

# TX SenseAbilities



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## All TX SenseAbilities Issues

**Español**

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**TSBVI Main Site Menu** ...➔

[Home](#) / [TX SenseAbilities Magazine](#) / [All TX SenseAbilities Issues](#) / [TX SenseAbilities – Summer 2018 Issue](#) / [DBMAT – Early Days to the Present](#)

## TX SenseAbilities – Summer 2018 Issue

### Family Wisdom



Capturing the Beauty of Jayana

After Graduation Happenings

Support Service Provider (SSP) Bills

A Wide Spectrum of Scenarios Needs a Variety of Service Options

**DBMAT – Early Days to the Present**

How Does an Intervener Differ from an SSP?

Deafblind International Network of the Americas Conference Reflections

Effective Practices



News & Views



## **DBMAT – Early Days to the Present**

**Authors:** Pat McCallum, Former DBMAT President

**Keywords:** Family Wisdom, DeafBlind, Family Organization, Systems Change, Advocacy, Education, Adult Services

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**Abstract:** The author shares the history the Deafblind Multihandicapped Association of Texas (DBMAT) and how they worked together to build services for individuals who are DeafBlind.

**Editor's Note:** *The following article was part of the May 2007 In-Touch issue, which is the newsletter for the Deafblind Multihandicapped Association of Texas family organization. It was edited from a National Parent Network 1991 Monograph by Steve Schoen. The National Parent Network is now known as the National Family Association for Deaf-Blind. DBMAT is an affiliate network member. We thank DBMAT for permission to reprint this article in Texas SenseAbilities.*

The world-wide rubella epidemic, 1963-1965, wreaked havoc on many Texas families. Our story began with the birth of our children who are deaf-blind. At first, families struggled virtually alone with the severity of their pre-schoolers' disabilities while randomly seeking assistance. Then the Texas Education Agency (TEA) 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 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 Deafblind Multihandicapped Association of Texas (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 DeafBlind 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.

[Previous Article](#)

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Family Wisdom