



Sense Abilities

A QUARTERLY PUBLICATION ABOUT VISUAL IMPAIRMENTS AND DEAFBLINDNESS
FOR FAMILIES AND PROFESSIONALS

A collaborative effort of the Texas School for the Blind and Visually Impaired
and the DARS Division for Blind Services

Spring 09

Contents

Volume 3, No. 2

Large Print Edition

Family Wisdom

BFF: Our Lives So Far	2
Reaching for Skye	5
Living the Good Life	11
Grandparenting a Deafblind Child	14
Third Annual Texas CHARGE Retreat—A Day of Fun & Learning!	17
TAPVI Talks	19

Effective Practices

Teachers of Students With Deafblindness: Professionalizing the Field	22
Purpose, Satisfaction and Joy in the Lives of Students with Deafblindness and the People who Care	29
Successful Transitions Between Programs	36

News & Views

Together We Do More	39
No Place Like Texas!	42
All Blind Children of Texas has Funding for You	44
AFB Teen Video Series: On Your Mark, Get Set...Go to Work	45
Audio Description by CaptionMax.com	46
Books for You!	48

The Texas Ramp Project: Building Freedom for the Homebound 49
 Paying It Forward: Sharing Your Wisdom, Sharing Your Profession 49

Bulletin Board

Regional, State and National Training and Events 52



Patsy Izaguirre and Amanda Huston made their keynote presentation from the student perspective during the 2009 Texas Symposium on Deafblindness. Their ideas about friendship supported the theme of the symposium: Purpose, Satisfaction, and Joy in the Lives of Students with Deafblindness and the People who Care. Their's is one of several symposium presentations highlighted in this issue of *TX SenseAbilities*.

BFF: Our Lives So Far

By Patsy Izaguirre, Student, Copperas Cove, TX
 and Amanda Huston, Student, Nevada, TX

Abstract: Two students with deafblindness share their thoughts on becoming BFF, Best Friends Forever, and how the friendship enriches their lives.

Keywords: Family Wisdom, deafblind, friendship, Texas Symposium on Deafblindness

Editor's Note: Amanda and Patsy wrote keynote presentations for this year's Texas Symposium on Deafblindness. We wanted to once again share their delightful messages. The two articles that follow, "Reaching for Skye" and "Living the Good Life", are also based on 2009 Symposium keynotes. Remarks made at the Symposium are the source of "Purpose, Satisfaction, and Joy..." in the Effective Practices section as well.

PATSY'S SPEECH

Hi my name is Patsy Izaguirre. I am 21 years old. I was born in January 8th 1988. When I was born and I was very small.

I have my parents, mom and Dad, and two brothers, Alex and Jerrad, and two dogs, and one rabbit. My mom learned a lot of sign because she know that I am deaf and blind. My dad know some signs. So he is still learning to sign language and my two brothers knows the signs, they can learn more signs too.

When I was three years old I went to learn my new sign language so I can sign so good. My mom went to sign class to learn the sign. My grandma, Aunts and Dad went to sign class with my mom.

When I was three years old I learned to Braille because I was blind. But I was very scared to read the Braille. My vision teacher helped me to Braille better on the Braille writer.

When I came to the Texas School for the Blind and Visually Impaired in Austin I was very nervous because it was my first time to come here from my home. I was very excited to meet the people who know the signs.

After summer school I am feel happy to go home.

After I come home and I talked with my mom about the summer school. I showed her the pictures the school. It was fun. After I graduated from HHHS and I came back to Austin and start school and I learned new things with Deanna.

I met the other roommate name Amanda. Amanda is deaf and blind like me. Amanda and I are the best friends. We had fun things. Charity, Amanda and I went to the trip to have fun. Charity threw the water on me and Amanda.

Last summer Amanda came to my house to spend night with me for three days. At my house we went swimming in my pool. It was fun. Then my other friend, Cheyene came over to my house and we went bowling. It was wonderful. Amanda like to stay at my house with me because she love to swim in my pool.

When I will be adult I will have the jobs. I will work at elementary school to teach the blind and deaf children to learn to read the books and do fun math. Then we will work on the computer.

When I graduate from TSBVI Amanda and I hope maybe Amanda and I would live at apartment in Austin and my family will visit with me to have fun.

Maybe they can spend night with me at my house. Maybe Amanda and I will have the friends that can come to visit with us and spend night. I hope Amanda's family can come to visit with Amanda and spend night with her. Amanda and I will be friends for long time.

AMANDA'S SPEECH

Hi my name is Amanda Huston. I am 18 years old. I was born blind and with ataxia. I lost my hearing when I was 4 years old. I learned sign when I was 7 years old in O'Henry school. My mom did not know sign until I was 9 years old and I misbehaved. When I was 11 years old I got a Cochlear Implant. Before I got my CI could hear a little bit not very much. After I got my CI I was 15 I could hear a lot. I got my hearing aid when I was 18. My CI and HA are very fancy my HA have sparkles on the mold and my CI have many different colors.

I came to TSBVI when I was 12 years old in the summer then I came here when I was 14 in the school year. I had a lot of friends but they do not know sign. My teachers needed to help me talk to them. That made me feel sad. I met Patsy two years ago in 2007.



I have been best friend with Patsy for 2 years. She is deafblind too like I am. We sign in our hands and we talk a lot. That made me feel happy. Patsy was the only one that I can talk without help. When I first met Patsy I felt nervous and shy. I was happy that Patsy was here because no other friends know sign. Patsy and I learned how to cook in the oven but all by our selves we were scared.

This summer we went to Camp Summit for one week. At Camp Summit we rode horses, went swimming, climbed ropes, did arts and crafts, did sports and game, had cookouts, went on hayride, had dance night. We had a lot of fun.

I went to Patsy's house last summer for four days. We went swimming, bowling, and ate dinner at a Mexican restaurant. I met Cheyenne Brown. She is Alex's girlfriend. Alex is Patsy's brother. In August we all went to Six Flags. Patsy's mom, dad, two brothers, Cheyenne, my mom and dad we all went together. I had so much fun. We rode different rides there. Patsy and I were very scared of the fast ride. They all know how to sign.

We are staying at TSBVI for one more year then we will graduate. When we leave, we will feel scared because we love to stay at there. It is fun and people are very important to us. After we graduate TSBVI we are going to Helen Keller school in New York

Patsy and I hope we can live in a house with friends. Patsy and I will be friends forever.

I love giving speeches. It is fun to talk about your life. I love to talk with a lot of deafblind people and meet them I hope you all have a great day.

Reaching for Skye

By George and Christine Givens, Parents, Spring, TX

Abstract: Parents share their keynote presentation from the 2009 Texas Symposium on Deafblindness, about their family's journey in finding purpose, satisfaction, and joy with and for their daughter who is deafblind.

Keywords: Family Wisdom, deafblind, in-home therapy, community, Texas Symposium on Deafblindness

Christine: We're here today to talk about our daughter, Skye Marie Givens and that's actually one of our favorite topics. Skye is deafblind, speech impaired, motor impaired and has cerebral palsy. She is fed through a g-tube and does not walk...yet. Our presentation is titled "Reaching for Skye" as we have struggled almost her whole life on how to communicate and effectively teach Skye about the world around her. And, how Skye can tell us what she wants. We want her to experience a life full of joy, have a purpose, and be able to participate in her life. Our desires are no different than most any other parent—with the exception of "how" do we reach our deafblind daughter?

There's so much we could talk about, but we've been asked to focus more of our talk on the therapies that are done at home and the significance of them. Before we get into that, we'd like to share some background on our daughter; because when you have an understanding of where she started, then you have a greater appreciation of how far she has already come.

George: In the summer of 1997, Christine and I had been married for 7 months and we were on a business/vacation trip in the UK. My ancestry is

Scottish and I lived and worked in Scotland for several years earlier in my career, so I was very excited that Christine was able to come with me. We landed in London and checked into a hotel across from Kensington Palace. We woke that following Sunday morning and looked out the hotel window to large crowds of people flowing onto the grounds of Kensington Palace and carrying flowers. Turning on the TV, we heard news that Princess Diana had been killed in a car crash hours earlier that morning in France. We left London for Glasgow, Scotland, and drove across to Edinburg and up the east coast to Aberdeen for business. After finishing in Aberdeen, we drove across the Scottish highlands and headed for Balmoral Castle, summer home for the royal family. Near Balmoral Castle, officials motioned us and several other cars off to the side of the road as the Queen and her family passed by on their way to the local church to attend the family memorial service for Princess Diana. It was a moment that left quite an impression.

A little later, we continued our drive and arrived at Loch Ness—maybe in hopes of getting a glimpse of the Loch Ness Monster. Having no luck seeing Nessy, we continued our journey to the west coast and on to a quaint little island to stay the night at a B&B. We were on the Isle of Skye. This is a very tranquil part of the world. One lane roads with occasional wider sections to allow for the almost never occurrence of an oncoming car. It is home to ancestral beginnings for several of the Scottish clans.

You're probably wondering what this has to do with the topic of deaf blindness, or being parents of or about caring for someone who is deaf blind. For us, this trip was the beginning of a much longer and still ongoing journey. About 24 weeks later our daughter, whom we named after the Isle of Skye, was born. She arrived 4 months premature, and on the day before our first wedding anniversary. Like the Isle of Skye, she was very tiny, tranquil, primitive but would prove, at 1 lb 6 oz, to be a fighter, even though the odds were stacked against her. She spent 5 ½ months in the NIC Unit (Neonatal Intensive Care Unit) at Texas Children's Hospital and every day for the first several weeks, Doctors did not expect Skye to live to the next day. She suffered a bilateral brain bleed which destroyed portions of her brain, along with her auditory pathway. She survived heart surgery, countless infections, and detrimental side effects from drugs that kept her alive, but seriously affected her senses. Skye developed Retinopathy of Prematurity (ROP) which caused her retinas to detach in both eyes. The retinas were reattached and sclera buckles were placed around the eyes to

aid in keeping the retinas partially attached. In July of 1998 we finally brought Skye and her entourage of oxygen, monitors, and medical equipment home. Our daughter was deafblind, speech impaired, motor impaired, and had cerebral palsy. Throughout this part of our journey, the road ahead seemed very dark and uncertain—no cars in sight, no map to guide us, and unknowing where we were headed.

Our primary goal for Skye during the first several years was mostly centered around survival. An extremely weak immune system susceptible to the RSV virus, pneumonia, and aspiration were just a few of our major concerns. The doctors advised us not to take Skye out of the home unless it was for doctor visits or medical emergencies.

We had been advised by prominent vision specialists at both of the major children's hospitals in Houston that Skye had no vision and no probability of vision due to the ROP. Determined to do all that we could so that Skye would not live her life in total darkness, we set out to find an expert in ROP. This led us to meeting Dr. Michael Trese in Royal Oak, Michigan. His life long commitment to children with ROP and ongoing participation in research put him on the cutting edge of ROP technology. After several delicate surgeries, Skye began to distinguish light and dark out of the lower quadrant of her right eye and has been able to maintain and use that ability. We traveled to Michigan twice a year for the first 3 years and once a year thereafter for follow-up visits. It has become our annual vacation road trip, allowing us to visit close family members in Ohio, Kentucky, Alabama and Mississippi, that otherwise might not have happened.



Christine: When Skye was 7½ years old, many changes came to the family. Skye became a big sister on August 16, 2005, when we traveled to China to finalize the adoption of Leili Gayle. There are no words to describe the joy and satisfaction that we have with our two daughters. They get along great together, and Leili has a basic understanding that Skye has disabilities and we just need to do things differently with her. Leili is very accepting of the differences and very loving

to her big sister. On occasion, you'll even see her trying to feed her baby doll as though she has a G-tube just like Skye's.

George: We have struggled for years on how do we actually communicate with Skye. How do we reach her and how can she reach back to us? For most of her 10 years, we have relied on her sounds, yells, and screams, trying to decipher what she wanted, what she needed, what could possibly be wrong, and many times we asked God, "Just give us a clue."

For too long we were going down a path that seemed to go nowhere. We had been depending on the school system for guidance. As time went along, it became more apparent to us that the education methods being used with Skye were not consistent with those of the deafblind professionals. Two years ago, TSBVI Deafblind Outreach was invited to her school to evaluate Skye and make recommendations. They provided a comprehensive report which the school district has been slowly implementing. This school year a paraprofessional intervener in training was assigned to work with Skye in the classroom.

Christine: After waiting approximately 7 years, Skye finally made it into the CLASS program. This is a Medicaid waiver program for children with disabilities. It was a huge blessing and a true turning point in Skye's life—truly JOY to the 100th degree. The most significant impact to our family and especially to Skye was that CLASS provided a portfolio of specialized therapies, and Medicaid opened the door to the traditional OT, PT and Speech services. The therapists have reached out for Skye and to us as a family because they genuinely care and see the potential in her. They are willing to commit to goals that challenge her and are determined to be successful. They have not been limited in their thinking; to this day, if something is not working, we study the issue, back-up, and try another tactic. All the therapists are aware of how Skye is progressing with the other therapies and are eager to help each other when issues arise.

Music Therapy started approximately 2 ½ years ago. In the beginning we didn't know what to expect from this therapy, but Skye enjoys music so we had hopes that she would be responsive. And she was. Skye went from reaching with limited movement of her right hand and no reaching or movement of her left hand to strumming a guitar with both her right and left hands. Using music interaction as an enticement, Skye can hold an object in each of her hands for several minutes; she can gently beat a drum with a

stick and she's learning to move just her fingers to explore a keyboard. Our first Music Therapist began signing "yes", "no" and "music" with Skye about 2 years ago. It took perseverance and lots of patience to allow Skye to process, but Skye started to sign.

George and I attended a Barbara Miles seminar and I still remember her talking about the need to give our kids language in many different mediums. We felt like we needed to immerse Skye in sign language because we saw the potential in her being able to communicate back to us, since she was now signing three words.

Kristen Shultz (Recreational Therapist) is the driving force for signing and other activities. She is knowledgeable in many of the therapy disciplines and has a vast understanding of muscle patterns. She can almost immediately identify what is hindering Skye from progressing. Kristin has literally opened Skye's world with Recreational Therapy. Because we are beginning to have a mode of communication and we can now give Skye information about what we are about to do, we've been able to reduce her stress level and we've actually been able to ride the train at the zoo, have lunch on Sundays as a family at a local Mexican Restaurant, explore Wal-Mart, meet Governor Rick Perry at the State Capital in Austin, plan shopping trips to the mall, and attend the prom that was hosted by our church with her dear friend Travis Dafft, who is also deafblind. You can read all about their wonderful evening in last fall's issue of *TX SenseAbilities*.

Kristen is also our Aquatic Therapist. Two years ago when she put Skye in the pool, she was lifeless and very weak. She now she kicks her legs, plays games and works on strengthening muscles that she probably never knew she had. The water provides an environment in which Skye is totally free of all braces and she can move as freely as she wants.

OT services just started in June and Della Copper has already made a drastic change in Skye's life. Initially the goals were set to strengthen arms so that Skye could learn to bring a spoon to her mouth. Skye was resistant and appeared confused. Della worked with Kristen to develop a signing routine to take Skye back to the beginning of, "what is a spoon? What do we do with the spoon?" Della just started this new routine the week of Christmas and Skye is already showing signs of understanding the steps of the new routine.

Mary Knight (Speech Therapist) has over twenty years of experience (including signing experience) that she brings to the table—literally. Skye is now exploring Cheetos Cheese Puffs, Lorna Doone Shortbread Cookies, and Ritz Crackers along with the usual applesauce and yogurt. Her goal is to get Skye to the point that she can safely eat these finger foods, and then our OT will be able to teach Skye to bring the finger foods to her mouth.

Kerry McGuire (PTA) has accomplished great things with Skye during this past year. She has worked with Skye to stand up from a sitting position with little assistance. She has also worked with Skye in a gait trainer to take steps with assistance. Upcoming plans are to work with Skye in a “Spider Cage”, which is an intensive therapy to isolate and strengthen the weaker muscles due to her CP. This is a therapy originally developed for Russian cosmonauts who have spent extended periods of time in an anti-gravity environment. We hope that this will help to strengthen Skye and progress her further in the gait trainer and all other movements.

Skye also receives 2 massages a week to help with the muscle tone issues related to CP. Silahis Loyola is her masseuse.

These therapies would not have been possible or as effective without assistance from the CLASS program and Pros Home Health Care. We are grateful for the program and the dedication of the therapy team.

George: We enjoy being able to take Skye to church. That is something that we were not able to do as a family for many years. We are fortunate to be part of a church which has an ongoing mission in the community to serve people with disabilities and their families. Our church is The Woodlands United Methodist Church, located north of Houston. It is a large church with an impressive special needs program serving more than 150 kids and their families.

In the beginning our journey seemed dark with no direction or understanding of what it takes to reach out to Skye. Today, she is beginning to communicate and participate in her life. Skye has worked hard to get to where she is, and so have many other people for which we are very appreciative. Tomorrow is Valentines day. It is also Skye’s birthday; she will be 11 years old and is our Valentine. The day after tomorrow is our 12th year wedding anniversary. So, our journey continues. Thanks for listening.

Living the Good Life

By Jamie Pope, Executive Director of AADB and Randy Pope,
Private Consultant on Support Service Providers, Silver Springs, MD

Abstract: A couple shared their story at the 2009 Texas Symposium on Deafblindness, showing how people who are deafblind can lead lives of purpose, satisfaction, and joy.

Keywords: Family Wisdom, deafblind, American Association of the Deaf-Blind, AADB, adult life, marriage, Texas Symposium on Deafblindness

Hello! We recently did two presentations on “Living the Good Life” and “A Glimpse into Our Lives as a Deaf-Blind Married Couple” at the Texas Symposium, “Satisfaction, Joy, and Purpose in the Lives of Students who are Deafblind and the People Who Care”, hosted by the Texas Deafblind Project, this past February. We were asked to write this article to share excerpts from our presentations with families who have a family member who is deaf-blind.

Deaf-blind People Can Live Good Lives

To introduce ourselves, we are both deaf-blind. Jamie: I became deaf-blind at age 2½, which was caused by serious illness with high fever. The fever damaged my optic and auditory nerves, which resulted in my low vision and hard of hearing. The fever also caused my balance difficulties. Randy: I have Ushers Syndrome, Type II. Although, I was born hard of hearing, I did not find out I had Ushers until age 35 when I experienced significant vision loss. To this day, I only have central vision, very little peripheral vision, and am hard of hearing.

Living the Good Life Starts with Family—No Surprise!

We have four things in common with our families: love, “can-do” attitude, involvement, and humor. Our parents love for us came through many times even though communication was not perfect. They have “can-do” attitudes, believing in us and that we can accomplish many things. They made sure we were involved in family activities, did chores the same as other family members, and have some experience with developmental and age-appropriate tasks and milestones the same as other kids our age. We



learned from our families early on that having a good sense of humor is an important social skill, as it makes people happy and contributes to living a good life.

Education is a Stepping Stone to a Good Life.

Jamie: My parents strongly believed that getting a good education was my key to a successful future as a deaf-blind person. During mainstreamed elementary school years, I was very fortunate to have a caring itinerant teacher who went beyond reading, 'riting, and 'rithmetic to teach me about feelings, relationships, friendships, and shortcuts to doing things like counting money faster. This extra help early on was a boost for me in later years.

Randy: My parents are also strong believers in getting a good education for me. In my elementary and junior high school years, I was taught lipreading and speech. Later in high school, I used total communication, which is signing and using speech at the same time. My education evolved around preparing myself for college.

Transition to the Good Life.

Jamie: I had three pivotal experiences during high school that helped me successfully transition to college and beyond. I was an American Red Cross volunteer, and devoted many hours to help students at Michigan School for the Blind with recreation activities. My first job was in my family's farm market where my dad taught me to not to be too shy to address customers and say, "hello, how are you, and how may I help you?" Also, I learned how to navigate the public transportation system in my hometown at the same time my peers were learning how to drive. Learning the bus system helped to meet my needs for independence at that time and now.

Randy: For my first job, I worked in a pet store taking care of animals, including a monkey. My next job was at McDonald's restaurant as a "bun boy". My responsibility was to ensure the buns were toasted and prepared for the meat to be placed on them. I also served as a cook, often cooking 96 meats at one time. These two jobs during my transition period were great learning experiences.

Let the Good Life Begin!

Jamie: My parents encouraged me to go to Gallaudet University even though I got acceptance letters from other universities in Michigan. They

believed Gallaudet would provide me with a well-rounded education beyond academics, e.g., fine tune my social skills, and broaden my world. They were right! I graduated with B.A. in Social Work and went on to get a M.S.W. from Catholic University of America.

I had various jobs during college and after graduation. The two most memorable jobs I had were to work as a maid at Yellowstone National Park one summer, and as a tutor of Algebra I to college prep students. I've been a counselor/social worker and technical assistance specialist. Now I am Executive Director of the American Association of the Deaf-Blind (AADB).

Randy: My time in college only lasted one semester; however, I was able to enter into the Tool and Die maker trade, which only employed the highest technical people in this field. This kind of job depends heavily on good vision; I was forced to leave when my vision deteriorated twenty years later. Now I'm working as a volunteer web administrator and public relations specialist for AADB.

The Joy of Family

Randy: I have 7 sons from a previous marriage. Yep, 7 boys! Oh joy! They are now all grown (ages 20 – 34) and doing well. All except two have engineering degrees, or currently are majoring in engineering in college. The other two are working as a computer network administrator and welder. When my vision deteriorated and my ex-wife left the family, I quit work to take care of my boys full-time. There have been difficult times, of course; but my devotion to my sons has paid off, and they are all doing quite well in their own lives right now.

Jamie: Like many little girls, I dreamed of getting married, but interestingly, I never dreamed of becoming a Pope! Randy and I will celebrate our 5th anniversary in May. Randy and I are a team in our marriage. We help each other with mobility, reading, and communication needs. For example, when we enter a self-serve restaurant where the only menu is posted up high, I am not able to see what they have due to my low vision. Randy, on the other hand, can see pretty well straight ahead at a distance, so he reads me the menu. However, he sometimes has difficulty seeing chairs, tables, and people around him; but since I don't have tunnel vision and I can see things close up, I can see enough to guide him to the empty table to sit down and eat. We take the famous quote, "opposites attract" to a new level in our marriage!



The Good Life Continues

Social contact with other deaf-blind friends is important to us. AADB is one place to find deaf-blind friends from all over. AADB is famous for national conferences where hundreds of deaf-blind people come together for networking, support and training with the help of support service providers (SSPs). Check out AADB's website for more info on what we do <www.aadb.org>.

Local and state deaf-blind organizations or groups are also places to socialize with deaf-blind friends. In Texas, there is the Texas Association of the Deaf-Blind. (Contact Kim Powers-Smith at <krazykimdb@earthlink.net>)

Helen Keller once said, "Life is a daring adventure or nothing." That quote fits our life to a "T" and we're deaf-blind too! Jamie: I had many adventures, but two stand out: 1) went white water rafting on a wild river; and 2) participated in a Discovery program that had various challenging activities including climbing alone over and through a jumble of wires suspended high up between trees. Randy: Likewise, too many adventures to name here, but my most memorable adventure was when I went body surfing on the Pacific Ocean.

We hope we clearly demonstrated that people who are deaf-blind can lead lives of satisfaction, joy, and purpose!

Grandparenting a Deafblind Child

By Dick Newton, Grandparent, San Antonio, TX

Abstract: A grandfather shares his family's journey in adopting their grandson who is deafblind.

Keywords: Family Wisdom, parenting grandchildren, deafblindness, community support

One of the many things my wife, Phyllis, and I planned to do when we retired was to buy an RV and visit every major league baseball stadium in the country. That came to a halt.

Our daughter, Julianne, who was a brittle diabetic, was in and out of hospitals with health issues for many years. When she became pregnant, she began having complications. Our grandson, Nate, was born at 24 weeks and weighted one pound, six ounces. Nate was in a huge hurry to experience his new world. He was required to stay in NICU for five and half months. It was later determined that Nate was deaf, blind in one eye, and developmentally delayed. After our daughter passed away due to complications from diabetes in 2002, we took the necessary legal action which resulted in first temporary custody, then permanent custody, and finally an adoption on July 14, 2004. Life changed.

Phyllis and I love our grandson dearly and we just know he loves us too. One of the first things we did was attend to his medical needs. It's always interesting to walk into the pediatric clinic with Nate for an appointment and see the looks Phyllis and I get. Most of the parents in the waiting room are young enough to be our children. Whenever the nurse calls us in for "weights and measures" she usually says, "Is Nate your grandson or son?" We just respond, "Yes." Nate has had a tonsillectomy, hernia surgery, MRI's, and was screened for a Cochlear implant. Unfortunately, he does not have the "eighth nerve" necessary to proceed with the implant.



Once we felt his health needs were being satisfied, we turned our attention to communication. Nate knew very few sign words and we were in the same boat. Phyllis and I took a sign course, bought "signing for dummies" (appropriately titled), and obtained some VCR tapes depicting life with the Bravo family. He also began speech/occupational/physical therapy. Our plan was to learn at home and Nate would learn at school. We REALLY didn't want to travel anyway! Oh, by the way, how do you spell ARD?

What an experience! Age and wisdom are not interchangeable. I can say that first hand. I didn't realize schools hired teachers and administrators who look so young. Anyway, the process is quite preformatted until you get to the IEP part. Then the clouds start rolling in. How do you come up with an IEP for a child who has a difficult time communicating?

It was through TSBVI Outreach that we learned about other supports that have been a blessing. We have learned so much through the Deafblind Multihandicapped Association of Texas (DBMAT). By attending the annual DBMAT conferences, the information we have obtained has been so enlightening. For example, at one of the conferences we were encouraged to get Nate on the Medicaid Waiver lists, and this has proven to be most beneficial. Nate really enjoys the activities for the children. The support and networking with other parents of deafblind children has been priceless. Nate is in the DARS Division for Blind Services (DBS) children's program and MDCP waiver, both of which have helped financially and with respite care opportunities.

Nate was less fortunate, however, when it came to schooling. That was until last year. It was through TSBVI Outreach and excellent coordination from Nate's school that we were able to apply and be accepted at TSBVI. Nate started last August and has shown quite an improvement in his communication skills. We are trying to keep up with Nate's signing. He doesn't initiate as much as he should, but you start signing and he's there with you. It's amazing what a good education can do! He does get frustrated with us sometimes because our limited communication skills.

Nate is a real sport when traveling. He likes to fly and run through airports. Road trips are now more frequent with two hour bus rides each Friday and Sunday to and from school. Also backpacking has taken on a new meaning. They are now filled with pull-ups, pediasure, carnation instant breakfast, and spare clothes. Nate went from being with us 24/7 to being a real semi-sightseer.

It took us almost two years before we were comfortable enough to leave Nate with a sitter. That meant "dinner and a movie" was merely a term and not reality. Finally we were able to have Nate's intervener from public school sit with him. Since attending TSBVI, "date night" has returned once a week or so.

Throughout Nate's young and turmoil-filled life, he has been a real trooper. He has some behavioral issues which have interfered with his education, but are being controlled with medication and lots of patience. Nate loves to play with his shirts and also likes to rip them at times when things aren't going his way. Thrift shops are now our "Gymboree" stores.

Life certainly has changed for Phyllis and me, but we are thankful that we have Nate and never give it a second thought about raising our grandson/son. While he has been “a work in progress,” he has been the thunder and lightning of our life. Our retirement plans have been put on hold and we will just have to visit those ball parks using our “walkers”. It has been and will continue to be the experience of a lifetime.

Third Annual Texas CHARGE Retreat—A Day of Fun & Learning!

By Josh Fultz, Texas CHARGERS Board Member, Navasota, TX

Abstract: A Board member of Texas CHARGERS, Inc, a nonprofit organization for families of children who have CHARGE Syndrome, shares his thoughts on the group’s 3rd Annual Family Retreat, which drew families from across Texas for a fun-filled day of fellowship and learning.

Key words: Family Wisdom, deafblindness, CHARGE Syndrome, family retreat, training

The hot Texas wind made a strong cooling shift to the north, welcoming participants to the 3rd Annual CHARGE Retreat held at the Merritt Bois D’ Arch Buffalo Ranch in Denton, Texas. Anticipation was high among those who had waited all year for the event, which was originally scheduled on the same weekend as Hurricane Ike’s arrival, and had to be postponed until November 16th, 2008. The wait was well worth it.

Over 30 families made the journey with approximately 150 total attendees. The Texas CHARGE board, as well as many others behind the scenes, had worked diligently to make the rescheduled event happen, and to make it the retreat everyone had looked forward to.

The activities began on Saturday morning during registration when family members received their CHARGE designated shirts and thus began the reunion of friends old and new. Volunteers designated by white shirts waited anxiously inside the door to meet their little CHARGErs. The day had been well planned with lots of emphasis on fun for the kids, including arts, crafts, games, scavenger hunt, hayride, and many fun events.

While the kids were being entertained the parents, grandparents, and siblings were offered educational information in the form of a speaker’s panel from Texas state agencies. Agencies attending included TSBVI,

DARS, Helen Keller National Center, and an Education Service Center Specialist from Region 13. They discussed the challenges of deafblindness. It was a poignant reminder to everyone that there is help out there.

The lead speaker Amy Parker, a doctoral student from Texas Tech working with the National Coalition on Deafblindness, explained her goal of helping gain assistance from the federal government for children with sensory impairments. She indicated that the funding for deafblind children has stayed generally the same, 12.8 million dollars, for the last 20 years. She assured the audience she was working to get that number increased, and asked for assistance from participants in supporting the increase.

Always emotional and thought provoking, the parents panel gave the unique perspectives of those parents dealing with CHARGE. Five parents of children with Charge Syndrome ranging in age from 6 to 26 participated as panelists. The parents shared their struggles and their achievements parenting children with CHARGE. One parent compared raising a child with CHARGE to swimming up a waterfall; one should stop and take a look back because the view from a waterfall is beautiful. The profoundness of the statement struck a deep chord with all.

Also included in the day's activities were the varied forums. Participants could attend the most appropriate one, including different forums for fathers, mothers, and grandparents. The fathers sat in a large circle downstairs and shared their experience with challenges of parenting a child with CHARGE. Also discussed were the differences in dealing with charge as fathers compared to mothers. Each father praised their wife/girlfriend for all the support and additional responsibilities that the role of mother entails.

The mothers met upstairs in the loft meeting room and discussed how important it is to take time for themselves, as well as being the best moms possible for their CHARGE kids. They shared their ideas and shared stories of how their CHARGE child has made them laugh or smile. It was a great bonding time for all the mothers. They also discussed the frustrations and emotional challenges of being the primary care giver to a child with special needs. The grandparents networked and discussed the many facets of being grandparents to a CHARGE child, including concerns about their children, the parents of CHARGE children. Each forum provided an excellent and unique opportunity for openness and honesty in sharing ideas and mindsets.

After serious the discussions, it was time for a little fun. Everyone was lined up to immortalize this 3rd retreat in a group picture. Then it was time for some good eats. Not only was the meal great, so was the 2008 Star Charger, Kayla Ortegon. Kayla shared her life challenges with CHARGE. Everyone was delighted when she declared, "I have CHARGE Syndrome, but I like to think of it as I am in charge, and can do a lot about it."

Kayla's goal included helping other people in life, and she thanked her family for all their support. She stated she considered herself just like any other young woman.

Following dinner, a genuine Texas CHARGER Hoedown, was celebrated with a bonfire and smore's, music, popcorn and cotton candy. Everyone danced and played with one another, bringing to end another educational, emotional, and life changing retreat for families and children with CHARGE.

TAPVI Talks

By the TAPVI Board:

Michele Chauvin, President;

Lynn Novay, Secretary; and Christina Silva, Newsletter Coordinator



Abstract: Three board members of a statewide organization for parents of children with visual impairments introduce themselves and their families.

Keywords: Family Wisdom, parent organization, parent support, parents of children with visual impairment, parent training, volunteering, advocacy

Please join us at the Texas Parent-to-Parent Conference on June 26-27, 2009 at the Omni Hotel Southpark in Austin, TX. The Texas Chapter of the National Association for Parents of Children with Visual Impairments (TAPVI) will sponsor a family get-together from 5:00–6:00 pm, Friday, June 26, 2009 at the hotel. TAPVI has collaborated with TSBVI Outreach to offer breakout sessions specific to visual impairments and some cool activities for families. You can read all about it and register at www.txp2p.org/conference/confannouncement.html.

Michele Chauvin, TAPVI President <MICHELECHAUVIN@YAHOO.COM>

Hi! Here is the scoop on my family and me. We live in Sugar Land, which is near Houston. I have been a TAPVI member since 2003, when our group formed at Texas Focus in San Antonio.

Luke and I have been married for 14 years. He teaches high school senior English and coaches boys' soccer and academic decathlon. Our daughter, Lauren, is 8 years old. She loves exploring Braille books, listening to Hanna Montana (or any) music, listening to Disney descriptive videos or PBS kids shows, swimming, and playing at playgrounds. Lauren was born at 26 weeks weighing 1 lb 2 oz, and she is blind due to retinopathy of prematurity (ROP).

I keep busy working and playing with Lauren when she is home, learning how to do life with a child who is blind, informing our legislature about the needs of our children who are blind or visually impaired, volunteering in the community, and entertaining my 5 nieces.

We truly enjoy meeting and connecting with other families at blind and VI events or activities, attending workshops and conferences, applying what we learn at home, and challenging our community to accept and to embrace our special children.

Last year, I wrote our legislature and traveled to Austin twice. Once we encouraged them to increase funding for DARS-DBS, providing more case workers and smaller caseloads rather than a wait list. Last fall I spoke before a state board sharing the importance of training our TVIs before completing their certification by exam only.

Reaching out in this way was a first for me, so it was definitely a learning process. The more we learn, the more we stretch and grow as individuals and as a VI family. Together we can make a difference in the lives of our children.

Please feel free to contact me, share your own story, get connected with other families, or let me know how TAPVI can help you or your family.

Lynn Novay, TAPVI Secretary <LMN291@VERIZON.NET>

Hello! I would like to introduce myself. I have been a member of TAPVI since 2004. I am now the secretary for TAPVI (Yes, you voted me in for Newsletter, but things change). I did create, complete and e-mail one edition

of the newsletter for TAPVI members. If you are a current member you should have received one. Currently, my job as secretary is to participate in monthly board meetings, which are held by conference call, and to take minutes.

I live in Garland, a suburb of Dallas. I am married to a wonderfully supportive husband, Tim, for 30 years. We have 2 sons, Taylor who is 24, and Luke who is 14 years old.

Taylor is living on his own (Hallelujah!), works for Whole Foods, and does Tai Chi and Kung Fu. He is enrolled back in college and is considering becoming a teacher (Amen, brother!).

Luke is very active in Special Olympics. He loves basketball, soccer, vaulting (gymnastics on horseback), equestrian riding, gymnastics, and golf. He also loves hanging out with his older brother, his friends, and his new girlfriend. (Oh fun, puberty on top of everything else.) He has CVI, Nystagmus, and Suppressed Scotoma. I stay busy learning about Luke and how to help him, taking him to therapy, and chauffeuring him to all his activities.

And now, the school district has "Star Portal," so I can see all his grades and any missing work. Unfortunately, it's more work for me, but it really is a good tool and has shown to be very helpful already. Also, I volunteer for just about everyone who has helped Luke and our family. (And anyone who asks. Wow! I can't believe I keep doing that.) My husband has his own business, Advantage Hail & Dent Repair, LLC. and I do the accounting for the business.

So, that's me in a nutshell. I can't wait to meet all of you at the TAPVI gathering on Friday evening of the Parent-to-Parent Family Conference.

Christina Silva, TAPVI Newsletter Coordinator <MELONIUS3@MSN.COM>

Hello! I agreed to take over the newsletter duties when Lynn became secretary. My job is to round-up stories from family members for the TAPVI TALKS section of this publication, *TX SenseAbilities*. I have been a TAPVI member since summer 2008. My husband of 14 years is Pete. We have two boys, Peter, age 9, and Christian, age 7. We live in Harlingen.

I keep myself busy taking care of the boys and our home. Sometimes you can find me volunteering at the boys' schools or at Christian's therapy sessions. Pete works in a warehouse, shipping and receiving supplies.

Peter, our oldest, is in fourth grade. He loves playing and watching football and basketball. Peter's basketball team in the Boys and Girls Club of Harlingen won first place in their division this year!

Christian is in the second grade. He was born at 23 weeks, weighing 1lb 1oz, and is blind due to retinopathy of prematurity (ROP). He loves listening to music, dancing, singing, and playing with musical toys. He also enjoys jumping in the moon jumps at parties and swimming. He continues to receive speech and occupation therapy. Christian has come a long way in his speech and learning this year.

Please contact me if you want to share something about your family that might benefit other families and the professionals that work with them. If you are more comfortable writing in Spanish, please do, as I am bilingual.

Teachers of Students With Deafblindness: Professionalizing the Field

By Robbie Blaha, Holly Cooper, Chris Montgomery, Educational Consultants, Texas Deafblind Outreach, Texas School for the Blind and Visually Impaired, Phoebe Irby, classroom teacher, and Amy Parker, doctoral candidate, Texas Tech University

Abstract: The authors discuss the history of the field of teaching students with deafblindness, personal experiences teaching such students, and how the deafblind teacher of the future will do the job.

Keywords: deafblind, deafblind teacher certification, deafblind education

In recent decades the population of students with deafblindness has grown more diverse, and teachers with credentials in special education, visual impairments, and deaf and hard of hearing have struggled to gain knowledge and modify teaching approaches to serve these students. Deafblind students are often served by educators who have never met a deafblind student before, or have never met one like the individual they currently serve. Often students and their parents are told to be patient while staff members try to discover and implement an educational program. Sometimes a professional with an interest or expertise in deafblindness serves only a small number of deafblind students while also providing services for students with other disabilities. There is a history of educational practices and a growing body of knowledge specific to the education of

children with deafblindness that addresses their unique educational needs discrete from students with multiple disabilities (McInnes, 1993). We believe it is time again to raise the issue of teacher certification in deafblindness.

Recent History of Deafblind Education

From 1970 to 1975 most states had several specialized programs for children who were deafblind (Collins, 1993). Federal funding supported over half of the cost of these projects, which provided quality direct services by staff members with specific knowledge and training in deafblindness. These projects provided ongoing training and consultation to local programs and produced publications and training videos. Preservice programs were developed to train teachers of deafblind students (McLetchie, 1993), and teaching jobs in the field of deafblindness were available in any state. Regional centers and pilot school programs resulted in a strong body of knowledge utilizing effective intervention approaches. In the 1980's a technical assistance network emerged in the form of state deafblind projects and a national technical assistance project. In the early 90's a national clearinghouse on deafblindness was funded.

Shifts in educational philosophy and policy have had implications for students who are deafblind. As students moved from self-contained pilot programs to local school districts, they were spread over larger geographic areas, and often in classrooms with heterogeneous groupings of students. As a result, there were fewer jobs available for teachers trained in deafblindness, and the quality of services suffered (Collins, 1992). In most school districts deafblindness is too low incidence to justify hiring specially trained teachers. Currently in the field of deafblindness, there is a defined population of students tracked by a state and national census, a body of knowledge and educational practices, a technical assistance network at state and national levels, an emerging paraprofessional model of service delivery in the form of deafblind interveners, but no certified teachers.

Experiences of Teachers of Students with Deafblindness

What would a teacher certified in deafblindness do? Some experienced professionals in the field of deafblindness share their stories.

A longtime classroom teacher of students with deafblindness shares her work.

The grocery manager smiles as the deafblind students locate the produce department and begin an intense tactile examination of all the fruits and vegetables. Even though he has watched my “roving classroom” working on new concepts in his store once each week for the past several years, he stops for a moment to observe the flurry of signing activity as the students select items from their shopping list and put them in the cart.

After locating “the money person,” the students are given numerous opportunities for teachable moments. This ranges from waiting in line appropriately, checking out the conveyor belt, making sure all their items are out of the shopping cart, facing the cashier, getting the concept of paying money and waiting for change.

Returning to class, they eagerly locate their individual calendar systems (utilizing a variety of concrete objects, photographs, tactile symbols, large print or Braille) and realize that their next activity is putting up their groceries. This “learning by doing” teaches classification concepts (e.g., refrigerated items and cabinet items are stored differently). Finally, during their cooking activity, they enjoy the end result of their labors that day.

An itinerant vision teacher describes her role teaching a student with deafblindness.

Just as I did on each visit three days a week, I came into the special education classroom and plopped down on the floor with my “bag of tricks” to work with Kayla. Her intervener stayed nearby and talked to me about the latest ear problems she’d been having. Kayla was profoundly deaf, and had cortical visual impairment. She was one of the first students in Texas to have an intervener trained by the Texas Deafblind Project. I unfolded my black and white quilt to the black side, sat down on it, removed some brightly colored and shiny metallic toys from my bag, and placed them on the quilt. Kayla glanced at my arrangement out of the corner of her eye, and walked over. While we played and explored together, I encouraged her to maintain eye contact with objects, and to use her hands and eyes together.

After playing on the floor, it was time to go to the restroom. The intervener showed me her toileting chart on which she recorded successful use of the potty and incidents of soiled diapers. We discussed ways Kayla could increase her participation in this routine activity by being more active in

pulling up her elastic-waist shorts, turning the water faucet off as well as on, and improving her frequency of actually hitting the waste can when she threw away the paper towel.

Later the music therapist came to lead a music activity with the whole class. Kayla joined the semi-circle, and her intervener sat behind her. I sat nearby. The music therapist used Meyer-Johnson picture symbols to offer students choices of which instrument to play, or which song would be sung next. I had previously had conversations with the music therapist about using real objects, such as the actual instruments, for choice making. While she did eventually incorporate offering a basket with instruments in it for Kayla to choose from, I never succeeded in convincing her to make a choice board with real objects on a contrasting background with space between each. We enjoyed music anyway. While music was still in session, I quietly left the room to go to my next school.

An outreach deafblind consultant tells us his story of a student with deafblindness.

In my experience, there are one or two kids we take a special interest in, who absolutely hook us early in our lives working with deafblind students. “Tiny” was that student for me. I found it incredible how quickly he learned. I spent hours talking with my team members about the details of his communication system, or how we might teach him a concept we had encountered that day. I taught Tiny for three years at the Texas School for the Blind and Visually Impaired (TSBVI). Tiny returned home that next year, and I lost touch with him.

Fast forward six years and I was working as an educational consultant for the Texas Deafblind Project at TSBVI. I got a referral to visit Tiny and was excited at the chance to see him again, but also really nervous. I hadn’t seen him in a long time. Would he remember me? How would his life have changed? It wasn’t good. He had become very aggressive, and spent most of his days sitting on a couch in the classroom. His mother had moved to a new school district after he left TSBVI. Then he was separated from her, moving into a group home. He had gotten “lost in the system.” His team at school was trying everything they knew. A teacher of students with visual impairments and a teacher of students with hearing impairments were both providing services, but they didn’t know how to meet his needs. He was after all, uniquely deafblind, and they didn’t have that expertise.

Tiny remembered me and we immediately fell back into the bond that we had when he was my student. At one point we were playing on some drums in the music room. I realized there were a bunch of Tiny's teachers around us watching. Tiny's teachers were amazed; they had never seen him communicate so clearly or be so interactive before. I had so many mixed emotions after my visit. I was very angry and sad that Tiny's world had changed and that so much time had been lost. On the other hand, I had an incredible sense of joy at being reconnected with him, seeing how invested his teams at school and home were, and how eager they were for Tiny to do well. They couldn't wait to get started now that they had some ideas to work with.

An rehabilitation counselor for adults tells her story.

It begins with a connection. That's the story I have heard over and over again when I talk to professionals in this patchwork quilt of a field that we call deafblindness. Many people believe it's the connection of the child to the greater world around her, the bridge to communication with another person, and often that may be true. Yet the other part of connection that is thematic in these accounts of entering the field of deafblindness is the light that comes on for the teacher when he or she connects with a person who is deafblind.

My connection came in meeting a supported employment client, a young woman with congenital rubella syndrome (CRS) who had aged-out of the school system. As a fresh-faced college graduate, I was stunned when her parents told me that she wanted to work on the police force or as a dentist. I was warned about her "behaviors", which included screaming, signing furiously to imaginary friends, trying to examine strangers' teeth, and engaging in ritualized, repetitive movements during transitions. Our adventures in trying out several jobs, learning to communicate with each other, and making the right match was a part of my connection. It was an awakening of the desire to be in the field of deafblindness and to learn all I could from people who are deafblind.

Defining the Field

What would a teacher of students with deafblindness do? Many states have itinerant teachers of students with visual impairments and itinerant teachers of students with hearing impairments. A teacher of students with

deafblindness would fill a similar role. Individual situations would vary, and some students would have all three types of teachers serving them, while others may have only a teacher trained in deafblindness serving their educational needs. These teachers would provide both direct and consultative services. Direct instruction may include activities incorporating the following:

- vision awareness or vision efficiency activities;
- auditory awareness or training;
- activity routines which facilitate use of object symbols, tactile symbols, spoken, signed or picture symbols;
- tactile awareness training leading to tactile symbol or pre-braille activities;
- spacial awareness and exploration;
- literacy awareness including pre-braille or print activities; and
- assistive technology devices and applications.

Consultative services include supporting and participating in planning with the entire educational team, particularly the classroom teacher and intervener. Areas in which the teacher of students with deafblindness will have particular expertise are:

- assessment and evaluation of sensory and communication skills;
- creating, providing and supporting the use of materials appropriate for the student's sensory needs;
- information and support of communication systems;
- supporting the use of assistive technology;
- collaborating on accommodations and modifications of instructional materials and activities to meet the students sensory needs; and
- developing meaningful educational activities.

In some areas, sufficient numbers of students may exist to form a special class taught by a teacher certified in deafblindness. Such a class would have the advantage of infusing appropriate communication modes into all activities, and modifications for students' sensory needs would be present throughout the day. Education in a special environment would enable students to develop trusting relationships with capable communicators including adults and peers. This classroom teacher would have the opportunity to fully know their deafblind students and understand their needs and abilities. Educational approaches would be individualized for

each student. Both academic and Expanded Core Curriculum areas would be addressed by the teacher with the support of interveners.

The Future of Services for Students with Deafblindness

We believe the time has come to advocate for teacher certification in deafblindness at the national level. With a national teacher certification in deafblindness, many states would follow the lead and recognize or require teachers certified in deafblindness as vital educational team members serving students. It is the right of students with deafblindness to receive appropriate educational services in an appropriate setting, utilizing appropriate communication modes, individualized to meet their unique sensory needs (Davidson, Miller and Collins, 1993).

References

- Collins, M.T. (1993). Educational services: Presentation. Proceedings of the National Symposium on Children and Youth Who Are Deaf-Blind (pp. 165-178). Monmouth. OR: Teaching Resources Center, Western Oregon University.
- Davidson, R.C., Miller, H., & Collins, M.T. (undated). Educational programming for individuals with deaf-blindness. Reston, VA: Division on Visual Impairment/Council for Exceptional Children. DVH Quarterly, 38, summer 1993.
- McInnes, J.M. (1993). Educational services: Reaction. Proceedings of the National Symposium on Children and Youth Who Are Deaf-Blind (pp. 179-186). Monmouth. OR: Teaching Resources Center, Western Oregon University.
- McLetchie, B.A.B. (1993). Personnel Preparation: Presentation.. Proceedings of the National Symposium on Children and Youth Who Are Deaf-Blind (pp. 180-196). Monmouth. OR: Teaching Resources Center, Western Oregon University.

Purpose, Satisfaction and Joy in the Lives of Students with Deafblindness and the People who Care

By David Wiley, Texas Deafblind Project, TSBVI Outreach

Abstract: The author discusses services for individuals with deafblindness and talks about the importance of joy, satisfaction and purpose in education as well as life.

Keywords: deafblind, deafblind education, quality of life, fun for individuals with deafblindness

Editor's note: In Austin on February 12-14, the Texas Deafblind Project sponsored the 2009 Texas Symposium on Deafblindness. This event included 31 presentations on a variety of issues related to deafblindness, and was attended by over 300 participants, including family members and professional from across Texas and around the nation. The theme of the 2009 symposium was "Purpose, Satisfaction, and Joy in the Lives of Students with Deafblindness and the People who Care." I made these remarks to introduce the theme before the opening session.

The theme for our conference this year is "Purpose, Satisfaction, and Joy in the Lives of Students with Deafblindness and the People who Care." That is a rather long sentence, and in the center of it we find the phrase, "joy in the lives of students with deafblindness." How often do you come to a conference about education, and find that the theme is joy? What were we thinking?

In August of 2003 I had the opportunity to attend the Deafblind International Conference in Toronto, Ontario. Deafblind International, or Dbl, as the name suggests, is a worldwide association promoting services and support for people with deafblindness. The organization sponsors a conference every four years in a location somewhere around the globe. This past one, in 2007, was in Perth, Western Australia. The next one is scheduled for 2011 in Dehli, India. So the locations are typically too far for me to travel. But five years ago the conference came to North America, Toronto, so it was more accessible. I went and had the experience of a lifetime, learning about deafblind services from people who live all around the world—different cultures with different perspectives. Linda Mamer, tomorrow's keynote speaker, as chairperson of the DBI Scientific Committee that year, was responsible for the program of speakers I got to hear at that event.

What stuck me on the very first day, at the opening plenary session, was how people from other cultures, with different perspectives, spoke in different terms than I was used to in the conferences I have attended here in the USA. The theme for the opening panel was “Celebrating Communication Around the World” and one of the speakers was Sheela Sinha, from the Helen Keller Institute for Deaf and Deafblind in Mumbai, India.

She started by saying, and I took these quotes from the conference proceedings:

“As we all know, we are here today to rejoice in our common will to give each child ‘the right to communicate to his fellow beings’ and to celebrate what we have achieved in this direction till now.”

Rejoice? I knew immediately that this was striking a different tone than most conference presentations I had been to or scientific papers I had read. Rejoice!

As she started describing communication strategies used at her school, she said:

“Using ‘Total Communication Approach’ where one uses all possible modes of communication, varying from basic movements, cues and gestures to pictures, objects, signs, intonation pattern and even speech to some extent, we try to help each child maximize his/her ability to communicate in a manner which is not only effective but enjoyable too.”

Rejoice. Enjoyable. She was using terms related to joy. Then we watched some video of her students, which she described in this way:

“Communication is also ‘having fun together’—fun which we can have only if we leave behind our ‘adult wisdom’ and enter the child’s world as a comrade to discover what he enjoys and to be a part of that joyful experience... Communication is ‘the joy of sharing too—sharing little pleasures of childhood, sharing the dreams and thoughts of youth’.”

And she concluded her remarks by saying:

“Lastly I would like to mention that whether the topic of conversation in these clippings was as simple as sharing a few candies, or a more complicated issue like marriage and friendship, it evoked joy in both the

partners. And that according to me is the essence of communication. So let us all strive together to spread the message of 'joy in communication' around the world, as joyful communication is the very life-blood of all human interaction."

This was like nothing I had heard at a conference before, and it has stayed with me to this day—this emphasis on joy. I was used to the good old American emphasis on competence, independence, skill acquisition: “the student will respond accurately 80% of the time with minimal prompts.” Shouldn’t we also be thinking about joy?

I contrast the views on joy in that presentation with those expressed to me by a teacher on a phone call I had received a couple of years earlier. She called me asking for advice on a student who was exhibiting some challenging behaviors. She described the problem like this. The behavior most often occurs when the bus arrives in the morning to bring the student to school. The student usually refuses to get on the bus, and the behavior escalates as the bus driver and her parents try to make her get onboard. Many days she doesn’t make it to school, and if she gets on the bus, the behavior continues until she gets to school, and often on into the day. I asked if it happened every day, and the teacher’s response was, and I’m paraphrasing here to the best of my memory, “No. She is well aware of her schedule, and on days when there is something fun planned—a party, pep rally, or something like that—she gets on the bus without a problem. On those days we don’t have any problems at all. It only happens on days when there aren’t any plans to do something she thinks is fun.”

I explained that these situations are complicated, and over the phone it is hard to get all the information. So typically I don’t give advice until I’ve had the chance to visit, observe, and learn more about it; however, one thing kind of jumps out at me. What would happen if she has something fun to look forward to every day?

There was a long pause, after which the teacher replied, “We can’t do something fun every day. This is school!” She pretty quickly ended the conversation, and I suggested she get back in touch and request a visit if the team wanted to follow up, but I never heard back from her. She was no doubt convinced that someone with such a dumb idea had nothing to offer in improving the situation. So I never knew how this turned out, but still I

wonder why it is unreasonable to suggest that we can find a way for a student to experience joy every day. We should be thinking about joy.

In planning this symposium, we looked at the proceedings from the 2007 Dbl Conference in Perth. There was a keynote presentation called “Happiness as the Key to Success...” by Paul Hart from an organization called Sense-Scotland. We tried to get Paul to come and talk to you on this topic today, but the schedule didn’t work out. Among the things that stood out to me from the transcript of that presentation was a reference to a list of 12 steps to help your mental wellbeing, put out by the Mental Health Foundation there in the UK. Well, I googled this list, and found it in many places on the Internet, encouraging the people of Britain to have an outlook that fosters good mental health. So I copied the list, and I’m borrowing Paul’s idea to use it when discussing students with deafblindness. Keep in mind, this is not a list for people with deafblindness, or disabilities, or mental illness, or any other specific situation. It is a list for everyone of things to improve one’s outlook and well-being, avoid depression, and I suppose find happiness and joy.

This is the list. Doctors recommend 12 steps that can help protect your mental well-being:

- Keep physically active
- Eat well
- Drink in moderation
- Value yourself and others
- Talk about your feelings
- Keep in touch with friends and loved ones
- Care for others
- Get involved and make a contribution
- Learn new skills
- Do something creative
- Take a break
- Ask for help

Consider which items on this list may present barriers for students and adults who are deafblind. Which ones might people who are deafblind find few or no opportunities to accomplish? Something like keeping physically active, which can be so simple as typical children run and play, often

requires planning and support throughout the life of a person who is deafblind. Communication issues may form barriers to sharing feelings and keeping in touch. Individuals with deafblindness may not have as many opportunities to make a contribution as people typically do. Even something as ordinary as taking a break becomes complicated when a person must continuously be working hard to gather basic information from the environment, and processing the implications of the fragmented information that does come through.

It also stands out that this list of things leading toward happiness or joy doesn't really include playing or partying. Valuing yourself and others. Caring for others. Making a contribution. Learning new skills. Doing something creative. These things that lead us toward happiness involve gaining satisfaction from having a purpose you value. Purpose, satisfaction, and joy, the elements of our theme, go hand-in-hand. They involve motivation—tapping into personally rewarding things our students can anticipate and look forward to. This is something we can do every day in school. Helen Keller said, "Many persons have the wrong idea of what constitutes true happiness. It is not attained through self gratification but through fidelity to a worthy purpose." We talk a lot about results and outcomes these days. What better post-school outcome could we have for our students than preparing them for a life in which they can find purpose, satisfaction, and joy.

In the fall issue of *TX SenseAbilities* we ran the story of Katy, a teenager from Copperas Cove with deafblindness resulting from CHARGE Syndrome. Katy's intervener at school had very long hair. Upon having it cut she donated her hair to Locks of Love, an organization that uses donated hair to make wigs and hairpieces for disadvantaged children who have lost their hair due to disease or medical treatments, such as chemotherapy. When Katy heard about this, she wanted to donate hair as well. As it turns out, you must donate at least twelve inches, and Katy's hair wasn't near long enough. So she only wanted her bangs cut from that point forward. Every time she went for a trim they would measure her ponytail to see if it had gotten long enough to donate. After three years she made her contribution, and immediately set out to do it again. Now, six years after she learned about Locks of Love from her intervener, she has been able to make two contributions, and is planning to do it again. When asked why, she signs, "To help sick girls get wigs." This is purpose, satisfaction and joy.

Mary Scott, our colleague at the Region 3 Education Service Center, recently sent out a link to an article in the Victoria paper about a teenager who was working to become an Eagle Scout. He also has CHARGE Syndrome. The story was about a project he had organized to collect tattered and worn out American flags, and have a dignified retirement ceremony, in which they are respectfully destroyed as specified in the U.S. flag code. The paper reported him saying through his interpreter, “We’re supposed to honor and respect the flag of the United States of America. We respect the old and worn flags by burning them with dignity.” Community service can lead to purpose, satisfaction, and joy.

At this symposium in past years we have celebrated many deafblind individuals who have found opportunities to experience purpose, satisfaction, and joy in their everyday lives: Jaceson, who joined his grandfather in volunteering to visit and lead activities for seniors in a veteran’s facility; Chris, who has a job at a factory to makes custom prosthetics; Christian, who started his own business; and LeeAnn, who is trying to single-handedly bring a touch of marine biology to the west Texas high plains in Amarillo with her Shark Center. There are many others.

Jenny Lace, my colleague here with the Texas Deafblind Project likes to remind us to teach students about generosity. This basic building block of a purposeful life is described in Larry Bendtro and Martin Brokenleg’s article describing “the Circle of Courage”—Native American principles for nurturing children.

The four directions of the Circle portray the four developmental needs of children: belonging, mastery, independence, and generosity. The various Native tribes do have many differences, but these four principals can be found in the traditional writings and practices of indigenous peoples throughout North America.

In addition to the students, our theme refers to purpose, satisfaction and joy in the lives of the people who care—family members, teachers, caregivers, and friends. In his article, “10 Things You Can Do to Support A Person With Difficult Behaviors,” David Pitonyak includes as number 4: develop a support plan for the person’s supporters. In his article he said, “Just as it is simplistic to treat a person’s behavior without understanding something about the life the person lives, it is simplistic to develop a support plan

without considering the needs of the person's supporters." He suggests that caregivers develop support plans for each other. We all have the same needs for purpose, satisfaction, and joy.

So as we plan for our children and our students, we need to plan for ourselves as well. In his *Toolbox for Change: Reclaiming Purpose, Joy, and Commitment in the Helping Profession* David writes, "So take the time to celebrate together. I believe that a great many of our struggles would be easier to resolve if we would just take the time for joy."

There will be a lot to learn here in the next few days. You will find strategies, methods, techniques, and information. You may find some motivation and inspiration as well. As you hear new ideas, we invite you to apply them to our theme: Purpose, Satisfaction, and Joy in the Lives of Students with Deafblindness and the People Who Care. So let me leave you again with Sheela Sinha's words that started my experience in Toronto five years ago:

As we all know, we are here today to rejoice in our common will to give each child 'the right to communicate to his fellow beings' and to celebrate what we have achieved in this direction till now.

References

- Bendtro, L. & Brokenleg, M. (2002). "The Circle of Courage: Children as Sacred Beings" in *Schools With Spirit, Nurturing the Inner Lives of Children and Teachers*, edited by Linda Lantieri. Boston: Beacon Press.
- Bozick, T. (2008). "Scouts honor flags in fiery retirement." *Victoria Advocate*, November 15, 2008.
- Hart, P. (2007). "Happiness as the Key to Success – But What is Success? Health, Wealth or Wisdom?" *Proceedings of the 14th Deafblind International World Conference*. [CD ROM]. Burswood, Western Australia: Senses Foundation.
- Pitonyak, D. (2005). *10 Things You Can Do to Support A Person With Difficult Behaviors*. Blacksburg, VA: imagine (www.dimage.com).
- Pitonyak, D. (2007). *Toolbox for Change: Reclaiming Purpose, Joy, and Commitment in the Helping Profession*. Blacksburg, VA: imagine.

- Siekierke, B. (2008). "Katy Bids Another Ponytail Farewell" TX SenseAbilities 2(4). Fall, 2008.
- Sinha, S. (2003). "Celebrating Communication Around the World." *13th DbI World Conference on Deafblindness 2003 conference proceedings*. [CD-ROM]. Brandtford, Ontario: Canadian Deafblind and Rubella Association.
- Wiley, D. & Moss, K. (2004). "Where is the Joy in This IEP." *SEE/HEAR* 9(4). Fall, 2004.

Successful Transitions Between Programs

By Maurice Belote, CDBS Project Coordinator

This Fact Sheet reprinted with permission from *reSources*, Fall 2004, (Vol. 11, No. 4) California Deaf-Blind Services, <www.sfsu.edu/~cadbs>

Abstract: The author shares strategies to facilitate successful transitions from one program to another.

Key Words: Effective Practices, transition, deafblind, collaboration

Editor's note: California Deaf-Blind Services, has a number of Fact Sheets available in several languages on their website at <www.sfsu.edu/~cadbs/Facts.html>.

For educators, transitions that students make from program to program happen so frequently that we can forget the significance of these events to children and their families. For families, transitions can be a time of uncertainty, fear, and doubt about new programs; this is particularly true of transitions from home-based early intervention programs to center-based preschools and from pre-school to elementary school. The following represents some strategies that might help students, their families and educational teams during transitions between educational programs.

Choose a specific date for the transition and stick to it. This may seem like a minor point, but consider the following example. A student is slated to move to a new program on a specific date, but two weeks before the date, a vacancy opens in the program so the student is unexpectedly moved two weeks early. This sudden and unexpected move might get in the way of all

the planned transition activities on the part of both the school staff and the student's family. In addition, the student might not have the opportunity for the farewells with teachers and classmates. We must remember that without a well-planned transition to a new program—such as the case in which a student's bus simply drops him or her off at a new school one morning—the lack of access to information and the lack of control are sure to create a level of passivity in the student that will hinder his or her success in the future.

Collect all personal materials—including communication systems—and make sure they move with the student. Some equipment the student uses may not be able to be moved to a new program; there may be issues of ownership among educational agencies. But materials such as a communication system specifically developed for a student must move with the student if we are to give the student every chance to succeed in her or his new setting. It's surprising how often personal belongings of students get left behind during moves—pictures, books, puzzles, CDs, etc.

Provide the new program with as much useful documentation as possible. The new staff is sure to appreciate any documentation that might assist them to better meet the needs of the student who is new to their program. This might include a personal communication dictionary, a Personal Passport (visit the Call Center at <http://callcentre.education.ed.ac.uk> for information), videotape footage of the student in various settings, etc. This information is likely to be much more useful than written reports taken from the child's school records.

Familiarize the student with the new setting. If possible, allow the student a few opportunities to visit the new program prior to the transition. Of course these opportunities are essential when a student needs support and time to orient to the new environment, learn new routes, etc., often under the direction of an Orientation and Mobility Specialist. All students, however, are likely to benefit from these early visits; the visits are sure to take away much of the mystery and fear of the pending move.

Establish time for the sending and receiving teams to meet. Whenever possible, it makes sense to provide two opportunities for the two teams to meet. The first meeting should occur prior to the move so that the sending program can provide as much information about the student to the receiving team, especially information that might not be in the child's file, e.g.,

personal communication dictionary, home-to-school log, etc. The second opportunity to meet should occur after the student has been in the new program for a short period of time. This is when the most questions arise—once new program staff has a chance to get to know the student and his or her idiosyncrasies.

Consistency of DIS staff and/or one-on-one assistant. Whether a student is moving to a new school or merely changing rooms within a school, it might be beneficial if the student's DIS staff, e.g., vision specialist, physical therapist, orientation and mobility specialist, etc. can follow the child to her or his new program. This will lessen the magnitude of the change; the location and classroom teacher might be new, for example, but at least some of the other familiar staff remains constant and this may make for a much smoother transition. We want to capitalize on the variables we have some control over, such as itinerants and one-on-one aides, since we have much less control over other variables such as buildings and teachers' classroom assignments.

Set clear and high expectations from the start. Resist the temptation to wait a few days to get to know new students before clear and high expectations are identified and set. Days turn into weeks and weeks into months, and suddenly the realization hits that time truly is fleeting.

Change is stressful. A child may exhibit many reactions to a change as monumental as a transition to a new program, especially if the child had been in the former program for a long time. Some students may be on their best behavior and provide staff with what's been called a honeymoon period, while others might be at their most obstinate and grumpiest worst. Whether a child exhibits some of these reactions or seems to show no reaction at all to the move, we have to remember that the stress of change will manifest itself one way or another—that's for sure.

Change is good. Change, as stressful and disruptive as it can be, can also be a positive force in many ways. It is said that when one door closes, another opens, and this open door can be the pathway to new experiences, relationships, and possibilities. The student who has been in a comfortable special day class preschool for three years might discover a world rich with new activities and language models in an inclusive kindergarten. The student who has been in a comfortable high school class might discover the

excitement of job training and community recreation found in a transition program.

Schedule visits to the former program. Whenever possible, it is a great idea to have the student visit his or her former program. Among students in general education, think about how often they come back to visit former programs and teachers to relish in their own growth and maturation and to re-live the memories and good feelings of days gone by. For students who are deaf-blind, they may not have any idea what happens to former teachers, staff members and classmates when they transition to a new program. It may seem, to the child who is deaf-blind, that these former friends and teachers just vanished off of the end of the earth. In addition, the student who is deaf-blind has probably developed closer relationships with program staff than other students might, and it will help the student deal with feelings of loss if he or she can visit occasionally and keep these special relationships alive.

Editor's Note: When I went to the website listed in the article for additional information about Personal Passports, it stated that most of the information had been moved to this website:

<www.communicationpassports.org.uk/Home>.

Together We Do More

By Barbara J. Madrigal, Assistant Commissioner, Division for Blind Services

Abstract: This article discusses DARS' five-year anniversary and the accomplishments and opportunities from consolidation.

Key Words: blind, visually impaired, Division for Blind Services (DBS), Department of Assistive and Rehabilitative Services (DARS), House Bill 2292, consolidation, collaboration, Health and Human Services (HHSC), Early Childhood Intervention (ECI).

On March 1, 2004, a new state health and human services agency was born in Texas. It was created by merging four agencies into one, as mandated by the state legislature in 2002. That new agency is now striving to provide world-class services to more consumers as it advances with increasing dynamism into the future. Of course, I'm talking about the Department of Assistive and Rehabilitative Services.

To refresh your memory, DARS was created by House Bill 2292, which consolidated 12 state agencies into five departments under the Health and Human Services Commission (HHSC). In March DARS celebrated five years of partnership with Texans with disabilities and their families. Whether you've known us since the legacy days of the Texas Commission for the Blind or you have just been introduced, we hope that your encounters with us have made a difference in your life.

... over the past five years, as we have developed new partnerships and discovered new resources, we have found that being a part of something larger brings many opportunities for mutual support and collaboration.

For the Division for Blind Services, finding our niche within DARS and within the larger HHSC umbrella was an adjustment. And, as all of you are no doubt aware, adjusting to change is not always easy! But

over the past five years, as we have developed new partnerships and discovered new resources, we have found that being a part of something larger brings many opportunities for mutual support and collaboration. The theme of DARS anniversary celebration is "Together We Do More." I would like to share with you ways that we have done more, things that you might not observe when you interact with DBS staff, but which contribute to an effective and responsive service delivery team.

The starting point for our accomplishments is a culture of excellence that is focused on our mission to partner with our consumers to support their efforts to participate fully in society. The DARS culture encourages management practices based on open communication, mutual respect, and meaningful rewards for top-performing employees. We believe that a work environment characterized by respect, trust, and open communication will create an environment in which employees provide world class services to our consumers. Based on my visits in offices across the state, I'd say we've created a work environment that brings out the best in all of us.

There are several DARS initiatives that focus on improving the skills and abilities of the staff members in our organization. It is no secret that an effective organization requires top-notch skills of all their employees, and our organizational programs provide learning and development opportunities for management, mid-level and support staff.

For several years, DBS has invested in a FUTURES Program. FUTURES is a systematic approach to career development that provides opportunities for staff to gain leadership experience, develop specialized skills and gain a better understanding of other roles and departments in DBS and the DARS network. The purpose of this program is to develop a well-trained staff that will ensure a strong and effective partnership with consumers and other stakeholders. It produces and maintains a supply of qualified, competent workers throughout the organization who are really, willing and qualified to step into leadership positions.

DBS has always emphasized the partnership of the counselors and specialists with their professional support staff. And in April, DBS rolled out the first charter class of The Academy, a comprehensive training program for DBS support staff. The Academy offers this career development tool that will develop their leadership qualities, enhance their knowledge and job performance, and provide an expanded view of the agency.

So, in addition to our culture, what has been achieved in the last five years? Listing every accomplishment would take all day, so let me just touch on the highlights.

Two years ago, the Blind Children's Program began a process that would have resulted in a waiting list for services. As a result of compelling and passionate input from families, consumer groups and stakeholders, we received guidance and support from the Center for Consumer and External Affairs, an entity that was created during DARS consolidation, as well as DARS management and HHSC in seeking and obtaining emergency funding for ten new Children's Specialist positions. Many of you are working with our new Specialists and have provided invaluable assistance as they learn their new jobs.

Two of the agencies merged during the DARS consolidation were agencies that work with children with disabilities. We're talking about the DBS Blind Children's Program and Early Childhood Intervention State Office. Because blind children from ages 0 – 3 receive services from both the Children's Program and a local Early Childhood Intervention program, these two agencies have a long history of working together. Now that these two agencies are located within the same organizational structure, there are increased opportunities for collaboration and increased resources for developing mutually supportive services for our shared consumers.

During our collaboration meetings, we shared information about our respective programs and have provided avenues for cross-training opportunities. We also conducted a field survey to identify areas that need attention in our continuing collaboration. As a result of this partnership, we developed a state-wide videoconference to share collaboration strategies with our programs in the field.

In addition, Early Childhood Intervention state office and the Blind Children's Program are working together on a statewide conference for professionals and parents. This conference, "Together We Can," is on June 25-26 at the Embassy Suites Hotel and Conference Center in San Marcos, Texas. Experts in the field of blindness and vision loss will be presenting, including Tanni Anthony, Sandra Fox, Susan LaVenture, Ginny Bishop, and many more.

This year, while we celebrate DARS 5th birthday, we also commit to keeping DARS moving forward by providing Excellent Service to Every Consumer, Every Time. It's time to begin the next five years of DARS success!

No Place Like Texas!

By William "Bill" Daugherty, Superintendent,
Texas School for the Blind and Visually Impaired

Abstract: Superintendent Daugherty discusses the legislative session and legislative advocacy.

Key Words: blindness, visual impairment, deafblindness, Texas, legislation, advocacy, Texas School for the Blind and Visually Impaired, Judith Zaffirini, Florence Shapiro, Robert Duncan, Royce West, Scott Hochburg, Elliott Naishtat

This legislative session has pointed out what a great state we live in. I know that we sometimes take a perverse pleasure in complaining about Texas politics but, as a returning Texas expatriate, I've been really pleased at what I've seen in the hearings so far. The Texas School for the Blind and Visually Impaired has fared well, so it is only natural that I'd be upbeat about it all, but it is the rest of the story that has made the biggest impression on me and makes me proud to be a Texan.

First of all, there is some fabulous blindness and visual impairment legislative advocacy going on, and it has made a real difference. Texas is so lucky to have knowledgeable people who are willing to volunteer their time and to put their reputations on the line in public hearings. The second part of the equation is that Texas is lucky to have political leadership that understands our issues and is willing to put their reputations on the line to sponsor or back our field's most important issues. Just to name a few: Senators Zaffirini, Shapiro, Duncan and West, and Representatives Hochburg and Naishtat. In watching these and many of their colleagues work, it is amazing to see how much information they can keep up with. Blindness and Visual Impairment is such a relatively small issue within the larger context of state government, but somehow we manage to get treated as if we mattered.

What seems special about Blindness, Visual Impairment and Deafblindness in Texas is the network of professionals, parents, consumers, agencies and organizations that seems to pull together more so than in many other states.

What seems special about Blindness, Visual Impairment and Deafblindness in Texas is the network of professionals, parents, consumers, agencies and organizations that seems to pull together more so than in many other states. This didn't happen by accident or on its own—it's been built by many hands over many years. As a person who has had opportunity to wander around the field (blindness, not pasture) a bit, this view of Texas is widely shared.

What I'm trying to say here is only partially a "congratulations to us" letter. The main message is that we have to continue to nurture and grow this network. Some of the foundational people will be taking less active roles in the future, although most of them are not "retiring" by nature. Our parent advocacy groups are coming on strong and there is a very promising new generation of educators and adult service professionals now entering the field. The perennial issues of full access to education, employment and community integration will not fade during our lifetimes, but there is no place better to be than Texas to shape the future through our combined efforts.

All Blind Children of Texas has Funding for You

By Gloria Bennett, Coordinator of ABCTX

Abstract: All Blind Children of Texas (ABCTX) can provide funds to VI professionals in Texas for special projects outside of school.

*Key Words: News & Views, blind visually impaired, funding, special projects
A cooking day, an outing to the zoo, a ride on a train, a meet-and-greet with parents and siblings... Wouldn't you love to design a small program for your students—and have the budget to make it happen?*

All Blind Children of Texas (ABCTX) is a nonprofit organization that will help your dreams for your students come true. ABCTX has funds to support programs that you want to provide for your blind and visually impaired students outside of school. The board of ABCTX is aware of the dedication and knowledge that Texas VI professionals have in relation to their students. We want you to be able to create opportunities for your students to experience events and activities that will deepen their knowledge of the world and enhance their lives, without having to pay out of your pocket. We have funded cooking programs, travel on trains and light rail, camping and camps, arts & crafts, fine arts and many, many more. The board encourages programs that include sighted peers.

Our application identifies these categories. Your program can address one or more of them.

- Social and recreational activities
- Fine arts activities
- Summer enrichment
- Youth camp or class scholarship
- Parent education and support
- Assistive technology or low vision devices (not covered by DARS or some other agency)
- Tutoring and mentoring

What do we ask in return? We ask that you ...

- keep records of your expenses
- return any amount you don't spend
- send us an after-program report within 2 weeks of your program

- We also ask that you keep your requests to the exact amount that you need so that we can fund as many projects for as many children as possible from our limited resources.

The mission of All Blind Children of Texas is to advance the optimal physical, mental, emotional, and social development of blind and visually impaired children. We know that is your mission as well!

You can find the program application on our website at <www.abctx.org> where you can download, fill out and email it. If you have any questions, call Gloria Bennett at (512) 206-9234.

If you need funds for a summer program, please make sure your application is received by May 22, 2009, to give the Board of Directors of All Blind Children of Texas time to consider your application.

AFB Teen Video Series: On Your Mark, Get Set...Go to Work

Excerpted from AFB Career Connect Website

Abstract: This article describes new videos about teen employment

Key Words: blind, visually impaired, vision loss, employment, teens, American Foundation for the Blind (AFB), Career Connect

Who doesn't like a good adventure? Check out this series of short videos co-produced by CareerConnect and Braille Institute that are targeted at teens with vision loss. The first video in the series, "On Your Mark, Get Set...Go to Work," addresses the importance of first jobs and finding employment as a young adult. Interviews and footage of job sites where young adults are working include schools, offices, a call center, a lifeguard station, a restaurant, and a pet grooming center; in addition, there's footage of a young woman working as a sign holder. Find out how these young adults found their jobs and what they think of working. The video includes detailed narration that brings the message of the video to anyone who cannot see the footage. In addition, a verbatim transcript with descriptions of the visual content is available.

<http://www.afb.org/Section.asp?SectionID=7&TopicID=268&DocumentID=3426>

In the next video in the series, meet Aaron, a forward-thinking, awesome teen determined to get a job. Have fun and learn how to navigate common obstacles as you go with him on his adventures in employment!
www.afb.org/Section.asp?SectionID=7&TopicID=268&SubTopicID=156

In the newest video co-produced by CareerConnect and Braille Institute, learn what employers have to say about hiring teens with vision loss:
<http://www.afb.org/Section.asp?SectionID=7&TopicID=268&DocumentID=4471>

And don't miss this page: It's been hard not to notice the number of blind or visually impaired teens and young adults who have caught the attention of the media because of their awe-inspiring accomplishments in sports and other arenas. We were impressed enough to want to share them with you!
www.afb.org/Section.asp?SectionID=7&TopicID=268&DocumentID=4371

Audio Description by CaptionMax.com

Excerpts from www.captionmax.com

Abstract: This article provides information on video description and described programs that are now available.

Key Words: blind, visually impaired, DVI, audio description

Do you realize that there are lots of audio described programs available on television? Most PBS programs are described, including children's programs, documentaries, and other series. Activating audio description (AD) will make those programs easier for blind students to follow and enjoy.

CaptionMax is one of just a few companies that provide audio description (sometimes called video description) services for the blind. AD allows blind and visually impaired people to access a program's visual content. Our professional CaptionMax writers and describers bring to life the key visual images, body language and visual expressions needed to understand a program's content.

Skilled writers watch the program and produce a rough script describing the program's action, settings, on-screen titles, and characters' body language. The writers determine which visual elements are essential to the program and produce a script that can be easily read without interfering with existing

audio. Once the script is fine-tuned for style, clarity, and continuity, the writers, who are also professionally trained by voice coaches, record the narrative. These newly recorded descriptions are mixed with the original program audio and laid back to the master, which is placed in the Second Audio Program (SAP) channel of a program. A viewer at home won't hear the description unless the SAP channel is turned on.

Once the SAP is activated, you will hear the alternate audio if a particular television program includes this information and the station sends it to your TV. If a program includes a second language rather than audio description, you will need to turn off the SAP to hear the original audio.

There is no current FCC requirement to describe television shows; most of the shows currently described are educational programs that receive federal funding for the costs of creating audio description.

Turning on audio description can be a little trickier than turning on closed captions. The SAP channel is hidden in the audio of a described program, so you will need a tuner that can decode the SAP channel. This tuner can be part of your TV, VCR, or even your cable box. If your television set is not a stereo set, then your VCR or cable box must have a tuner with SAP decode capability, and the television feed must run through that box before going into the TV. Mono TVs will not be able to provide this feature on their own.

If you're not sure how to activate AD on your television, try our handy web guide: <http://www.captionmax.com/en/viewer-info/for-teachers/AD/TV>. Follow the menu links for additional hints on activating AD on cable, VCRs, and DVDs.

Check here for a list of television series that we describe: www.captionmax.com/en/viewer-info/shows-we-describe. In addition to series, we also do lots of documentaries and other programs.

CaptionMax is the largest producer of audio description services for non-broadcast educational media. Here's a list of the programs we've described so far, and we're adding to it every week:

www.captionmax.com/en/captionmax-services/webcast-captioning/product-list.

One of the coolest features of our educational DVDs is that the menus are auto-described. That means all you have to do is pop in the DVD, and you'll

start hearing the menu options. You can control everything with the forward and enter buttons. Another of my favorite features is expanded description, in which the video freezes to allow more detailed description of an object or scene.

“How do I get these programs?” you may ask. If you’re a parent or student, visit our page at the Described Captioned Media Program (DCMP) website: <www.dcmp.org/Categories/categories2.aspx?C=CAPTIONMAX>. Once you register on the DCMP site, you can obtain via download or DVD (including free shipping) any of our programs. There are just two requirements to be eligible for the service: 1.) You must be a parent of, teacher of, or student with a hearing or vision loss, and 2.) You must fill out a short evaluation form after use. To register visit DCMP’s registration page: <www.dcmp.org/Register.aspx>.

If you’re a teacher or librarian, we encourage you to follow the links on our website to the program distributors, where you can buy and learn about our described programs and more.

Books for You!

Excerpt from <http://tarheelreader.org/>

Abstract: This article describes a resource for free, easy-to-read, and accessible books.

Key Words: blind, visually impaired, literacy, disability, accessibility

Welcome to the Tar Heel Reader, a collection of free, easy-to-read, and accessible books on a wide range of topics. This site provides thousands of books, and each book can be speech enabled and accessed using multiple interfaces (i.e. switches, alternative keyboards, touch screens, and dedicated AAC devices). The books may be downloaded as slide shows in PowerPoint, Impress, or Flash format. The books are organized by topic, type, audience rating and language, and books are available in French, German, Hebrew, Italian, Japanese, Spanish and Swedish.

You may also write your own books using pictures from the huge collection at Flickr or pictures you upload.

Please be aware that there are books intended for teenagers who are just learning to read. You may find some books that are inappropriate for young

students. The website provides a Favorites page as a way to present your students with reading choices that you approve.

The website is a result of a collaboration between Center for Literacy and Disability Studies and the department of Computer Science.

The Texas Ramp Project: Building Freedom for the Homebound

Excerpts from The Texas Ramp Project Website

<<http://www.texasramps.org>>

In 1985, the Kiwanis Club of Richardson, TX began building access ramps for residents of the Dallas area. In the years since, this effort has grown into The Texas Ramp Project, with thousands of ramps built by a network of volunteers across the state.

Volunteers for the Texas Ramp Project say it's the most satisfying work they have ever done. If you'd like to become involved, either as an individual or if you represent a group, please contact us.

The Texas Ramp Project works with local cities, social-services organizations, and hospitals to identify clients who need a ramp. The Texas Ramp Project serves 115 counties and are located in Abilene, Amarillo, Austin, Bryan/College Station, Dallas, Denton County, El Paso, Fort Worth, Houston, Longview, Lubbock, North Central Texas, San Antonio, Texoma, and Wichita Falls. For more information, go to <<http://www.texasramps.org>>.

Paying It Forward: Sharing Your Wisdom, Sharing Your Profession

By KC Dignan PhD, Professional Preparation Coordinator, TSBVI

Abstract: This article discusses the shortage of VI professionals in Texas and recognizes those who volunteer to "Pay It Forward."

Key Words: blindness, visual impairment, Texas Fellows recruitment, education, job fairs, VI teachers, O & M specialists

It is no secret that there is a shortage of VI professionals in Texas, and the rest of the country, for that matter. Everyone wants to help. The challenge is to know how to help and when. There are many, many ways to help recruit new VI teachers and orientation and mobility specialists. One of

them is to share information about the field with new educators, and those who are considering a change.

We know a lot about recruiting VI professionals.

- We know that once you've decided that this is what you want to do, that it can take 2 years to make the change.
- We know that once certified, people will get jobs even if it looks like there are no vacancies.
- We know that VI professionals want to be good recruiters, but sometimes aren't sure what to do.
- We also know that most educators don't even know about working with children with visual impairments and what a difference they can make on the lives of their students.

That awareness-level recruiting is an important part of the process. That first contact isn't likely to change people's lives that day, but it is the most important first step.

For the past 3 years TSBVI has been attending job fairs to share information with new and existing educators. At the job fairs educators are given a Braille Activity Card to use with their students. They are also given information about working with students with visual impairments.

As the program has grown, so has the need for volunteers to help at the job fairs. This year we have even more "booth buddies" than ever.

We would like to acknowledge those who have made the commitment to "Pay It Forward" by volunteering to help at a job fair. These committed professionals have often had to take time off work to make it happen.

We thank them. If you know anyone on this list, please take a moment to thank them as well.

Joanne Murphy	Jill Brown
Elsie Rao	Dawn Adams
Colleen Davis (2 events)	Peggy Burson
Polly Goodier	Laura Hampton
Christy Householter	Sue Fowler
Diane Briggs	Scott Baltisburger
Tammy Durrett	Debbie Louder
Barbara Hanson	Cynthia Robles-Warnick

The following people expressed willingness to Pay It Forward, but were unable to schedule an event. We want to acknowledge them as well.

Irene Conlan
Cori Andrews
DJ Dean
Debby Cady

Debra Leff
James Ottaberry
Jill Gomez
Teresa Moore

Texas School for the Blind & Visually Impaired Outreach Program
Honors **Texas Fellows**

Recognizing VI Professionals in their Role as Recruiters



Texas Fellow

Terry Gaines
Terry Gaines
Diane Sheline
Brenda Jackson
Anita Pineda
Susan Butler
RosaLinda Mendez
Carolyn Rimka
Tressie Schindler
Sara Baker
Theresa Taylor
Kathy Krenek

Candidate

Cindy Harber
Monica Campbell
Monica Johnson
Lisa Gray
Alma Soliz
Julie Moyer
Carolyn Metzger
Elizabeth Meeks
Charlotte McKinney
Stacy Vance
Tammy Averitt
Julie Stanfield



For more information about becoming a Texas Fellow or working as a VI professional contact KC Dignan at kcd@tsbvi.edu

Bulletin Board

Announcements / Regional, State, and National Training and Events

Mail or email your item for the Bulletin Board to Beth Bible: TSBVI Outreach,
1100 W. 45th Street, Austin, TX 78756 or <bethbible@tsbvi.edu>
An up-to-date Statewide Staff Development Calendar is posted at
<<http://www.tsbvi.edu/Outreach/vi.htm>>

Orientation & Mobility for Students Identified with Autism

Marilyn and Jay Gense

June 23-24, 2009 — 9:00–4:00

Crowne Plaza Brookhollow Hotel, Houston, TX

Identify effective methods for teaching Orientation & Mobility (O&M) to students identified with autism. Gain skills for more accurate assessment and develop interventions to use during O&M training. Discuss strategies to enhance and facilitate a child's active exploration that will allow for learning from the environment.

Audience: Teachers of Students with Visual Impairments, O&M Specialists, Teachers of Students with Autism, Parents

Presented by the Region 4 Education Service Center. Please register at least two weeks prior to the scheduled session. Programs with fewer than 20 participants registered two weeks prior to the program date are subject to cancellation. Session ID: 359875 Contact: Karen Crone at 713-744-6324, kcrone@esc4.net or Suzy Scannell at 713-744-6315, sscannell@esc4.net

Many Hearts, Shared Dreams—One Voice

Texas Parent to Parent's 5th Annual Parent Conference

June 26-27, 2009

Omni Austin Hotel at Southpark, 4140 Governor's Row, Austin, TX

Join us at the beautiful Omni Austin Hotel at Southpark for 2 fabulous days of amazing speakers and unlimited opportunities to network with parents, selfadvocates, family members, educators, service providers, and community agencies, just to name a few! We are thrilled to offer more than 60 sessions over 2 days in addition to our amazing Teen Transition Expo and Sibling Groups. For more information, or to register online: <http://www.txp2p.org/>

Families Connecting with Families International Conference

National Association for Parents of Children with Visual Impairments (NAPVI), Junior Blind of America, and The Braille Institute are pleased to be co-sponsoring this event.

This will be an exciting time for families and professionals alike.

**Hilton Orange County/Costa Mesa Hotel
Costa Mesa, California,**

July 17-19, 2009

This conference is designed to meet many goals that support the growth and lifelong skills needed by children and youth with visual impairments. It will cover all aspects of raising and educating a child with a visual impairment. The National Family Association for Deaf-Blind (NFADB) will also provide a rich program for families of children who are deaf-blind. The conference will be important for the families of children who are deaf-blind, blind or visually impaired, or multiply disabled, and the professionals who work with them.

The activities and workshops will target families, infants and toddlers, school children, and youth to age 22 years. The conference will allow you many opportunities to meet and learn from other families and professionals.

Numerous fun activities are also planned for the children. Some of the fun activities will include the Paralympics for children 8-17 where they will be able to participate in various adaptive recreational sports activities. There will also be a children's story and theater time, a science and oceanography program, a children's art studio, Puppy Raisers and Guide Dogs, musical performers, and so much more.

For Saturday night, the conference planning committee has planned an unforgettable family outing where families will be able to mix and mingle with other families during dinner.

You may register quickly and conveniently online, or, you can download the registration form from the site and mail it to NAPVI. The instructions are on the registration site: <www.familyconnect.org/parentsitetime.asp?SectionID=91>.

For more information about the conference, please contact NAPVI at 800-562-6265.

**National Organization of Parents of Blind Children
2009 NOPBC Conference**

July 3—July 8, 2009

Detroit Marriott at the Renaissance Center Detroit, Michigan

This year the National Organization of Parents of Blind Children parent division conference will begin with a joint conference among parents, blind professionals, and rehabilitation professionals whose teaching is based on NFB philosophy. On the morning of July 3, the NOPBC will kick off jointly with NFB rehabilitation professionals in a large group presentation. Other meetings, workshops, and activities will take place throughout the weeklong conference. For the full agenda, please read the April Braille Monitor article.

During convention week children six weeks through ten years of age are invited to join in the fun and festivities of NFB Camp. NFB Camp offers more than just childcare; it is an opportunity for our blind and sighted children to meet and develop lifelong friendships. Our activity schedule is filled with games, crafts, and special performances designed to entertain, educate, and delight. Space is limited, so get your registration in early.

Pre-register now: <www.nfb.org/nfb/National_Convention.asp>. Additional information may be obtained by contacting the National Federation of the Blind at (410) 659-9314.

The 9th International CHARGE Syndrome Conference

July 24-26, 2009

Hilton Chicago/Indian Lakes Resort / Bloomingdale, Illinois

The conference will begin on Friday, July 24, 2009 at 8:30 a.m. and conclude on Sunday, July 26, at noon. There will be an informal get-together on Thursday evening. Childcare will be provided for all children that have registered for childcare during the meetings on Friday, Saturday and Sunday; interpreters and nurses will be available as needed.

Registration for the conference is available online. If you prefer a hard copy registration form, please call our office. You are urged to register early so we may plan for childcare, meeting room space, etc. Childcare can only be planned for those children on whom we have complete information.

For information or registration check the web at: www.chargesyndrome.org

CHARGE Syndrome Foundation, Inc.
Phone: (516) 684-4720 Toll Free: (800) 442-7604

HKNC National Training Team 2009 Seminar Calendar

September 20 - 25, 2009 / "IMAGINE THE POSSIBILITIES"

Expanding the Curriculum for Travelers Who Are Deaf-Blind (O&M)

Participation in this seminar is limited to Certified Orientation and Mobility Specialists (COMS), Nationally Certified Cane Instructors, agency trained mobility instructors with 5 years of experience under a certified specialist, and dog guide trainers, who are currently teaching or supervising in their field.

October 19 – 23, 2009 / "EMPLOYMENT: THE ULTIMATE GOAL"

Professional Development for Employment Training Specialists

During this seminar, the participants will utilize the Personal Futures Plan Mapping System to discover individual preferences in order to explore the most appropriate employment categories. This combined with the best practices in marketing and accommodations for the person who is deaf-blind will provide the tools to achieve the desired outcomes.

November 16 – 20, 2009 / "THE MAGIC OF TECHNOLOGY"

Adaptive Technology Training for Teaching Deaf-Blind Individuals

This seminar demonstrates the technology, the software and the methodology for teaching a wide variety of adaptive equipment to consumers who are beginners and/or advanced students in the world of technology. Vendors will demonstrate the latest state of the art technology and participants will have access to availability and funding resources.

January 11-15, 2010 / "TOUCHING LIVES"

Interpreting Techniques for the Deaf-Blind Population

Participants must be working interpreters with working skills. The seminar will allow participants to apply the knowledge and skills that are learned throughout the week to the hands-on interpreting activities. Participants will leave the seminar with a working set of skills that will empower them to work comfortably within the deaf-blind community. RID CEU and ACET credits will be available.

Training is held at the Helen Keller National Center – Sands Point, NY
Cost of Seminars: Full week: \$550. Includes lodging, meals, professional training and manual. 6-day Orientation & Mobility Seminar - \$625. Schedules are subject to change. For more information about these seminars, contact:

Doris Markham – NTT Administrative Assistant

Phone: (516)-944-8900 Ext. 233/239;

TTY: (516) 944-8637; Fax: (516) 944-7302

E-mail: ntthknc@aol.com

Information is available online at: <www.hknc.org/FieldServicesNTT.htm>.

TX SenseAbilities Published quarterly: February, May, August, and November
Available in Spanish and English on TSBVI's website at <www.tsbvi.edu>
Contributions to the newsletter can be mailed to TSBVI Outreach,
1100 West 45th Street, Austin, Texas 78756 or emailed to section editors.

If you no longer wish to receive this newsletter, please call
Beth Bible at (512) 206-9103 or email <bethbible@tsbvi.edu>

Deadlines for Submitting Articles:
December 1st for the Winter edition / March 1st for the Spring edition
June 1st for the Summer edition / September 1st for the Fall edition

PRODUCTION STAFF

David Wiley (512) 206-9219, <davidwiley@tsbvi.edu>

Beth Bible (512) 206-9103, <bethbible@tsbvi.edu>

Beth Dennis (512) 377-0578, <Beth.Dennis@dars.state.tx.us>

Jim Allan (512) 206-9315, <jimallan@tsbvi.edu>

Jean Robinson (512) 206-9418, <jeanrobinson@tsbvi.edu>

B.J. Cepeda (512) 377-0665, <Bj.cepeda@dars.state.tx.us>

SECTION EDITORS

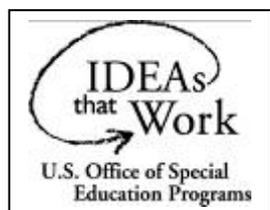
Edgenie Bellah (512) 206-9423, <edgeniebellah@tsbvi.edu>

Holly Cooper (512) 206-9217, <hollycooper@tsbvi.edu>

Stacy Shafer (512) 206-9140, <stacyshafer@tsbvi.edu>

Beth Dennis (512) 377-0578, <Beth.Dennis@dars.state.tx.us>

The audio version provided by Recording f/t Blind and Dyslexic, Austin, Texas



This project is supported by the U.S. Department of Education, Office of Special Education Programs (OSEP). Opinions expressed herein are those of the authors and do not necessarily represent the position of the U.S. Department of Education. The Outreach Programs are funded in part by IDEA-B Formula, and IDEA-D Deaf-Blind Federal grants. Federal funds are administered through the Texas Education Agency, Division of Special Education, to the Texas School for the Blind and Visually Impaired. Texas School for the Blind and Visually Impaired does not discriminate on the basis of race, color, national origin, sex, religion, age or disability in employment or the provision of services.