to give a family member or friend as a holiday gift!

FOR MORE ART IDEAS YOU CAN DO WITH YOUR CHILD: VSA arts publishes a number of resources for parents, including START WITH THE ARTS AT HOME and guides to journal writing and poetry. Please contact info@vsarts.org or 202-628-2800 for ordering information, or visit www.vsarts.org and click on resources, many of which you can download for free. You can contact Emily at 512-454-9912 or emily@vsatx.org

What is a Medical Home?

A Medical Home is a model of care delivery that your family should already be receiving. It is the end result of parents and health care professionals acting as partners. After all, you both want the same thing, right? Healthy children and families who are able to achieve their maximum potential. Unfortunately, most parents are not aware of what “medical home” means, most professionals think they already provide it, and the ones that don’t are trying to figure out how to build for it!

Medical Home is not the “term of the month”. The definition was introduced in 1992 by the American Academy of Pediatrics. Their belief, as found on their website, h t t p : / / w w w . a a p . o r g / c a t c h / index.html, is “that all children should have a medical home where care is accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally effective”. So, you might ask, why is it taking so long, what does it mean, and where can you get it?

It is taking so long because, well, because this is Texas and not only does “everything grow bigger” but everything takes longer when it comes to human services, not to mention the whole legislation/money issue. This doesn’t really seem like an answer but for now, it is the only one I have. Also, most families and physicians don’t know how to “make” a medical home. There are other states that have made the Medical Home (MH) concept a reality and some that have done a great job! South Carolina, through their statewide parent-to-parent program, is starting to put patient coordinators, who just happen to be parents of children with special health care needs, in pediatricians’ offices. And to be fair, there is a work group of parents and professionals that are working hard to bring a true MH medical model to

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What is a Medical Home?

Texas. Presently, the Texas Medical Home Workgroup participants are researching, discussing, planning, creating, writing grants, and working towards some changes, all of which seems to take time.

Once again, to be fair, health care professionals are not taught about Medical Home in school. Nowhere did social services, human services, or touchy feely services play a part in their medical education. Doctors learned to fix what was broken or bleeding, take out what didn't belong in, add in what was missing... but no where in the “rule book” was there anything that said “play nice with the patient,” never mind be “accessible,” make sure that you take all forms of payment (yes, that means insurance, Medicaid, Medicare, etc.), provide care in the families’ community (not the big city 150 miles away), and make yourself available to speak directly to the families (and not after the family has left 10 messages). The MH model gives “bedside manner” a whole new meaning!

The best thing that a medical professional has ever said to me was that I know my child better than anyone. Well, if you think about it, that’s true. Who knows our children better than we do? Family-centered care means just that - parents are the experts on their children, so why not be teammates with the health care professionals? In a true MH, recognizing that the family is the principal care-giver, the core, the one true constant in the child’s life is just an extra tool for the provider. Nowhere else can you find a more reliable source for information. Unless you are dealing with someone who knows your child, that information is of no use. Unless you are dealing with someone who knows your child, that information is of no use.

Continuous means that you have the same health care professionals available from infancy through adolescence and young adulthood. AND, they assist with transitions including those to other pediatric providers or into adult health care systems. But let’s slow down or we’ll have to get into the whole “transitioning to adult care” and that is a whole other topic for someone else’s article! Being able to access health care 24 hours a day, 7 days a week, 52 weeks a year emergency needs. Providing resources falls into both comprehensive and compassionate services. Connecting families to support, educational, and community-based services only proves that the health care professionals understand and are working towards helping your family be the best they can be; it demonstrates concern for well-being, understanding and empathy. The same can be said for being culturally effective. Professional translators or interpreters are great but truly understanding that a family’s culture, beliefs, rituals, and customs are a part of the “whole” family, are the “frame work” of the family is critical and should be recognized, valued, and respected as families and physicians work together to develop a care plan.

Lastly, the family care plan should be coordinated. It should be developed by the health care provider, child/ youth, and family, and shared with other providers, agencies, and organizations involved with the care of the patient. Families are linked to support, educational, and community-based services and a central record containing all pertinent medical information (including hospitalizations, and other specialty care like outside therapies, etc.) is kept and maintained in a central record by the primary provider. This can be your pediatrician, family practitioner, or as in one family I know, your dermatologist.

Hopefully, this gives you a better understanding of what it means when someone says Medical Home. If you would like more information, there is a great website with lots of tools and resources by the National Center for Medical Home Initiatives at www.medicalhomeinfo.org. If you would like to be involved with the Texas Medical Home Workgroup, you can email Desiree Pendergrass, MD at Desiree.pendergrass@dshs.state.tx.us. If you would like to be involved with parents educating medical residents through one of our Medical Residency Program in Austin, Temple, Dallas or Ft. Worth or one of the other residency training programs in the state, email Tammy Mann at Tammy@txp2p.org or call (512) 458-8600 or toll free (for parents only) please) at (866) 896-6001.

Raising Richie . . . A Story of Hope

After an exhausting day of excitement and jubilation due to the birth of our son, it was nice to have the visitors gone and some rest time in the hospital room. I laid my head on the pillow, closed my eyes and smiled as I played back the scenes of the joyful day. Unexpectedly, a doctor came into my room with a serious air about her. “Mrs. Hughes” she said solemnly, “I need to speak to you about your baby. We have reason to believe that he has been born with Down syndrome.” Shock, sadness, disbelief...the moment will be forever etched in a mother’s mind. All the happy thoughts about this little guy seem to be smashed in seconds. As the days go by, my hope for his future seems to go from bad to worse. All the research that was done on the topic of “Down syndrome” was negative and depressing. Literature seems to tell you everything they WON’T be able to do. Every expectation that was planted in your mind for this child seems to be uprooted and yanked out like a weed from the ground. That was four years ago.
Raising Richie . . . A Story of Hope

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Things don’t have to be that way and they shouldn’t be! I wish someone could have told me then that this journey was not going to be such a harsh one. Perhaps, folks in our support group did, but because of all the negative information I read, I refused to believe it. Today, our son, Richie, is 4 years old and is attending a regular education Pre-Kinder class. It is amazing to see how he interacts with his peers and how he follows routines and directions. He tries to be very independent and competitive. At this time he does not have clear speech, but is learning to sign at a remarkable rate. His receptive language and cognitive development are excellent! His teachers have very high expectations of him and treat him like any other student in their class. I have no doubt that Richie will blossom into a beautiful, responsible, successful adult. That little seed of hope has been cultivated. It’s like a little sprout determined to push its way out through the hard ground. With extra help, assistance, and patience the possibilities are endless. It is natural for parents of babies with Down syndrome to be concerned and saddened at the news. We are all human and we all want our babies to be born “normal”. I don’t think parents should be bombarded with harsh, negative information. Reality is that Richie has brought such joy and happiness into our lives that words can’t be found to describe the positive impact. Parents should be informed about how bright and intelligent children with Down syndrome may be. Parents should be informed about the acceptance and inclusion that has come about within the last several years for children with Down syndrome. Literature should inform parents of everything their child CAN do, and what they might be able to achieve with the right attitude and motivation from the ones that surround them on a daily basis.

I would like to plant that seed of hope. My mission is to produce a positive video or documentary on the successes of children with Down syndrome to give new parents inspiration. I’d like to educate parents and educators on what our amazing children can do, if given the opportunity. Yes, there will be a lot of challenges along the way and every child will learn at a different rate just like any regular student without an extra 21st chromosome. I have been an elementary teacher for 20 years and now I’d like to educate others in this area. The mission statement for the documentary I wish to produce someday goes as follows: God doesn’t make mistakes. Having a child with Down syndrome sent on your path of life is part of God’s plan. Society should not overlook them, educators should not shun them, and parents should move past mourning the child they could have been. Instead, we need to include them, nurture them, and love them, so their light can shine through and God’s plan can unfold. We, as parents of children with Down syndrome, need to keep each other informed with inspirational stories. We need to be updated on the positive things that are achieved so our children and our families can stay optimistic and uplifted.

If you can help in any way to further my goal in producing this documentary, please contact me at Lytle Elementary, Lytle, Texas. I am confident that this generation of children with Down syndrome will break many barriers. Please help me shatter the misconceptions that have kept our children from excelling in society. My name is Belinda Cortez Hughes and I hope to have shed some hope on the lives of those who have a newborn with Down syndrome. I can be contacted at belinda-richie@hotmail.com. Good luck and God Bless!

Continued on Page 7
At a fundraising dinner for a school that serves learning-disabled children, the father of one of the school’s students delivered a speech that would never be forgotten by all that attended. After extolling the school and its dedicated staff, he offered a question. “Everything God does is done with perfection. Yet, my son, Shay, cannot learn things as other children do. He cannot understand things as other children do. Where is God’s plan reflected in my son?”

The audience was stilled by the query. The father continued. “I believe,” the father answered, “that when God brings a child like Shay into the world, an opportunity to realize the Divine Plan presents itself and it comes in the way people treat that child.”

Then he told the following story: Shay and his father had walked past a park where some boys Shay knew were playing baseball. Shay asked, “Do you think they will let me play?” Shay’s father knew that the boys would not want him on their team. But the father understood that if his son were allowed to play it would give him a much-needed sense of belonging. Shay’s father approached one of the boys on the field and asked if Shay could play. The boy looked around for guidance from his teammates. Getting none, he took matters into his own hands and said, “We are losing by two outs and the bases loaded, the right fielder had the ball. The pitcher picked up the soft grounder and could easily have thrown the ball to the first baseman. Shay would have been out and that would have ended the game. Instead, the pitcher took the ball and threw it on a high arc to right field, far beyond reach of the first baseman. Everyone started yelling, “Shay, run to first, run to first.” Never in his life had Shay ever made it to first base. He scampered down the baseline, wide-eyed and startled. Everyone yelled, “Run to second, run to second!”

By the time Shay was rounding first base, the right fielder had the ball. He could have thrown the ball to the second baseman for a tag. But the right fielder understood what the pitcher’s intentions had been, so he threw the ball high and far over the third baseman’s head. Shay ran towards second base as the runners ahead of him deliberately circled the bases towards home. As Shay reached second base, the opposing shortstop ran to him, turned him in the direction of third base, and shouted, “Run to third!” As Shay rounded third, the boys from both teams were screaming, “Shay Run home!” Shay ran home, stepped on home plate and was cheered as the hero for hitting a “grand slam” and winning the game for his team. “That day,” said the father softly with tears now rolling down his face, “the boys from both teams helped bring a piece of the Divine Plan into this world.”

And now, a footnote to the story: We send thousands of jokes through e-mail without a second thought, but when it comes to sending messages regarding life choices, people think twice about sharing. The crude, vulgar and sometimes the obscene pass freely through cyberspace, but public discussion of decency is too often suppressed in school and the workplace. If you are thinking about forwarding this message, you are probably thinking about which people on your address list aren’t the appropriate ones to receive this type of message. The person who sent this to you believes that we can all make a difference. We all have dozens of opportunities a day to help. So many seemingly trivial interactions between people present us with a choice: do we pass along a spark of decency and caring? Or do we pass up that opportunity and leave the world a bit colder in the process?

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The Baseball Game

This story has passed my computer several times via email – each time, the boy’s disability was different – once it was Down syndrome, once it was autism. Parents apparently made it fit their child and then pass it on. I hope you enjoy it! Laura J. Warren, Texas Parent to Parent
<table>
<thead>
<tr>
<th>Date</th>
<th>Conference Title</th>
<th>Location</th>
<th>Registration Information</th>
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<tbody>
<tr>
<td>Saturday, January 29, 2005</td>
<td>Successfully Managing Strong Willed and Defiant Children and Teens 8:30 a.m.—12:15 p.m.</td>
<td>Christ United Methodist Church 3101 Coit Road Plano, TX 75075 North Building, Room 255</td>
<td>For more information, contact ADDA-SR at 281-897-0982 or go to the website <a href="http://www.addasr.org">www.addasr.org</a></td>
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<tr>
<td>Wednesday, Feb. 9-Saturday, Feb. 12, 2005</td>
<td>Inclusion Works! 12th Annual Conference Co-sponsored by The Arc of Texas &amp; Texas Education Agency</td>
<td>Renaissance Austin Hotel Austin, TX</td>
<td>For more information, call The Arc of Texas, 512-454-6694 or 800-252-9729 or go to their website at <a href="http://www.thearcoftexas.org">www.thearcoftexas.org</a></td>
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<td>Friday, February 25 thru Saturday Feb. 26, 2005</td>
<td>2005 Texas Symposium on Deafblindness</td>
<td>Hyatt Regency Hotel Austin TX</td>
<td>For more information, contact Beth Bible at 512-206-9103 or <a href="mailto:bethbible@txbvi.edu">bethbible@txbvi.edu</a> or go to the website <a href="http://www.tsbvi.edu">www.tsbvi.edu</a></td>
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<tr>
<td>Friday, February 25 thru Saturday Feb. 26, 2005</td>
<td>ADDing Up to Success ADDA-SR (Attention Deficit Disorders Southern Region) 17th Annual Conference</td>
<td>Sheraton North Houston George Bush Intercontinental Airport</td>
<td>For more information, contact ADDA-SR at 281-897-0982 or go to the website <a href="http://www.addasr.org">www.addasr.org</a></td>
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<td>Saturday, February 26, 2005</td>
<td>2005 Greater Austin Walk F.A.R. for NAAR Sponsored by Friends &amp; Family for Autism Research, proceeds to benefit National Alliance for Autism Research</td>
<td>The Dell Diamond Round Rock, TX</td>
<td>For more information, contact Carroll Brown Arnold, TX Regional Director, at 972-960-NAAR (6227) or go to the website <a href="http://www.austismwalk.org/austin">www.austismwalk.org/austin</a></td>
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<tr>
<td>Sunday, March 6, thru Tuesday, March 8, 2005</td>
<td>25 Years of the Independent Living Movement in Texas Cooperative convention by Coalition of Texans with Disabilities &amp; the State Independent Living Council</td>
<td>Austin Marriott Austin, TX</td>
<td>For more information, contact Coalition of Texans with Disabilities at 512-478-3366 or go to the website <a href="http://www.cotwd.org">www.cotwd.org</a></td>
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