



In Touch

The Newsletter of the Deafblind Multihandicapped
Association of Texas
Spring Edition ~May 2007

From the President's Pen



This article is going to be a little personal. Susie, Jaceson, and I appreciate the support of our DBMAT family during Dad's lengthy illness. We feel lucky to have friends like all of you.

In May, DBMAT lost a friend and a champion for the deaf-blind and we lost our Dad and Grandpa. Our Dad (Leo Welch) was an inspiration to us with his support, encouragement and love. His love of family, God and country went hand-in-hand in life. When I took over the role of President of DBMAT, Dad was there cheering me on and encouraging us to be selfless, stubborn, dedicated, and to believe in ourselves. He was a very good role model for us to follow, as he was very active in our community and in veteran's affairs. He had fought a lot of causes in our community and supported our endeavors with his support of DBMAT. He taught us that there is no cause or belief that is not worth fighting for.

When I went to Austin to meet the Legislature, Dad came with me. He knew the legislators that we visited by name and they knew him by name because they had met him before. He told them about "our kids" and DBMAT. Another time Dad went with me to a state training for DARS. I was there to tell them about our family support group--DBMAT. Dad attended one of their sessions, and during the meeting, he stood up and thanked them for all their dedication and hard work with our children. That was our Dad! Until we automated the newsletter we did a lot of the work by hand on our dining room table. He was always there to lend a hand in sorting, stapling, folding and labeling the newsletters.

We have a huge void in our life, and feel an emptiness that will never be filled again. Jaceson doesn't quite understand it all, but you can tell that he really misses his Grandpa. We miss him forever.

Paul, Susie and Jaceson Welch

DBMAT- 35th Anniversary In this issue:

We reflect on DBMAT's history and accomplishments with:

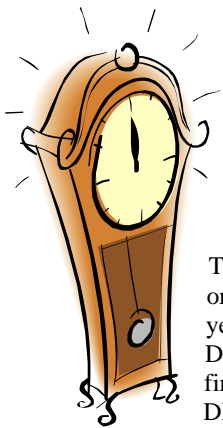
- *Things Change- Current Executive Director describes why he thinks DBMAT continues to make a difference*
- *DBMAT- Early Days- Past DBMAT Executive Director Pat McCallum describes DBMAT's start and success.*
- *Early DBMAT veterans, Celeste and Riley Rand, and Jackie Bryan, reflect on how DBMAT has been in their lives for over 30 years.*

We then bring ourselves to our current activities with:

- *Intervener Vision- Melanie Knapp describes the ongoing effort to make the intervener vision a reality. She also tells how you can help!!!!*
- *Leslie Fansler- Tells how her son Preston, (who is deafblind,) is making a living and making a difference.*
- *DBMAT VP Wayne Thompson describes the experience of testifying to politicians and state employees with his son Caleb (who is deafblind.)*
- *We remind you to mark your calendars for the next DBMAT Family Conference*

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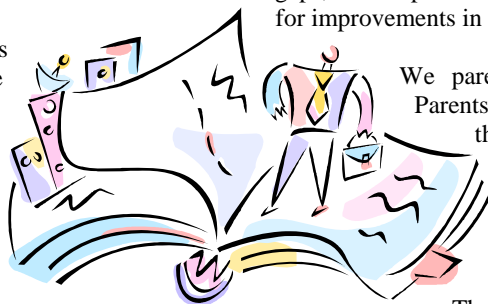
Changing with the Times

by Stephen Schoen

Time passes, things change, and it is rare for an organization such as DBMAT to last for even 5 years, let alone 35. I've been involved with DBMAT for more than one third of these years; first as a state employee who was "educated" by DBMAT, and now as the Executive Director of DBMAT.

The features of DBMAT which I believe lead to longevity include:

- **DBMAT welcomes all people** including parents, people with deafblindness, and professionals serving these people. We share our experience and the methods we use to deal with challenges.
- **With a spirit of openness**, DBMAT has always been able to work with state agencies, educators and legislators in the spirit that positive communication will lead to a desired outcome. This outcome may be different than any one of us may initially desire, but it will be what our group awareness knows is right.
- **Our flexibility** has allowed us to change our goals with the times. One of our early goals was to be sure that a number of deafblind children had a group home program to go to after they finished their education. Later, we wanted to be sure that other options were available including living with families and living in small apartments. Now we are focused on ensuring that skilled intervener services allow individuals who are deafblind the ability to interact with the world successfully. And we want our children to receive these services at as early an age as possible.



DBMAT- Early days to the Present

by Pat McCallum (edited from a "National Parent Network" 1991 Monograph by Steve Schoen)

Our story begins with the birth of our children who are deaf-blind. The world-wide rubella epidemic of 1963-65 wreaked havoc on many Texas families. At first, families struggled virtually alone with the severity of their pre-schoolers' disabilities while randomly seeking assistance. The Texas state education agency brought parents together for a series of annual conferences entitled Parent Education Project (PEP.) Over 200 moms and dads were provided a vehicle through which they compared notes, commiserated, problem solved and bonded together.

By 1974, with the encouragement of Texas Education Agency (TEA) parents established a by-laws committee to create a mission statement and a set of guidelines for a parent support group. In 1976, we became an "official" non-profit organization with the name of DBMAT.

Our early goals were geared towards ensuring the appropriate provision of educational services to our children. Parent education in understanding their child's disabilities and training

in self-advocacy were also primary goals of DBMAT. As our children began to mature, the group's focus naturally expanded to include services beyond school. The parents of DBMAT considered which services were needed for adults. A decision to advocate with state agencies for quality and appropriate programming for our children was made. We wanted our family members to have a place to live, a place to work, a place to socialize and recreate and a place to receive medical care within our own communities.

DBMAT represented parent's views in a study group comprised of representatives from each state agency serving people who are deafblind and Helen Keller National Center (HKNC). This led us to the establishment of the Interagency Task force for Future Services to Deaf-Blind. The purpose of the task force was to work together to improve services in Texas for persons who are deafblind. This task force has continued to meet regularly since 1979. It is a clearinghouse for information, identifies service gaps, holds open discussions on issues, problem-solves and plans for improvements in the service delivery systems.

We parents were novices in the political game. Parents knew what they wanted for their children... they did not know how to get it. We brought our concerns regarding the future to the Interagency Task Force. While we explained our deaf-blind and multihandicapped children to them, the agencies informed us about their systems. They were empathic but not eager to "jump-in" with services without a legislative mandate. DBMAT developed a legislative initiative.

The Texas Commission for the Deaf (TCD) was willing to help us maneuver through the complicated legislative process. Their new Executive Director was willing to take our request to their Board for approval. Now we had our lead agency!

Simultaneously, DBMAT approached some legislators seeking a sponsor for our proposed bill. We found a newly elected and first-time congressman who agreed to help us. Coincidentally, his name was Keller! Instinctively, we made many of the right moves. Our membership wrote letters to each legislator about their children and their needs, seeking support for our legislative endeavor. We held an open house for legislators and agency personnel at the Deaf-Blind Annex to the School for the Blind. We testified at Human Services committee hearings both in the Texas House and Senate. We spoke as one voice with a single purpose – to create small group homes in Texas for persons who are deaf-blind and multihandicapped to enable them to continue learning functional living skill while accessing the community.



Our first legislative endeavor was discouraging. Although TCD received the mandate, no money was appropriated by the legislature to establish the services. During our annual conference, which immediately followed the close of the legislative session, Congressman Keller gave the membership a congratulatory pep talk. He encouraged us to continue our momentum into the next biennium. We took his advice and educated legislators regarding the needs of our children who are

deaf-blind during their hiatus. We maintained our strong relationships with TCD, CTD and the Task Force. We geared up for the next session.

Additional activities took place during the interim. TCD conducted a statewide survey to locate persons who are deafblind. DBMAT gathered information from the TEA Pilot Project justifying the viability of group home living arrangements for persons who were lower functioning. This information was included in our legislative package.

On the advice of an individual who was close to the governor, DBMAT requested a Governor's Study on Deaf-Blindness. This study gathered pertinent data on needs vs. service delivery. Consumers, parents, siblings and service providers testified at a hearing conducted by the Governor's Committee for Disabled Persons. Statewide awareness and additional support for our cause was evident at this time. We had momentum!

During the legislative session, we wrote letters once again and testified at hearings. We brought our children with us for visibility. On the final day of this second session, through the tenacity of Congressman Keller, monies were appropriated from a portion of the prison system budget to establish the Deaf-Blind Program! As a low incident disability group, we had succeeded with the help of our friends. Our hope became a reality for our children.



In 1982, TEA established a "group-home living" pilot project in Dallas for students who were deaf-blind and severely multihandicapped. Six young men ages 15-19 resided five days a week in a converted two story apartment with round-the-clock staffing. On weekends, the residents visited their parents' homes.

This three-year project set the precedent for establishing group home community-based living for individuals who are deaf-blind and multihandicapped within our state. Not only did the group home overcome community biases, but it also proved that these young men could improve their skills considerably by residing in a natural environment.

Another valuable component was ongoing parent counseling which allowed these families to share their concerns, fears, hopes and tears with each other in a supportive environment. Separation from a child with special needs, for whom you have been the primary caregiver, isn't easy. The counseling helped ease the separation pains these parents would experience as their children entered the adult service arena.

With the passage of the legislation and consequent funding, the first adult group home opened its doors in Dallas during the fall of 1984. Shortly thereafter, a group home in Houston was established. Both residences were funded from the state coffer with supplemental dollars from the Title VI-C federal dollars for those residents under age 22.

During the 1985 legislative session, it was decided to move the programs from TCD to the Texas Rehabilitation Commission (TRC) for the next funding cycle. Parents were concerned that deafblindness would take a back seat within the realm of a large rehabilitation agency. We voiced our concerns to legislators and the agency, both of which reassured us that this move would be

positive and provide additional services. The third group home was established in San Antonio in 1987.

Postscript---Over time, more group homes were established. In 1995, the group homes were made part of a statewide Medicaid Waiver for people who are Deaf Blind with multiple disabilities. DBMAT has played a key part in planning and implementing this program (the only one of its kind in the country) which is now run by the Texas Department of Assistive and Rehabilitative Services.

DBMAT: 35 Years of Service to Families

by Riley and Celeste Rand

Over 30 years ago, as young parents of a deaf/blind child, we were clearly aware that there was a lack of resources available to us. We were "reaching" for what's next? "What can we do now?"

While our daughter Jo Ann was in school, we first learned about DBMAT and how they had created a way to help us join other parents and share the joy and pain of the needs of our children. For the first time, we learned about the various agencies that could help us provide the best education, and future training possible for her. No other organization could have provided the collective efforts of education, resources and support. Over the years we've learned our legal rights as parents, and joined the effort to create a voice to be heard in our legislature. As an organization, we now make sure funding and other needs are heard on behalf of the rights of our children.

By linking us to other families and professionals, we've never felt alone in dealing with the challenges our family has faced as we tried to provide the best care for Jo Ann. Now that she's an adult, we face different challenges, but DBMAT has created the network of resources available for all families regardless of what stage of life their children are in. For example, having an Intervener provided has been one of the best programs made available to us, and has greatly improved Jo Ann's quality of life.

No government agency could possibly duplicate the passion, drive and commitment of DBMAT. Thanks to the ongoing efforts, it can continue building the services, education and resources in the future. We will be forever grateful for what DBMAT has meant to our family.

We Were There at the Start

by Jackie Bryan

Our daughter Lee Ann was born in February 1965. She has had many operations starting with open heart surgery at age 5 weeks and cataract surgery at age 3 months. At age 3, testing in Utah found her to be unable to respond to any sound. We met Dr. Ed Hammer in Dallas, and he introduced us to early DBMAT members Bud and Lynn Freeman.



In 1972, Jane Elsworth let us know about a school which was starting in Austin on Cedar Street for people who were deafblind. Lee Ann was the first student chosen to attend this school. It sure was hard to drive away and leave her there. We could not see her for six weeks. Then we brought her home for a week. She went around and patted everything in the house. At the end of the first school term, all the parents realized we needed to get together with other parents. This is when DBMAT started. My husband Everett was the first treasurer for the organization. Our first meeting took place in the School for the Blind that summer.

Our program grew every year till it got to be what it is today. We met in a lot of places that are not as nice as Camp John Mark, where we meet now. Lee Ann goes to Amarillo Jr. College two days a week. Her intervener, Helen Porter goes with her to class and to other activities such as swimming. Lee Ann is very interested in sharks, and May 3rd this year, we went to Sarasota, Florida to visit with an expert, Eugenic Clark.

Intervener Vision

by Melanie Knapp

Before I climb on my soap box for this article, I want to take a few lines and share with all of you about what I feel for this organization, DBMAT.

My husband Gary and I are not “old timers” in the organization. Yes...we are old...but we didn't join DBMAT until just a few years ago. These days, I ask myself why we were not a part of DBMAT...a fabulous group of families and professionals working and playing together to improve and enhance the lives of the deafblind.

When Christian died our world as we knew it changed drastically. I am not sure what we would have done if we did not have our DBMAT friends in our lives. If we have not thanked you, this is my message to each of you. Thank you for being there for us. We will always remember and appreciate each one of you.

DBMAT celebrates 35 years this year! It takes a lot of dedicated people to keep an organization running. Congratulations!

DBMAT's vision is for all deafblind individuals to have quality Interveners lifelong. How do we get there? What do we need to do?

I know we have to be focused and vigilant. We have to be proactive. We have to be 1-2 steps ahead of whatever “forces” that may stand in our way. We need to be prepared.

What is going on now?

1. DBMAT has proposed to DADs that the Deafblind Medicaid Waiver be changed:
 - a. To include children from time of diagnosis (deafblind) throughout their lives (currently eligible at age 18 years.)
 - b. To raise the educational requirements for the “Interveners” who are working with the deafblind individual.
 - c. To increase the salary for the Interveners who have completed the required minimal education.

2. DBMAT has deemed a “special fund” for scholarships for individuals to take the classes offered online from the Ski-Hi University out of Salt Lake City, Utah, entitled “Understanding Deafblindness.”
 - a. Scholarships are to be awarded to individuals working with a deafblind child or adult.
 - b. In February, at the Deafblind Symposium, the DBMAT board awarded two scholarships. Both recipients are working with deafblind individuals.

What do we need to do?

1. Ask yourself, would my deafblind family member benefit from having quality intervention?
2. Tell us about your child/adult family member. Write your story. Video your story. We need to share your stories with people who will have an influence on your family member's care/education.
3. If your family member has an Intervener, tell us about your experiences. What did you have to do to make this happen? Is it working for you? What would you change? What could be better?
4. Fund-raising is, I know, not everyone's gig, but it is very important. Think about some of the things you might do to help fund education for training Interveners.

Our deafblind family members deserve to have access to this seeing and hearing world. Communication is the key to every relationship. Our family members deserve to have every opportunity to learn to communicate and to have people around them that understand their communication methods.

I dream that we will have a “pool” of Interveners in the state of Texas and throughout the United States.

I dream that my “Great Motivator” would be proud of his Mom...because Christian taught me that this was the right thing to do.

OK...off the soapbox...**BUT – REMEMBER:**

PLEASE E-MAIL YOUR STORY TO ME – MELANIE KNAPP AT: rmkrrn1@aol.com
PLEASE ATTACH PICTURES OF YOU WITH YOUR CHILD.

Preston Goes to Work

by Leslie Fansler

Our son Preston is 19 years old and a junior in High School. He is a small business owner. His business is beginning to show a small profit. Preston is deafblind and developmentally delayed.



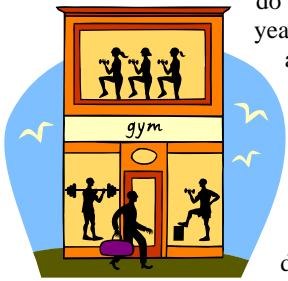
The data that has been collected on adults with deafblindness shows that Preston having a business is amazing. It has always been our family's goal that Preston would have a job. We believe this is the best way to ensure that he has a life after he graduates from high school.

Several years ago we discovered that Preston loves to shred paper. He will shred up to an hour without a prompt. His team at school and his futures planning team began working together towards this becoming a vocation for him. In the beginning he shredded on a volunteer basis. Two years ago his small business, "Handy Able Hands," became a reality. He has a resume, business cards and a business slogan, "You create confidential data and I destroy it confidentially."

Preston has three regular weekly customers as well as several customers that call him when they need shredding done. He also does small, one time contract jobs. His business has grown mostly through word of mouth and some wonderful networking by his team members. Some customers have him shred on site while others have us pick up on a regular basis and he shreds at home. Starting in January 2007, Handy Able Hands has sent out monthly statements and Preston receives paychecks in the mail.

The Texas Department of Assistive and Rehabilitative Services-Division of Blind Services (DARS-DBS) purchased two industrial size shredders for Handy Able Hands. The new shredders have made a great impact on Preston's business.

Preston does not make a great amount of money but he is productive, busy and feels successful with his job. What does he do with his paycheck? What any nineteen year old young man would do. He pays for a membership to a local gym where he swims, uses the treadmill and tries to meet girls! Business is good and going to the gym is good. Our family hopes that Preston's business will continue to grow and he will be able to stay productive as an adult. So many deafblind adults have very little going on in their lives. We are thankful that Preston has a future.



We Are the Experts

by Wayne Thompson

My son Caleb and I recently had the opportunity to attend a task force meeting related to case management changes being considered by the Department of Human Services.

I understand that consideration is being given to creating one department that would oversee and dispense services to all individuals who are disabled. It is difficult for me to envision a system that could determine and dispense services to individuals with varying disabilities in an expedient manner.

All consumers who attended the meeting agreed that the way to make case management more efficient is to lessen their caseload and hire more workers.

I feel it would behoove all of us who have a vested interest in this proposal to approach the decision makers in our area with questions, concerns, or comments that we have relating to this issue.

As stakeholders, we have an opportunity as well as an obligation to help shape the systems that serve our family

members. The decision makers want and need to hear from or meet us and to hear our stories.

I know from personal experience that each of us can make a difference. A few years back, Caleb and I had the opportunity to testify at the consolidation hearings that were being held in our region. We left Temple, where he had undergone surgery on both legs, and drove to Lubbock to testify. It was difficult, but I felt that it was necessary for him to be there with me.

Later, I learned that because we were there to help shape the decisions of the committee, the children's program was positively impacted by one child's testimony. By the way, as many of you know, Caleb is non-verbal. His presence alone gave POWER to my words. He testified!!!

WE are the EXPERTS and **WE have the POWER!!**

*Mark your
calendars for
the next
DBMAT
Annual
Family
Conference*



The next DBMAT Conference will be at Camp Jon Mark in Meridian, Texas on October 12th – October 14th, 2007. The Conference Planning Committee is busy developing a program and activities. Watch for our Conference Edition of this newsletter which will be mailed early in August, 2007.

We'd love to hear from you

Have comments on this newsletter?

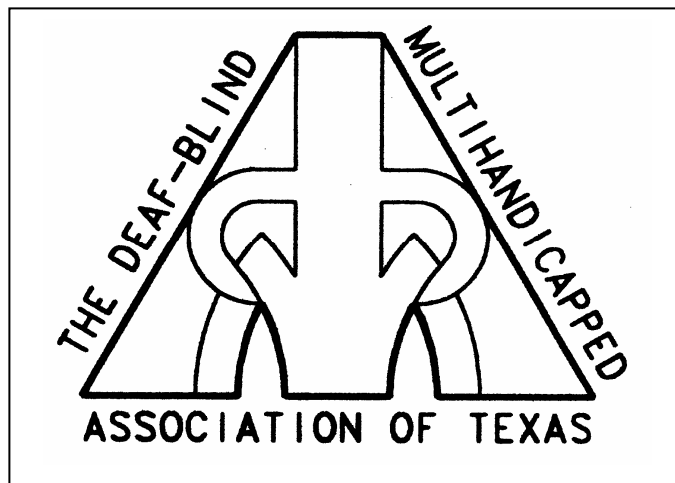
Have an article you want to contribute to our next newsletter?

Send an email to stephenschoen@sbcglobal.net

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