



In Touch

The Newsletter of the Deafblind Multihandicapped Association of Texas

Winter Edition ~March 2008

From the President's Pen



It was great to see everyone at camp this year! Our 35th Family Conference was a big success. We hope that by now that everyone who attended the Family Conference has received the DVD of the camp. If you didn't receive one please let me know so that we can have one sent to you. Our thanks go to Brad Carlson who has edited these pictures and has arranged for the Texas Department of Assistive and Rehabilitative Services to put them in the mail to all participants.

The election of Officers and Board Members was held during the Family Conference. The following members were elected:

- Denise Sewell - Member-at-Large
- Alaine Hines - Member-at-Large
- Vivecca Hartman - Treasurer
- Paul Welch - President

This year has already begun with a lot of activity for the DBMAT board members. There have been a lot of things going on behind the scenes. DBMAT has participated in several Stakeholder Meetings for the Deaf-Blind and for Blind Services.

Each family needs to introduce themselves to their legislature. It's really easy to do. This will help the lawmakers know who you are and that you are in their area. This way if any issue comes up in the future you can contact them for assistance. If you need to know who represents you in the Legislature, go to this website: <http://www.capitol.state.tx.us/> and enter in your address and zip code.

Some board members have made great contacts with Legislators. Wayne Thompson introduced himself and his son Caleb to Representative Susan King in December. This made her aware of DBMAT and our children. When Steve Schoen, Wayne Thompson and I met with Representative Susan King in January to discuss legislative issues concerning the Deaf-Blind

Medicaid Waiver program she was well aware of our group and our needs. Steve Schoen and Melanie Knapp met with Representative Elliot Naishtat in January. The actions we are hoping for from the Legislature are mentioned in detail in Melanie Knapp's article in this newsletter.

During the Deaf-Blind Task Force Meeting I proposed that we celebrate Deaf-Blind Awareness *month* in June in Texas to celebrate Helen Keller's birthday instead of the traditional week celebration. We would like each family to try to do something in their community to educate the public on Deaf-Blindness... an article in the newspaper, something on the radio, something at their church or school. This is to celebrate Helen Keller's birthday and create public awareness.

Please check out our new website at <http://dbmat-tx.org>. Steve Schoen, our Executive Director, and board member Jackie Carter worked with a non-profit organization called Knowbility to revamp the site. Please visit the website and let us know what you think.

The First Annual Christian Knapp Memorial Golf Tournament will be held September 25th in Friendswood, Texas (south of Houston) at the Timber Creek Country Club Golf Course. A flyer will be in the next newsletter.

Please mark your calendars for our next Family conference – October 10-12th. Anyone that would like to participate in conference planning contact Vivecca Hartman at: hartmanfam28@sbcglobal.net.

Please come join us!

Paul Welch

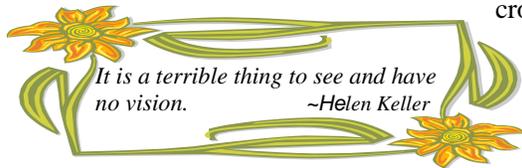
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DBMAT: Now, Then and the Future

by Bud and Lynn Freeman

We just received our DVD for the 35th Annual Family Conference held October 12-14th 2007. This was attended by families and professionals/friends of the deaf-blind multihandicapped. After viewing it several times: "It deserves an Oscar for reality!" It brought back fond memories of not only the conference, but also of nearly fifty years of life as the parents of Sandy, our son who has been Deaf-Blind Multihandicapped since birth due to mainly prematurity.

It is encouraging to look forward when you can look back for half a century and remember the many happy times and challenges that we have enjoyed. A very wise person once said "This too will pass." The pessimist will say "It's not so bad that it can't get worse." Whereas the optimist will say "It's not so good that it can't get better." We have been both over the years. More can and will be accomplished when we can be positive about the outcome of our families and children. A lot of the credit for our successes over the years goes to the other families of the Deaf-Blind and professionals who have helped us in being objective when we were at crossroads in our lives.



The efforts put forth to have these conferences for 35 years and DBMAT's "brain power" have given a quality of life for our family to enable our son to "thrive" rather than to just "survive."

Never is our annual gathering just more of the same because of the intelligent and synergistic planning of DBMAT and the several state agencies who sponsor and support the conference and network to provide information.

Those involved have truly worked "Hand in Hand" over the years. Join us.... *We need you!*

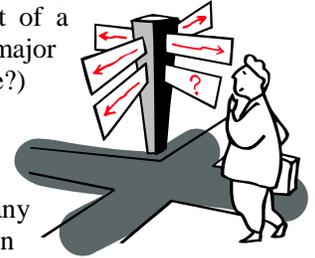
Being the Parent of a Special Needs Person

by Vivecca Hartman

I have recently been feeling in awe by the words "you have power as a parent" and what it means to be a "Parent Advocate".

When we first found out about our precious baby's inability to see and then a few months later his inability to hear we were (and probably still are) in shock. For every family the news of any imperfection is overwhelming. Then you start having therapy session with Early Childhood Intervention (ECI) which you cling to like butter on toast! Then you find out about other services or groups that are more specific to

your child (like The Texas Deafblind Project) and you just start calling until you find a way to cope for you and your family with the daily challenges life brings. Well that about sums it up of what being a Parent of a Special Needs Person is. (This is a major understatement – wouldn't you agree?)

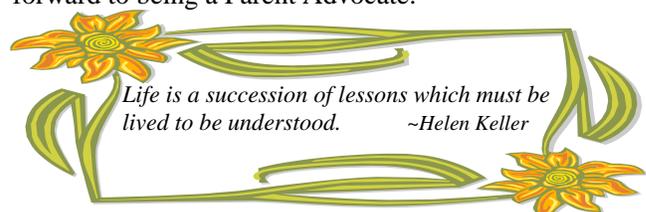


That is how I feel about the term "Parent Advocate." You will hear it over and over with regard to so many different areas. For me it started in ECI. They would tell me I will learn how to be a "Parent Advocate" and I would just stare and think about what does that mean. Why do people put so much value to that term "Parent Advocate"? I found it quite annoying that people would say this to me with such a nonchalant expectation and yet I had no idea what it meant.

Well, I have been "in the business" of Special Needs for 10.5 years (my deafblind child's age) and I think I only recently caught on to some of what they really meant. At first I thought it was to be at every therapy session, school meeting, constantly search the internet (after everyone was in bed) to stay up on all the related research, read every newsletter and just about anything you can find that is relative to your situation, keep it all filed and organized, and contact any services that are related that can help. All the while you are doing this, maintain a household, try to be a supportive spouse, don't forget to parent the other children and oh if you work do a good job at that too.

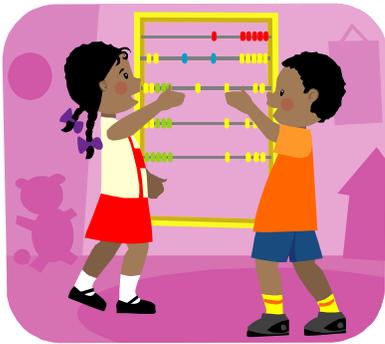
So, what I realize today is that there are differing levels or steps at being a Parent Advocate. Getting through the first phase of dealing with the news and getting services started is an important step in becoming a Parent Advocate, because you have to start somewhere.

I have been told so many things over the years and read so much, there is no way I could retain all of it. So, in some ways we do filter through all of the information and advice to find what we can cope with. For us, there was a definite stage of filtering through the information and attending seminars and trying to maintain a routine home for the family. We were in this stage for a while. Suddenly, it dawned on me that I do know my family's needs and my deafblind son's needs as well. Although, I admit I do (and did) not know everything, I knew enough to speak-up and be heard. I realized I had to be a voice for him and let others know what is important to him. As the "expert" on your child, you have that ability to express to the school (or whomever) what his/her abilities, likes, and needs are. You know what makes them happy and what makes them upset – you are the EXPERT on your child. This is what brings you forward to being a Parent Advocate.



Suddenly I found that I was taking a chance and speaking out to say what my child's needs are and people listened!

For example, I knew he needed physical play for both his emotional and physical well being. It was imperative to me that he had it during his school day or we would be going down a very bad road of behavior issues. I took a chance and approached the school Principal about a "Sensory Motor Lab" of some sort so he could play in a safe environment. (Unfortunately, due to the blindness and caution on his part he does not just run and play outside on his own and he does not currently have enough communication to participate in regular PE.) Amazingly, the Principal had also been addressed by the Health Fitness Director of the school district about potentially being a pilot school for something called "Action Based Learning".



Let me tell you, this "Action Based Learning" is a wonderful brain research based physical play program that develops the whole child. It takes physical actions that target certain parts of the brain for

development. It was originally established for regular education students to help with their mathematics and academics, but also develops the vestibular part of the brain and so much more! (You can find out more at www.actionbasedlearning.com.)

The three of us met and devised a plan of how we were going to make this Action Based Sensory Motor Lab a reality. I had said I would do the fundraising to cover the equipment – which I am sure helped, but I think it would still have happened, just with less equipment. By working together we have been able to make it GREAT for all the students in the school. Now our school district is even considering it for other schools too!

It really does mean a lot when to the school system when a Parent feels strongly and is compelled to work with them in determining the means to get things done!

It has been a nice journey finding out what being a "Parent Advocate" would mean for me up to now. Where I had mostly been overwhelmed with my child's diagnosis and what life would be like for him, as well as us, we found our "survival coping" stage, realized we were the "experts" on our son, and now realize we are "Parent Advocates." What a journey...and it is no where near over!

Next, we (that includes you) will have to figure out the Legislative Processes to further improve the lives of our children. If we do not speak up for them, no one will!

So, Good Luck to all of you, from the new to the 30+ year members of DBMAT! You are a Parent Advocate, because you do have the power to affect your child's surroundings at home and at school, or wherever they may be in life!



The First Annual Christian Knapp Memorial

Golf Tournament will be held on September 25, 2008 at Timber Creek Country Club Golf 4554 FM 2351 Friendswood, TX 77546 (just minutes south of Downtown Houston)



The flyer with all the details will be in the next newsletter!



Deafblind Waiver Update

by Melanie Knapp

DBMAT has been pursuing changes in the Deafblind Waiver for approximately two years. Members of the DBMAT Board and Legislative Committee met with DADS in Austin last September. This meeting was held specifically in response to DADS reply.

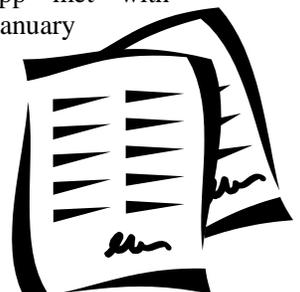
DBMAT has requested that the:

- 1.) Age of eligibility be changed from age 18 years to – eligible at time of diagnosis of deafblindness.
- 2.) Increase the educational requirement for the Intervener working with the deafblind child/adult within the Deafblind Waiver.

Unfortunately, we were told that these changes could not be made to the Waiver without Legislative action. We were encouraged by DADS that in order to make changes in the waiver, we needed to contact members of Legislature.

Three members of the DBMAT Board Paul Welch, Wayne Thompson, and Steve Schoen met in early January with Representative Susan King. Rep. King expressed her support for these issues.

Steve Schoen and Melanie Knapp met with Representative Elliot Naishtat on January 22, 2008. Rep. Naishtat has committed to helping DBMAT make these changes within the DB Waiver.



Now.....a personal note. As Christian's Mom, I never gave up the dream that he could be the best that he could be. When Christian was given the chance to have a well trained Intervener (Ann Bielert), his world opened up. His quality of life improved beyond what I imagined in just 3 short years. Our family,

our friends and our community all witnessed what we called a miracle at the time.

But, it wasn't a "miracle". It was a lot of hard work for Christian, Ann, and all of us.

What I want is for every deafblind child or adult to have that same chance that Christian had. I know the Intervener Model works. I have proof. I can't say that enough.

Things need to change in our school systems as well....and there are many people who have been working for years on behalf of the deafblind.

I know how hard things can be. Gary and I have been down a long road with Christian.....and now without him. I encourage you to please email me with your stories. **Your voices ... you Parents.... and your children Together ... we can make changes.** Not only here in Texas, but throughout the United States.



DOWN THAT LONG HIGHWAY!

by Wayne Thompson

I recently attended a stakeholders meeting in Austin, TX, concerning the proposed waiting list for children with visual impairments. I came away from that meeting feeling the program was in need of repair for many reasons. It appears the need came about gradually over the last ten years.



On the way home, I was thinking how different our highway systems are compared to the roads that we as family members of the deaf blind and multi-handicapped travel. For instance, when damage to the highway occurs, warning signs go up almost instantly.

The signs tell us to "slow down" and proceed with caution. The signs can detour us around obstructions, perils, and conditions that lie ahead of us. On the road of life that we families travel, the signs are practically non-existent.

NO SIGNS...to guide us through the detours that often become necessary for us to take.

NO SIGNS...to warn us of sharp turns ahead.

NO SIGNS...to warn of the rough road ahead.

NO SIGNS...to warn us of obstructions that lie ahead.

NO SIGNS...to guide us through the mix master so we can arrive at our destination.

NO SIGNS...to tell us where we can take a break and get some much needed rest.

NO SIGNS...to tell us how far it is to our destination.

NO SIGNS...to the scenic overlook where we can observe the beauty of the road we have taken.

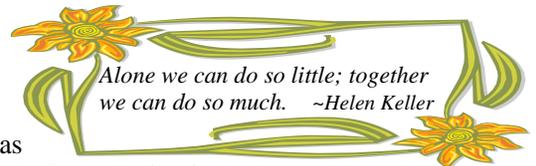
I have also noticed that when damage occurs to the highway, within days the repair crews are on the job. The crews are skilled at their job to insure that repairs are long lasting.

When repairs are needed in the programs for our loved ones, they are often "patched up" or even neglected. Therefore, our road becomes very difficult to travel and costs much more to "fix."

I also thought of another similarity between our highway system and the road that our deaf blind family members travel. In the 1950's, the powers that were envisioned an interstate highway system that would serve our entire nation. The result was a system that enables us to travel safely and expediently throughout our nation.

Several decades ago, a few individuals envisioned an organization that would help other families with deaf blind family members negotiate the road that we travel throughout our lives. This organization is known as DBMAT. I would like to say a special "thank you" to the charter members that started this organization

over 35 years ago. Now it is up to you and I as



members of DBMAT to maintain and upgrade the roads of life that we travel so that future families have a less bumpy road. DBMAT is our organization and each one of us has an opportunity to become involved and serve our loved ones and pave the way for future generations.



DBMAT Celebrates Its First 35 Years!

By David Wiley, Texas Deafblind Project at TSBVI and DBMAT member

On the weekend of October 12-14, 2007, the membership of DBMAT gathered for the 35th Annual Family Conference at Camp John Marc. The event was enjoyed by entire families, as the agenda included activities for the adults and children alike. The parents had an opportunity to learn from a variety of conference speakers, as well as from each other. The kids got to participate in camp favorites like fishing, hiking, games, baking, and crafts, as well as the challenging ropes and climbing wall.

The entire families and professional friends joined together for a rocking carnival/dance. As always the Screaming

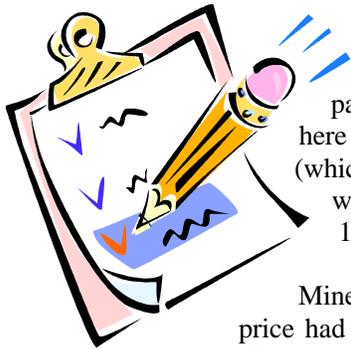
Almonds, DBMAT's house band, entertained at the enjoyable fund-raising auction.

This year's event was special in that it celebrated 35 great years together. It is rare for an organization such as DBMAT to carry on for so long, and still be going as strong as ever and taking on new challenges. It is a testament to the value of DBMAT's mission that some founding members continue to participate, and new families join every year. As the organization continues to grow stronger and evolve, it is clear that DBMAT has celebrated just the first 35 years, and needs to start planning the next 35, as DBMAT continues to serve as a "home" where families can turn to one another for knowledge, friendship, and support.



Reflections from the DBMAT Executive Director

I was having consumer difficulties today (having to deal with a New York parking ticket and a rental car) and it made me think of parents dealing with "the system." Quite a few parallels (having nothing to do with parallel parking) occurred to me. So here are Steve's rules for self advocacy (which I learned from some of you when I was the bureaucrat.)



1) **Get the facts.** In my traffic case I needed to call the Village of Mineola and figure out why my ticket price had grown to a scary amount. In the case of a parent, it pays to look at the system you are dealing with (school, private provider of services, state program), and educate yourself about how the system works.

2) **Review the legitimacy of your claim.** In the case of my rapidly growing traffic ticket, I asked my wife Marian what she thought, and she said, "Just pay it".... which I ignored. In the case of a parent, it pays to look at what it is you are wanting, and be sure that the request is reasonable. It helps to ask a friend (who is knowledgeable about disability and special needs) to review the facts with you. Many times, parents know their children better than the professionals. They also may know about more effective training or treatment possibilities through their experience as parents and attending training from others.

3) **Don't accept the first "no."** In talking to the rental car person, I found her saying the same thing over and over despite my incredibly erudite explanation of where her company was at fault. When you are talking to a professional about your claim, you may hear this type of repetitive response amounting to "No," or "The system doesn't work that way," or "We know what your child needs," or "No one has ever asked for this

before." (I could go on--- but I bet most parents can create a far better list than I could.)

- 4) **Take it to the next level.** There is almost always a next level. After hearing the rental car person tell me the same company policy 3 times, I said, "I understand what you are saying, and I understand that at your level in the organization, this is all you are authorized to say... I want to talk to a supervisor." Each time she repeated her "company policy" statement, I repeated my "supervisor" statement. After only 3 more replays of this scenario, I actually got transferred. When parents are dealing with systems, this rule is very important. The person at the first level is not the final word. And frequently, there is more than one level where you can take your request.
- 5) **Stay calm.** My family will attest that when my volume and pitch of speech go up, I am out of control when talking to "the man." This time I focused on my breath, kept my eye on the goal I wanted, and stayed very peaceful. It helps to think of the entire process as a game and that one rule of the game is to stay calm. I know.... I know... that the stakes parents are dealing with are significantly higher than a traffic ticket fee. But that's all the more reason to stay calm.
- 6) **Try to identify with the person you are talking to and give them some credit.** Woops--- To be perfectly honest, I forgot to do this with my traffic ticket. But you can do better than I. Easy things to identify with are: "I know you have a hard job.... What with all of those pesky rules and such," or "You have done a great job explaining this to me."
- 7) **Don't gloat when you get your way.** In my case I only had to pay 58% of the original fine (but who's counting?) I thanked the supervisor for being reasonable and told him I thought this was a fair settlement. It would NOT be good to say the things that are just itching to come off your tongue like: "Wouldn't we have saved a lot of time if you were just reasonable from the start" or "You people are really difficult." Remember, you may be back soon enough on another issue.

All of these thoughts will be important as DBMAT tries to advance its Legislative agenda. I hope we will be able to report on our success as the year progresses. And my last thought is to remind everyone to visit our newly revised website at <http://www.dbmat-tx.org/>.

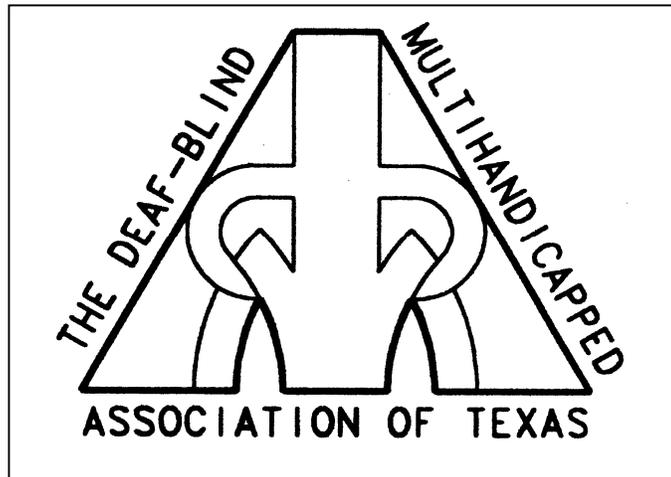


You will find many new features including: online application for membership, contact information for our regional coordinators, online application for intervener scholarships, and fancy opportunity to contribute to DBMAT online and receive a premium of DBMAT cap and cup. See you online! *Steve Schoen*

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