TASK

GUIDANCE | EDUCATION | SUPPORT

The Wings of TASK

The 50th Anniversary of TASK … an incredible Team of Advocates for Special Kids who has enabled the “wings” of millions of families and their special children! This celebration evokes the reflection of so very much personal pain and joy. Many of you know who I am but few of you know how the wings I developed with TASK helped my husband and me navigate a complicated and rewarding life with our son, Matt McHugh. The feelings of sadness and fear still can take my breath away as I recall the child our family had anticipated for nine months to welcome to the world in 1972 was no more. Instead we brought our Matt home … a child who was filled with so many enigmas but also a huge contagious smile. We learned that he had severe spastic quadriplegia and a profound hearing loss. Consultations with two noted pediatric neurologists produced divergent diagnoses. The first was that the child’s greatest disability would be his “overly involved mother” and the second was that he was so very damaged that he required institutionalization … “Mr. and Mrs. McHugh, in the card game of life you have been dealt a losing hand.” We knew that our path had to meander between the two extremes.

We are so very fortunate that our path led us to a petite elderly Developmental Pediatrician at UCLA, Margaret Jones. She evaluated Matt as I held him on my lap and flipped the pages of a book. She said that he was interested in the pictures in the book and not with the “thing” book … he was capable of learning! She also called in a rehab engineer and asked for a device with a “yes” and “no” which he could access with his right arm of which he had some control. She made us promise to have him decide on every article of clothing, type of food, or activity he wanted. “Do not ever let him become a victim!”

UCLA helped us chart the developmental path for Matt and also introduced us to Jean Turner and her vivacious blonde daughter, Tracey, whom Matt adored. We shared our weekly drives to UCLA from Orange County and the subsequent hours on the San Diego Freeway.

We had ample time to share our joint frustrations with the difficulty of finding and coordinating services for our children. We also shared our excitement about P.L. 94-142, The Education for All Handicapped Children Act, which guaranteed a “free and appropriate public education” for all children. We started to identify other families and the first meeting of TASK was in my living room. Every one of our children represented a different disability with varying needs but we all shared the urgent need to educate ourselves on the legislation. We were supported by Regional Center, Dayle McIntosh Center, and the Western Center on Law and Poverty. Two dynamic young attorneys, Terry Friedman and Cathy Blakemore, helped us write our first parent advocacy training course … we were on the way to enable the wings of other families with special children. Terry Friedman also helped us file two major lawsuits to assure summer school and appeals rights for our children. This initial litigation was crucial to TASK’s success as we succinctly defined the intent of the legislation and the school districts learned that we were becoming an army of education advocates with which to reckon. In fact many of the Directors of Special Education against whom we had won administrative hearings joined our training.

On our family journey we knew that communication was the key to Matt’s development. We decided on a Total Communication program utilizing sign language. The McHugh family learned sign language and successfully entered Matt in a program for the aurally handicapped … though they weren’t thrilled with a child in a wheelchair who was only going to be able to do modest signing due to his quadriplegia. Our days were segmented and full as after school hours we had to fit in his other needs for various therapies. For 6 years I felt we were trying to fit our square peg into a round hole. We were living in a state with categorical funding for special education and Matt didn’t fit neatly into a category. We decided to take the knowledge we had gleaned from TASK and the many families we had been privileged to work with and CREATE a program for our unique son.

The wings of TASK had prepared us for this decision which took us to a small town on Lake Tahoe, Nevada with no special education. As a result I went down to the State Department of Education in Carson City and wrote an IEP for Matt which was designed specifically for him … rather than an IEP which was designed to fit an established program.

I can guarantee you that when an IEP is written with the State Department of Education there is absolutely no problem with its implementation! It had become apparent that Matt's receptive language would be sign and that his expressive communication would be through various forms of Augmentative Communication. The rehab engineers at Stanford University and the augmentative communication pathologist at Michigan State University kept us on our toes. We had assembled Matt's team. It was infinitely more rewarding to build a team than to jump the hurdles thrown our way by a program which was frustrated that Matt didn't conform to their "norms".

The entire town joined the team. Matt wanted to snow ski so the be Ski Patrol locked his KAF orthoses and he skied. We went horseback riding, boating, snowmobiling and most certainly fishing -Matt's ultimate passion. Matt was invited to birthday parties. The town sponsored Special Olympics at our ski area. To help in the classrooms we founded a Foster Grandparent program. Consequently, EVERY student had special attention and many elderly people felt needed for the first time in years. We even had the opportunity to meet our new dentist on the spur of the moment prompted by a phone call from Matt's school … "Mrs. McHugh, were Matt's teeth baby or permanent teeth?" The key word was 'were'! He had been running relay races in his weight relieving walker and a wheel had gotten caught on a rock and tipped. They were deciduous teeth but the important thing was that Matt was in the thick of things! He developed socially, learned to read, his receptive sign language soared and he was developing skill in communicating with his augmentative communication boards.

Our teams at Stanford and Michigan State informed us it was time to use those TASK wings again as Matt had developed to point of requiring more sophisticated support. This took us to the Chicago suburbs and Northwestern University. We petitioned the high school district to take Matt a year early as we explained our desire to create one comprehensive team for the remainder of his public education years. They welcomed the opportunity and provided incredible wings for Matt. We started a Peer Mentor Program beginning with the football team and cheerleading squad as I was concerned that Matt was receiving too much "care" from adults.

The Augmentative Communication Department at Northwestern University connected us with the engineers at Prentke Romich in Germany and Matt received his first Touch Talker especially designed for a deaf individual who couldn't actually hear what the device was saying. One day he came home from school and told me he needed a new word in his Touch Talker … 'SHIT'. The next morning I called the Dean of Students to explain that I expected consequences if Matt was inappropriately using his new vocabulary. Sure enough there was detention that day!!

This team of teachers, peer mentors, therapists and engineers provided the necessary support for Matt to fully enjoy the very best years of his life. The District Superintendent even sent his IT supervisor to Matt for the first day of each year to assure that all of Matt's tech gear was functional in his classrooms. He attended homecoming dances and football games. As part of his IEP we also included vocational assessments and rehabilitation. His team had him ready to move into the workplace and file tax returns after his graduation. That graduation included a standing ovation from all 500 of his classmates.

After graduation Matt moved into a small group home and started working at a local bank. The men in the mailroom discovered that Matt really enjoyed hockey and they frequently included him in their beer and Blackhawks outings. The years of spasticity continued to ravage his slight frame and he arrived at the point of requiring even more orthopedic surgeries than his previous 12 procedures. A brachial artery was accidentally cut in the last surgery requiring a grueling 11 hour vascular repair. He was terribly weakened … physically and emotionally. He now would have to face countless skin grafts from where arteries and veins had been harvested. He said "No more!" Doctors were doubtful he would ever make it through the future surgeries. I couldn't help but think of Dr. Jones' admonition to never let Matt become a victim … allow him to always make his own decisions. The hardest decision we made in Matt's 34 years was to allow him to use his wings to make that most important decision … call in hospice. Two days later our boy with the abundantly contagious smile soared on his very own wings!

It was immensely exciting to have been involved in the creation of TASK. It is also deeply humbling to see what a dedicated Team of Advocates for Special Kids has become. With education and support you have enabled the wings of millions of families and helped them in pursuing heights for their special children not imaginable with the first diagnoses that the had received. My very sincerest wishes are with you to continue developing those “Wings of TASK”!

Jan McHugh

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Photos & captions courtesy of Jan McHugh:
Matt at 13 months with his first binaural hearing aids and belly board, digging in the dirt; at age 6 after major orthopedic surgeries at Children’s Hospital Stanford; and at age 9, fully immersed in one of his greatest passions.