Table of Contents

FAMILY
Telling Your Story: What’s the Point? .................................................................3
The Unseen Bean: The story of how passion outwits obstacles ........12
Finding My Way Around the Figurative Mountain: Lessons Learned While On the Inca Trail .................................................................21
National Federation of the Blind National Convention: A Parent’s Perspective .........................................................................................23
What my Daughter Taught me About Active Learning—or, Whose Goal is it Anyway? .................................................................25

PROGRAMMING
‘This Is Who I Am’ .........................................................................................30
Braille Music Technology: Opening the World of Music Notation to Readers of Braille .................................................................46
It Takes a Team to Teach Independent Living Skills .........................53
I Want My Computer Games! .................................................................60

NEWS & VIEWS
Looking to the Future ....................................................................................64
A Momentous Anniversary Year .................................................................68
Expanded Opportunities for Secondary Academic Students in Texas School for Blind and Visually Impaired’s Summer 2006 Programs .75
Short-Term Classes for Academic Students at the Texas School for the Blind and Visually Impaired ...............................................................79
CdLS Foundation Provides Comprehensive Information Packet Free-of-Charge .............................................................................................81
Dots For Families ......................................................................................82
Bring a “Fella” to the Dance: Be a Texas Fellow! .....................................83
CLASSIFIED
Regional, State and National Training Listings and Events .............86
Telling Your Story: What’s the Point?
By Jeanine Pinner, Training & Outreach Coordinator

Texas Parent to Parent

Abstract: A parent leader shares her strategies as for using story-telling to influence decision makers concerning issues parents think are important for their children with disabilities.

Key Words: Family, Parent Leadership, Advocacy Skills, Evidenced-Based

Editor’s Note: Story-telling has long been used by effective parent leaders as powerful tool for helping decision-makers understand their issues. The phrase “influencing the heart to influence the head” comes to mind. Recently, the national focus on promoting evidence-based effective practices has given a new importance to recording success stories. Documenting successful outcomes with stories can help provide evidence about what works. Jeanine Pinner, with expertise pulled together through research and extensive personal experience as a parent leader, has spent the past year training other parent leaders across the nation to master the fine art of story-telling.

A few weeks ago, I attended the Texas State Autism Conference in Dallas with my son, Jake. Our keynote speaker was Taylor Crowe, a 25-year-old self-advocate who has Autism. Over 2000 people listened intently as this extremely impressive young man talked about his life as a person with Autism. Although we all heard the same words and felt many of the same things, I’m sure that we each also left with a little different “take” on what we heard and saw.
Through a video, we were privileged to see Taylor as a baby, a toddler, and finally, a young man. We saw Taylor before and after the onset of his Autism and listened to the experiences and perspectives of several of his family members. After the video, Taylor’s father spoke about their lives together, adding yet another dimension to our understanding. When Taylor took the stage, you could practically feel the anticipation of the crowd. He didn’t let us down! Taylor shared not only the events of his life, but his thoughts, feelings, regrets and dreams. He was amazing!

I watched and listened both as a mom and as an advocate for people with disabilities. I was impressed with Taylor’s poise and eloquence, his open heart and his willingness to share his journey with so many others. Although my son is already making his own journey very successfully, it was inspiring and reinforcing to hear Taylor talk about his. This was exactly what I came to hear and see!

As an advocate who helps others learn to tell their own stories to make positive change for their children and in systems, I admired the numerous tools Taylor and his family utilized to tell a story that covered 25 years in little over an hour. They utilized technology (the video) to cover a lot of years of Taylor’s life and development. When Taylor spoke to the audience, he relied very little on the hard copy in his hands, making it clear that he had worked very hard on his presentation. Every technique used to share Taylor’s story was centered around his strengths and gifts.

My son, Jake, listened as a self-advocate, and as I shot sideways glances at him (so he wouldn’t notice me watching
him), it was clear that he was listening intently to every word. Through several later conversations with Jake, I came to understand that he identified with many of the experiences and feelings that Taylor talked about. He realized, once and for all, that he wasn’t the only one making a journey with autism, that he shared many experiences and feelings with a lot of other people. There was a new bounce in his step and a more confident air about him.

The keynote session was full of service providers, too: teachers, therapists, psychologists, social workers, administrators ... it was obvious that they were also inspired by Taylor’s message. I’m sure that many of them were thinking of the young child with autism back home that they work with, and now they were seeing that child with a slightly different vision ... one of even higher expectations and possibilities. Taylor’s presentation touched the hearts of many people that day, and surely demonstrates the awesome power of telling a story and making it personal!

I first began to put our story together when my friend Tracey, who’s an Autism Specialist, asked me to co-present an autism workshop with her for a group of regular and special education teachers, sharing the parent’s perspective. It was scary, initially, but then exciting!

An opportunity to share what was in my heart with people who have a huge impact on our kids—wow! I wanted them to know how important they are to all of us, and that most parents treasure a positive and meaningful partnership with their children’s teachers. I knew that if they had an understanding of where Jake “started” and where he is now, they would want
to know how he got there. I worked hard to develop the story in a way that would convey to them just how powerful an impact they could have in the life of a child with autism.

The first couple of times I told this story to a group, I got a little teary-eyed and choked up for just a moment. It was a little like reliving the journey, with all the joys, roadblocks and successful arrivals coming back to life. I told my children’s story with pride because they worked so hard to accomplish their goals, and to live lives of their choosing. From time to time I ask my children for their permission to continue sharing their story. It is really their story, after all.

It meant a lot to me (and still does) to use these precious opportunities to let people who work with our kids know that they are absolutely essential to our children achieving their own visions of success. I also wanted to remind them that no one works harder than our children, and that their desire to be successful is a critical part of achieving that success.

My reasons for telling my daughter’s and son’s story cover a lot of ground and vary, depending on the audience. As an example, when presenting it as part of a workshop for teachers or parents, my overall goal is to emphasize how important it is for a child with a disability to have a really good support team. Their story also demonstrates other important points. To list a few...

• The impact and value of a strong positive home-school relationship
• The value of true and meaningful inclusion
• To focus on strengths, not deficits
• How changes in special education law over time have made a positive impact
• To believe in the promise and goodness of our children
• To emphasize that all children want to be successful and can, if provided the appropriate support and tools
• Not to put limits on expectations … keep them high

Putting 20 years’ worth of experiences, feelings, and learned lessons into a short story was not an easy task, but focusing on the outcomes I desired from the intended audiences and the setting of the presentation helped a lot. I thought about it for a long time before I actually started. I have to actually visualize things before they make sense to me, so as I thought about the 20+ years the story covered, it began to come alive.

The very first time I told our story to teachers, I knew it had touched some hearts when I saw a few people wiping away tears. That connection meant that their hearts were wide open to hear more about the magnificent difference they could make in the lives of our children. (Actually, they already know it … they just don’t hear it from us often enough!) Tears from parents sometimes mean, “Someone else understands how I feel”, or “I’m not alone!”

**Effective storytelling is one of the most basic and valuable tools in an advocate’s tool box.**

I guess I always knew instinctively that telling a story to illustrate a point was effective, and I’ve used this technique all my life. Until I started sharing my children’s story in an advocacy setting, though, I never really thought about it much
or recognized it as a tool. Now, I see stories everywhere I look – in the newspaper, magazines, emails, television … they’re everywhere and they bring the subject to life.

**Keep it simple … keep it short … make it interesting … repeat the top 2 or 3 key points often.**

The points I focus on at any given time may change and depends on the audience. In order for a story to make a positive impact to affect change (whether in an ARD/IEP meeting, the state legislature, or with an acquaintance), it is important that the listener “connect” with what you’re saying. Make it real! When the listener “connects” with some or all of your story in a personal way, it becomes a shared experience … they begin to remember their own experiences, those of a loved one, a friend or an acquaintance. Connecting in this way makes the story so much more powerful and makes the outcome you desire more likely!

**Make it personal!**

Most of us will not remember the impressive facts and figures we heard at a presentation or read in the newspaper, but when the tally sheets and legalese are translated into how something affects one or more individuals, our ability to understand and remember is far greater. We tend to remember those personal details about people and experiences far better (and longer) than the statistics because we identify with them in some way. We may not always remember the name of the speaker, but we frequently remember a story they told to illustrate a point they were making.
I’m not saying that statistics aren’t important; I’m just saying that by themselves, they only tell part of the story. Make the statistics meaningful by making them personal! Bring the statistics to life for the listener by illustrating how they impact the life of a real person.

“You know, as a preschool director, the connection and empathy I feel with others—parents and professionals alike—is so powerful when I hear stories that connect somehow with my own. I get tired sometimes of hearing broad statements about how important collaboration is in thinking about family-centered services and programs. What really makes a difference for me is when I hear stories about what happened today at the center … what kind of difference we made in the lives of the families we serve.” (Gabbard, 1998)

Choose the most effective way to share your story for its greatest impact.

Is that verbally? Putting it in a letter? Creating a Portfolio for your child? How about a narrated or captioned videotape showcasing your child? Sometimes, it’s who is telling the story that makes the most powerful statement—is it you or your child, a self-advocate?

Be clear on what your purpose is for telling the story.

Is the purpose of telling your story geared to generating a specific response or outcome? Or, is it to make people think about something in a different way? There are times that omitting a specific conclusion so that listeners draw their own is the most effective method to use.
Whatever method you choose to tell your story, take time to practice telling/showing it to a family member or a friend who will give you honest and constructive feedback; pick your toughest critic. Here are some questions you can ask of your critic:

Some questions to get feedback (Gabbard, 1998)

- What key phrases and words caught your ear?
- What was the most successful part of the presentation?
- What was the most difficult to understand?
- If you knew the story was going to be told again, in what ways could it be different?
- What were the major themes?
- How did the audience respond?
- What about volume? Pace?
- Did I use humor effectively?
- Did the story make logical sense?

So what’s the point? Telling your story effectively and making a difference by making it personal ... that’s the point! Happy endings to you all!

“For the sakes of our children, we must strive to be patient with those whose experiences have not given them access to our perspective. It is our duty to lead these people to a fuller understanding of the beauty and ability within our children. To do this we must become effective advocates.” (Bollero, 2002)
RESOURCES TO CHECK OUT


2. <http://www.cppp.org/real_stories.php> (Center for Public Policy Priorities: real stories of Texans affected by state budget cuts and/or changes to state programs and services.)


6. <http://www.new-horizons.org/expwri.html> (*Disability Experiences: Writings and Perspectives* is a collection of writings that have been submitted and links to websites that share personal disability experiences and the perspectives of people with disabilities.)


REFERENCES


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**The Unseen Bean:**

**The story of how passion outwits obstacles**

By Alice Ashmore, *ANCHORA* writer

**Abstract:** How many options does a man blind from birth really have in the world of work? Gerry Leary proves there are plenty.

**Key Words:** family, blind, career exploration, adult mentor

**Editor’s Note:** I first learned of Gerry through a family in Pearland, TX. On their summer vacation in Colorado, they visited a blind coffee roaster in Longmont. In their posting on the Texas Visually Impaired Family Network, they encouraged families to contact Gerry—both for his coffee and his ability to give great advice to parents. “The Unseen Bean: The story of how passion outwits obstacles” originally appeared in the summer 2005 issue of the *ANCHORA* of Delta Gamma. Delta Gamma is a women’s organization dedicated to Service for Sight since 1936. Reprinted with permission.

Gerry Leary is a man of passion; for both life and great coffee. The fact that he is blind from birth hasn’t kept him from enjoying a 30-year career as an independent auto mechanic or from becoming a master coffee roaster.
Gerry, now 52, was born after only 24 weeks of development. His family moved from Chicago to Los Angeles shortly after he was born. His parents later learned a heartrending fact: Their infant son had developed Retinopathy of Prematurity (ROP). With the definitive ROP diagnosis, a surgeon decided to remove the eyes from Gerry’s ten-month-old body and replace them with plastic ones.

Gerry spent just over two decades in California before an offer from a friend lured him to the Colorado’s Front Range. With two years of study in Business Administration at L.A.’s Pierce College under his belt, he decided to open his first garage. Gerry’s Auto Service opened its doors in Boulder in 1984. After all, Gerry’s experience with cars spanned his entire life.

A MODEL OF DETERMINATION

Gerry’s precocious nature often made life interesting for his parents. From an early age, he was fascinated with his father’s garage and cars. “I could play with them and take pieces off of them,” he explained. Fearing that his blind son would inevitably get hurt, Gerry’s father kept the garage door securely locked.

But Gerry was hardly deterred. At just three years old, Gerry and his older brother made a trip to a nearby hardware store. “I went back to the key thing and said I wanted a key blank so I could pretend to have a house key.”

He soon found his parents’ spare key and hatched a plan to get into the garage. Simply by feeling and comparing, Gerry scraped the blank key against the driveway, eventually making
a match. “It took days and days and finally it worked. There I was back with the cars!”

Gerry made the most of his time exploring the cars, but soon the carefully executed plan was foiled. “My parents kept finding me all greasy,” he said, and they took the key away. “I broke the lock with my next key.” At that point his exasperated father decided to teach him the mechanic’s trade.

His work as an automobile mechanic drew some interesting reactions. “Basically you’d hear people say, ‘a blind mechanic?’ Sometimes people would just show up to watch,” he said with an easy laugh. His skill as a mechanic was rarely in question. “In all my time of working on cars, I may have had a handful of unhappy customers.”

FROM CARS TO COFFEE

Gerry became intrigued by coffee roasting while in San Francisco in 1994. “I heard this machine that sounded like a rock polisher,” he said, remembering the noise emanating from a coffee roasting machine. He asked his friend and traveling companion Elizabeth Johnston what it was. “The owner took me over and showed me how it worked,” he said. “I realized that coffee roasting was a true art form.”

Gerry returned to Colorado and to his cars, but the experience stuck with him. In 2001, he decided to stop fixing cars. His hands were becoming numb, making mechanical work difficult. The advent of computerized car systems also dealt Gerry a harsh blow. “I couldn’t open a book and read the diagnostic codes,” he explained. “I realized I was becoming
illiterate.” It was then that coffee moved to the center of Gerry’s attention. The search to find a coffee mentor was on.

IN SEARCH OF A TEACHER

Gerry began to cast about for a roaster willing to teach him the craft. “I thought the best way to do it was as a trainee.” That idea met with resistance. “Everyone I talked to said, ‘Boy, you really have to see to do this. I don’t know how to teach you.’ One person said I’d never be able to roast coffee.”

“I must have talked to 15 roasters,” he allowed. He learned that most roasters relied on visual cues to glean information. “They would talk about color and structure and what was happening to the beans, how they broke open and how oily they were.”

Gerry eventually received training and certification as a Master Coffee Roaster from the Coffee Training Institute and West Coast Specialty Coffee Company in San Francisco. With a future still unclear, the training came with a steep price and definite risk. “It cost me about $2,000. I borrowed the money and refinanced my house.” With his new certification, Gerry returned to the roasters he’d talked to previously. No one needed any help, and no one was willing to take a risk on a blind man.

Undaunted, Gerry began experimenting with a quarter-pound “sample roaster” in a shed in his backyard. With each batching requiring about 15 minutes, Gerry literally prepared hundreds of roasts on his “practice” machine.
LEARNING TO ADAPT

Determined to go it alone, Gerry used his mechanical abilities in his quest to adapt sighted equipment for the needs of a blind coffee roaster. The first necessity was a talking kitchen scale. (He’s since progressed to a talking digital scale with precision to one-hundredths of a pound.)

Another major concern was how he could read the temperature inside the roaster. He considered removing the glass from his gauges, cutting a series of notches and feeling where the needles pointed. The technique he developed served him well while working with cars.

One day, however, Gerry came across a talking multi-meter that included temperature measurements. He was dozing on his couch when his brain made a connection that “woke me out of a sleep.” He attached a thermo-coupled probe to the talking multi-meter and found success. “That made me really excited. I could actually tell the temperature!”

As his roasting abilities grew, the demand for his coffee overwhelmed the small machine. His backyard wasn’t adaptable to a larger enterprise, but Gerry was. He acquired a 20-pound roaster and commercial space in Longmont, Colorado in August 2004.
Inside his expanded roasting business, the aroma of freshly roasted coffee wafts through the air, greeting visitors at his doorway. Gerry is considered a “custom roaster,” roasting only small quantities and adapting each to his customer’s tastes. He prides himself on the quality and freshness of his gourmet coffees. “I try to roast and ship in a 24-hour period.” His coffee travels to such far-flung places as British Columbia and Florida.

**MAN’S BEST FRIEND**

A black Labrador retriever named Midnight is Gerry’s guide dog and constant companion. Star of The Unseen Bean logo, Midnight’s drawn version has sunglasses and a nose directed toward a steaming cup of coffee. On holiday packages, the dog sports a winter scarf against a backdrop of snowflakes. Gerry’s slogan encourages customers to “Taste the passion in blind-roasted coffee.”

The same friend who had accompanied Gerry on that fateful trip to San Francisco doubles as a graphic artist and was there when Gerry needed her expertise. Elizabeth Johnston and her company Lizzardbrand Inc. formed a sizeable focus group to help develop the company’s identity. Her husband Jeffrey Hill supplied the name “The Unseen Bean.”

“It made us laugh so hard we figured it had to be the right one,” Elizabeth recalled. The name stuck, and a business was born.

**YOU DON’T KNOW BEANS?**

Neatly lined 55-gallon bins of green coffee beans stand in a row along one wall of his tidy, spacious workspace. Braille
labels allow Gerry to distinguish between varieties. Others wait on pallets in their burlap bags for transfer into the bins. Beans whirl and tumble in the barrel of his natural gas-fired roaster as the beans reach temperatures in excess of 400 degrees.

“There are audible cues,” he explains. The coffee goes through two “cracks” when it roasts. The first crack releases the water in the green beans. Gerry leans in close toward the large metal machine. “They quiet down as they get to the water crack.”

His talking multi-meter, a good nose and a practiced attention to sound tell Gerry when the beans should leave the roaster. The variety of coffee also affects roasting time and temperature. The release of beans into the cooling tray triggers a cloud of aromatic steam and smoke. As the beans cool, a slight crackling sound comes with the release of oil that dapples their surface.

Although his selection may vary with seasonal availability, Gerry offers a broad range of coffees from around the world, including selections from Zambia, Sumatra, Malawi, Ethiopia, Guatemala, Peru and 100 percent Kona Fancy from Hawaii. His personal favorites come from Panama, Malawi, Uganda.
and Zambia. “When it is possible, I try to buy organic, shade-grown, fair-trade beans. All of my decaf coffees are organic.”

Gerry has developed several unique blends including one appropriately dubbed “Passion Blend.” Ordering information and tasting notes on all of Gerry’s coffee are available online: <www.theunseenbean.com>. He maintains meticulous notes of customer preferences using an East German Brailler and can consistently produce the exact coffee expected.

**SOMETHING BREWING**

Cathy Miller, a longtime friend, joined the business in December 2003. “I called her when I needed help around Christmas,” Gerry recalled. “We got an order for 90 pounds, and it took us about three weeks.” Cathy weighs and packages the coffee, and prepares it for shipping.

But coffee wasn’t the only thing brewing. Romance blossomed about a year ago, and Cathy now shares both work and life with Gerry.

Cathy’s assistance has been just one factor in The Unseen Bean’s growth in business. Gerry relies on word-of-mouth customers and public appearances instead of advertising to generate sales, but the media exposure helps, too. He’s been featured in The Denver Post, on Denver’s NBC affiliate.
KUSA, in 5280 – Denver’s Mile-High Magazine and many other area newspapers and magazines.

Not surprisingly, local Delta Gammas have become regular customers and big fans. “His coffee is amazing,” raved Meredith Meyers, an initiate of Beta Tau-Miami and member of the Denver alumnae chapter. In fact, Gerry recently agreed to develop a special Delta Gamma blend at the request of area alumnae as a thank-you and nod to Delta Gamma’s philanthropic project, Service for Sight. Using DG coffee-lovers as taste testers, Gerry readily played “bartender,” tweaking the roast to the panel’s delight.

Gerry has grown accustomed to bringing joy to his customers. With two very different careers to compare, Gerry finds he’s happiest while making the beans he knows so well into a product his customers have come to love. “People hate spending money repairing their cars,” he realized, “but with coffee, they come in and leave with a smile! It’s a much happier work environment!”

Update: Gerry has just perfected a unique Delta Gamma blend with an anchor on the roast’s label! And, to support the “Service for Sight” sorority, Gerry has also agreed to offer reduced rates for DG fundraisers.

Visit: <www.theunseenbean.com> for more information.
Finding My Way Around the Figurative Mountain: Lessons Learned While On the Inca Trail

By Justin Grant, History Major at University at North Texas, Arlington

Abstract: A young person shares the insights he gained while participating in a hiking expedition up the super Inca trail and to Machu Pichu in southern Peru.

Key Words: Family, blind, personal experience, vision loss, mountain climbing, world travel, confidence building

In 1999 I was diagnosed with Stargarts disease. I was told there is a possibility of me losing all my central vision. I was told everything would change and my world would be turned upside down. I was only in the fifth grade.

From elementary on to junior high, I wanted nothing to do with anyone who asked about what was going on with my vision. I was irritated whenever anyone asked me if I needed help to see anything. I knew they were just trying to help, but I didn’t want to be in the position where I needed help. I was young and I wanted to fit in with everyone else. I thought there was no way I could fit in at high school if I always needed enlarged copies of everything we did in school. My parents noticed how I was reacting to the new way things were working out after I began losing my vision. They both came from homes where the lesson of “if something is in your way, find your way around it” was taught. So as any other parent might, they passed it on to me. I wanted to find my way around it. I knew though, if I were going to settle the score with losing my
vision, something would have to happen; I would have to change my attitude and my outlook on what was going on with me.

This wasn’t until my junior year in high school, when my DARS / Division for Blind Services counselor sent my parents an e-mail about a trip for blind and sighted students going up the super Inca trail and to Machu Pichu in southern Peru. When my mom first told me about the e-mail and the trip, I wanted so much to go. Luckily the company that was sponsoring the trip accepted me into the group. There were 18 of the “supers” as we were called. Nine were sighted, five were totally blind and four were visually impaired. We all met for a retreat in Estes Park Colorado, where we met Erik Weihenmeyer, the first and only blind man to summit Mt. Everest. We had been told that he would lead us up the trail in Peru.

When we arrived in Lima Peru, my first impression was, “Wow, this place is chaotic.” I couldn’t even imagine how much of a foreign world this place was for a totally blind person. After I got to know everyone pretty well, I began to notice how self-centered I was being, coping with my vision loss. Being around people that had lost all of their vision made me realize that yes, I may be losing my vision, but I still have some. At first, losing my vision seemed unfair to me. But sometimes these things happen, and just like I learned to do during this experience with people who are now some of my best friends, I am finding my way around this figurative mountain. Just because they are blind, doesn’t mean that they can’t achieve the summit.
This trip to Peru turned the way I look at my impairment completely around. It’s a part of who I am, and just as one of my blind companions, Terry Garret said, “I do not let my blindness control me, I control my blindness.” Terry Garret and all of the other blind students that went with us taught me that even though I had a disability, along with them, it didn’t mean that I couldn’t achieve higher goals in life. The trip to Peru changed the way I think about my disability, as well as opening new doors for me.

National Federation of the Blind National Convention: A Parent’s Perspective
By Sally Thomas, Parent, Pearland, TX

Abstract: A parent shares her family’s experiences while attending the National Federation of the Blind (NFB) National Convention this summer in Dallas, Texas.

Keywords: blind, blind children, blind adults, blind technology, blind simulation, NFB

Editor’s Note: Sally, whose son David is a fourth grader at Challenger Elementary in Pearland, first shared her comments on the Texas Visually Impaired Family Network. Learn more about this listserv for families at <http://lists.topica.com/lists/txvifamily>. We appreciate her sharing them here as well.

We went to the National NFB Convention in Dallas this summer. It was GREAT! We were able to reconnect with
people we met in Atlanta two years ago, participate in some fun activities, and hear great speakers. It is so empowering to hear the parents and blind adults talk about their successes in making the world accessible. To see close to 3000 blind people together in one place really helps my son know that he is not alone. It is such a positive experience that at one point my sighted daughter looked at me and said, “sometimes I wish that I was blind too!”

We especially love the cane walk. Everyone who wants to participate (sighted or blind) gets a sleepshade and a cane and travels around the hotel with an O&M instructor. This year we were with a blind instructor. It really makes an impression on my son that using his cane is important and that he can be successful in travel, even under sleepshade. He really wants to get a guide dog some day, so excellent independent travel skills are a must.

I especially enjoyed a talk on Braille literacy. “Can’t” is not in the vocabulary of these people. Learning about the possibilities and resources available for Braille readers provides me with great tools for my son and will help at our next ARD. There is so much information available at this conference especially geared to school-aged kids.

My husband was very excited about a talk he heard on tools for teaching math to blind kids. The speaker was Susan Osterhaus from TSBVI. She really knows her stuff. It’s so helpful to know that there are people out there who have the knowledge to teach our kids anything they want to know. We hope our son can go to the math program at TSBVI this fall. It’s great that we have this resource so close at hand.
One of the really great things about NFB is the opportunity to talk with other blind people. Everyone says that if you wonder how your child can participate in an activity, ask another blind person how (s)he did it. There is a network of people who have faced the challenges our kids will face and they have insight on how the challenge can be met.

Another fun part is the technology displays. It’s an opportunity to see what is out there and to ask questions of the vendors. I was able to meet one of the people who designed the braille notetaker my son uses and ask him questions about things the notetaker can do. It’s a lot easier than asking local professionals who may or may not know! My son loves to try out all the gadgets. He was born at the right time to embrace all the technology that is out there.

Next year the convention will be in Atlanta. We’re planning to spend a longer time there than we did in Dallas. It’s really worth it.

What my Daughter Taught me About Active Learning – or, Whose Goal is it Anyway?

By Jean Bugbee, Parent
Reprinted with permission from Future Reflections, Winter/Spring 2006

Abstract: A parent shares her journey in encouraging her daughter’s learning through play—on her own terms at home and at school—to illustrate the importance of respecting our children for who they are, communicating with them the way they communicate, supporting their learning in the way they
learn, and being mindful of whose goals we are trying to achieve.

**Key Words:** family, blind, active learning, communication, concept development, educational programming

**Editor’s Note:** The following article is edited from a presentation given at the North American Active Learning Convention sponsored by the Lilliworks Foundation, February, 2005. For more information about Active Learning, see these Websites: <http://www.lilliworks.org>; <http://www.penrickton.com>; <http://www.visionkits.com/Lilli_Nielsen.html>; and <http://www.tsbvi.edu/Education/vmi/nielsen.htm>.

In 1983, I adopted my daughter Renee. I was single; I had experience working with disabled adults but not a clue about babies. Renee was five-and-half-years-old, weighed thirty-five pounds, functioned at about the nine-months level, and was very cute. When she smiled and reached out her hands to be picked up, it was love at first sight.

Renee was injured by a medical mistake when she was fourteen-days-old in 1978. She has moderate cerebral palsy, mental retardation, epilepsy, and hydrocephalous that is controlled with a shunt. She has no ability to suck, and had a great deal of difficulty mastering swallowing. She went from the hospital to a medical foster home at age sixteen months. She sat up alone when she was four-years-old, and crawled and walked holding hands at age five. Today, she is twenty-six-years-old, and still walks that way.
I met her at her special school. It had lots of equipment for training severally disabled children. Her IEP goals were to stack blocks, stack rings, work shape sorters, brush her teeth, brush her hair, use the toilet, feed herself, walk, and talk. They used patterning, modeling, hand-over-hand modeling, and verbal and physical prompting. None of it was working.

She was throwing, banging, and dropping things; mouthing objects; taking off her clothes; pulling hair; grabbing people’s glasses (and anything else she could grab); and vocalizing at the top of her lungs—all with great joy and gusto.

I took her home, but it took two months to convince her social worker it was OK. It was “Catch 22.” Only a crazy person would want this kid, and they don’t give kids to crazy people. She had a great foster home. Her foster mother was a retired physical therapist. She was surrounded by love, which was good—but she was also always surrounded by her crib, playpen, high chair, or stroller—which was not so good.

Our first few weeks together were an incredible learning experience for me. She threw her bottle over and over again, so I got her a tippy cup. I put her in her play-pen with lots of toys. She threw them all out, so I put her outside of the playpen and she filled it up. I let her take my hands and lead me around the house to explore things. I made the house Renee safe. I put her mattress on the floor, put a baby gate on her door (so I could sleep at night), and I turned her loose.

When she showed interest in something, I got more of that type of thing. She likes “busy boxes” so I started collecting them for her, and I continue to search for things that interest her.
The house was a wreck, but she was busy and happy. This went on for over two years. We were having a lot of fun, but I was worried that I wasn’t doing it right.

For years the teachers told me that she had to learn sorting and stacking skills so she would do well on IQ tests. The school also offered Renee functional skills training, like teeth brushing and toilet training. When she wasn’t making enough growth in sorting, stacking, and functional skills, the doctors and teachers said that either I wasn’t trying hard enough or she was just too retarded (or both).

Somewhere along the line I realized that everything she really knew how to do, she had learned from her own play. She had to be motivated by the activity in order to do it. She liked sound, so she banged, dropped, played with musical toys, vocalized, and shook things to see if they made noise. She liked what she could do with her hands, so she did more of all of the above. As for sorting or stacking, she could care less about those activities. If it didn’t make a pleasing sound, why do it? She liked having her hair and teeth brushed by me, so she didn’t want to learn to do it herself, even with praise. She didn’t seem to have enough language to understand what I wanted, but maybe she didn’t care to please me by doing something that was meaningless to her.

I learned to let her show me what she was interested in and what she could do. If she didn’t have the component skills and the activity wasn’t motivating in itself, she wasn’t doing it—period. If I wanted her to learn to do something, I had to provide materials or activities that would develop the essential
skills, then make the activity “pay off” for her. I had never heard of Active Learning, but I was doing it.

By middle school, she was the only student at her level of disability in her class. She was one of a kind. I decided I didn’t care about IQ tests, and a lot of self-help skills were not going to happen. I was tired of them testing her on what she could not do, instead of valuing what she could do. I used the IEP to protect her rights and opportunities, but didn’t expect them to teach her much.

But I persisted in providing her opportunities to learn through play and on her own terms at home, and over time her skills became functional. She turns lights on and off, puts laundry in baskets, garbage in the trash can, and mail in the mailbox. It’s her job to carry the plastic basket in the grocery store, put things on the counter (usually with a bang), and carry the bag of groceries home. And Renee communicates with me very well, just not in English.

Today, her adult day program has to have goals, and insists that she must learn to wash her hands. They complained that it took a long time to get her to do it; that she was dependent on a lot of physical and verbal prompts. They worried that they just didn’t know how to teach her. I explained that Renee loves to play in the water and wants to get as much attention from the staff as possible. Renee had a goal, too, and she has achieved it. She is retarded, but she isn’t stupid.

Renee is very happy. She can do a lot more than anyone ever thought she could. She now “gets” the whole concept of cause and effect. She can feed herself, play for hours without
frustration, and hold the hand-held shower. She can take her clothes off, and put socks on her feet and hands. And she thinks the remote control for the automatic garage door is wonderful!

We must remember to respect our children for who they are. Communicate with them the way they communicate. Support their learning in the way they learn, and be mindful of whose goals we are trying to achieve. Raising kids takes love, patience, and a sense of humor. It is also the hardest and most fun you will ever have.

‘This Is Who I Am’

By Diane Rogers
(Reprinted with permission from STANFORD Magazine, published by Stanford Alumni Association, Stanford Univ.)

Abstract: This article describes the experiences of Liz Phillips, a blind college student at Stanford University. It provides information on accommodations for college students with disabilities, accessibility issues, study skills, self-advocacy, and the importance of a good sense of humor.

Key Words: Programming, blind, visually impaired, deafblind, disabilities, self-advocacy, accessibility, accommodations, assistive technology.

By the time he got to class, philosophy professor John Perry found only a bare plate. The chocolate chip cookies one of his students had baked were all claimed. What was a hungry ethicist to do?
“He was like, ‘Maybe I could steal a cookie from Liz without her noticing,’” says senior Liz Phillips, a blind student in the course. “I had a pretty firm grip on my cookie because I had a feeling he’d try something, but his hand swooped out of nowhere and took it. It was hilarious.”

Hilarious? Indeed, Perry wasn’t taking advantage of a student with a disability, but rather, making a point. “Liz and I have a pretty good relationship, so I like to occasionally exploit the fact that she’s blind, to get other students used to being matter-of-fact about it,” he says. “Besides, she has a nice laugh, and anything that gets students laughing early in the lecture helps them stay awake.”

That level of acceptance, where professors and classmates can acknowledge a student’s disability and then move ahead with the business of learning, is comparatively rare. In some classes, instructors aren’t sure how to treat Phillips. “A lot of times people have a hard time seeing me,” she says. “If I’m raising my hand and other people are raising their hands, they get called on. It’s happened often enough that I don’t think, ‘Oh, [that professor] must be having a bad sight day.’”

Phillips’s solution? “I call out.”

She also has to remind faculty to describe anything they put on the blackboard. In one class, “I constantly raised my hand and asked, ‘What did you write?’” she says. The professor “wasn’t being mean, he just constantly forgot.” After several days of reminders, the instructor finally said something like, “Oh, you need me to tell you what I’m writing?”
“Yup,” Phillips replied. “I still can’t see.”

Phillips is one of almost 900 Stanford students who receive accommodations from the University’s Office of Accessible Education. Their disabilities are diverse, falling into 11 main categories that range from chronic illnesses to learning disabilities, hearing impairments to psychological disorders. Their challenges may be academic, social, health- or mobility-related—or all of the above. Some need only occasional assistance: a student with severe food allergies may require access to a peanut-free dining hall, or someone with a broken leg may need rides to class on a golf cart. Others visit the OAE, on Salvatierra Walk near the Haas Center for Public Service, nearly daily. Phillips, for example, goes there to obtain books and tests in Braille, and training in assistive technology. In addition, she must often figure out creative ways to approach her schoolwork and advocate for herself in the classroom.

Stanford was Phillips’s first choice of colleges because it is a research university—“and I do want to discover something.” She was admitted early decision, and arrived a month before classes started her freshman year to learn her way around campus with her guide dog, Bonds. Four years later, getting to class is still a challenge, especially when the physical terrain changes unexpectedly. If Bonds walks under a piece of caution tape—he’s smart, but he can’t read—Phillips is liable to bump into a piece of construction equipment. When a familiar pathway is blocked by parked bicycles, she may take them out with an inadvertent swing of her backpack.
“Lots of kids don’t think about blind people or people in wheelchairs, and they park all over campus,” Perry says. “So occasionally I’ll pick up an offending bike and throw it in the Dumpster.”

Phillips met Perry when she was searching for a building on the Inner Quad and he stopped to ask if he could help with directions. Last summer, she received a grant from the office of the vice provost for undergraduate education to work with Perry on his “Philosophy Talk” radio show, researching topics that included dignity, suicide and the environment. “I don’t know beans about global justice,” Perry says. “But if somebody smart like Liz reads what’s on the net and boils it down to 30 pages, I can sound like I know something.”

Thanks to advances in technology in the past 10 years, Phillips can turn to the Internet almost as easily as a sighted student. Using screen-reader software, she reads by hearing, listening carefully as a synthetic voice pronounces the words on her computer screen. It takes time—most blind students hear about 300 words per minute, while a sighted reader typically processes 400 to 500—but it’s faster than scanning material and printing it out in Braille.

When OAE director Joan Bisagno came to Stanford in 1996, the Disability Resource Center on the ground floor of Meyer Library was staffed by two people; they had one computer to run a screen-reading program for the blind. Today, the OAE’s Student Disability Resource Center, which coordinates services for all students with disabilities, has a staff of five full-time professionals and eight part-time interpreters. The recently launched Schwab Learning Center, which provides services to
students with learning disabilities and attention deficit hyperactivity disorder, employs three professional staff and 16 part-time tutors.

Similarly, Rosa Gonzalez, the University’s compliance officer for the Americans with Disabilities Act and Section 504 of the Rehabilitation Act, received four to five student grievances per quarter in the early 1990s. Most complaints were about physical inaccessibility—students couldn’t get up the stairs of the Old Fire Truck House or onto the Marguerite shuttle, or couldn’t take dorm trips. One decade and $10 million later, most physical barriers on campus have been removed. Ramps, power doors, elevators and accessible bathrooms have been installed in buildings with the highest academic and public use. Today, fewer students are filing grievances—typically two per year—and they usually concern academic accessibility.

The fastest-growing group of students with disabilities are those with diagnosed psychological or psychiatric problems, such as severe depression and bipolar disorder. Psychologist Alejandro Martinez, who directs the counseling and psychological services at Vaden Student Health Service, says that during the 24 years he has been at Stanford, he has seen a “significant increase” in the number of students needing psychiatric hospitalization and psychotropic medications. “In the past, there wasn’t much that could be done for students who had psychiatric disabilities,” he says. “But with the advent of accommodations for them, that’s changing.” Instead of leaving school for treatment or because of academic difficulties, “many more of those students are able to remain on campus.”
Students work with OAE staff members to develop accommodation plans that meet their needs. Often, these plans combine technologies and strategies. For example, students with visual-processing difficulties might use the reserved computers in a lab on the second floor of Meyer Library to highlight words and sentences in bright colors or alter fonts, since changes in the presentation of text can improve their ability to distinguish written words. Many students with disabilities take 12 units per quarter, rather than the usual 15.

A blind student arrives on the Farm with a U-Haul’s worth of equipment. He has a screen reader—Window-Eyes or JAWS—and often a scanner plus Kurzweil reading software. He carries a portable BrailleNote, which looks like a laptop and enables him to take notes in class. And he probably has a Perkins Brailler in his dorm room—a small typewriter with six keys that produce Braille dots.

To get an alternate-format textbook, the student provides a course syllabus to Lisa Sheftman, an alternate format and accommodation coordinator at the OAE, who contacts the book publisher. Once the student verifies that he is enrolled in a course, confirms that he has purchased a textbook and agrees not to distribute the electronic version to anyone else, the publisher transfers the electronic text to Sheftman, who has it converted to Microsoft Word, Adobe PDF files, digital audio files (MP3), Braille or whatever format the student prefers.

But an electronic version isn’t always available. “It’s a challenge if a professor requires a particular edition,” Sheftman says. “Even though The Brothers Karamazov always ends the same way, the faculty may want a specific
Such textbooks can be translated into Braille, usually by an off-campus committee of specialists.

Alternate-format textbooks aren’t ideal for all situations. When it comes to taking notes on an assignment or going back to look for quotes, Phillips prefers a more personable reader—ideally, a classmate. She will ask a professor to announce at the start of a course that she’s looking for a reader, and she usually gets a number of responses. “Liz was someone I wanted to get to know better,” says junior Emily Fletcher, who started reading with Phillips two years ago and has become a close friend. “When I’m taking a class, I really like to talk about the material, and Liz and I not only read, but we stop and argue and talk.”

Bottom line: it takes a lot of time for blind students to read and review course materials. “In general, my approach is to use a [human] reader, or read in Braille, or listen to tapes or read online versions of texts. I use all of those in preparation for studying,” says senior Tyler Dumm.

Then there are exams. Whenever Dumm takes a quiz, he launches an OAE-wide effort. Let’s say Professor Green announces the quiz. She composes it and gives it to TA White, who delivers it—72 hours in advance, ideally—to Sheftman. While Dumm goes online to reserve an exam room at the OAE, Sheftman takes his quiz to the Braille Box, a windowless office in the basement of Meyer Library where Braille specialist Gay Baldwin and alternate format and accommodation coordinator Alice Wong transcribe it into Braille. Dumm takes the test at the OAE, then prints out his answers on 11-by-11.5-inch Braille sheets, which are returned to the Box.
Baldwin or Wong “interlines” his answers, writing them out in pencil between the lines of his Brailled responses, and hand-carries the quiz back to the OAE. From there, it is returned to the TA, and finally to the professor. Just in time to start preparing for the following week’s quiz.

Coordinating all these steps depends on meeting deadlines, and when a faculty member is late delivering a test to the OAE, Dumm says, it can throw everything off. “Sometimes you’re frustrated: ‘Damn, this professor didn’t come through.’ But no worries. They’re busy. I’m busy. We’ll get there.”

Dumm lost his sight to cancer as a toddler, then had his cancerous left leg amputated at age 10. A member of the board of directors of the Northern California unit of the nonprofit Recording For the Blind & Dyslexic, he is headed for an advanced degree and eventual career in physical therapy. This year, Dumm became the first blind student to enroll in Surgery 101, part of his sports physiology and rehabilitation concentration in the human biology major. While other students refer to a skeleton in the front of the room, Dumm feels the human bones given to him by co-instructors Ian Whitmore and John Gosling, both teaching professors of surgery. But the lectures also rely heavily on diagrams that are projected onto a screen—typically inaccessible to Dumm.

Enter the talented alternate format crew of the OAE. Baldwin already had provided Dumm with textured aluminum-foil reproductions of the brain for a psychology course, bringing in a pastry cutter from her kitchen to form a bumpy pattern that designated neural pathways. This time around, the specialists relied on Dumm’s lab assistant for the course, Shelley Hou,
'00, MA ’03, who took the same surgery class several years ago and kept her notes. Using a Tactile Image Enhancer, which suspends teensy polypropylene beads in heat-sensitive paper, the formatting team created diagrams with lines of varying thickness to designate muscles, vessels and nerves in the chest cavity. Strung-together beads stood in for ribs.

Because he wears a prosthetic leg, Dumm says he’s particularly interested in the way the human body works and he wants to get as much as he can out of the lab section, in which students dissect cadavers. “Shelley provides a verbal description of things that aren’t really distinguishable by touching them, like colorations of tissues,” Dumm says. “She also aids me physically in the dissecting process, guiding my hand when I’m using a scalpel to separate connective tissue attached to a muscle, or paring away some of the fat in the subcutaneous area.” (Postscript: Dumm earned an A+ in the class.)

Liz Phillips came to Stanford hoping to minor in physics, and mastered the difficult Braille Nemeth code to study quantum mechanics and relativity. But she concluded it would take too long to get through school. “It was all about manipulating equations, and astronomy classes would have been impossible for me,” she says.

Instead, Phillips focuses on philosophy, which she wants to teach at the college level. She found her passion in Philosophy 80: Mind, Matter and Meaning. “Have you ever had one of those moments when you can remember the exact second when something happened?” she asks, igniting a megawatt smile. “I just looked around the room that day and was like, ‘This is
who I am.’ I said, ‘Mom, I had no idea I could get credit for
doing what I do all the time.’ And it’s never changed. I still
wake up and go, ‘Yup.’”

Still, Phillips says it can take time to figure out how to
approach some of philosophy’s subfields. Logic, for example,
depends on notation systems, symbols and proofs not unlike
those used in mathematics and physics. This year she has been
working with graduate student Patrick Girard to learn the old
Polish notation system that was used in logic before the advent
of computers, and they are now translating it into a more
contemporary, more accessible system. “We are trying to
propose a standard notation for logic that would help in
transcribing logic textbooks for blind students, and would help
blind logicians in general,” Girard says. One project-related
discovery particularly pleases Phillips: she learned, from a
sighted friend, that Girard had blue hair. Then red.

Given her experience with a disability that’s apparent, Phillips
empathizes with those who have so-called hidden disabilities.
“People can be really disrespectful to students with
psychological or learning disabilities,” she says. “It’s like,
‘You can do calculus on the board—why can’t you read?’ Or,
‘You’re really smart, you’re getting A’s—what do you mean,
you have a disability?’”

Because of those attitudes, most students with learning and
psychological disabilities prefer not to reveal them. (Those
who spoke with STANFORD asked that their names be
changed.) “There is a social stigma attached to it, especially in
academia,” says one graduate student who is dyslexic. “I don’t
want someone to say, ‘You can’t edit our journal,’ and I don’t want it to affect future jobs.”

Like many students with attention deficit disorder, sophomore Ellen Cooper spent years resisting a “disability” label. Although she was diagnosed in seventh grade, initially she declined the accommodations her school district offered: “I didn’t want to be different, and it’s really awkward for a 12-year-old to explain to her classmates why she gets extra time on a math test.”

Cooper got through high school by putting in extra hours on long-term projects and with help from her parents, who reminded her to organize assignments and deadlines. But in her freshman year, she had to read hundreds of pages each week for IHUM, the required yearlong course in the humanities, and her schedule spiraled out of control. Cooper cut back her course load and asked for extra time on exams. The hardest change? She realized she needed nine hours of sleep each night, and friends were staying too late in her room. “It took me a quarter to be able to say, ‘You need to leave.’”

Laurel Weeks, a learning strategies coordinator at the OAE, says many students with disabilities need to break down big projects into manageable steps. “It’s a lot less scary thinking, ‘Today I just have to think of three possible topics for a term paper, and tomorrow I’ll find some source material,’” she says. “It takes the emphasis off, ‘How am I going to finish this?’ and puts it on, ‘This is where I’ll start.’”

Weeks, who works with about 100 students with learning disabilities each quarter, acknowledges that those study tips
may sound simplistic for competitive Stanford students. But information-processing challenges, including reading disorders and memory issues, require specific remedies. That’s why Weeks is surprised when she hears about faculty members who accuse students of gaming the system. “If they saw the kinds of documentation I see, I’m sure they would understand it differently,” she says. “I see profiles of students who are so capable in so many areas, and then there’s an area so discrepant, that it makes [the disability] very real. It’s not something someone would try to make up — there’s no benefit in that.”

Doctoral candidate Connie Stillwell recalls that as fast as her mother would enroll her in gifted classes, she’d have to drop out because she couldn’t pass the reading tests. “The number of summers I spent under house arrest when I was 8 and 9, reading books—” Stillwell begins. “It was, ‘You can’t go outside until you’ve finished a chapter of The Black Stallion or The Secret Garden.’”

Stillwell always suspected she was dyslexic: “I screwed things up all the time.” But she also thought nothing could be done about it. She got through college, went on to earn two master’s degrees and then applied for a PhD program at Stanford. When she was accepted, her boyfriend insisted that she get tested for learning disabilities. “He said, ‘You’re going to a new school—maybe there’s a center there.’”

There was. And on one memorable afternoon, Stillwell and her OAE tutor made a discovery: if she listened to a paragraph being read aloud while she read the text silently to herself, she
got it. “I can’t see my mistakes,” she says. “But I can hear them.”

Stillwell now has all of her textbooks digitized by the OAE and she uses two different screen readers on her computer. She says her comprehension has “skyrocketed.” The Schwab Learning Center has lent her a laptop and iPod so she can download MP3 files and “read” assignments while she commutes by train. “The office has bent over backwards for me,” she says.

The OAE also pays for four hours of foreign-language tutoring each week since learning a new language—a requirement for Stillwell’s doctoral program—is one of the toughest academic challenges for dyslexic students. Many students with learning disabilities have difficulty mastering the phonemes of a new language, Weeks says; some have trouble spelling because they can’t retain pictures of words in their heads. “It really turns up on vocabulary quizzes and in essays,” says Kathryn Strachota, a senior lecturer for the Language Center who has been teaching German at Stanford for more than 30 years.

Strachota, MA ’70, says it can be challenging to restructure class activities to accommodate students who need visual and kinesthetic cues. But she recalls a recent exercise in teaching prepositions, when she paired students up and had them tell one another to demonstrate placing a book auf den Tisch (on the table) or putting a picture an die Wand (on the wall). One student with a learning disability came up to her after the class and couldn’t stop pumping her hand. “That was good,” he said. “We should do that more.”
Strachota argues that whatever she does to help students with learning disabilities helps the rest of the class. “It forces you to find more ways to expand your repertoire, and helps you think in different ways to jump-start your creativity.”

In fact, making course exercises and materials more accessible to all students is the focus of a new movement called universal design for instruction, or UDI. The philosophy takes its name from architectural principles that were intended to make public spaces more accessible for people with disabilities but ended up benefiting the general population—like curb cuts, originally designed for wheelchair users and now beloved by parents with baby strollers. Similarly, UDI takes advantage of technology to build educational curb cuts into classroom instruction. Take a whiteboard that can capture and later reproduce anything that is written on it. It can be essential for students with visual or learning disabilities, but it likely helps all students organize and remember their notes better. “Now professors make announcements in class to find readers and notetakers,” says the OAE’s Bisagno. “But if you had UDI technology in a classroom, it could do away with accommodations, and there would be no need to identify yourself as having a disability.”

Despite the specific demands of Surgery 101 and logic, Dumm and Phillips say that often it’s relatively minor adjustments that help them most in their classes. In a letter she was asked to write for instructors in the program in writing and rhetoric on teaching students with disabilities, Phillips made several specific suggestions: send assignments in accessible e-mail attachments; give students the option of doing research online, rather than going to the library; include both visual and
auditory information in presentations; assign seats in small classes and ask all students to say their names before they speak; distribute outlines of upcoming topics of discussion; get handouts to the OAE well in advance of assignment deadlines; don’t be afraid to ask questions. Oh, yes, and don’t pet guide or hearing dogs when they’re working.

For many students with disabilities, academics demand significant extra time. “It’s a constant struggle to stay caught up,” Phillips says. Nevertheless, they make time for interests outside of class. “We don’t miss out on much,” says junior Beth Graham, Dumm’s girlfriend of almost two years. Graham and Dumm recently finished the third book in the Chronicles of Narnia and they’re now embarked on an audio tape of The Da Vinci Code. They play poker with Brailled playing cards and chess with pegged pieces that don’t tip over when someone makes a move. Dumm frequently heads outdoors for hiking, riding horses, kayaking or rock climbing.

When he and Graham take in a movie at a Palo Alto theater, Graham describes the action in a whisper. “And I enjoy it because it makes me see more things about the movie.” But she also remembers a Chieftains concert in Memorial Auditorium, when she was telling Dumm about the musicians’ instruments and a guy sitting next to them asked why they were talking. “He might not have realized Tyler was blind, but he was so rude,” Graham recalls. At least when they go to Flicks there’s no danger of offending anyone. “I could probably yell the description if I wanted to.”

Phillips also enjoys attending Flicks with one or more of the gaggle of friends who invariably surround her. She writes
poems and songs, which she has performed at a Parents’ Weekend event hosted by the Writing Center, and is at work on a science fiction epic.

For many years, Phillips has been a spokesperson for the National Center on Shaken Baby Syndrome, and she frequently gives speeches to groups like the American Academy of Pediatrics and the Child Welfare League of America. At those conferences and in an appearance on Good Morning America, Phillips describes how she lost her sight when she was 6 months old and a neighbor’s nanny shook her violently, detaching both retinas and endangering her life.

Phillips has hosted many meetings in her dorm room in Storey House to try to revive a community of Stanford students with disabilities, whose members would provide resources and support to other students, and lobby as a group for continued improvements—like more Braille signage in campus buildings. But only one other student has shown up so far, so Phillips is instead putting those off-book hours into doing what she loves most—philosophizing. About free will versus determinism. And blindness.

“Blind is not how I identify myself,” she says. “I don’t say, ‘I’m a blind person.’ I say, ‘I’m a philosopher.’ Or, ‘I’m the mother of Bonds.’”

Phillips continues to be surprised by the number of people who want to talk with her about what it’s like to be blind. She always obliges, but she also likes to move on. “By age 22, it gets old,” she says. “Yeah, I’m blind. Yeah, I can’t see. But I have a lot to say about other things.”
Braille Music Technology:
Opening the World of Music Notation to Readers of Braille
by Bill McCann, President and founder of Dancing Dots
and Holly Cooper, Ph.D., TSBVI Outreach Deafblind
Education Consultant

Abstract: During a summer program offered by TSBVI in 2006, students learned how to use computers, software and MIDI keyboards to compose music, input it into a computer, and read and edit it with screen reading software.

Keywords: programming, braille music, braille technology, blind musicians.

Many teenagers are big music fans and some are also interested in playing or singing in organized settings. Ask almost any teacher of students with visual impairments (TVI), and she will probably say her students are even more likely to be interested in music than the average person their age. However, many TVIs are at a loss for how to support students with blindness in music classes if they are not musicians themselves. Few TVI’s know how to read music, let alone braille music. Some students with visual impairments are fortunate enough to have access to braille music; some learn to play new songs by ear. But now technology exists which can translate print music into braille, and use screen reading technology such as JAWS with music editing software, so users who are blind can compose and edit music notation.
This past summer, Texas School for the Blind and Visually Impaired (TSBVI) offered a special summer session on braille music, and plans are underway to repeat a similar program in 2007. The class was taught by TSBVI music director, Jane Rundquist, John Castillo, assistant music director, and Bill McCann, president and founder of Dancing Dots, a software company which develops products for musicians who are blind. Bill McCann describes below the summer program in which he and the students and teachers participated.

**BRAILLE MUSIC TECHNOLOGY SUMMER SESSION**

During our first-ever Braille Music Camp at the Texas School for the Blind and Visually Impaired in Austin, held in June 2006, nine talented and highly motivated young blind musicians learned how to use technology from Dancing Dots to prepare musical pieces. They learned how to enter individual notes by typing on the PC keyboard or playing on an attached musical keyboard. They played their pieces back to listen for places that needed improvement, and applied new skills they learned to make needed corrections. When they were satisfied with the results, they learned how to print their pieces for sighted musicians to read, and how to create a companion braille score using GOODFEEL from Dancing Dots. Individual selections ranged from songs by Brahms to Elvis, along with a few original compositions.

Our students also refined their braille music skills using a braille music course authored by Richard Taesch of the
Southern California Conservatory of Music. Jane Rundquist coached the students in the ancient art of solfeggio singing. Each degree of the musical scale has its own solfege syllable: C is “DO”, D is “RE”, E is “MI”, etc. This system was made famous in the “Doe, a Deer” song from the popular musical *The Sound of Music*.

Although we definitely focused on how to read and write music in both braille and print, the students had some time for creative expression through the performance medium of sound using the SONAR software. The result was a mix of original arrangements and compositions. Most notable was a protest song entitled “I Want to be a Rock Star” written and performed by Daniel Martínez. Danny first recorded himself playing his guitar. Then, as he listened to his guitar track through headphones, he sang and recorded his vocal track. The results were impressive.

On the final day of our camp, we gathered in TSBVI’s auditorium. Teachers, parents, school staff and fellow students gathered to witness our presentation of the fruits of the labor of our young musicians. Sighted members of the audience watched a video screen that displayed the music notation for each student’s class project. Everyone listened to the pieces played back on a laptop computer. Then Kristi Kneedle, a talented player of the baritone horn, played a duet with her teacher on cornet. With her left hand, Kristi read the bass line to Bach’s *Sleepers Awake* from a braille score created by Dancing Dots’
GOODFEEL software while she worked the valves of the baby tuba balanced on her knee! This demonstration was a great crowd-pleaser. The crowd also enjoyed a few SONAR recordings produced by some of the students, "I Want to be a Rock Star" in particular. After that, Ms Rundquist led her chorus of solfege singers in their unique arrangement of *My Country ’tis of Thee* sung first as separate parts, and then in the traditional four-part harmony with Kristi accompanying on her baritone. Each group sang their part of this familiar song using the solfege syllables instead of the well-known words while reading their own part in braille music notation. Yes, blind people can “sight read”!

The program ended with a surprise musical presentation to Mr. McCann in which the students expressed their thanks for what they had learned at our camp in a lovely song. Young Miss Kneedler told the group during their final rehearsal that the camp had been “the best thing that ever happened to her in her whole life!” To say that hearing that statement made her teacher’s day, would be the understatement of the year!

Certainly each of these young, talented, and intelligent students learned some new musical and technical skills and sharpened the skills they brought with them. But what I hope I gave them all, in addition, was the confidence to believe that they could move into a new situation, work hard, and excel. Music and technology can teach us so many life skills: discipline; patience; tenacity; concentration; teamwork; presentation techniques; poise; self-assuredness; and on and on and on. It was my pleasure to watch these young people
progress over the two short weeks we shared and increase their own store of these life skills.

THE FUTURE

Plans for next year are still tentative. Sharon Nichols, the program coordinator, Jane Rundquist and Bill McCann had a conference recently to discuss possibilities. Everyone agreed that the program had been a success on many levels and that we would like to do an encore next summer. There are a number of ideas for making this an even more productive session. More information will be available in the Summer Program information that will be posted to the TSBVI website.

THE TECHNOLOGY

Dancing Dots offers a suite of mainstream and assistive technology software that provides many features to musicians. Sighted individuals who can read conventional printed music (staff notation) can scan, edit and automatically transcribe print music into the equivalent braille music notation. These “copyists” need not necessarily know anything about braille. Music can also be played directly into the software’s editor via an electronic musical keyboard, or even imported from programs like Finale and Sibelius, the two music notation editors used by the majority of music educators in the U.S. and abroad.
The following are the tools used in the Braille Music Technology summer program at TSBVI.

- **Sharp eye** scans printed music and converts it to various music file formats (MIDI, NIFF and MusicXML). The software also has a playback which allows you to listen to the piece through your PC computer’s soundcard.

- **Lime** is a free mass market music notation writing and editing software used by many schools and universities. Lime alone is not accessible to blind users.

- **Lime Aloud** works together with JAWS to make Lime music files accessible to blind users. When using Lime Aloud, a musician can read music using the arrow keys to move through the music notation (Lime) file. Lime Aloud plays each note or chord and describes any notation associated with the music. In addition, musicians can enter music from a PC or music keyboard and Lime Aloud will convert it to music notation. Lime Aloud produces sound and printed music notation; it does not include a braille music translator.

- **GOODFEEL** is a braille music translator that allows users to scan printed music, convert it to braille, and emboss it.

- **Cakewalk SONAR** is a mass market music editing software that allows users to record, edit, mix and arrange digital music files on a personal computer.

- **Cake Talking** allows JAWS to make Cakewalk talk. It includes a tutorial for learning to use the software.
**RESOURCES**

**Technology**
Dancing Dots. Braille music technology applications and tools.
  <http://www.dancingdots.com/index.htm>
Lime music notation editing software.
  <http://www.cerlsoundgroup.org/main.html>
Lime Version 8.5 is available from Dancing Dots at
  <http://www.dancingdots.com/lime/8/LimeSetup8.50.EXE>
Opus Technologies. Maker of braille music translators and other applications
  <http://www.opustec.com>

**Books and Instructional Materials**
  <http://www.dancingdots.com/prodesc/currdet.htm>
  <http://www.dancingdots.com/prodesc/whosafraid.htm>

**Web Resources**
National Resource Center for Blind Musicians.
  <http://www.blindmusicstudent.org>
Braille Through Remote Learning, online instruction in the braille music code.
<http://www.brl.org/music/index.html>

It Takes a Team to Teach Independent Living Skills
By Eva LaVigne, Education Specialist and Kate Moss, Statewide Staff Development Coordinator, TSBVI

Abstract: The first in a series of four articles discussing the importance of teeming to teach independent living skills to students with visual impairment.

Key Words: Programming, visually impaired, blind, deaf-blind, independent living skills, teaming, Expanded Core Curriculum

Editor’s Note: This is the first article in a series about the importance of teaching independent living skills, including specific strategies for parents and teachers. We are very interested in hearing from our readers about their experiences (both successes and challenges) in teaching these skills to students with visual impairments and deafblindness. Please send your documentation forms; ideas for teaming and identifying/teaching skills; and successes working on daily living skills to Kate at <katemoss@tsbvi.edu>.

Unless you are an unusually rich and spoiled prince or princess, there are some things you need to learn to do for yourself, or at least be able to manage for yourself, if you want to be a part of mainstream life. If you are visually impaired, learning to do some of these basic things requires systematic
The “National Agenda for the Education of Children and Youths with Visual Impairments, Including Those with Multiple Disabilities” lists nine areas as part of an expanded core curriculum that is needed for any student with visual impairments. These areas are: compensatory or functional academic skills (reading, writing, math, etc.); orientation and mobility; social interaction skills; recreation and leisure skills; career education; technology; self-determination; visual efficiency skills; and independent living skills. It defines independent living skills as “all the tasks and functions persons perform, in accordance with their abilities, in order to lead lives as independently as possible. These curricular needs are varied, as they include skills in personal hygiene, food preparation, money management, time monitoring, organization, etc.” (Hatlen, 1996)

Almost no one would dispute the necessity of learning independent living skills. The reality of teaching these skills in current school environments, where great emphasis is placed on academic subjects, is that too often many of these skills are “introduced as splinter skills, appearing in learning material, disappearing, and then reappearing.” (Hatlen, 1996) Systematic instruction in independent living skills often seems an unachievable goal. The ‘when’ and ‘where’, not to mention the ‘how’, of instruction is a real challenge for VI professionals, most carry big caseloads, who must provide instruction in less than ideal environments on typical school campuses. Still, these skills can and must be taught. To do it well, we think it requires a team.
WHO’S ON THE TEAM?
Ideally a team is made up of the student, the student’s family, and the VI professionals (TVI, COM, Rehabilitation Teacher). Depending on the individual situation, special and regular educators may also play an important team role. The student and family are key players since they need to be able to identify priority skills areas, and commit energy to practicing skills daily in real-life settings. The VI professionals need to carve out time for individual instruction with the student, and/or coordinate with other educators and professionals to see that skills are taught using appropriate adaptive techniques. The regular and special educators need to make sure that learned skills are applied in all school settings, and give necessary feedback about the student’s progress to the student, family, and VI professionals.

WHAT DOES THE TEAM DO?

Determine priority areas
The first task for the team is to determine priority areas for instruction. What are the skills that are most important for the student to learn at any point in time? To a large degree, only the family and the student can say. Each family has its own dynamic. If you don’t believe us, just tune in to an episode or two of Wife Swap. In one family it may be very important for the children to participate in a variety of chores and take care of many of their own basic needs such as making a snack, choosing their clothing, grooming and dressing themselves, and keeping their things organized. In other families, there may not be as much emphasis placed on younger family members doing these things. Unless the family supports the
instruction that takes place at school, the student with visual impairments probably won’t be highly motivated, or get enough practice or praise to achieve real levels of independence in a particular skill.

Evaluate

Once priority areas are identified, the VI professionals should see that there is a thorough evaluation of the student’s current skills. That way the team can find an appropriate starting point, and guide the development of skills along a continuum. For example, you wouldn’t start out having the child learn to button his shirt if he didn’t have the necessary fine motor skills or he couldn’t yet take off his shirt. There are a variety of assessment tools available. Some of these include assessments/checklists found in: Independent Living Skills: A Curriculum with Adaptations for Students with Visual Impairments (Loumiet and Levack, 1993); Basic Skills for Community Living: A Curriculum for Students with Visual Impairments and Multiple Disabilities (Levak et al, 1996); “Student Performance Indicators (SPI)” developed by Region 13 ESC <http://www.tsbvi.edu/Education/spi.rtf>; Addressing Unique Educational Needs of Individuals with Disabilities: An Outcome Based Approach (Frey et al, 1991); or Functional Skills Screening Inventory (Becker et al, 1984).

Determine When Instruction and Practice Can Take Place

Some of the adaptive techniques a student may need to accomplish an independent living task have to be taught initially in a one-on-one pullout situation. Once the technique has been taught, the opportunity to practice skills usually can be embedded in activities throughout the day in a variety of
school and community settings. For example, the TVI might teach the student strategies for identifying money and organizing it in a wallet during an individual lesson. The family, teachers, and paraprofessionals who interact with the student most are the ones who are most likely to support the student in practicing the skills in the cafeteria, on a field trip, at the grocery store, and at home. They are also the ones who will be most often in a position to insist that the student practice these skills in these settings. This helps the student more readily understand how that skill can make life easier and help him fit in with his peers.

Some skills, like cooking and cleaning, may be easier to teach in a home setting. If the TVI cannot regularly access a kitchen at school, perhaps a Vocational Rehabilitation Teacher from DARS Division for Blind Services (DBS) may be able to teach more advanced cooking skills in the home. However, the TVI may be able to collaborate with a home economics teacher to provide instruction during the school day. Every type of skill the student needs to learn can be taught, but some brainstorming will be needed to figure out when and where.

When it comes to practicing skills, everyone has a role to play. Family members should identify activities for practice in the home, and have the expectation that the student will be responsible for completing activities using these skills. Regular and special education teachers also need to systematically identify opportunities for skills practice within the context of the daily classroom routine. Some skills are easier than others to infuse, but with good team planning and
collaboration almost any skill can be practiced multiple times every day.

If the family’s priority is learning better skills for eating, evaluation might reveal that the student needs to focus on eating different food in an efficient and acceptable manner. The TVI might work with the student to teach some particular strategies, such as finding food on the plate, or using a fork to eat meat and vegetables while using a spoon for items such as pudding, ice cream, or soup. The TVI would also make sure the parents and other adults who are with the student during the rest of the day know what strategies the student needs to use. At home the parents may try introducing new foods, perhaps by having the child help to prepare the food item or by asking him to “try one bite.” They might also ask the child to locate the food items on his plate before beginning to eat, and suggest which utensil to use on each one. The general education teacher might oversee the student during lunch to see how well the student can use these skills independently in the cafeteria or during snack time. If the teacher is planning a unit about a particular country, good nutrition, or plants and animals, opportunities to learn about and try new foods might be included in these units. Planning how each team member will support the goal is a very important part of the process.

**Document and Share Progress**

An effective team will also have a plan for documenting progress and sharing that information with other team members. The more each team player is aware of what the student can and cannot do, the better they will be able to support him/her. They can also encourage the student and help
build his/her self-esteem as goals are accomplished. Some teams may want to start a journal to share progress notes. Other teams may use other types of documentation of skills such as a Skills Matrix (see example below).

<table>
<thead>
<tr>
<th>Skill</th>
<th>Lunch</th>
<th>Science</th>
<th>Math</th>
<th>P.E.</th>
<th>Home</th>
</tr>
</thead>
<tbody>
<tr>
<td>Measure dry ingredients using a cup, half-cup, Tablespoon, teaspoon</td>
<td>+ measured sugar with tsp.</td>
<td>+ w/ Tbs. &amp; tsp.</td>
<td>- had trouble with 1/2 c. line</td>
<td>+ used c. and 1/2 c. in recipe</td>
<td></td>
</tr>
<tr>
<td>From memory, select appropriate coins for familiar vending machine</td>
<td>+ id. quarters to purchase chips from vending machine</td>
<td>+ found quarters in change to buy coke on field trip</td>
<td>+ 2 quarters and dime for chips</td>
<td>- confuses nickel &amp; quarter at coke machine</td>
<td></td>
</tr>
<tr>
<td>Use a brush, comb, or pick to style own hair.</td>
<td>- needed assistance with pocket comb</td>
<td>+ brushed hair on his own this AM</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

It is also powerful if the school and family can videotape examples of the student working on independent living skills. This serves to provide feedback to the whole team, and highlights successes and problems the student may be having in generalizing the skills that he/she has learned.

Teaching independent living skills may be challenging in many of our school environments, but it is also critical for our students with visual impairments. Better instruction and practice can take place if there is a team approach to planning, evaluation and, instruction.
RESOURCES AND READINGS


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I Want My Computer Games!

Sharon K. Nichols,
Assistive Technology Consultant, TSBVI Outreach

Abstract: This article describes educational and entertainment computer games available for students who are blind or visually impaired.
Key Words: Blind, visually impaired, computer games, accessible games, educational games, resources.

How many times have you heard your child or student ask for computer games which are accessible? Did you know that they do in fact exist? Or are you still struggling to view playing computer games as a viable learning experience? While I might agree that students might benefit from more educationally sound games, accessible computer games offer a “fun” way to learn computer skills. It is also important to remember that games may require the player to apply, and therefore develop, such skills as information and resource management; strategic planning; and thinking skills.

You are not alone in your concern about computer games, but that has not stopped computer gaming from becoming a multi-billion dollar industry. According to “Off to college to major in ... video games?”, an article in the Christian Science Monitor, “video games seem to be gaining academic stature”. The article goes on to state that, “A few big-name universities are toying with the serious side of video games. The Massachusetts Institute of Technology, the Georgia Institute of Technology, and Carnegie Mellon University offer curricula on video-game criticism, games as educational tools, and game design.” For more of the article, go to: <http://www.csmonitor.com/2003/0829/p01s04-ussc.html>.

But I digress. There is still the question of your student or child who is visually impaired having access to quality, accessible games. I will take this opportunity to familiarize you will the wealth of choices available for accessible games. The games are listed in alphabetical order, with no preference
or ranking. Please read the accompanying web pages for game information and pricing.

- <http://www.bavisoft.com/> – Bavisoft Software for the Blind and Visually Impaired

  “Bavisoft has amazingly and irrevocably changed the computer gaming industry. In place of graphics, our audio games are powered purely with sound imagery, opening a new world of entertainment for the blind and visually impaired. Utilizing the skills of professional programmers, sound engineers, musicians, and voice talent Bavisoft provides game players with unparalleled music and sound quality, creating a gaming experience like they’ve never imagined possible. Absolutely no vision is required to play these games!”

- <http://www.bscgames.com/> – BSC Games

  “We specialize in creating accessible computer games for the blind or visually impaired. We use the latest Microsoft DirectX technologies in our games to bring quality entertainment to our customers at extremely competitive pricing. BSC Games is owned and operated by Justin Daubenhmire, who himself is blind.”


  Maker of Mobile Speak software for cellular phone accessibility, this company also offers educational and entertainment games.

“Draconis Entertainment is dedicated to delivering high quality entertainment products to both sighted and non-sighted persons, with a focus on accessible computerized audio games for the blind and visually impaired.”

• <http://www.gamesfortheblind.com/> – Games for the Blind

“Accessible Games SV are designed specifically for visually impaired and blind computer users. I am totally blind and wrote these games myself.” The games are self-voicing and do not require a screen reader.

• <http://www.generalcoffee.com/futureboy/about.html> – Future Boy!

This game is not specifically designed for students who are blind or visually impaired, but you can set the prompts to be spoken from the Options menu. This game requires a screen reader, such as JAWS or Window Eyes for full accessibility.


“Games and Entertainment Files”

• <http://www.audiogames.net/listgames.php> – Audio Games

This site is a database of all available audio games. Not all links on this site are valid, so use at your own discretion. This web site also has a link to Audyssey Magazine, a magazine dedicated to blind and visually impaired gamers.

I hope this information is useful, and don’t forget Christmas is coming!
Looking to the Future
by Barbara J. Madrigal, Assistant Commissioner, DARS-Division for Blind Services

Abstract: This article reflects on Division for Blind Services performance during fiscal year 2006 and discusses activities that will occur during the upcoming fiscal year.

Key Words: blindness, vision impairment, DARS, Division for Blind Services, Vocational Rehabilitation Program, Business Enterprises of Texas, Independent Living Program, Criss Cole Rehabilitation Center, Blind Children’s Program, employment, News and Views

The Division for Blind Services is closing yet another year of services to blind Texans and moving quickly into the new federal fiscal year that begins on October 1, 2006. This is an important moment in time for us because it gives us an opportunity to look simultaneously at both the old year and the new year.

The past year has been excellent. As this article goes to press, we still have several days in the current reporting period so we don’t yet have the final figures for the year ending September 30, 2006. Still, the preliminary statistics point to the continued successful efforts by all our program and support staff to focus on quality services for each of the individual consumers we have worked with during the past twelve months.

In our Vocational Rehabilitation Program, competitive employment closures at or above minimum wage are strong.
This measure means that our staff have helped people who are blind or visually impaired prepare to enter (or reenter) the world of work successfully. More importantly, it means that more blind Texans are moving towards a solid future based on economic and personal self-sufficiency; more employers are recognizing that the decisions they make about hiring qualified employees should be based on ability, not disability; and that negative social attitudes about blindness are continuing to fall. Business Enterprises of Texas (BET), a federally sponsored, state-administered program that provides food management opportunities for Texans who are blind, is also reporting a solid year. We have negotiated several new locations around the state, and we look forward to opening even more locations in the coming year—which means more growth opportunities for the individuals who are already in the program and new opportunities for successfully closed consumers who are interested in pursuing a career in the food service industry.

Our Independent Living Program for older Texans continues to provide excellent services and achieve first-rate results, despite the inevitable “growing pains” attributable to an increasing number of people who experience vision loss as they age. Program services, which focus on the consumer’s desire to maintain personal independence in their own home and community, include all of the elements encompassed in our Texas Confidence Builders philosophy: adjustment to blindness; independent living skills (such as reading, cooking healthy meals, keeping personal financial records, and doing routine home maintenance); communication skills; independent travel skills; and building confidence in one’s own abilities.
The Criss Cole Rehabilitation Center (CCRC) in Austin continues to offer an extensive array of services designed to meet the specific needs of individual consumers. During the past year, CCRC has also increased the availability of “outreach” programs that take the skills and knowledge of the Center directly to small groups of consumers in their local communities. These innovative training activities help consumers gain self-confidence and a positive attitude about blindness. Indeed, successful completion of an outreach training program will often provide the motivation a consumer needs to travel to Austin and participate in the more intensive and comprehensive CCRC program.

The specialists and staff with our Blind Children’s Program continue to work with our youngest Texans to help them build self-esteem, discover their unique strengths and abilities, and create a firm foundation for learning the skills they will need as adults to meet the challenges of life. And, of course, Transition Program staff have been busier than ever preparing students to move from school to work.

Yes, 2006 has been a very good year. But now it’s time for the Division for Blind Services to look forward to the new year. We recently initiated a voluntary mentoring program for staff that we call FUTURES. This program is a succession plan designed to ensure we will have highly qualified people in all positions within our organization well into the future. FUTURES will match staff who have extensive experience in rehabilitation with staff who want to expand their knowledge in their current position or, in some cases, positions in other specialized areas of consumer services and/or management.
We’re very excited about this new program, and we anticipate our first “graduating class” in 2007.

When we look to the future, we also recognize that we must continue to strengthen and grow the essential cornerstone of effective and innovative services for Texans who are blind or visually impaired: employment assistance services. For adults of working age as well as young adults preparing to enter the world of work for the first time, employment-related services represent the foundation of personal and financial independence.

To ensure the quality of future services in this critically important area, we have initiated a major task known as the Employment Assistance Quality Improvement Project. Improving our employment assistance efforts will put us in a better position to adapt to all the changes confronting today’s workforce and the ever-increasing growth of technology in the workplace. This project will help us improve what we are already doing and identify new ways to provide better employment-related services in the future.

Both of these initiatives are major projects. We have chosen to undertake them now because they represent the future of our organization as well as our ongoing goal to continuously improve the rehabilitation services we provide for our consumers. In terms of the more immediate future, we have already begun the Legislative Appropriations Request (LAR) process for the 2008-2009 biennium, and we are working closely with Legislative Budget Board staff prior to the next legislative session that begins in January to review our program funding requests for the next biennium.
The upcoming new year will also mark an especially important milestone for all of us — our organization will celebrate 75 years of quality services to blind Texans! We plan to announce the newest addition to our Wall of Honor in October (and, no, I can’t divulge the honoree’s name until the plaque is officially unveiled!). We will also have a brief ceremony with several great guest speakers at our Criss Cole Rehabilitation Center in Austin. We anticipate the celebration will give us a unique opportunity to look at services for blind Texans with the past, the present, and the future all rolled into one!

Happy New Year!

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A Momentous Anniversary Year

By Gloria Bennett,
Director of Community Resources, TSBVI

Abstract: The author summarizes recent events celebrating the 150th birthday of the Texas School for the Blind and Visually Impaired, including the Alumni Reunion held this August.

Keywords: Family, TSBVI Sesquicentennial Celebration, Alumni Reunion, News & Views

THE BEGINNING

One hundred fifty years ago, on August 16, 1856, Governor Elisha Pease signed “An Act to Establish an Institution for the Blind.” A sum of ten thousand dollars was appropriated for the establishment of the Institution of the Education of the Blind of Texas, to be located at the city of Austin. Five trustees were
designated to administer the funds, rent a building, hire a superintendent and manage said institution.

2006 has been a significant year in the history of Texas School for the Blind and Visually Impaired, as we celebrated our origins and our pride in today’s mission. To mark this milestone, Governor Rick Perry recognized August 16, 2006 as “Texas School for the Blind and Visually Impaired Day,” and issued a message of congratulations:

“Since 1856, the Texas School for the Blind and Visually Impaired has been committed to providing the best education to its students. In addition to a quality education, the school’s teachers and staff also instill in the students the idea that, regardless of their challenges, they are able to achieve greatness. With activities ranging from sports to the school newspaper, the school provides its students with an incomparable learning experience that will ensure their future success...I commend past and present instructors, staff and administrators for 150 years of outstanding service. Your work and tireless efforts highlight the best of the Lone Star State.”

He concluded his proclamation: “To all the students, remember always that within you lies greatness, and the ability to dare, dream and do. No obstacle is too great for you, as you are Texans. I have no doubt that you all will excel in your future endeavors.”

THE CELEBRATION

The celebration began in January of 2006, with a glittering evening event in the Goodenough Performance Hall honoring
the staff, students, and graduates of the Texas School for the Blind (1856), Texas Blind, Deaf and Orphan School (1887), and Deafblind Annex (1970). Mayor Will Winn, Dr. Phil Hatlen, and 1956 graduate Wilton Harris, among others, spoke to the crowd of current and former TSBVI staff and students, as well as community friends. Former students of TSBVI provided musical entertainment, and a reception followed the program.

We continued the yearlong festivities in April by hosting a regional track meet for students of schools for the blind from New Mexico, Louisiana, Alabama and Mississippi, as well as our Texas team. In May, the drama department presented five public performances of the musical Into the Woods. On August 16, the United States Post Office provided a special 1-day commemorative cancellation recognizing TSBVI, hand-canceling stamped envelopes at the school. Through the research and hard work of TSBVI’s Kristi Sprinkle, we created the Hatlen Museum on our campus <http://www.tsbvi.edu/school/museum/index.htm>. This wonderful repository of TSBVI history was dedicated on November 4, 2006 at our final event of the year, Parent Weekend, with the theme “Happy Birthday TSBVI” and birthday cake for all!

**REUNION WEEKEND**

One of the highlights of our Sesquicentennial celebration occurred on August 18-19, 2006, as TSBVI hosted an Alumni Reunion. Over 150 former students and staff of the school attended. The weekend began with a ‘Meet and Greet’ on Friday evening at the Park Plaza Hotel where many out-of-town alumni were staying. Music was provided by Marcus
Cardwell’s Lime Trio of saxophone, piano, bass and drums. At registration, attendees were given packets containing the weekend program as well as a Reunion Weekend t-shirt, a Sesquicentennial water bottle and material explaining TSBVI’s many programs.

Saturday morning activities included tours of the campus, and brunch in the cafeteria. Alumni filled out a questionnaire about age, dates of attendance, family details, travel details and more. From this information we learned that the oldest alumni in attendance was 80 and the youngest 22, a span of more than half a century! We had alumni come from as far away as New Jersey and California, and as near as down the street. We learned that the all-time favorite teachers of those attending were Louise Hancock and Art Cruser. When asked what life lesson should be shared with young people, answers included:

“Finish what you start. Stick with it, and do not quit.”

“Be yourself.” “Make up your mind and go for it.”

“Be independent. Assert yourself.”

“Believe in yourself – you’re capable of more than you know – never give up with really trying. Give everything and try and have fun. You’ll never regret an honest try.”

“Work hard; laugh often; treat others with respect; dress nicely.”

“Keep your mind clear and your heart healthy.”

“Practice what you learned at TSBVI.”

“It’s not as scary as it seems being on your own.”
“Become a part of your community as soon as you can.”

The afternoon began with a choice of activities: visiting the TSBVI museum or the traveling Callahan museums exhibit, “In Touch With Knowledge: the Educational History of Blind People”; recording school memories on videotape; watching old school videos; meeting with classmates in rooms by decade; or attending a technology demonstration. Later that afternoon, a Musical Memories Program took place in the Goodenough Performance Hall, with Principal Miles Fain acting as Master of Ceremonies. Alumnus Aundrea Moore sang the national anthem, and former music teacher Patsy Cruser led the assembly in singing of the school song, which many former students knew well enough to sing along. Many people came up to the microphone to share their memories, including 1967 graduate Anne Foxworth, who told about the ringing of the bell to start and end every activity while she was in school. She even brought a bell to put in the TSBVI museum. Music was provided by former students Marcus Cardwell, Robert Kelley, Steve Johnson, Krisha Hagler, Terutada Simazu, Andrew Venson and Rodney Hyder. Miles Fain told the gathering about the state of the school today and Dr. Hatlen talked extensively about the renovations planned for the campus in the future.

Dinner was served in the gymnasium, transformed by balloons and table flower baskets in school colors of maroon and gold. A delicious dinner was catered by Harvey and Georgina Stavinoha of Phoenix Kafay Katering and served by cheerful wait staff. Art and Patsy Cruser and Matthew Caldwell served as Masters and Mistress of Ceremonies for the evening. They gave out prizes for such accomplishments as “came the
farthest,” “married the longest,” “most children,” and “most times married.” Time was taken to remember those who had passed away. A very special guest was Mrs. Mable Myers, a beloved teacher from long ago. Mrs. Myers sent a thank-you to the Reunion committee in which she wrote, “I had such a delightful time visiting with you and my former students. The food, the atmosphere and the memories with the former students was just breathtaking. I loved every minute of it!!”

Another comment on the meaning of the Reunion Weekend came from 1975 graduate Rick McCracken:

To The Administration, Faculty, Staff And Volunteers At Texas School for the Blind and Visually Impaired:

To each of you, thank you so very much for an extraordinary opportunity to gather and celebrate the school’s sesquicentennial last weekend. Your care and kindness for each of us was simply stellar.

I went through the school at a time when students lived like brothers and sisters, and when staff and faculty were regarded as family elders. And let me say that the sense of family was greatly evident in the weekend’s proceedings, even though I did not meet many of you for more than a moment in passing. To Dr. Hatlen, thank you for opening your campus to us again. As you no doubt surmised during the program, we are deeply rooted in not only the traditions of TSBVI, but the places where those traditions allowed us to blossom into a community. To Mr. Caldwell and Mr. and Mrs. Cruser, my sincere gratitude for the warmest welcome I could imagine. It’s good to know your memories are as clear and warm as mine. To Ms. Bennett, and all the staff and volunteers who sacrificed a weekend with their own families, you exemplify
the dedication and caring far beyond the call of duty that has always been a hallmark of TSBVI teachers and staff.

I can only speak for myself, but I know there are other former students who understand that your obligation to us ended when we accepted our diplomas and tossed our tassels. This memory weekend did not have to take place, but YOU saw to it that something so central to our development as men and women should be celebrated. And you were right. It is my hope that we as students will be inspired anew to fulfill our obligation to honor the memories of the school, and more importantly, the work that you continue to do by outstretching our hand of aid and friendship to help you further the cause of bringing the light of knowledge to blind and visually impaired children throughout Texas and the world. Even though I am now far away and long removed from my TSBVI family, I stand ready to do whatever is in my power to ensure that the Texas School for the Blind and Visually Impaired is no less important for the future than it was during our present, and during this most memorable weekend.

Again, Thank You:

Rickey (Rick) McCracken”

The staff of TSBVI have used the occasion of the 150th Sesquicentennial anniversary to look back and celebrate our history, look inward to assess the job we do, and look forward to the future of serving blind and visually impaired of children at a newly beautified campus and throughout the state with comprehensive programs, short term and summer programs, post secondary programs, curriculum development, accessible website, and outreach services.
Expanded Opportunities for Secondary Academic Students in Texas School for Blind and Visually Impaired’s Summer 2006 Programs
by Kay Pruett, TSBVI Special Programs Instructor

Abstract: Texas School for the Blind and Visually Impaired offers an array of unique and innovative summer programs for students with visual impairments from around Texas.

Key Words: News & Views, TSBVI, Special Programs, summer.

Secondary academic students with visual impairments often spend their school year focused on the core curriculum at the expense of the expanded core curriculum, and rarely get opportunities to interact with other visually impaired students. TSBVI offers programs designed specifically for this group of students as part of a wide array of exciting summer programs for various groups of students with visual impairments.

During the summer 2006 session, TSBVI greatly expanded their offerings for secondary academic students with visual impairments. All of these programs provided students opportunities to build a meaningful social network, to practice the unique skills necessary for successful living as adults with visual impairments, and to learn and practice skills related to a specific teen interest.

Several successful classes from the past were offered as summer programs along with eight completely new programs. To meet expressed needs of local districts two Short-Term
Programs usually offered only during the school year were held in June. Here is a sample of the 2006 offerings:

- **Braille Music**: Nine students worked with Jane Rundquist (TSBVI’s music teacher), Bill McCann (Professional Musician, Programmer and President and Founder of Dancing Dots Music Technology Company), and Sharon Nichols, (TSBVI Outreach Department technology consultant). Students improved braille music reading and writing while learning Dancing Dots braille music and recording programs and creating music together. They worked hard, but were always smiling and ended their work with an outstanding performance of their music on the TSBVI stage.

- **Restaurant Management**: Under the capable guidance of Mark Paredes (Certified Chef and TSBVI instructional staff member), eight students studied restaurant management and materials, searched the Internet for recipes, planned the menu and ran a well-received restaurant on the TSBVI campus. They also skillfully catered the reception and cast party concluding the always-inspirational Camp Fine Arts performance.

- **Camp Fine Arts**: This quick and intense program of creative expression served more students than ever before. TSBVI drama teacher, Robert Pierson, and creative teaching assistants were responsive to student interests and supported the original student production of the film: “Pirate: The Adventures of Pierre Sorrel”. Meanwhile, Jane Rundquist and others supported students in developing vocal and instrumental music, writing and performing original songs, and choreographing and
performing several dance pieces. Several students capably performed art forms or on instruments they had never played before.

- **Rock Band Camp**: This new program was lead by a team of skilled Austin musicians who are also long term TSBVI instructional staff members. Seven students traveled by public transportation into the community to learn about equipping and recording rock bands. Back on campus, they selected their instruments and songs and worked hard to master them for both live and recorded performance. Several of the students learned to play new instruments, including guitar and bass guitar. They exercised growth in personal and social skills, as they became a mutually supportive performing band. They created a recording of their pieces and concluded their camp by playing live in the Camp Fine Arts performance.

- **Radio Station Management**: As in past secondary academic summer projects, students created their own radio station with the support of TSBVI staff and a volunteer radio professional. Trips to local radio stations and interviews with a DJ who is blind provided good models for students. Eight students had fun with their friends in this and other programs as they practiced technology, communication, social and other skills of successful adult working and living.

- **Getting There**: As in the past, these students were on the go. They traveled by foot, bus, boat, train and taxi. With the guidance of a certified O&M instructor, they practiced planning their trips, staying safe in interactions with the public, and requesting the information and help they
needed. They toured the airport and documented their experiences in individual scrapbooks.

- **Writers Workshop**: Badgerdog Literary Publishing, Inc. and TSBVI jointly offered this opportunity for students to write, publish and perform their own work. Under the capable leadership of Katie Williams of Badgerdog, and Robert Pierson, TSBVI language arts teacher, students created a supportive environment where they shared and critiqued one another’s written work. The student authors completed all the steps of the publishing process to have their work included in the *Youth Voices in Ink* and *Youth Voices Embossed* summer anthologies. The class concluded with an impressive reading of original essays, poetry, and short stories, as well as the dramatization of an original play.

- **Recreational Technology**: Students improved and practiced their computer skills as they explored recreational uses of computers. They created a culminating PowerPoint document including student research and writing about individual student interests.

- **PE: Recreational Sports Camp and PE: Athletic Sports Camp**: These sports camps offered middle school students the opportunity to experience and explore specific sports they may not have been invited to try in their home communities. Recreational sports included noncompetitive and community activities such as ice skating, bowling, swimming, scuba diving, billiards and hiking. They also explored camping equipment and other recreational equipment. Athletic sports addressed team and individual competitive sports such as football,
basketball, baseball, goal ball, track and field, and swimming. This group joined the Cheerleading Camp to enjoy a tour of athletic facilities on the UT campus. Both groups got a jump on learning adult living skills by doing most of their own shopping and cooking, and traveled daily by public transportation to their outings in the community.

• **Cheerleading Camp:** The group in this one-week camp did concentrated work on the skills needed to participate in a cheerleading squad. The group worked out daily, learned routines, cooked for themselves, took public transportation to meet up with the sports camp for a tour of the UT athletic facilities, and documented their work in individual scrapbooks of their original creations. They developed from a group of individuals into a supportive working team. Their week concluded with a sharply executed and fully synchronized performance of sideline cheer routines.

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**Short-Term Classes for Academic Students at the Texas School for the Blind and Visually Impaired**

By Lauren Newton, Principal, TSBVI Special Programs

**Abstract:** This article provides a calendar and descriptions of the TSBVI short-term classes.

**Key Words:** News & Views, TSBVI, special programs short-term

Academic students with visual impairments can best reach their potential for successful employment and adult life in the
community when provided with the specialized tools and strategies essential for accessing the curriculum. Since the 2000 school year, school-aged students have attended short-term classes at TSBVI to receive 3–5 day intensive instruction in the various areas of the Expanded Core Curriculum for Visually Impaired Students that lead to successful adult living. In addition, many of these classes focus on the knowledge and skills needed to access the Texas school curriculum, to help students perform more successfully on the Texas Assessment of Knowledge and Skills (TAKS).

The remaining calendar of classes for the 2006-2007 school year is presented below. You can read a description of each class by going to our web page <www.tsbvi.edu/school/special/short-classes.htm> and clicking on the name of the class you wish to learn about. You are also encouraged to call the program’s principal for information about how to enroll a student in one of the short-term classes.

**SHORT-TERM PROGRAMS**
**FOR ACADEMIC STUDENTS**

**Remainder of the 2006-2007 School Year**

**Fall Semester 2006**
- Nov 26 - Dec 1  Math Tools and Concepts (secondary)
- Dec 7 - 10 ** Middle School Independence Weekend
- Dec 14 - 17 ** Elementary School Independence Weekend

**Spring Semester 2007**
- Jan 14 - 19  High School Access to Academic Skills #2
- Jan 28 - Feb 2  Middle School Access to Academic Skills #2
Feb 7 – 11** Technology Weekend (secondary)
Feb 22 - 25 ** Low Vision Weekend (secondary)
Mar 4 - 9 Secondary Technology Week #2 (secondary)
Apr 20 - 24 ** Capitol Experience (secondary)
Apr 26 – 29** High School Independence Weekend
Apr 29 – May 4 Elementary Academic Access #2:
  • Elementary Academic Access
  • Elementary Technology
** weekend classes
Contact: Lauren Newton, principal
<laurennewton@tsbvi.edu>
(512) 206-9119

 CdLS Foundation Provides Comprehensive Information Packet Free-of-Charge
Announcement from CdLS Foundation

Abstract:  Cornelia de Lange Syndrome Foundation announces availability of comprehensive information packet to anyone who is interested in learning more about the syndrome.

Key Words:  CdLS foundation, Cornelia de Lange Syndrome, blindness, visual impairment, News & Views

As the end of September is upon us, we know that many children with CdLS are in new classrooms or working with new professionals through various programs. We receive calls daily from families, doctors, teachers, nurses, therapists, and students, etc., who are providing services to children with CdLS or doing presentations about CdLS and would like to have more
information. In an effort to educate families and professionals about CdLS, a comprehensive packet of information is available free-of-charge to anyone who is interested in learning more about the syndrome.

This packet includes a recent issue of our Reaching Out newsletter, a copy of our Find One Child DVD, the Foundation awareness flyer, the FACTS about CdLS brochure and the CdLS Foundation brochure, as well as an informational bookmark.

You can request a packet by calling Barbara at 1-800-753-2357 or emailing her at <info@cdlsusa.org>. Please include the names and specialties of all professionals for whom you are requesting a packet. Inform someone today about CdLS!


Dots For Families
Website Announcement

Abstract: this article describes “Dots For Families,” a website for families and others to learn about braille and how the young child might learn braille to develop literacy skills.

Key Words: braille, literacy, Arizona State Schools for the Deaf and Blind, blindness, visual impairment, News & Views

Designed by L. Penny Rosenblum, Ph.D., University of Arizona, and Linda Reed, M.Ed., Arizona State Schools for the Deaf and Blind Outreach Program for the Visually Impaired, this site is for families and others to learn about braille and how the young child might learn braille to develop literacy skills. Starting with the
braille alphabet, families and others can learn to read and write braille through 15 short lessons. Other pages on the web site include Who’s Who in Braille, Fun and Games, Stories and Resources. Check it out at <http://www.ed.arizona.edu/VILiteracy/default.htm>.

The web site was made possible through the ASDB Parent Outreach Program for the Visually Impaired.

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**Bring a “Fella” to the Dance: Be a Texas Fellow!**

By KC Dignan, Ph.D., Professional Development Coordinator, TSBVI

*Abstract:* Substantial incentives are provided to Texas Fellows who recruit new VI professionals.

**Key Words:** visually impaired, blindness, TVI, COMS, recruitment, VI professionals, News & Views

Almost all of us have a story about how one person, *one person*, affected our lives, and after that the lives of many children and students. Recruiting is most effective when it happens person-to-person. As a VI professional or parent you are a powerful recruiter. We want to recognize your efforts through a new pro-gram that acknowledges and rewards the power of that recruiting — “Texas Fellows.”

Texas Fellows are special people who take extra steps to recruit VI pro-fessionals. Texas Fellows are leaders, helping keep caseloads manageable, and ensuring that students have access to TVIs and COMS.
HOW DO TEXAS FELLOWS RECRUIT?

Texas Fellows seek out educators who are curious, good problem-solvers, and committed to students’ success. They share stories of success and not frustrations. They know it can take 12-18 months for someone to apply, so they don’t give up easily, providing encouragement during the application process.

Texas Fellows understand what future VI professionals want to hear. People want to know that:

- **Jobs are available.**
  Districts may create a full or part time position within 12-18 months.

- **Training is available without having to leave home.** Training is provided through Region 2 ESC, Stephen F. Austin or Texas Tech Universities. Training is via distance learning methods so it isn’t necessary to leave for long periods of time.

- **Tuition is paid.** Besides free tuition, there may be local or regional assistance for books.
Future VI professionals will also want to know why they should work with students with visual impairments. There are many good reasons; these were the most typical from a 2003 national survey:

- Having a nontraditional job, or working with non-traditional students;
- Making a difference, a real difference in the lives of children;
- Being student-need driven;
- Working with intriguing students, student that continue to fascinate and inspire you;
- Being respected by parents and administrators as a unique and knowledgeable professional;
- Working 1-to-1 with students, or in small groups;
- The on-the-job diversity; working with both adults and students.

**ANY BENEFITS TO BEING A TEXAS FELLOW?**

- Texas Fellows will be recognized at all statewide events sponsored by TSBVI.
- Texas Fellows and candidates will be listed in the See/Hear newsletter for a year.
- Texas Fellows and candidates will get *free* registration at the next Texas Focus (up to 20 people).

If you are interested in being a Texas Fellow, contact KC Dignan <kcd@TSBVI.edu> for more information. Your candidate must have enrolled in a program (ACP or university) after May 1, 2006 and be taking classes at the time of application. Be a Texas Fellow!
TSBVI On-Campus Workshops
For more information, contact:
Karen Brown at (512) 206-9314

Hands-On: Teaching Daily Living Skills
Presenters: TSBVI Outreach and Comprehensive Skills Staff
December 9, 2006 / 9 AM-4 PM

High Tech Math: Using Scientific Notebook with Duxbury to Produce Nemeth Code and an Introduction to the Accessible Graphing Calculator
Presenter: Susan Osterhaus
January 27, 2007 / 9 AM – 4 PM

Preparing Students for Math
Tactile Graphics on the TAKS
Presenters: TSBVI Outreach Staff
January 26, 2007

QPVI Training
Presenters: Nancy Toelle, Cyral Miller and Chrissy Cowan
Contact: Nancy Toelle (nmt10@sbcglobal.net) or ph 512-494-8658
January 31 - February 1, 2007
Breaking the Isolation
14th Deafblind International World Conference
September 25-30, 2007
Burswood Convention Centre
Perth, Western Australia
Register online:  www.dbconference2007.asn.au

Training from TSBVI
Broadcast on TETN

For more information, contact
your Regional Education Service Center

Improving the FVE and LMA
Presenter: Nancy Toelle
January 24, 2007 / 1:30 PM - 3:30 PM

Assistive Technology and Play
or Recreation and Leisure
Presenter: Holly Cooper
February 21, 2007 / 1:30 PM - 3:30 PM

LID Review of Sensory Learning Kit Activities and Routines

Presenter: Millie Smith
TETN Broadcast: January 17, 2007
Sponsor: Region 3 ESC, Low Incidence Disabilities Project.

For listings of training opportunities around the state, check the
Statewide Staff Development Calendar:
http://www.tsbvi.edu/Outreach/vi.htm
The Texas Deafblind Project presents

The 2007 Texas Symposium on Deafblindness

For parents, adult family members, professionals, interveners, and paraprofessionals who are currently serving or planning to serve children or youth with deafblindness ages birth to twenty-two.

February 16-17, 2007

Omni South Park Austin
4140 Governor’s Row
Austin, Texas 78744

This two-day event includes keynote/general sessions, breakout sessions (eight each day), and presentations of this year’s deafblind service awards. Sessions will be presented by Texas families, educators, and related professionals, as well as national leaders in fields associated with deafblindness. Friday also features a special luncheon for interveners and an evening social for families hosted by DBMAT. Saturday will feature a luncheon for Project SPARKLE families.

Alone we can do so little. Together we can do so much.
– Helen Keller

Registration materials can be found online at: <www.tsbvi.edu>

Early Registration Deadline December 18, 2006
All registration ends January 19, 2007!

For more information contact:
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SEE/HEAR

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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

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