



In Touch

The Newsletter of the Deafblind Multihandicapped Association of Texas
Summer Edition ~June 2009

From the President's Pen

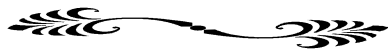


So much has happened since the January Edition of the Newsletter I don't know where to begin. I guess I will begin at the part where we say that DBMAT had a dream. The board met after a training session in Dallas at the home of C.C. Davis and made a wish list or dream list for DBMAT. We have finally realized goals from our list and we still have several others to work on. Our two bills, SB 37 and SB 63 have been signed into law by the Governor and I am so proud!

There was a lot of behind the scenes work on our bills. This newsletter is a special edition dedicated to describing how DBMAT got involved in the political process. Thank you everyone who worked so hard to make our bills happen.

Conference planning has begun. Our DBMAT Family Conference will be at Camp John Marc on October 9-11th. Please mark that on your calendars. Anyone who would like to help us with conference planning should contact Steve Schoen or me. We welcome new ideas and any and all help!! See you at Camp!

Paul Welch



Learning the Legislative Process

by Steve Schoen Executive Director

About 30 years ago, DBMAT advocated for and successfully brought about the Deaf Blind Program which over time has morphed into the Deaf-Blind Medicaid Waiver. None of the current active members of DBMAT were around back then. So, when it became clear that the changes we wanted in the Deaf-Blind Medicaid Waiver would require Legislation our learning began. DBMAT now knows from very personal experience how a bill becomes a law. This first hand type of learning experience can't be beat. We are celebrating the passage of our bills by telling stories of events which happened along the way. Without all of you loyal members of DBMAT who

wrote emails to your Legislator, called their offices, and nagged your friends and relatives to contact their relatives, these bills would not be law. So thanks go out to all of you.

These bills (in a nutshell)

by Steve Schoen

Senate Bill 37 makes children eligible for the Deafblind Medicaid Waiver. Until now, the DB-MD Medicaid Waiver only served adults. That made sense 30 years ago, when most of the Deafblind consumers who needed this program were graduating from residential Special Schools. But, in this day and age, most deaf-blind children are living at home with their parents who need the support which a Medicaid Waiver can provide.



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Senate Bill 63 creates a career ladder for Interveners. When this bill is implemented, interveners in the Deaf-Blind Medicaid Waiver should have a real career with a decent salary. And their salary will be based on the amount of training and skill they possess.

The two bills should make a tremendous difference in the lives of people who are deafblind with multiple disabilities. But, it may take a number of years before all children who are deafblind proceed through the waiting list (this depends on funding from the Legislature), and some time before Interveners pursue the training they need. So patience is still needed.



I Meet My Representative - Susan King

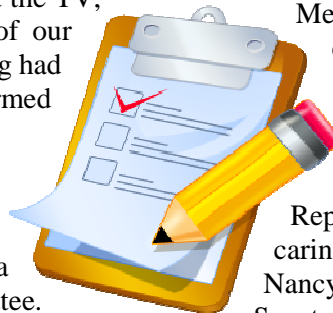
by Wayne Thompson

About a year and a half ago my wife Diedra informed me that State Representative Susan King was holding an open forum meeting at TSTC's campus in Sweetwater. I decided to attend and to take Caleb to meet her and perhaps get an opportunity to discuss issues pertaining to our lives.

We arrived early as did Rep King. While signing in, I was able to introduce myself and Caleb to her. We struck up a conversation and learned that she is a registered nurse. Therefore, the initial conversation centered on Caleb's medical issues. This led to the subject of deaf-blindness and of course to DBMAT. She was unaware of DBMAT, and indicated to me that she had never really thought of the issues concerning dual sensory loss. What an opportunity to help inform her. During the public meeting, I asked her a question. She said that we needed to meet later and talk. She had opened the door.

Over the next few weeks and months and many contacts with her and her aides, we arranged a meeting in her Abilene office. At her request, we provided her our "talking points" so her researchers could help her become informed prior to our meeting. Steve, Paul, and I came prepared, too. I brought chocolate chip cookies that my wife had made. I introduced her to Steve and Paul. Steve brought his "white paper" and Paul had brought the TV, DVD player, and CD's to show her visuals of our family conference and Jason's story. Rep King had done her homework, too. She was truly informed about DBMAT and our vision.

The rest is history! We had made a friend who was willing and able to champion our cause. When I made the initial contact, I had no idea that Rep King was co-chair of the DHS committee. She was later appointed to the appropriations committee.



Last, but not least, who would have dreamed that Rep King was a high school class-mate of our wonderful secretary Melanie Knapp.

I want to extend a special thank you to Rep King and her aide Robyn. I also want to thank the numerous other legislators who took up our cause and supported our bills. Thank you to all of you who made phone calls and sent emails to their local legislators. You were a crucial member of the team. We also owe a special thanks to those who waited for hours to make personal testimonies before the legislature. Way to go, Team!

Note: Susan King plays an important part in the article below: "Chubbed by Chisum"



An Important Legislative Contact

"Happens"

by Steve Schoen

I was playing with my band, "Casa del Swanko" at the Tree House Italian Restaurant in Austin and a friend brought his sister to engage in fine dining with musical accompaniment. During the band's break, I sauntered over to the table and a polite conversation ensued. The friend's sister replied to my usual question "What do you do?" with the answer, "I'm Nancy Walker, the Legislative Aide for Representative Naishstat." Chance, luck, or the hand of a higher power: Be that as it may, a friendship developed.

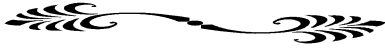


Over the next few months, Nancy introduced Melanie and me to Representative Naishstat at his office. This was Melanie's very first visit with a real life Congressman (and my second- see Wayne Thompson's story) and we were somewhat nervous. We presented our papers explaining the needs of deafblind people and started to talk.

Representative Naishstat put us at ease immediately. I was impressed with his knowledge of Medicaid and long term care, and with his easy comprehension of our story. After talking for some time, he said the magic words, "Let's do it." Later in the year, I heard another member of the House Human Services Committee refer to him as Elliot "Gandhi".

Representative Naishstat's calm demeanor and caring attitude made this an apt comparison. Nancy introduced us to Jessica Ramos, the Aide to Senator Zaffirini, who sits on the Senate Human Services Committee, and we had a great meeting with

Jessica. Representative Naishstat authored our bills in the House with Representative King as co-author and Senator Zaffirini authored them in the Senate.



DBMAT Meets the Governor

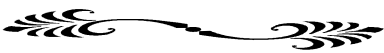
*Excerpted from Vivecca Hartman emails
(while she vacations in Italy)*

One of the highlights of our Legislative year was a “photo-op” which President Paul arranged with Governor Rick Perry. Paul diligently used his persuasive abilities to convince the Governor’s staff to arrange the meeting. Those of us who have been on the receiving end of Paul’s persuasiveness felt sorry for the Governor’s staff, but we knew the meeting would eventually occur. On August 25th the Governor met with many DBMAT families and their children. Vivecca Hartmann ended up being our spokesperson. Here are a couple of emails she sent out afterwards under the heading: “Christopher Meets the Governor”

8-25-08: We even got to meet the Governor today and tell him all about Interveners!

Gov. Perry was just AWESOME. He said we should not have a problem getting our 4 goals passed to ensure deafblind individuals are able to get Intervener services from the age of diagnosis and to get legislative support for all school districts across Texas to recognize it as a related service. He said to just keep "squeaking" about it to ensure people know about it and gave us some tips!

8-26-08: It was very cool, because it certainly seemed he had done his homework before we got there! He recommended to us that it be a 2 year degree program! We said we totally agree. He said there are many Texans that need to get going for a 2 year degree and I followed up by saying not everyone needs a 4 year degree and this is a perfect example of one. He agreed!



Who Ya Gonna Call (Well, it's not Ghostbusters this time)

by Robbie Caldwell

It's funny; I had somehow joined the DBMAT-Legislative group. I'm still fuzzy on how that came



about. So, I found myself on a conference call regarding the “BILLS” we were trying to get support for this session. I understood, hmmm, let’s say maybe a third of the conversation that night. I had already silently committed that I was going to make myself completely available to DBMAT’s efforts. Not unlike many of you, I am overwhelmed with raising a Deafblind child. However, in the words of Vivecca, “I don’t know about ya’ll, but I can only keep this up for a few more months.” So I thought that was fair and I could give this my best effort for the next few months.

Back to the DBMAT conversation that night. I didn’t understand most of it, but I did know that I wanted to do something. Aha! Within days emails went out to everyone I knew in the state of Texas. Really. I called on everyone whose contact information I had. I called on every person that had ever heard Gabby’s story. I called on each individual that I had worked with as a professional and a volunteer. I emailed friends that I had gone to school with back to elementary. Facebook is a wonderful tool. Luckily, I had not been bombarding them with messages or forwards. (Just the occasional picture or two of Gabby being brilliant.) So the call went out in the form of an email titled “Your help pleeeeeeaaaaasssseeee!!!!” I knew that they would open it and hopefully a percentage would read it and act. I went so far as to write a fill in the blank letter for them. Included in the email was the link to find out who their representatives were. It worked! Within a week, I received numerous confirmations of letters written.

Fast forward a couple of months. By May the bill had finally gotten to the Calendar Committee. A friend of Steve’s, Bob Kafka, who we ran into at a previous hearing, had told us that this is a committee where bills can easily get hung up. I was worried as I walked into one of the Conference Committee member’s offices and introduced myself. When I mentioned DBMAT and the bills to the staff person (probably the receptionist) from across the room, another aide said, “Oh yeah, we just got a letter from a constituent about those bills yesterday.....” Jackpot!



MY TIME IN THE HOT SEAT!

by Susie Welch

When I was going to Austin for the Deafblind Task Force meeting with Paul, I never thought about having to testify in front of the Senate Finance Committee. The trip started out as just a relaxed fun and learning trip. I was going to attend the Task Force meeting and the Deafblind Symposium. Next thing I find out that our Legislative Committee needed another person to testify. Guess what?



That person was me!! I didn't know what to expect. This was really scary. I haven't had to get up in front of strangers in a very long time and I had no experience in politics. I have always been a behind the scenes person not a stand up in front of people person.

Testifying in Austin with my Deafblind Daughter and Her Intervener

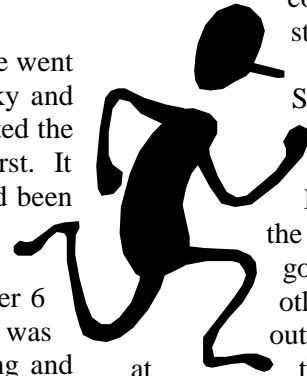
by Becky Harmon

Vivecca Hartman, Alaine Hines and I left the hotel around 7:45 am for the Capitol. Becky Harmon, her daughter Kersten, and her daughter's intervener Aja were free until after lunch and they volunteered to come testify. We joined Steve Schoen at the Capital who was there for moral support. When we got there we had to go register to testify. Then we went to various offices to leave a packet about our organization and the bills that we wanted passed. We met up with Marty Murrell who was testifying for bills that AVIT was working with.

After all our trips to different areas of the Capital we went back to wait our turn to testify. They called Becky and her daughter early because Senator Zaffirini suggested the Committee should let people with children speak first. It was a long day and by 4 pm we all felt like we had been waiting forever. I think somewhere after 5 pm Marty testified and then Alaine Hines. Alaine was there testifying for AVIT's bill. Finally, it was after 6 pm and Vivecca testified. She sounded so good. I was so proud of her, and I was so so nervous!! Sitting and waiting is not one of my strong points. Several of the members of the Finance Committee had to leave but thank goodness Senator Zaffirini was still there. I felt more encouraged. At least I knew that someone there on the committee was for our bills. It finally came my turn. I had three minutes to say what I had experienced in a lifetime with my son and how having trained people providing services to him at an early age would have made a BIG difference in his life. I tried to cover all the main points. I know I stumbled a few times but I said what I needed to say. Every time I would look at Senator Zaffirini she would just smile and nod her head. I knew that maybe I was saying something right. I did know that after listening to a lot of the people testify about their bills that it seemed that the committee listened more attentively to the people that spoke from the heart and didn't read a paper the entire time.

I felt good after it was over. I know now what to expect. I know that you must be prepared to wait and wait a long time! I won't say I still will not be nervous. I just know that everyone who went to testify spoke for all our kids. Our kids can't advocate for themselves so we have to do this. These bills are really going to make a big difference in the lives of the young children that are coming up.

Wow, February 12th 2009, that day in Austin was a blur ... The reason for even being in Austin was for the Deafblind Symposium that only happens every two years. Vivecca Hartman had called earlier in the week and said that it would be great if Kersten (my 14 year old deafblind daughter), Aja Kash (her intervener), and I could testify at the Senate Finance Committee. I said I guess we could and that it would be great for the Senators to actually get to hear from an intervener. All the rest of the week I kept telling myself "there is no way I can do that... what would I say?" I had already emailed both my Senator Jane Nelson and House Representative Kelly Hancock and received replies from both of their workers who return emails but that was easy because I was sitting at my own computer on my own time with no one staring at me.



So, when we finally get to the State Capitol we are rushing around from one end of the building to the other (oh, how I wish I would have brought Kersten's stroller for the day!) Bless her heart; she just kept right on going along with us. No complaints at all other than you could tell she was getting worn out. The very first thing we did was to sign in at the Committee meeting in order to get a spot to testify. We kept checking back in between visits and face-to-face meetings with several Senator's offices. The building was beautiful but very big and I can't even remember where all we actually did end up.



Steve found us at one point and told us to hurry back over to the Committee meeting because they were calling for children who would be testifying so here we go back down the long hallways. We found a seat and after someone had testified the Chairman asked for any children left to testify. I immediately raised my hand and volunteered. I thought to myself, "What have I done? Now, what will I say? Someone help me! Vivecca... where are you?" Just minutes earlier, I started jotting down notes (I know this is not the way Melanie taught us!) I was trying to think of what would make the most impact in the 3 minutes we had. So, we took our seat and found ourselves next to a mother of an autistic child who is testifying and crying with the emotion of it all. Talk about nerve racking... I was still trying to stay composed and now I have Kersten sitting on my knee (she's almost as big as me) with Aja signing to her under her hands and out in



front of her. I'm a little... no a lot frazzled because I feel like we are pulling the attention away from this mother. But then I realized that is what we are there for! We need to be noticed and we need these bills to be passed. I knew that I had better ask for help so I quickly closed my eyes and asked for HIM to guide me.

I started with introductions and then let them know how much we appreciate their time. I saw that Jane Nelson was up at the front but we didn't make eye contact so I just proceeded to let them know about Kersten and how deafblindness is such a low incidence disability and that there was no reason why all children who are deafblind shouldn't have services at the onset of diagnosis. The Senators were all there for business so I just let them know if they would put money into helping these children early on then we could have them be productive citizens giving back to society. I let them know how I employ Aja after school to help with a transition from school to home. I totally believe that this transition and having a dedicated intervener for almost 5 years has made a **huge** impact on Kersten's learning and overall life! The whole time I was speaking, Aja was signing and giving them a little taste of what an intervener does. But, of course, it all boils down to money. When I was finished speaking, the Chairman Ogden asked about who has been paying for this help. He wanted to know which category she fell under. I told him **me!** I pay for Aja's assistance. Kersten is on all of the **waiting lists** for any kind of help. That really seemed to get all of their attention but nothing I could have said would have had the impact of watching Aja with Kersten. Aja was signing the entire time to Kersten and I think they were all looking at them. Thank goodness it was over. Our time was up and at that point I felt so relieved to have been able to just do it!

It took so many different people working to get these bills passed. We will never know how many people called or emailed on behalf of these bills but I do know that I had so many family members keeping up with everything that they would know before I did what was happening. I even had a cousin in New Mexico making calls to friends in Texas. I never thought in a million years I would ever be testifying at the capitol but I'm so glad that we were able to help. We were at the right place at the right time and I know it wasn't a coincidence!

Note: After Becky's great testimony, Committee Chair Ogden said: "You are aware that Senator Zaffirini has a bill to expand the Deaf-blind Waiver?" Becky answered, "Yes." "So you're testifying in favor of her bill is that right?" Becky answered again with, "yes." And Senator Ogden said, "I bet she'll bring you back." This brought much laughter and nods of agreement from the Committee.



Guest Star

by Steve Schoen

On Thursday, April 9th, Melanie, Vivecca Hartman, Dick Newton and Robbie Caldwell were waiting to testify at the House Human Services hearing regarding our intervener bill (with our friend Marty Murrell again providing us support.) Waiting is an art which we learned well. We looked up from our conversation and a nice lady introduced herself as Donna Harp with her son Larin. It took no time at all to realize that Larin was deafblind. My "Old-timers" memory kicked in and I remembered Donna and Larin from my days as the Deafblind Medicaid Waiver program specialist. Donna explained that she was at the Legislature to testify about an issue unrelated to DBMAT, but that she would like to help. We had a long conversation about the bills, and Donna was in full support. When she testified she added a new wrinkle. As Donna talked to the Legislators, she was signing to Larin. Here was another example of Legislators for the first time seeing an intervener in action. It was amazing to watch Donna talk to Legislators off the cuff about a bill she had just heard of that very day while interpreting for her son.

What Happens When You Have to Wait 10-12 Hours Before You Testify

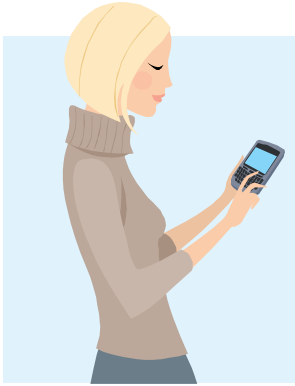
by Melanie Knapp

Let me set this up. I had driven to Austin for three Thursdays in a row to testify. On this third Thursday of April 2009, Robbie Caldwell, Dick Newton, and Steve Schoen were there also that day to testify, and our friend from AVIT, Marty Murrell was also there.

By time, I kind of knew what to expect. Get there on time and wait. And wait. And wait. Oh.....and wait. Ok, so we were there at 0930 that Thursday morning. I believe I was even early because I didn't want to miss my chance to speak.

We were allowed 3 minutes. How do you get 28 years of living with deafblindness down to a 3 minute talk? This is what you do. You spend 6 hours of frustration in a hotel room.

The Committee Room was filled with people and the people spilled out into the halls of the Capital. Most everyone had cell phones (on silent) and it was hilarious that 99% of the “users” were staring at them, reading or sending text messages or reading their emails.



I had my Blackberry (or “Crackberry”, because I am addicted to it). We could actually leave the room ...with the confidence that we could “text” each other if it was “our turn”.

9:30 that night. It was our turn. They called Steve up first. Then me. Since I had testified in front of this committee 2 weeks prior, I had decided to say a few words about who I was. I mean besides being Christian’s Mom, they didn’t know that I had a husband, another son, a daughter-in-law, and a granddaughter.

So when they called my name (did I tell you all that it was 9:30 pm by now... 12 hours after I arrived?) I walked up and sat down at the table provided.

The Committee sat behind this huge looming curved structure. They all have leather swivel chairs. Their legislative Aides sit behind them and you see the Aides peek around the Representatives when someone of interest to them is testifying (I assume). The Committee members all have microphones that they adjust to fit their posture throughout the day. The Committee Members also have a “secret” room. At any given time, one or two of the Representatives would get up and go through this door. I wanted to take a look in there myself. I could tell that there must have been food back there. Some of them would come back to their chairs still chewing. They gotta eat, right?

So I take my seat, and I adjust my microphone. I introduce myself and then I say, “I wanted to let you all know a little bit about myself. I have been married for 35 years. My husband is here...” At that moment I saw all the Committee Members stop looking at me and raise their eyes to the audience... searching for Gary. I realized that I should have said the words “symbolically,” which I did immediately because Gary wasn’t there physically. I wonder who they thought was my husband out there in the audience? Everyone laughed! It was a funny moment!

Driving home that night, I stopped to get some strong coffee and bottled water. I had a 3 hour drive back to Sugar Land and I was driving a rental car (my Explorer was in the hospital). It was after 10:00 pm and I needed to stay awake. Not that I wouldn’t... I still had some adrenaline running from the excitement of the day.

I was sort of going over my testimony in my head. I had hoped that what I said, and Robbie’s, Dick’s, and Steve’s testimony would move this bill out of the committee to the Calendar Committee. And then... to be voted on by the House. How exciting that would be.

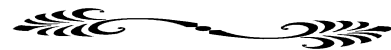
I continued to go over what I had said, and then it hit me. I told this committee I had been married for 35 years. I probably will reach 35 years of marital bliss, but I have 2 more years before Gary and I hit that milestone.

Now that the bills have passed and been signed by the Governor, I can take a deep breath. This, by far, is a highlight in my life. I never thought that I would be involved in anything like this. I feel very blessed that



Representatives Susan King and Elliot Naishstat, and Senator Judith Zaffirini believed that our deafblind children and adults in Texas deserve these changes in the DBMD Waiver. Nancy Walker, Rep. Naishstat’s Legislative Aide and Jessica Ramos, Senator Zaffirini’s Legislative Aide have worked very hard for us. We DBMATers have a lot to be thankful for.

Note: The attached picture was doodled by Melanie during this wait.



Chubbed by Chisum

by Steve Schoen

By the time a bill reaches the floor of the House and Senate, there is little for an advocate to do besides watching the proceedings live on the Internet. Here is one such story.

It’s Thursday, May 14th 11:45 p.m. HB 166 is to have its second reading at the House of Representatives. (All bills must be read three times, before they are passed by the

House and Senate.) If House bills don't get their second reading by midnight tonight, they die. I've been watching the House proceedings since the afternoon on the Internet. Hours go by. As a bill is introduced, various Representatives get up to ask questions about them. I notice that the Representatives appear to be trying to top each other in demonstrating their ability to ask irrelevant and inane questions. At 11:45 p.m. (with 15 minutes left before adjournment) our bill is brought to the table. Representative Naishstat, our hero, explains the purpose of the bill. Immediately afterwards, Warren Chisum, Representative from Pampa, gets up to ask questions. He asks "Do we need to get another waiver to do that?" Representative Naishstat responds calmly explaining that "I don't believe we do... if we do, we'll get it." Representative Chisum follows with: "I just can't imagine why we're not covering children already." (I'm thinking: "Out of the mouths of babes.") Naishstat responds with: "We're not covering children because we never authorized the Commission to cover children." More questions arise from Rep. Chisum., asked and answered, asked and answered, and the clock keeps ticking. As the questions arise, it becomes clear to me that Representative Chisum does not understand all the intricacies of Medicaid, for instance, the difference between general Medicaid which covers basic health for needy people, and Community based Medicaid Waivers (which cover long term care needs in the community for people with disabilities.) Immediately behind Representative Chisum, I see a familiar face, Representative Susan King (see related article by Wayne Thompson). In the background I hear Representative King say, "Charlie, this is a tiny population..." And talking to other people, she says, "I can't just push him away from the mike." Finally, as she gently nudges Rep. Chisum away from the mike, "C'mon Warren." I assume she is trying to impress on Chisum the need to let this one pass. I hear someone say to Representative Naishstat, "move adoption, " and this he does, and the ayes have it, and the second reading is finished. Our friend Nancy, Naishstat's aide, emails me with one word shortly after midnight, "Whew!"

The next day I'm haunted by the question, "Why does Representative Chisum hate our bill?" I discuss this with Melanie Knapp, who decides to call his office and ask. She is shocked to be connected directly with Representative Chisum, who proceeds to tell her that ours is a fine bill, but that he was "chubbing." He explains that he didn't want to hurt deafblind children, but that there were other bills he didn't want to get passed, so he was stalling their hearing by asking questions about our bill. Melanie ends the conversation with, "Next time chub on someone else's bills," and they both have a good laugh. But a few days later SB 37 comes up for a vote, and Chisum votes against it. His vote didn't hurt the bill, but I wondered why he would say it was a good bill and yet

vote against it. This leads me to Google "Warren Chisum" where I find a March 19, 1999 Austin Chronicle article. The article states that Rep. Chisum: has a "propensity for killing off legislation that conflicts with his conservative agenda..." "Chisum has sunk literally hundreds of bills. Chisum says that *"most of them don't come back up again. ... "The only thing the law ever does is, it either takes away your money or your freedom, so there's 100 times that we didn't take away your money or your freedom."*"

Postscript: By the end of this session "chubbing" has become a well known term. The Democrats use chubbing to delay discussion of the Voter I.D. bill. While they succeed in killing the Voter I.D bill hundreds of bills never get a hearing because they were chubbed to death. The big lesson for people who want to get bills passed, start early, or you could get chubbed.



To see history in action

If you want to see the actual video of all of the testimony given by DBMAT and AVIT members during this session, go to the DBMAT website <http://www.dbmat-tx.org>. You will find links to archives of all Senate and House hearings with instruction on finding our testimony.

And the Story Continues...

With the signing of these bills, DBMAT has accomplished two out of four objectives. We are not resting on our laurels. We shall bring the lessons learned from our Legislative experience to accomplish the remaining DBMAT goals:

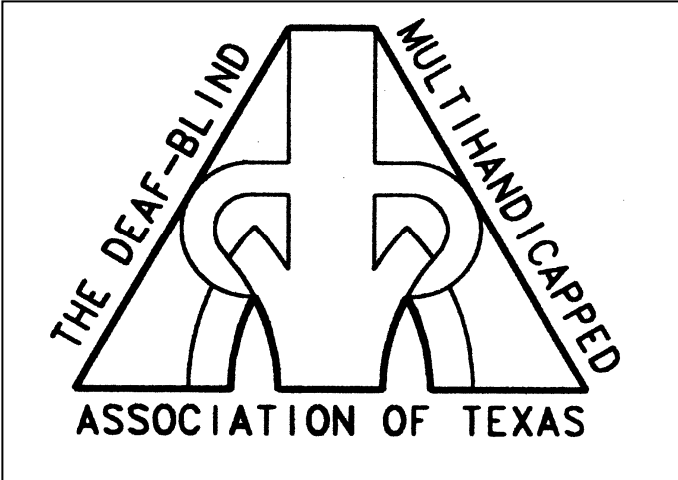
1. Add Intervener as a "related service" in Texas Education Agency rules. This definition should mandate that interveners meet the credential developed by the National Intervener Task Force and certification standards being developed by The Academy for Certification of Vision Rehabilitation and Education Professionals (ACVREP). DBMAT is working actively on these National efforts.
2. Create a college curriculum for Intervener studies based in Texas. Currently, Texans can get training through the Utah State University online intervener course. We hope to see a Texas based course which expands on this model. DBMAT is exploring this with three college systems at this time.

If you want to get more involved in helping DBMAT achieve its' goals, we are always looking for active participants. Contact stephenschoen@sbcglobal.net and your life can get more interesting.

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The Deaf-Blind Multihandicapped
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