

# In Touch

The Newsletter of the Deafblind Multihandicapped
Association of Texas
Winter Edition ~Ianuary 2009

# From the President's Pen



The 36<sup>th</sup> Annual Family Conference is over and we begin a new year with a lot going on behind the scenes. First, I would like to thank everyone who worked so hard on the Conference Planning Committee. The conference was a huge success! It is so wonderful to have everyone working together to make it happen. All who attended had a great time! It was so good to meet new families and catch up with the old ones as well! It always amazes me how much we get to do in such as short time. The parents have the opportunity to learn from the conference speakers, as well as from each other. The kids stay very busy doing all kinds of fun activities such as arts and crafts, cooking, games, the ropes course and much more.

The election of Officers and Board Members was held at the annual board meeting. The following members were elected:

Wayne Thompson - Vice President Melanie Knapp - Secretary Jackie Carter - Member-at-Large Rosa Douglas - Member-at-Large Cyndi Hunley - Member-at-Large

#### **AWARDS**

Caleb Thompson received the Christian Knapp Award for being a great motivator. Caleb has been DBMAT's "Ambassador." Gary and Melanie Knapp received the Olivia Cruz Award for their hard work as a family in trying to make the life of our deafblind child better with a trained intervener. They have fought hard for this. C.C. Davis received the Everett Bryan Award for Professionals who goes "above and beyond." C.C. has always been willing to share his valuable time with our organization to attend meetings and to help individuals. It has not mattered to C.C whether this was day or night, weekday or weekend. Congratulations and thank you for all that each of you do.

The first Annual Christian Knapp Golf Tournament was held on November 11<sup>th</sup> to raise money for the Intervener scholarships. There were 48 golfers. Everyone had a good time! The Tournament was a huge success!! Jaceson even got to drive the golf cart! Next year we hope to have more golfers and raise more money. We want our Interveners to get the specialized training they so desperately need to teach our children.

Again, I want to remind everyone about the bills that are going to be coming up in the Legislature soon. Please read Melanie Knapp's article about the bills in this newsletter. I want to remind each family that we need to introduce ourselves to our legislatures and tell them about the bills that we would like passed and why. This is every important that we make them aware of our children's needs. We are our children's Advocate!

Anyone that would like to sign-up for any of our committees please contact Stephen Schoen or me. We welcome any and all help.

I wish each of you a Happy New Year! See you at the Deafblind Symposium in February.

Paul Welch

Table	01	<sup>f</sup> Contents
	-	

President's Pen	1
A Very Big Decision	2
Another Year Gone By	2
Desiree Thompson, Intervener	3
Deafblind Waiver Bills	3
DBMAT Lemonade	4
Finding a Good Provider	5
Grandparenting a Deafblind Child	6
Having Fun at Camp John Marc	6
Notes from a "Newbie"	7
Goodsearch	

## A Very Big Decision

by Sheryl Palasota, Parent and RC for DBMAT

"Mrs. Palasota, I suggest you terminate this pregnancy", were the words that cut through my heart that sad day. I had a rash, rubella, and the doctor said it could affect the baby. The doctor left the room, and I cried quietly. My husband and I prayed about the decision, and decided to let God take over. We wanted this blessing from above passionately!

God definitely had a plan. Chris was born January 1, 1974, New Years Day, a day my ordinary life became extraordinary. With his vision impairment and special needs, he has had a full life. Chris can sign, finger spell and print (he writes checks and shops for groceries.) In addition to his Special Olympic golf and bowling league, he loves special parties and dances, reading, traveling, bookstores, malls, libraries, camps, amusement parks and carnivals. He's a member of the ARC. He loves riding on a jet ski with his younger brother Jason!! He also boat rides with his brother and sister-in-law Kendra.

Chris has spoken through his intervener at a class at Texas A&M University (an education class to future teachers). They sometimes come up to us in the community. He has a special skill in doing "calendars" and when you share your birthday (Nov, \*\*, 19\*\*), he can tell you what day of the week (Monday, Tuesday, etc.) you were born on.

He sometimes helps with our church's Thanksgiving baskets and has helped with Habitat for Humanity houses. He receives communion on Sunday at our Catholic church, sometimes visibly glancing at his watch right before he receives it! (It's close to lunch time) (The Eucharistic ministers smile at this).

I am his main intervener and day habilitator. And a wonderful lady, Mrs. Carla Zgabay, is working with him part-time. She has been with Chris many, many years. God, Miss Susie Junek, and Shelley Campbell (his providers through the Texas Deaf-Blind Medicaid Waiver) are also a very huge part of his success, as well as Bryan schools and Texas School for the Blind.

On December 9, 2004, Chris received a kidney transplant! Chris lives at home with me, his mother. He has his own room, and helps with the chores. He does his fair share! I guess you might say we enjoy life together and live it to the fullest! Chris has been on a cruise and many trips; he especially liked Vegas (air travel also). He enjoys movies and popcorn, bowling, parties and camps! He loves to read.

Chris has the ability to inspire me and keep me focused on the important things in life.

### Another Year Gone By

by Wayne Thompson

Another year has gone by! What an eventful year it has been for our family, as well as for our extended family in DBMAT! As I review last year, I am reminded how blessed we are as families who have loved ones with special needs. I was re-elected to serve as vice president of DBMAT. It is indeed an honor and I thank all DBMAT members for their confidence and trust in me to serve the organization.

We had yet another wonderful family conference in October. A special "thank you" goes out to those who stepped up and made it happen! As many of you know, our son Caleb was honored as the recipient of the Christian Knapp "Great Motivator" award during the family conference. Caleb has been an advocate for himself and others since he was five years old. Words cannot express the honor our family feels has been bestowed upon Caleb. Each DBMAT family has at least one great motivator.

Our local newspaper did a wonderful front page article – *including a color picture* – about Caleb receiving the award, as well as a great plug for DBMAT. As a result of the newspaper article, Caleb later received a

special recognition commendation from K Michael Conaway who is a member of the House of Representatives, Eleventh District, in Washington, DC. We are sooooo proud of him!!!

In August, Diedra, Caleb, and I, along with several other members of DBMAT and their families, had an opportunity to travel to the state capitol in Austin and meet the Governor of Texas, Rick Perry. It was an awesome experience to be a part of the meeting to make Governor Perry aware of DBMAT and our goals and vision for the deaf blind community in our state.

Our daughter, Dugan, age 15, has been asked to be a part of a sibling panel at the deaf blind symposium coming up in February. She is a sophomore at Sweetwater High School where she plays tennis and is a member of the school choir and she is making all A's on her report card!!! She is also one of Caleb's primary caregivers. Her mom and I do not know what we would do without her help. She will start driving and probably start dating this year...both subjects create a bit of anxiety in her dad...all words of wisdom or encouragement will be welcomed! We are so very proud of her

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Our son, Kevin, age 12, volunteered to serve on the internet committee for DBMAT. He is a seventh grader at Sweetwater Middle School where he maintains A's and a few B's on his report card and is very active in his school and the community. He is a real live wire! He is a member of the school choir, he writes articles and helps publish the school's newspaper, he is a member of the Gifted and Talented program, he is involved in student council, and he played football for the first time this year. His team went undefeated for the season. He placed first in UIL competition for Listening Skills. He is a finalist in the Star Search competition for the eighth year in a row. He auditioned and was selected to participate in the State Honors

\*

Choir in San Antonio last summer where he performed with about 150 other children from across the state of Texas. Recently he has been helping with a project to save and restore a historic movie theater in town, where he and his GT classmates have raised over \$3,000 for the cause. He has also become known as the "Little Greek" as a result of his two guest appearances on the local radio

station program known as "The Chopping Block." It is a weekly program during the football season where you pick the winners in the area football games. We are so very proud of him.

Caleb has an older brother, J.R. Sanders, which some of you have met and we are hoping others will get to meet in the near future. J.R. graduated from Roscoe High School and went off to Sam Houston State University in Huntsville the year we started attending the DBMAT family conferences. He has since graduated with a master's degree in accounting and married his high school sweetheart, Stephanie Hagerman. They have been married for three years. This past summer, they made us grandparents to a beautiful baby girl named Chloe Madison. They live in Palestine, TX...too far from home... where J.R. works for a large accounting firm. Diedra and I hope to talk him into doing some probono work for DBMAT in the future.

I am also proud of the accomplishments of DBMAT members. We have made contacts in the legislature that hopefully will lead to great improvements in the programs for the deaf blind population across the state and perhaps the nation. Now is the time for each of us to develop a relationship with our local and area legislators and decision makers. If there is anyone out there that wants to be more active, but you are just not sure what to say or do, feel free to contact any of the officers of DBMAT and they can guide you or possibly go with you to lend moral support.

Yes, last year was a great year for DBMAT...and the good (Lord willing and the creeks don't rise...we will have even more to be thankful for and proud of in the next year.

I recently attended the Utah State University Deafblind training classes. This class is a two-part session. I Deafblind population, and have about working with the training program, because of the valuable information that is value because of the classes are instructed by work as a result.

Desiree Thompson Intervener

#### **Deafblind Waiver Bills**

by Melanie Knapp

**VERY IMPORTANT - PLEASE READ!** In June of 2006, DBMAT made another commitment to better the lives of our deafblind children and adults in Texas.

Our group chose to focus on the "Intervener" and since has become our vision that any deafblind child that needs an Intervener should have that opportunity from time of diagnosis of deafblindness. Included in DBMAT's vision is that the Intervener should have college based training with a career ladder.

We have been working with DADs to make these changes within the Deafblind Medicaid Waiver. We were advised that legislative action would have to take place in order for these important changes to happen.

It is with great excitement that I am sharing with all of you that we have 2 bills that were filed in the House and Senate on November 10, 2008....well, 2 in the House, and 2 in the Senate that are identical.

These bills will have a POSITIVE affect on many of your deafblind family members.

The DBMAT Legislative Committee needs your help to make sure that these bills get passed.

**PLEASE** take time to contact your Legislators in your area. It is so important to let our Legislators know about your children and how important these issues are for their well-being.

Below are the links to the Bills and to the Legislative website (you can click on this and enter your zip code to find out who represents your area).

Vivecca Hartman, Steve Schoen, and myself will be available to help anyone who wants/needs assistance.

You can reach us at: Melanie Knapp(Christian's Mom) Secretary rmkrn1@aol.com 281-302-5454

Vivecca Hartman (Christopher's Mom) Treasurer hartmanfam28@sbcglobal.net 713-231-7508

Stephen Schoen (Executive Director) <a href="mailto:stephenschoen@sbcglobal.net">stephenschoen@sbcglobal.net</a>
512-336-7859

#### Bills and Legislative Link:

1) House Bill (HB) and the associated Senate Bill (SB) related to reducing the age from 18 to the age of diagnosis for deafblind individuals to become served through the Deafblind Waiver (for services outside the schools, i.e. at home and in the community).

#### **HB 166:**

http://www.legis.state.tx.us/BillLookup/history.aspx?Leg Sess=81R&Bill=HB166

#### **SB 37 (same as HB 166):**

http://www.legis.state.tx.us/BillLookup/history.aspx?Leg Sess=81R&Bill=SB37

2) House Bill (HB) and the associated Senate Bill (SB) related to improving the education requirements and the associated improved pay for Interveners serving clients through the Deafblind Waiver (outside the schools).

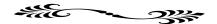
#### **HB 165:**

http://www.legis.state.tx.us/BillLookup/history.aspx?Leg Sess=81R&Bill=HB165

#### **SB 63 (same as HB 165)**

http://www.legis.state.tx.us/BillLookup/history.aspx?Leg Sess=81R&Bill=SB63

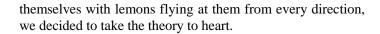
Now we all need to be contacting each of our own State Representatives and State Senators. To find out who yours is, here's the link ("Who Represents Me" box on the right): http://www.capitol.state.tx.us/Home.aspx



#### DBMAT Lemonade

by Christina Weller

It's an old saying that still rings true: When life gives you lemons, make lemonade. So, when four DBS families (and this DBS professional) found



It all began during Amarillo's regional family camp, known as EXCELS. Mr. Wayne Thompson encouraged people to participate in the next DBMAT (Deaf Blind Multihandicapped Association of Texas) Conference, and several families expressed an interest in attending. In fact, Wayne was so convincing that I pledged to provide

transportation for anyone from the Amarillo area who wanted to attend and six families took me up on my offer.

As soon as I got back to the office, I began contacting charter bus companies. Despite internet research, extensive phone calls, and the very helpful assistance of other DBS employees, the idea of renting a charter bus soon became nothing more than a new folder that needed to be filed under "impossible feats."

My next plan was to enlist one of the families to drive their own van and then rent a 15-passenger van for the rest of the group. The family agreed to my suggestion without hesitation, but going through the proper channels to rent a passenger van presented a few new obstacles. It seems that large rental vehicles were nowhere to be found (there was going to be a Texas/OU football game the same weekend). After two weeks of working with rental car companies and numerous hours of effort by several hard-working individuals, only two medium size SUVs could be obtained.

Imagine our surprise when one of the "medium" SUVS turned out to be a small Mazda 5-hatchback! There was no way five individuals were going to fit comfortably in this little matchbox car, not to mention their luggage. Nevertheless (and more than an hour after our original planned start time), one family with a minivan and one family with a truly medium SUV finished loading up and were ready to start the almost ten-hour trek to Camp John Marc. Our group arrived after dark, hungry and tired.

On a side note, a third family who had planned to drive their van had to cancel at the last minute. And two other families from our area rode together in another van. This van proved to have mechanical problems upon arrival at camp; however, with the very competent assistance of several helpful DBMATers, the problems were soon resolved.

I have to say that the kiddos were real troopers throughout the entire trip (and they really enjoyed their portable DVD and MP3 players!). Even when the wind tried to steal their lunch on our picnic stop, laughter was abundant. After all, this trip was all about the precious cargo we were transporting.

Now it is time for me to tell you about the delicious lemonade.....

For those of you who have never been to Camp John Marc, it is beautiful. The facilities are very nice, the new building is amazing, and the staff is incredible plus they really care about all the children. And, although the wildlife and scenery at sunrise are breathtaking, it is the people who make the difference -- the conference is more like a family reunion than a scheduled learning event.

I have to say that the family fun night was the biggest highlight for our campers and me. Daniel's face painting was terrifying. Jessica's flour-covered face was inspiring. Tiffany's eating ability was unbelievable. (We still don't know where she put all that food!) Clay's game playing was awesome. Trevor's basketball shots were incredible. Vontesse's dancing was fantastic. Michael's bean bag tosses were champion. Even I proved to play a mean game of Texas Hold 'Em. While no money was exchanged in the poker game, there was plenty to be found at two auction events. Raising funds for this inspirational group was a snap, primarily because the handmade items and the campers' artistic works were instant crowd pleasers.

DBMAT has proven itself to be a very valuable asset for the advancement of individuals with disabilities. They don't just sit back and talk about things – these people go to the state capital and get things done! Just this last year several families visited with Governor Rick Perry about their concern for services, not just for their own children, but for children around the state. Their work for changes and improvements in the area of providing interveners and making this a respected profession is priceless. This group of family and friends are on fire!

By the time the annual conference was over, we were all excited, encouraged, enlightened, and exhausted. On behalf of the Amarillo area families who attended, I would like to thank everyone involved in making this conference such a success. And, if I may borrow a quote from Bob Hope, I would also like to say "thanks for the memories."



# Finding a Good Provider

by Stephen Schoen

This month I've been thinking about my mother-in-law and her residence in an assisted living facility for people with Alzheimer's disease. It struck me that considerations for choosing a provider are the same no matter what disability we are dealing with. My wife Marian and I were lucky to find a good provider at a fairly reasonable price. But "lucky" is the key word here, because we didn't arm ourselves with the type of information that I am suggesting you procure. So, I hope this article is helpful to parents of people who are deaf-blind with multiple disabilities who are trying to choose among providers.

So first off – *What is a provider?* By provider I am talking about the employer of the people who work directly with your child. In Texas, providers are typically paid by Medicaid Waiver programs. When a person is accepted into a Medicaid Waiver program (whether it is the Deaf-Blind Multiple Disabilities Waiver, or others such as CLASS or HCS) the person must choose from a list of provider agencies. This choice can end up being very important, because the provider agency determines the quality of

services which your loved one receives.

How to choose? Given a choice of names of provider agencies, how can one possibly decide which one will be best for their child? My advice is to dedicate a good amount of time to this decision and keep a notebook to record all of your findings. The two basic strategies I propose are:

- 1) Ask friends. Find out the good and bad experiences of your friends who have used provider agencies, and
- 2) Interview providers: Remember that you are in charge as the consumer. Be sure that providers answer all of your relevant questions. If a provider acts like you are imposing on their time by asking questions, that in itself is important information.

#### Ouestions could include:

- I. Questions about direct care staff. While direct care staff are the lowest paid employees in the provider agency, they are the people who most impact the lives of your loved one. So most of the questions I'm suggesting are about direct care staff.
  - a) What is the turnover rate for direct care workers? Chances are good that providers don't keep an accurate tally for this, so you need to ask related questions that will help you decide the likelihood that a direct care worker will stay on the job.
  - b) What is the salary you pay to starting direct care workers? Providers should be able to answer this honestly. While the state pays a specific rate to provider agencies for hourly direct care worker salaries, the provider gets to decide how much of the rate translates into a salary and benefits.
  - c) Do direct care workers get raises? What is the company policy toward raises? If a direct care worker stayed for 2 years and had excellent performance reviews, what salary would they earn?
  - d) What benefits do direct care workers receive? How long do they need to work before they are eligible for benefits?
  - e) How does the provider agency let direct care workers know that they are valued? Providers can make the direct care worker's experience more pleasant by: letting them have input about work conditions, providing recognition for a job well

- done, explaining how the direct care relates to the "big picture," etc.
- f) What training regarding deafblindness and developmental disabilities does a direct care worker receive? How many hours does the training consist of, who provides the training, and what continuing education is provided?
- g) How are direct care workers monitored (frequency, method)?
- II. Questions about provider philosophy. It pays to find out if the provider has a good knowledge of developmental disabilities in general, deafblindness, and resources available in the community.
  - a) How do you work with clients to enhance communication? For example, your child uses a tactile communication calendar, the provider should be able to explain how they make calendars a part of the deafblind person's daily life.
  - b) How do you work with clients to ensure that they participate in their own activities of daily living as much as possible? Are clients given opportunity to learn by doing?
  - c) How do you work with schools (when the child is school age), to ensure that goals are enhanced between home and school?
  - d) How do you allow clients choice in their daily lives?
  - e) How do you work with clients so that they can navigate in their environment as much as possible?
  - f) How do you work with clients to ensure that they participate in the community in activities which they enjoy?

This list is not meant to be exhaustive. If you have more suggestions, or have found helpful methods in your own experience, please email them to me, and I will post them in our next newsletter. Happy hunting!



# Grandparenting a Deafblind Child

by Dick Newton

Being a member of DBMAT my wife, Phyllis, and I realized we are in a somewhat unique situation. Our daughter Julianne, who was a brittle diabetic, was in and out of hospitals with health issues for many years. When she became pregnant, she began having complications. Nate was born at 24 weeks and weighed one pound, six ounces. He was required to stay in NICU for five and half months. It was later determined that Nate

was deaf, blind in one eye, and developmentally delayed. After our daughter passed away due to complications from diabetes in 2002, we took the necessary legal action which resulted in first temporary custody, then permanent custody, and finally an adoption on July 14, 2004. Nate had several medical needs including a tonsillectomy, hernia surgery, and the need for physical, speech, and occupational therapies. So

much for our easy living and being free to travel whenever we wanted. Yogi Berra said it best. "It's like déjà vu all over again." Change was in the works.

It was through TSBVI outreach that we learned about DBMAT and it has been a blessing. We have learned so much through this organization, getting on the waiver lists probably has been the most beneficial. By attending the annual conferences, the information we have obtained has been so enlightening. Nate really enjoys the activities for the children. The support and networking with other parents of deafblind children has been priceless. Nate is in the DARS program and MDCP, both of which have helped financially and with respite care opportunities.

Nate has been less fortunate, however, when it comes to schooling. He has attended three schools in two school districts resulting in little more than child care. It was through TBSVI Outreach that we were able to apply and be accepted to the school. Nate started last August and has shown quite an improvement in his communication abilities. While Nate has been "a work in progress" he has been the thunder and lightening of our life. It has been and will continue to be the experience of a lifetime



by Kevin Thompson

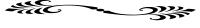
This past year was my ninth year to go to DBMAT camp. I really appreciate the opportunity to attend the camp. I also appreciate the college students who are counselors and Gay Bellamy the lady that makes camp run smoothly. They really help us out a lot.

On the first day, I get to make some new friends and see some of my old friends again.

on the second day at camp we start the day off with a superb breakfast in the dining hall. After that you go back to your cabin for thirty minutes. We have a fun schedule which includes arts and crafts, games in the barn, fishing, cooking, ropes coarse, and even nature hikes. After that we eat lunch and take a fifteen minute break. It's back to our schedule. After we do all the activities on our schedule, we have a thirty minute break to rest and get ready for dinner.

After dinner it's back to the barn where the kids enjoy a carnival. During the carnival the kids enjoy games like poker, flour tower, four square, and even football. You also get to eat junk food like cotton candy, sno-cones and lots of ice cream. After that it's off to the campfire for songs and smores. After that it's back to the cabin where some counselors decide to have pillow fights or tell scary stories and then go to bed.

The next day is the saddest one because you get up and eat breakfast then go back to the cabin and pack up. Then it's off to the barn for a castle building contest, but here's the twist you have to build the castle out of dry spaghetti noodles, marshmallows, pipe cleaners, and popsicle sticks, its lots of fun!!!!!



# Notes from a "Newbie"

by Becky Bilyeu

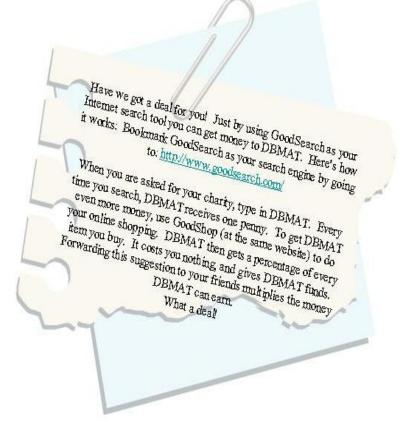
The flyer on my desk said "... a conference designed for families of children and adults who are deaf-blind multihandicapped, deaf-multihandicapped, blind multihandicapped and the professionals who serve them." Before I could fully digest this information my phone was ringing and Celeste Rand, parent of an adult child with deaf/blindness was encouraging me to attend the 36<sup>th</sup> annual DBMAT Family Conference. She has always been quick to help me learn new things about deaf/blindness, and as an educational consultant for Region 18 Education Service Center who works with teachers and parents of students with Low Incidence Disabilities, I knew this would be a great opportunity. O.K., so I didn't read the part about "... rustic environment." Celeste did tell me I would need to take bedding, towels etc, so I guess that should have been my first clue.

Celeste suggested I arrive before dark, so I left a meeting early in Austin, fought the Texas vs. Sooner football traffic, and arrived right at dusk, just in time to be greeted by truly the largest snake I have ever seen, crossing at the Camp John Marc entrance. Being a country girl, I did make note that the snake did have a pointed tail, which somewhat put my mind at ease. (Of course it was at this time I remembered reading something about bringing a flashlight and not wearing open toe shoes.) Because of the slithery distraction, I failed to really witness the awesome beauty around me. After I registered, found my assigned cabin, and wandered down to the dining hall, the beauty and the magnitude of the place really hit me. But, the best surprise awaited me...upon entering the dining hall I noted a room filled with adults, young adults, teenagers, children and infants all interacting, eating, talking, and laughing. It was a snapshot of what I envision an effective, inclusive public school to look and sound like. After dinner, since it was well past dark and I had not heeded the flashlight advice, I high-stepped it back to my cabin. More insight about the many issues our students face was given late that Friday night by a weary, but enduring, Vivecca Hartman who answered my endless questions. The weekend was a whirlwind of learning and networking. Highlights for me were the legislative updates and the State of the Intervener in Texas presentation.

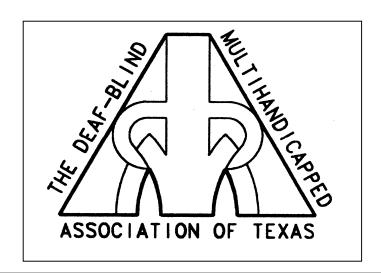
As the Low Incidence Disability consultant for Region 18, my main responsibility is to assist teachers, administrators, and staff meet the educational needs of **all** our students. Attending this conference gave me much insight and information on how to better do this.

One thing parents and teachers can look forward to from their Education Service Centers is a new literacy training which will be provided, tentatively early next school year, called "Teaching Literacy to Students with Significant Disabilities" developed by the Center for Literacy and Disability Studies at the University of North Carolina in Chapel Hill under the direction of Dr. Karen Erickson. The Low Incidence Disability specialists from across the state met last October to preview this training. It is great and I think many of our students with deaf/blindness, and, or multihandicapped will benefit as their teachers learn how to better teach literacy skills to them. To determine your education service center and who your Low Incidence Disability specialist is go to <a href="http://ritter.tea.state.tx.us/ESC/">http://ritter.tea.state.tx.us/ESC/</a>. Thank you for the wonderful opportunity to attend the conference. Let me know if I can be of assistance to you or vour children.

Becky Bilyeu Educational Consultant Region 18 Education Service Center 432/567-3239 rbilyeu@esc18.net



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