



In Touch

The Newsletter of the Deafblind Multihandicapped Association of Texas
Winter Edition ~January-2007

News from the President



Conference Wrap- Up

In mid October 2006 DBMAT held its 34th annual family conference, “DBMAT is Deep in the Heart of Texas.” A great time was had by all. The weekend was full of activities and fun. We learned a lot, made some new friends and got to visit with old friends.

Awards

Leeann Bryan received the Christian Knapp Award for being a great motivator to deafblind people. The award was presented by Christian’s parents, Gary and Melanie Knapp. Bud & Lynn Freeman received the Olivia Cruz Award for their long years of service to DBMAT. Craig Axelrod received the Everett Bryan award for Professionals who go “above and beyond.”

Conference Highlights

Al An Kessler of DARS led off the conference with a presentation on keeping families healthy. Al An was a big hit with the participants. Robbie Blaha, Melanie Knapp, David Wiley and Steve Schoen presented on Intervener services. Melanie’s ability to present personal experiences in an entertaining manner helped convince many in the audience about the importance of quality intervener services in their children’s lives. June Griffith was again very convincing on the need to look at guardianships and other legal matters. And Jacqueline Carter presented a sibling’s view to a very interested audience. I appreciate all the hard work of the conference planning committee who helped make our conference a success! We appreciate the support of all the state agencies, staff of “HandsOn,” Camp Jon Marc staff and all the other volunteers who helped us make camp happen. We appreciated Brandy from Discovery Toys who again shared these educational and fun items.

In our general membership meeting Wayne Thompson was elected as Vice President and Melanie Knapp was re-elected as Secretary. We elected three members at large: Jackie Carter, Cyndi Hunley, and Rosa Douglas. The other members of the board (whose terms are still ongoing) are: Chris Hartman, Treasurer, Alaine Hinds, Denise Sewell, and me, your proud president.

New Goals for a New Year

DBMAT has a new direction. What better time to present this view than the New Year? The new vision for DBMAT took shape during a Board and RC** Training event sponsored by the Texas School for the Blind Outreach Program in June, 2006. Barry Silverberg of the Texas Association of Non-Profits led the Board in exercises to improve the work that we do. As a result, we made two major decisions:

- 1) DBMAT determined that to be a strong organization, we needed a shared vision. Goals and views were discussed, and the vision of DBMAT became: **Quality Intervener Services are provided to all Deafblind Individuals Lifelong.** (More on this in page 4.)
- 2) The **subcommittees** of DBMAT were strengthened so that our goals and vision can be carried out. (More on this in page 4 & 5.)

** If you wonder what an RC is: answer is on page 5.

President, Paul Welch

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Family Training Feedback...

Amazed and Grateful!

by LaChandra Noel

It is amazing how much information one can absorb in a DBMAT conference! The deaf blind community is a family of individuals who are parents of the deaf blind and those who care about the issues of the deaf blind.

I recently attended yet another DBMAT conference in October 2006 and I was not disappointed with the information offered. It would seem that some of the same topics are discussed in many of the conferences across Texas but when it is done in DBMAT style I receive a new perspective on the information offered.

I must say being a part of the DBMAT family is not only a privilege but also a treat. I am truly grateful for both the families that share their stories and experience as well as those who volunteer their time and efforts to the deaf blind community.



"Because of the Past, We Have a Future!"

by Bud & Lynn Freeman

We received an award from DBMAT at the October 2006 Annual Deafblind Family Conference with the above inscription. It was presented in the memory of Olivia Cruz because of her dedication and efforts on behalf of persons with deafblindness.

It is true! DBMAT gives us hope for the future. This organization has been blessed in the past and will continue to be marked by God's favor because of the sense of gratitude our members have for those who are served along with those who are serving—the families of the deafblind.

Several state agencies (DADS, TSBVI, and DARS) not only provide the financial support needed but also devoted professionals (active and retired). They help us in planning and implementing the annual family conference for members and guests of the deafblind community.

Siblings of deafblind persons look forward to this annual event and enjoy the activities and fellowship with their peers. Over the years we have heard excited remarks made by the "sibs" of how much they look forward to this annual event and how privileged they are to come to "camp" because their sib is deafblind.

This annual conference is an educational opportunity for the parents and an occasion to network with professionals and caregivers of all ages of the deaf blind. Many families make contacts with other families resulting in lifelong relationships and mutual aid.

We encourage family members and professionals alike to continue this annual conference which benefits all attendees. We especially encourage the younger families who sometimes feel "lost" in this new world and need the support they find here.



DBMAT appreciates the donation from the Golden West Branch of Foresters of Illinois.

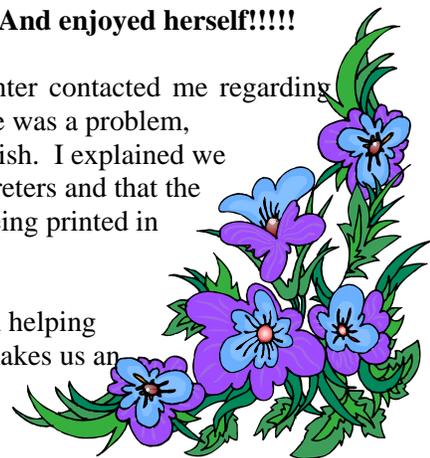
Report From the "Conference Registrar" by Cyndi Hunley

The conference was a great success again. The registrations were early and most were in before the deadline. That gave me plenty of time to organize the sleeping arrangements and to give the information to Gay Bellamy on the children attending and any special handling needed for those children. A great awesome friend helped me enter the information into an excel spreadsheet that will be used in the future.

We did have several new families come this year. Even though this is a Texas Deaf Blind Group, a parent called from Oklahoma needing information on her daughter's disability and we were able to extend an invitation for her to come. SHE CAME...**And enjoyed herself!!!!**

An Educational Service Center contacted me regarding the conference, but said there was a problem, the mother speaks only Spanish. I explained we had excellent Spanish interpreters and that the handout material was also being printed in Spanish.

We have come a long way in helping families. And that is what makes us an extended family.



"NO YOU DON'T"

by Wayne Thompson

I feel certain that it has happened to most of us who have a special needs family member. Usually, some well-meaning individual says to you "I know what it is like," or "I know how you feel." I usually think they don't know what else to

say. But there are times when I think to myself... **“NO YOU DON’T, YOU DON’T HAVE A CLUE!!”**

You don’t know about the 20,000 plus times we have cathed my son in the last nine years.....

You don’t know about the 13,000 + breathing treatments and CPT...

You don’t know about the 13,000 + tube feedings and thousands of meds pushed...

You don’t know about the hundreds of doctor appointmentsthe countless tests, procedures, and surgeries and hundreds of hours of therapy...

You don’t know about the weeks and months spent away from your other family, while attending your loved one at extended hospital stays...

You don’t know about the countless meetings and phone calls with the school and other professionals concerning your child’s education and other services....

You don’t about the times that your child is gravely ill, and you fear this may be the last day you have to spend with your child while here on earth...

You don’t know of the emotional and financial stresses many of us endure daily...

You don’t know the anger and sometimes guilt we feel because this happened to my child, my family, and ME...

You don’t know about the helplessness we often feel because we cannot “fix” our loved one...

Most of all...you don’t know of the blessings that have been bestowed on us because we have been given a gift that many never receive...blessings too numerous to mention...the insight that would have never been gained without our experience. These blessings and gifts can never be taken from us and will endure for generations to come.

You don’t know the blessings out weigh by far the hardships we endure...

You don’t know unless you have a loved one with special needs....and then you don’t know because the dynamics are different in each family.

I can only imagine what is like for you...but I don’t know.

P.S. I would like to take this chance to thank all of the DBMAT folks for giving me the honor of serving as your vice-president. I only hope I can serve in a meaningful way to accomplish the goals that we have set forth for DBMAT and all of our families. Thanks!

Learning Sign Language

by the Hartman Family

To anyone interested in learning sign language, do not feel intimidated!

Recently, my family and I have started learning sign language from our Auditory Instructor (AI) who is assigned to our son, Christopher. Let me give you a little background. For a few years we have learned the signs of all the basic needs.

Surprisingly so, having learned those simple signs have really paid off in getting us familiar with using our hands for communication. As our son is deaf and blind we use tactile sign with him. Tactile sign is basically sign language with the speaker’s hands under the listener’s hands. We certainly went through a transition in getting acclimated to this process.



Today, we feel eager to learn more sign so we can feed the language to our son with the expectations that he will pick-up on more and more language. He, too, will have to grow to be comfortable with the extended communication, from the one word statements we have been using. We are all in the learning stage, but I am confident we will get there!

If you by chance have any interest in learning sign, we recommend you try it. We are also having fun amongst the sighted members of our family, like Kaylina, by using the signs to communicate around the house and in places where our ears would not work well (i.e. from afar). We have even been showing signs to our nieces and nephews and they are having fun with it, too!

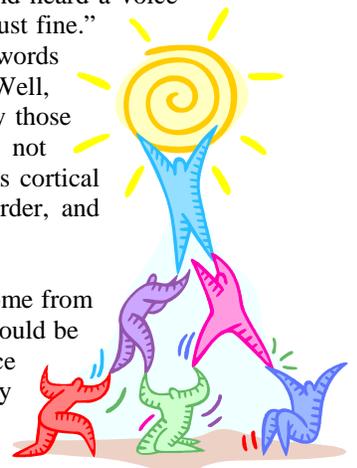
The biggest challenge is getting use to using your hands for communication. After getting started, you will find it is easier to learn than you may have originally thought. So good luck in getting started☺!

“She Will Be O.K.”

by Cyndi Hunley

My daughter, Elizabeth (but I have always called her Bethie) was 14 months old when she became deathly ill. She was a little slow in her cognitive and motor skills before the illness. Bethie had meningitis and encephalitis and the doctors were not sure if she would make it. As I watched Life Flight take her to Herman Hospital, I just sat in the truck and prayed to God that if it was his will to take her I would accept it and go on. I felt a peace come over me and heard a voice say, “She will be OK, She will be just fine.” For several years I hung on those words as meaning she would be normal. Well, I misunderstood what was meant by those words. She would be ok, but not normal. From the illness Bethie has cortical blindness, auditory processing disorder, and severe mental retardation.

About six months after she came home from the hospital, I got a call that there would be DBMAT Family Conference that probably would be very beneficial to me in Austin. That was my 1st year of many going to the DBMAT conference, 1982. Beth is



now 24 years old, and I still feel excitement at seeing families, like myself, year after year. It was uplifting to see the experienced parents before, and now, I'm in their shoes. I'm one of the more experienced parents helping to get the information to the young families. You may not talk all year long but you know when you get to camp you will catch up.

I feel the families of DBMAT and the professionals that I've met along the way through DBMAT are an extended family. I feel if I have or Bethie has a problem I can call anyone and if they don't know they will steer me in the right direction. My friends support me with Bethie but my DBMAT family understands.



New Vision for DBMAT

by Steve Schoen, Executive Director of DBMAT

During our June meeting people talked about many great ideas for improving the lives of deaf blind family members. When Melanie Knapp shared the story of her son Christian, many people were impressed with the changes, which occurred for Christian after provision of skilled intervener services. Christian's story became a rallying point for DBMAT.

Christian's story is published on the DBMAT website at <http://www.dbmat-tx.org/suggest.htm>. People were impressed that Christian's ability to communicate and express himself was directly affected by intervener services. These services were hard to come by. In elementary school, the Texas School for the Blind and Visually Impaired (TSBVI) Deafblind Outreach Program worked with teachers, administrators and aides to develop a communication system for Christian. When Christian moved to a new school which didn't understand the intervener model of service, his ability to interact with people was affected severely. Consistent advocacy from his parents, and training from the TSBVI outreach program, as well as a lucky match with a skilled and motivated intervener turned things around for Christian.

DBMAT realizes that Intervener services need to be provided to children at the earliest possible age, and that DBMAT has an important role in making this happen. For quality Intervener services to be provided to all deafblind individuals lifelong, a number of actions need to occur:

- 1) Intervener Training needs to be promoted and increased. DBMAT will work with TSBVI-Outreach, The Texas Deaf-Blind Waiver, and the National Intervener Initiative Parent Group to develop a consistent curriculum and training procedure for interveners.
- 2) The Texas Deaf-Blind Waiver needs to be amended to add ages 0-18 with a focus on providing interveners from a very young age. Children need skilled intervener services upon diagnosis of deafblindness. Amending the waiver to serve children will help in these early years.

- 3) The Texas Deaf-Blind Waiver needs to be amended to increase the skill requirements and salaries for Interveners. To motivate people to enter the field of intervention and obtain the necessary training, the Deafblind waiver needs to be amended to increase salaries and professional recognition.
- 4) Skilled Interveners need to be added to other Agencies including Early Childhood Intervention and Schools: Just as in the Deaf-Blind Waiver, schools need to increase the salary and recognition for interveners.
- 5) Add Services for Deafblind People who are Medically Involved and Aging: DBMAT recognizes that as deafblind people age, their needs increase and services are not always available and appropriate.

As Ringo Starr** once sang, Change, "It Don't Come Easy." No doubt, he was not thinking of Intervener services at the time, but the lesson is well to remember. The Legislative Committee of DBMAT is hard at work on this objective. Any person who wants to volunteer to help can contact me at stephenschoen@sbcglobal.net.

Email me if you would like to:

- 1) attend planning meetings of State agencies,
- 2) share personal stories about success with interveners, or the need for interveners in your own family,
- 3) share personal stories of what happens when providers are not properly trained,
- 4) any other thing that your creative mind can think of.

**For those younger readers: Ringo Starr was a member of the Beatles. This was a somewhat popular recording group in the 60's and 70's.

As mentioned in # 1 above, DBMAT is participating in the *National Intervener Initiative*. Their **DRAFT** statement of purpose is:

"The purpose of the National Intervener Initiative Parent Group is to establish the use of Interveners as an accepted standard of practice for individuals who are deafblind (ages birth to death) and to support the recognition of Interveners as related service providers under IDEA laws and regulations and as support service providers under Medicare/Medicaid law."

DBMAT

"Divides the Work"

By Steve Schoen

When DBMAT Board members and RCs met in June, we began to realize that if the work is spread to more people, DBMAT belongs more to the membership. The work groups listed below met in June and started planning for the future.

Currently, people who are Board Members and RC's serve on the workgroups. But, any one who is interested can contact me and add their name to a list. You might be wondering how work groups can function when DBMAT is a statewide organization. Thanks to President Paul's ingenuity, work groups mostly meet in a "1-800- Meeting room." Further communication between members takes place via email. Here is a summary of what the work groups are currently working on.

Fund Raising: No organization can exist without money. DBMAT has worked hard this year to increase the budget. More work will be necessary. Fund raising events include the silent auction at the annual family conference, and t-shirt sales. We have received grants from: the Hilton Perkins Foundation and the Women of St. Michael and All Angels Gift Committee.



If you are interested in raising funds for DBMAT, we can assist you with a "DBMAT Fact Sheet," "DBMAT Contribution Form" and "DBMAT Membership Application." A copy of these forms can be obtained from any of the board members.

Memorial or Living Honor gifts are also accepted by DBMAT. Any money donated to DBMAT is tax deductible since we are federally designated as a 501c(3) Charitable Organization.

Conference Planning: Conferences don't just happen; they are the result of hard work from many contributors. People on this committee worked very hard this year to make the conference a success. We will start planning next year's conference around March of this year.

Internet: Many times, the website is the first contact someone has with DBMAT. Our website has recently been modified and improved. Board Member Jackie Carter heads this work group and is constantly improving the website. As you use the website, contact Jackie with your findings. He appreciates both positive feedback and constructive suggestions.

Membership: This work group tries to increase membership, maintain records of members, and keep them informed of their status. Contact C.C. Davis if you want to add your name to the membership list. His email is ccfutbol@aol.com

Legislative: This work group affects policy of the State of Texas as it relates to deaf blind people. They are advocating to: legislators, state agencies, and other groups which serve people with disabilities.

Assistance to Families: As I promised on page one; here is the explanation of Regional Coordinator (RC). This work group consists of the RCs who bring the message of DBMAT to their communities. They assist people in their interactions with public schools, provider agencies and state agencies.

They share the results of their efforts and attempt to stay up-to-date so they can provide the very best of assistance.

If you want to participate on any of these work groups, contact me at stephenschoen@sbcglobal.net

Notice of DBMAT By-Laws Meeting

DBMAT will be holding a special phone meeting to review amendments to the by-laws. This meeting will be by conference call. Any member of DBMAT may participate by calling 1-800-580-9381. When the operator answers, enter 9016056. The meeting will be Sunday, March 3, 2007 at 8:00 p.m. The amended by-laws will be available for review online at the DBMAT website <http://www.dbmat-tx.org/> at least 2 weeks before the meeting.

The Texas Deafblind Project presents the 2007 Texas Symposium on Deafblindness

All registration ends January 19, 2007. But, if there's still room and your registration arrives close to the deadline, TSBVI may be able to accept your registration.

For parents, adult family members, professionals, interveners, and paraprofessionals who are currently serving or planning to serve children or youth with deafblindness ages birth to twenty-two.

**February 16-17, 2007
Omni South Park Austin
4140 Governor's Row
Austin, Texas 78744**

This two-day event includes keynote/general sessions, breakout sessions (eight each day) and presentations of this year's deafblind service awards. Sessions will be presented by Texas families, educators, and related professionals, as well as national leaders in fields associated with deafblindness. Friday also features a special luncheon for interveners and an evening social for families hosted by DBMAT. Saturday will feature a luncheon for Project SPARKLE families.

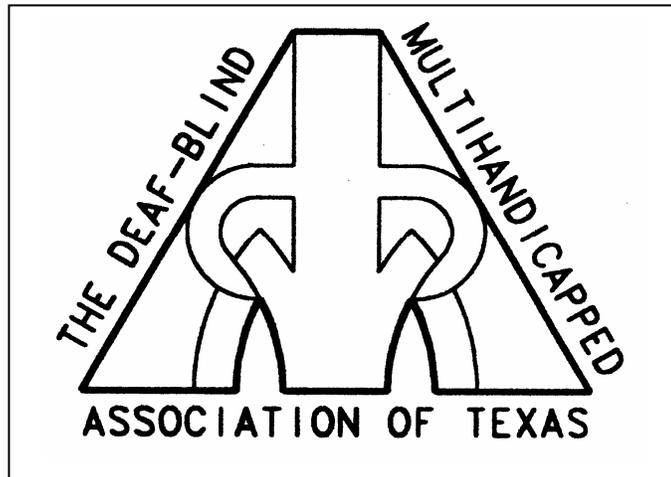
Alone we can do so little. Together we can do so much. - Helen Keller

[Deafblind Symposium Registration materials](http://www.tsbvi.edu/news.htm#dbs) can be found online at: <http://www.tsbvi.edu/news.htm#dbs>

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If you would like to be dropped from DBMAT mailing list or have a change of address
please contact: Paul Welch – Big Spring, TX.