

# SEE/HEAR

A QUARTERLY NEWSLETTER ABOUT VISUAL IMPAIRMENTS AND DEAFBLINDNESS FOR FAMILIES AND PROFESSIONALS  
A collaborative effort of the Texas School for the Blind and Visually Impaired and Texas Commission for the Blind

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## Kate's Corner

One of the best things about working in the field of visual impairments and deafblindness is the wonderful people who become your friends through the years. At the Texas Symposium on Deafblindness which took place in February in Dallas, many of my friends, new and old, came together to learn and to honor some special people we know. Beginning on page 9 you can learn more about this celebration and some special awards that were presented there.

Another event, the Texas AER Conference, took place in April, and a number of our friends were honored there. Join us in congratulating all these deserving folks and celebrating their achievements.

**Kate's Corner - continued on page 25**

*Editor's note: In this edition of SEE/HEAR we wanted to feature a number of individuals with visual impairments and deafblindness who are doing a variety of interesting things with their lives. As you read about each of them, we think you will be reminded that life is about more than a disability.*

## **Absorbing the Sights**

By Amanda Rogers, Staff Writer, *Arlington Star-Telegram*

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Reprinted courtesy of the *Arlington Star-Telegram*

Daynon Welch, 10, plows through the barns at the Stock Show, dodging poop and people with skill and trying to see everything at once. Not so easy when your sight extends only six feet.

“What’s in there?” Daynon asks as he darts ahead of vision teacher Joanne Kennedy’s group. Daynon heads inside a barn he can barely see.

“That would hurt if it fell on you,” he says as he leans closer to a Brown Swiss cow lying in the straw. “Can I touch it?” The Granbury fourth-grader sits down next to the cow to rub her side. Soon he has petted every cow in the area.

Daynon and 53 other youngsters got their chance Friday to “see” the Stock Show and Rodeo courtesy of the Telephone Pioneers, a service organization at Southwestern Bell of Ft. Worth for decades. The Pioneers picked up the \$1,200 tab for 75 rodeo tickets for the students, teachers and chaperones.

The Pioneers take the children to the Stock Show and the circus every year, said Delane Archer, one of the organizers.

None of the children focuses on what they can’t do, only what they can, Archer said. They visit the FFA Children’s Barnyard, cruise through the barn, then head to the rodeo.

To help the children “see” the rodeo, Southwestern Bell supplies 37 headphones connected to a microphone that Paula Reed-Tollet uses to describe what’s going on in the arena.

Rodeos are nothing new for 10-year-old Brittney Holland, who has been legally blind since birth. Brittney, a fifth-grader from Aledo, started riding horses when she was 4 and won her first belt buckle for barrel racing from Professional Youth Rodeo Association at age 9.

What’s so nice about this is they have headphones,” said her mom, Susan Holland. “Even though we go to rodeos twice a month, this helps Brittney know what’s going on.”

Brittney has no vision in one eye and has 20/400 sight in the other. To help her navigate the course, her barrel-racing sister, Hayley, 12, and her mom talk to her on walkie-talkies to tell her when to turn and when to slow her horse, Red. There are also people at each barrel telling Brittney when to turn.

After checking out the animals in the barns, Daynon and Brittney are eager to pull on the headphones to hear Reed-Tollet describe the opening ceremonies at the rodeo in the Will Rogers Coliseum. Both use hand-held telescopes.

“They’re riding a fabulous array of horses and some of them are going to do scary tricks,” Reed-Tollet says excitedly into the microphone. When a bucking horse bursts out of the chute, she tries to explain why the horse is trying so hard to toss its rider.

“We wear a belt to hold up our pants,” she says. “The horses wear a belt, but they don’t care much for it. These are wild horses and they buck.”

Reed-Tollet started doing the running commentary for Southwestern Bell 25 years ago when she worked on a children’s TV show, *Kid’s Korner*, on Channel 11.

“I just try to describe all the colors and what people are doing,” she says as fireworks explode inside the arena. “Ohh, fireworks! That sound you heard was fireworks going off. Don’t be afraid. They’re going off inside the building.”

## **Special Education Serves Diverse Students**

By Tommy Young, Staff Writer with the *Plainview Daily Herald*

Reprint courtesy of the *Plainview Daily Herald*

Many people think of mentally disabled children when they think about special education programs. But director John Hightower says the Plainview ISD Special Education program has evolved into an all-encompassing project.

“We serve students with all manner of both physical and mental special needs. We strive to give all of our students, disabled or not, a fair shot at having equal access to a free public education.”

The district serves 855 students with special needs and a number of the students have physical disabilities. The district has a wide array of programs to help students who need more than traditional instruction.

“We rely on a lot of technology to help our students compete on a level playing field,” said Hightower. “We also employ several individuals with specific training who incorporate the technology to assist our students.”

The district has one physical therapist, two occupational therapists, a school psychologist, a speech therapist, and several teaching assistants who give the students individual attention.

One Plainview student who receives a great deal of assistance from the various technologies and individuals involved in the ISD Special Education Program is Jeffrey Pruett.

He is a 16-year-old freshman at Plainview High. He has been diagnosed with Friedreich’s Ataxia, one of the 40-plus types of Muscular Dystrophy.

“It is a neurological disease that attacks the muscles, but Jeffrey has been hit pretty hard,” explains his mother, Jeanie Pruett. “It doesn’t normally attack as early in life as it did Jeffrey. It also has affected his vision – he is legally blind – and his hearing. He is deaf, and it doesn’t normally do that.”

Jeffrey is confined to a wheelchair and has lost the ability to swallow, necessitating his use of a feeding tube. But Jeffrey’s mind is sharp and vibrant.

As his father Brian put it: “His body is confined to that wheelchair but his mind is free, and he makes the most of that freedom.”

“Jeffrey has the same hopes and dreams as any other 16-year-old. He wants to have a girl friend and go to college and be a productive part of society,” says his mother.

Jeffrey also has the Special Education program at Plainview High helping him be as free as possible and attaining his goals.

“I think the school district and Mr. Hightower absolutely do the best they can to provide Jeffrey and all of their disabled students the best education they can,” said Mrs. Pruet. “They try and get him the kind of equipment he needs, and they’ve even gone as far as to rearrange the bus schedule where he is the last one on the route so he doesn’t become fatigued due to his bus ride. They’ve even customized his class schedule where they allow him to take two blocks of art class.”

Jeffrey displays an extraordinary talent as an artist that belies his physical limitations – enough talent that he is entering an art contest for disabled students sponsored by the Helen Keller Foundation.

Art teacher Sandy Smith feels Jeffrey’s talent inspires able-bodied students around him.

“Seeing the amount of talent he has and what he can achieve amazes them. He has a remarkable ability to transfer what he sees to paper or canvas. He is full of life and he brings that quality to his art work. I believe it inspires other students to go beyond what they expect of themselves,” said Mrs. Smith.

“He wants to be part of what’s going on and in art class he is able to do just that,” added Mrs. Pruet.

Classmate Bryson Davis, who is a football and basketball player for the Bulldogs, agrees with the assessment of both women: “It’s not every day you see a person with his disabilities do the type of work that he can do. He’s better than most of us in here.”

“He’s 10 times better than I am,” chimed in another classmate.

Other than his limitations, Jeffrey is much like any other 16-year-old boy.

When asked what his favorite kind of art project was, Jeffrey responded through teaching assistant Herminia Zuniga: “Painting.”

When pushed further Jeffrey admits, “I like painting pretty girls the most,” his response inviting a chuckle from his classmates seated near by.

Mrs. Zuniga has been with Jeffrey since his fifth grade year. The two have developed a special bond.

“Jeffrey is unable to communicate with his peers because they don’t know sign language, so the only people he is able to communicate with besides us are Mrs. (Jane) Holt, Deaf Education teacher for Plainview schools, and his teaching assistants Glenn Truett and Herminia Zuniga,” said Mr. Pruet. “At an age when you have a lot of questions to ask and no one to give the answers but those who can communicate with you, they have a special relationship that is deeper than what most students and their teachers have.”

Mrs. Holt indicates that, hopefully, the communication barrier between Jeff and his peers will lessen thanks to technology provided by the district.

“We are in the process of having a laptop computer mounted on Jeffrey’s wheelchair. It has Internet access and is loaded with AOL Instant Messenger, so his friends can tell when he is on line and they can write messages to him.”

“In an indirect way, having the computer will help Jeffrey with his fine motor skills, and strengthen his hands and

shoulder muscles, but it is mostly for social interaction and communication,” said Occupational Therapist Gretchen Foster, who holds therapy sessions with Jeffrey every other week.

The Pruetts are well aware of the fact that their son is in a very precarious situation, but they have a “life is terminal” attitude and focus on the fact of living life to its fullest.

They feel that the special education program of the Plainview school district helps their son live the same way.

“Everyone from Mr. Hightower to Mrs. Holt and Mrs. Zuniga and the therapists do an excellent job at letting Jeffrey experience school as normally as possible and by doing so enhance the quality of his life,” Brian Pruettt said.

*Jeff Pruettt works on an art project. He is legally blind and has to be extremely close to the subject he is drawing. Jeffrey is entering a drawing in a national art contest for disabled students sponsored by Helen Keller Foundation.*

## Baby Talk

By Thomas Fields-Meyer and Frances Dinkelspiel

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In her bedroom at her family’s Benicia, California, home, Dionne Quan keeps on video dozens of Disney movies that she has watched over and over, dreaming of one day performing in the kind of films that have captured her imagination since she was a child. But she watches them in her own unique way, pressing her face right up to the picture tube. “My nose is right next to the TV so I can see whatever I can see,” says Quan, 22. “Whatever I can’t see, I manage to figure out.”

Visually impaired since birth, Quan has never let her disability stop her from pursuing her dreams. Now with a voice-over role as Kimi, an energetic Japanese toddler in *Rugrats in Paris*, the latest animated feature based on the Nickelodeon hit series, she’s living them. “She’s an incredibly talented kid,” says the film’s voice director Charlie Adler, 44. “There was no doubt when she came in. She wanted this. She had the ability to do this.”

And do it well. Producers had to make some minor adjustments to accommodate Quan’s disability while they recorded, repositioning the microphone so it wouldn’t pick up the sound of her fingers on her braille script; they also avoided last minute dialogue changes. But before long, any difference between Quan and her castmates melted away. “She gives a fresh immediacy to all of her lines,” says her voice teacher Mike Matthews. “I forget she’s not sighted. She actually sees more, if you will, than most of us do.”

That insight has developed through hard work and dedication - both from Dionne and her parents, Daryl, 46, and Lori, 44, who run a sewing machine and vacuum store in nearby Vallejo. The older of their two children (brother Daryl is 20), Dionne seemed healthy at birth. But four months later Lori noticed that her daughter’s eyes weren’t following the mobile twirling above her crib. A CAT scan showed she had some brain irregularities, and at 6 months she was diagnosed with hypoplasia - or underdevelopment - of the optic nerve. The unusual condition left her with extremely limited sight, allowing her to make out only some colors and vague shapes.

Determined to help her daughter succeed, Lori rearranged her life to focus on Dionne, speaking to her all day and describing everything she did and saw to orient the child. “I wanted to help her as much as I could so she could achieve her dreams,” say Lori, who told her daughter: “You want to act, go act. You want to play ball, go play ball.”

Quan didn’t take long to choose. Drawn to reading, having learned braille at age 7, she liked to act out the characters in her storybooks. At 10, she enrolled in an after-school program at a San Francisco drama school, where she learned how to make her way around a stage. “Obviously things like pantomiming didn’t work so well,” she says, “because I couldn’t imagine something in my hand when it really wasn’t there.”

Then, when Quan was 12, her father heard voice-over teacher Samantha Paris on a radio talk show and took Dionne to study with her. “It just opened up a whole new world,” Dionne says, because I didn’t have to worry about gesturing.” In fact, her impaired vision may have heightened her other senses. “She has an incredible ear,” says Paris. “To hear this girl sing makes you cry.”

Having found her niche, Quan flourished, landing her first commercial job at 14 in an ad for a health maintenance organization. Voice-overs for such projects as jelly bean ads and children’s cartoons, including Nickelodeon’s *The Wild Thornberries*, followed. By the time she auditioned for *Rugrats*, Quan was a pro. “It was a challenge to find a voice that would meld with the ensemble and have the same youth, the innocence, the vitality,” says talent director Barbara Wright, who chose Quan from 200 hopefuls. “Dionne had a unique, very dear quality.”

So dear, in fact, that she was promptly offered - and accepted - a recurring role on the *Rugrats* television show. Early next year Quan plans to move out of her parents’ home and into one she will share with brother Daryl, a UCLA student, in Los Angeles, which presents its own challenges. “It’s going to be a good experience,” she says. “But in a way it’s scary.” To prepare, she got special training in programs that teach blind people basic skills. And for the first time, she learned to write in conventional script - for the express purpose, she says, of signing autographs.

## Blindness Isn’t an Obstacle

By Adam Shell

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Laura Sloate still remembers the sting of rejection, the mean-spirited words, the blatant discrimination. While interviewing for her first job as a securities analyst in the late ’60s - armed only with youthful enthusiasm and a master’s degree in history - a research chief at a brokerage firm basically told her to forget about a career on Wall Street. “He said, ‘You have three things against you: You’re a woman; you can’t see; and you’re inexperienced,’” Sloate recalls. She proved him wrong. Today, she manages a \$405 million stock portfolio even though she can’t read a stock chart, scan a spreadsheet or view a hot new product. Sloate, 55, has been blind since detached retinas robbed her of her sight at age 6. The handicap hasn’t stopped the determined Sloate from succeeding in the sighted world. She heads Sloate Weisman Murray & Co., an investment firm she co-founded in 1974. She also manages the Strong Value fund, which gained 13% last year despite the stock market’s worst performance in a decade.

Most blind people only dream of Sloate’s success. Of the estimated 1.3 million Americans 22 to 50 who are legally blind, about half are unemployed, says the American Foundation for the Blind. And one in three blind people 18 to 64 who do work earn less than \$20,000 a year.

Still, the fiercely competitive Sloate says sight isn’t an issue. “Blindness isn’t an obstacle,” says Sloate, who has worked on Wall Street since 1968. “It just forces you to do things differently.”

Like most on Wall Street, information is Sloate’s lifeblood. “I’m an information junkie,” she says. “If I went cold

turkey, I'd be in worse shape than a three-pack-a-day smoker without a cigarette." The trick - and the key to success - is getting data into her head. She spends her entire day doing just that. "My full knowledge input is through my ears," she says.

## ULTIMATE IN MULTI-TASKING

It is 10 a.m. and the trading day is in full swing. While her guide dog, an 8-year-old German shepherd named Quartz, naps at her feet, Sloate is doing what seems like 10 things at once: Listening to breaking business news that spills out of her PC's speakers at 320 words per minute.

Checking stock quotes. She hits the F3 key on her PC and punches in the symbol C. A robotic voice responds with a quote for Citigroup, her top holding: "C ... Bid ... 50 ... Point ... 5265 ... End ... Ask ... 50 ... Point ... 750 ... End." Head trader Michael Adamson serves as a human stock ticker, updating Sloate via speakerphone.

Reading e-mail. She double clicks on a message from a Wall Street analyst dissecting Citigroup's earnings report released before the bell. The computer reads the e-mail's content to her.

"Laura gets through inhuman amounts of information," says Chip Rewey, senior portfolio manager at Sloate's firm. Rewey sits directly across from his boss during the trading day, feeding her relevant tidbits from brokerage reports and trade magazines. Sloate retains everything.

"She has the equivalent of a photographic memory," says Neil Weisman, who co-founded the firm with Sloate and left in 1986 to start his own hedge fund. Not being able to see forces her to rely heavily on technology - and other people - to get things done. Friends and colleagues often serve as her eyes. "Maybe I can't tell whether the Gap's fashions are great, but I know enough people who do," Sloate says. If she needs to analyze a chart or spreadsheet, she'll ask a trusted business associate for help.

Sloate doesn't feel sorry for herself or make excuses, but she says being blind often frustrates her. "Sometimes it's wanting to do something that I can't do alone, like riding a bike." There are professional obstacles, too. The stigma associated with being blind tends to close doors. If she were shopping for a new job, she suspects prospective employers would be reluctant despite her track record. Prospecting for new investors is also tougher. Sloate says many just aren't comfortable handing their money to a blind person. So she doesn't go out of her way to tell people on the phone about her disability. "When I show up with a dog they are at best skeptical," she says. "But that wears off when they engage me in conversation and figure out I'm not a total idiot."

In fact, Dick Strong, founder of Strong Funds, admits that he talked to Sloate for 2 years on the phone and "didn't know she was blind." Co-workers and former colleagues describe her as fair, yet tough. "Some people like criticism to be delivered with a bouquet of flowers; you will not get that from Laura," says Donna Leone, the firm's chief operating officer who was hired 20 years ago as Sloate's personal assistant. Weisman, her former partner, says Sloate holds herself to the same high standards. "She's very tough on herself; she's her own worst critic." Always prepared, Sloate is described as loyal, caring and generous. Co-workers say she's a wonderful teacher, inviting members of her firm to dinner where she'll tell them what they're doing well and, of course, how they need to improve. She dotes over her dog, Quartz, like a loving parent. One evening long after the market closed, she plopped Quartz's tin dog dish on her desk and prepared dinner: low-fat cottage cheese mixed with dry dog food. Sloate says when Quartz underwent back surgery recently, she was "traumatized."

Sloate likes being prepared. When a potential client leaves a phone message, for instance, she'll quickly research who they are, where they work, and if they're on any corporate boards. When going somewhere for the first time, she checks which side of the street the building is on and where the entrances are. "She likes to be in control," Weisman says. When it comes to investing, Sloate looks for quality companies selling at cheap prices. But she won't buy a

stock just because it's cheap: A catalyst, such as rebounding earnings, new management or a restructuring, must be in place. *Toys R Us* is a perfect example. Sloate recently started buying the stock on the belief that business would improve in the wake of the death or near demise of dot-com retailers, such as *eToys*.

### 3:45 A.M. WAKE-UP CALL

Keeping up with Wall Street's best isn't easy. Sloate is a workhorse who sleeps less than four hours a night. Her day starts at 3:45 a.m. The minute she gets up she "flips on" the paper. Picking up the phone, she dials a number and keys in a six-digit access code. When the call connects, she gets a line-by-line account of stories published by top national newspapers. She feeds and grooms Quartz while "reading." It's common for Sloate to leave employees voice mail at 4 a.m. Working out comes next. "It's the way I get my stress relief," she says. By 5:30 a.m. she's climbing up and down 75 flights of stairs in her Manhattan apartment building. A personal trainer arrives at 6 a.m. to spot her during her workout with weights. The fit 5-foot-6, 110-pound Sloate bench-presses 60 pounds 60 times - in three consecutive supersets. She arrives at her Park Avenue office by 8:30 a.m. Her day extends well beyond trading hours, too. It's 6:45 on a Thursday night in early January and Sloate is still hard at work. As usual, she's doing two things at once. "I get bored fast," she says. It's not unusual for her to have two people reading newspaper and magazine articles to her simultaneously. This night, Tracey Paleo, an actress, is reading Sloate stories from *The Financial Times*. At the same time, Rewey is reading her breaking news from the Internet. Sloate "reads" in several ways. On weekends, she scans some 300 pages of magazine articles and other print materials into her PC, which converts it into voice. Software also lets her read Internet articles. Then, of course, there are the real-life readers like Paleo. The pay for the aspiring actresses and university students Sloate hires to read: \$8.50 to \$10 an hour. Hidden away in a corner office that doubles as a makeshift library, the readers can be spotted reading books and articles out loud into tape recorders. Managing money and analyzing stocks is the best job in the world, says Sloate, who also finds time to teach a securities analysis course at Columbia University. But her true passion is opera. She has attended about 1,000 performances, mostly at New York's Metropolitan Opera, where she's a board member. "The opera is very civilized," she says. And rock or rap? "It's just noise. My ears are very sensitive."

### A NIGHT AT THE OPERA

One night last month, a trip to a performance of Giuseppe Verdi's *La Traviata* at the Met illustrated Sloate's organizational skills. Because of long work hours, Sloate typically doesn't arrive at the opera house until the start of the second act. Prior to the season, she requests a timetable from the Met that lists when all the acts begin and end. "The joke at the opera is I'm an expert on the second and third acts," she quips. On this night, Sloate leaves her Park Avenue office at 8:15 p.m. sharp. Her driver, Michael Piniero, zooms uptown in a van. Dinner is served in the back seat. Sloate dines on popcorn and coffee. Arriving at the Met around 8:40 p.m., a few minutes too early, Piniero waits patiently on a nearby street. At 8:45 p.m., Sloate gives the word, and Piniero drives into the parking garage for the drop-off. Once inside, Sloate, with Quartz at her side, takes charge. "Go up the stairs. Walk to the left of the bar. The doors to the orchestra are straight ahead. We're in Row D." The lights dim just after Sloate sits down. The curtain rises and the crowd applauds before a note is sung. Sloate says the audience must like the scenery. "New Yorkers are very vocal about what they like and don't like. I've heard them boo the scenery," she says.

Sloate, who has never married, has two brothers and grew up in Brooklyn. She spent much of her childhood at home, where her mom, Elsie, now 94, would read to her. Her eye troubles kept her out of school until 14, her freshman year in high school. "I had a difficult time," Sloate says of her socialization problems at school. Her interest in stocks began when she was 10. Her dad, Kelly, who was an investor, would call her in on New Year's Eve to calculate the value of his portfolio. She says she'd do the calculations in her head faster than he could with a pad and pencil. She's still good with numbers, Rewey says. When Sloate gets the bill at a restaurant - and she eats out every night - Rewey says he'll read her the price of every item, and she is able to calculate the total, including tax and tip, to the penny in her head.

She landed her first job in 1968 with a tiny mutual fund that went out of business 4 months later. She then landed a

job as an analyst at a small firm where she earned \$200 a week, \$140 of which she paid to a secretary she hired to read for her. In 1972, she landed a job as an analyst at Burnham & Co. “Laura is in love with the business and committed to it, sadly, without a hell of a lot of other distractions,” says author Peter Tanous, who wrote a chapter about Sloate in his book, *Investment Gurus*. Sloate herself admits that she’s so devoted to and energized by her job that retirement is out of the question. “I don’t enjoy being away from the business,” she says. “I could have retired a long time ago.”

## **Just a Typical Teenager**

By Kate Moss, Family Specialist, TSBVI, Texas Deafblind Outreach

Kassandra Marie Luna, otherwise known as KC, is just a typical teenage girl from Laredo, Texas. She likes to spend her time talking on the phone to friends, listening to her CDs (preferably rap), and practicing drum cadences. During the school year she attends her local school, where she takes a regular schedule of academic classes. She is a good student with an easy going personality. Her qualities are apparent to all those who know her, which led to her being voted the 1999 Christen Middle School Homecoming Queen.

Although she enjoys her experiences in her home school, she likes to attend summer school classes at Texas School for the Blind and Visually Impaired. It’s nice to be around other kids facing the same or similar challenges. She also likes learning more about technology for people with visual impairments.

Some of her other favorite things include visiting relatives in San Antonio, Houston and other parts of Texas. She also likes taking vacations with her parents, Sandra and Luis Ramirez.

KC was born prematurely and has Retinopathy of Prematurity which resulted in her becoming functionally blind. Despite some of the challenges her visual impairment adds to life, KC plans to graduate from a university with a degree in rehabilitation counseling. She would like to live in a larger city, marry and have children eventually.

When asked not long ago how would she change the world if she could, KC replied, “...by giving teenagers much more freedom to do what they like, excluding anything having to do with a criminal nature. I would try to make people understand the blind more and have them stop being overprotective of us.”

## **A Celebration of Communities and Connections: The 2001 Texas Symposium on Deafblindness**

By Kate Moss, Family Specialist, TSBVI, Texas Deafblind Outreach

It was a dark and stormy night when families, professionals and paraprofessionals from across Texas began arriving in Dallas for the 2001 Symposium on Deafblindness. Despite the terrible weather typical for Texas in February, spirits were high as people gathered in the registration area to renew old friendships and make new connections. The Symposium that followed over the next two days proved to be both a valuable training opportunity and an event that celebrated the community of people who are connected by deafblindness.

The Friday morning general session opened with a welcome by Outreach Director, Cyral Miller, followed by a “state of the State” message from Marty Murrell, Texas Deafblind Project Grant Director with Texas Education Agency. The almost 400 individuals in attendance were then treated to a keynote address from Cathy Allen, parent of a young girl with CHARGE Syndrome who is deafblind. Cathy set the tone for the entire conference by reminding us of the importance of collaboration between the family and the professionals in achieving quality services and programming for a child with deafblindness. She made us laugh and also cry with her comments on the joys and struggles of parenting a child with deafblindness and navigating the educational and medical systems. Cathy was definitely a tough act to follow.

Probably the only person brave enough to take on the challenge of following Cathy was the next scheduled speaker, Dr. Jan van Dijk of the Netherlands. His general address, "Stress: The Destroyer of Healthy Brain Formation," reviewed information about how stress prevents the growth of neural networks in the brain of a person with deafblindness. In addition to giving the general presentation, Dr. van Dijk presented three other breakout sessions over the next two days, including a discussion of the essentials in his methodology, delayed manifestations of Congenital Rubella Syndrome, and information on a new CD-ROM curriculum on assessment of persons with deafblindness.

*Cathy Allen, a parent from Mesquite, Texas, shares the joys and struggles of collaborating with professionals.*

Following the keynote and general session, breakout sessions were held on Friday afternoon and Saturday morning. There were many wonderful speakers, and most participants had a great deal of difficulty deciding which sessions to attend. Some of the speakers presenting during these sessions included Barbara Miles, Jim Durkel, Millie Smith, Cathy Allen, Kathy Williams, Marsha Dunn Klein, Marlyn Minkin, Kim Conlin, Fran LaWare, Deanna Peterson, Lauren Lieberman, Maria Velarde Bove, Tom Miller, Sally Prouty, Linda Mamer, Melvin Marx, Casey Grim, Chris Montgomery, Tish Smith, Sandra Davenport, David Wiley, CC Davis, Steve Schoen, and Jeanne Reeves. Topics included information on touch, communication, routines, Usher Syndrome, CHARGE, Congenital Rubella Syndrome, assistive listening devices, family issues, assessment, home life, interveners, sexuality education, orientation and mobility, braille, feeding issues, self-determination, and mental health issues.

A new feature of this year's Symposium was the presentation of four awards during the Saturday luncheon. We hope this will become a regular feature of future Symposiums. Each year preceding the Symposium on Deafblindness a nomination form will be published in the Summer edition of *SEE/HEAR*. Anyone may nominate individuals for each of the four awards and return the form to Texas Deafblind Outreach. A committee made up of individuals with deafblindness, family members, educators, interveners, and rehabilitation staff working with individuals who are deafblind will review the nominations and select the recipients. Awards will be presented every other year at the Symposium on Deafblindness. The awards are the Trail Blazer Award, the Intervener Award, the Excellence in Education Award, and the Ann Silverrain Award.

The Trail Blazer Award is given to a family member who has, through their advocacy or efforts on behalf of their family member with deafblindness, blazed a trail that has made it easier for other families who follow. This year's Trail Blazer Award was given to the parents whose advocacy efforts resulted in the first school services in Texas for children with deafblindness. They included Gail and Paul Abraham, Mary and Dick Behnke, Jackie and Everett Bryan, J. W. Carter, Larry and Evelyn Clark, Wandene and Wes Coughran, Angie Dugan, Lloyd and Faye Eller, John and Geraldine Ellis, Sandra and Beau Faircloth, Marion and Lynn Freeman, Marilee and Clay Frost, Holton and Rita George, Richard and Joyce Hixson, Robert and Geneva Koonce, Vidal and Yolanda Maldonado, Patricia McCallum, Lorene and D.W. Murphy, Betty Murphy, Celestine and Riley Rand, Gilbert and Socorro Salazar, Delia and Andres Sanchez, Margaret and Michael Seguin, Homer and Mary Smith, Annie and Garland Wade, Evelyn Ware, and Anita Wheat. Accepting the award on behalf of these families were Evelyn and Larry Clark, Marion Freeman, Patricia McCallum, and Celestine Rand. Each of these families are still involved in supporting individuals with deafblindness. Dr. Evelyn Clark is a school principal in Houston and currently has a young deafblind student at her school. Marion Freeman is the Treasurer of DBMAT. Patricia McCallum is the Secretary of NFADB and a former Executive Director of DBMAT. Celestine is a DBMAT Regional Coordinator in ESC Region 18, the Midland/Odessa area.

*Dr. Jan van Dijk explains the impact of stress on individuals with deafblindness.*

The Intervener Award is given to an intervener who has demonstrated excellence in supporting a child with deafblindness and whose efforts have contributed to the success of the intervener model in Texas. This year's award went to Ann Bielert, who has served as an intervener for four different children with deafblindness and was one of the first official interveners in Texas. Ann has worked hard over the past nine years to improve her skills and knowledge about deafblindness through onsite visits from Outreach, participation in workshops, and involvement in the intervener training meetings. She has also shared her expertise with others by presenting at Outreach sponsored training, and at the Canadian Deaf-Blind conference held in Vancouver in 1998. Ann also serves on the Texas Deafblind Outreach Advisory Board.

The Excellence in Education Award is given to an educational professional who has made a long-term commitment to excellence in education for Texas students with deafblindness. Karen Buchine, Teacher of the Deaf and Hearing Impaired, with the Regional Day School Program for the Deaf in Alief, Texas was the first recipient of this award. Karen has worked with numerous deafblind children and has been a strong advocate for quality programming. She has also been a valued collaborator with Texas Deafblind Outreach, serving on our Advisory Board and helping with many special projects.

Our final award, the Ann Silverrain Award, is given to a person who has made an extraordinary commitment to improving the lives of individuals with deafblindness in the Texas. Randy Feille, Supervisor of Deaf-Blind Services for Texas Commission for the Blind, was given this special honor. Over the years, Randy has worked in many capacities to improve the lives of individuals with deafblindness. He began his career in deafblindness instructing deafblind students in after school activities and daily living skills at TSBVI's Deaf-Blind Annex. He's been a houseparent and instructor at Criss Cole Rehabilitation Center, and was instrumental in starting the Deaf-Blind Services department at Texas Commission for the Blind. He also served as the Co-Chair of the Texas Interagency Task Force for Future Services to Deaf-Blind from its inception in 1979 until 2000.

We are proud of these individuals and very thankful for the support they have given to Outreach through the years. We look forward to many more years of working together with them in support of individuals with deafblindness in Texas.

Some of the most valued sessions at the Symposium were presented by individuals with deafblindness. Alberto Gonzales from Austin, Texas talked about his life and how he has overcome many obstacles related to deafblindness. Sharing this presentation with Alberto were two professionals who help Alberto make connections in the world. These individuals are Nancy Kimbro, O&M Specialist, and Jackie Souhrada, Deafblind Community-Based Apartment Supervisor. One parent who attended Alberto's session commented that she now has hope for her son. Alberto helped her see that, despite being deafblind, her son can grow up and have a good life. This was a good reminder to me about how important it is for parents to have adult mentors and role models who are deafblind. There is no one more experienced about deafblindness than a person with deafblindness. As professionals, we really need to utilize this expertise more often.

*Alberto Gonzales and Edwin Carter  
get to know each other at the Saturday luncheon.*

Three other individuals with deafblindness, Andrew Prouty from Shoreview, Minnesota, Rosie Yanez from El Paso, Texas and Edwin Carter from Dallas, Texas also shared their experiences with us during the Symposium. These young adults were keynote speakers at our closing session on Saturday. All three of these wonderful individuals had participated in the "Self-Determination: Creating a Path to the Future" seminar held in conjunction with the American Association of the Deaf-Blind Conference in Columbus, Ohio during the summer of 2000.

*Andrew Prouty, Edwin Carter, and Rosie Yanez are three self-determined young adults. They presented inspiring closing keynote addresses at the 2001 Texas Symposium on Deafblindness.*

Edwin and Rosie were our final speakers. Their presentation had the greatest impact on me because I have known these “kids” for a very long time. Hearing them share their experience from AADB and talk about their dreams was very exciting. They were both eloquent about why the things they learned about self-determination are important. I know that Edwin and Rosie will always be leaders and friends. They will advocate for themselves as well as for others with deafblindness. They will face the challenges that come their way and persevere. I felt a deep sense of pride in knowing them; they truly inspired me with their message. I know that their parents, Linda and Jackie Carter and Suzanna and Oscar Santillon, their siblings, their friends, and all the professionals who have worked with them through the years are proud of them, too.

From the comments shared by the participants and presenters, and among Outreach staff, I consider the 2001 Texas Symposium on Deafblindness a success. I came away with a renewed sense of commitment to improving the quality of lives for all individuals with deafblindness in Texas. I also feel that my efforts will be magnified through the connection I have with a larger community of other committed individuals, throughout the state, the nation, and the world.

Andrew showed a video that his brother, Bill, had made as a graduation present when Andrew completed high school. It featured highlights of Andrew growing up in the Prouty family. Andrew talked about the challenges he faces, the two jobs he currently holds, and his dreams for the future. He reminded us of the important role his family has played in his life, but emphasized how important it is for him to believe in himself. Andrew also co-presented with his mother, Sally Prouty, Coordinator of the Minnesota Deafblind Project, in a morning breakout session. A parent whose young child has CHARGE commented later that seeing Andrew renewed her. He made her even more determined to keep pushing for quality programming for her child.

## **Trends in the Use of Braille Contractions in the United States Implications for UBC Decisions**

By Sally S. Mangold, Ph.D.

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The National Federation of the Blind, October 2000 *Braille Monitor*

### **OVERVIEW**

The practice of educating blind children in regular classrooms with sighted peers is growing worldwide. Hundreds of blind children have been successfully mainstreamed during the last two decades. Many of them are now adults with excellent Braille literacy skills allowing full and independent participation in society. It is unfortunate that an even greater number of blind individuals did not acquire adequate Braille literacy skills while in school and therefore remain unemployed. Experience has shown that blind children can be successfully educated in the regular classroom if they have abundant Braille materials equivalent to the print materials provided to their sighted peers. In addition to instruction from the regular classroom teacher these students must receive supplementary instruction from a teacher with knowledge of the Braille code.

The Unified Braille Code (UBC) committees are working diligently to create a more efficient Braille system for the English-speaking countries. Committee II is responsible for the selection of a recommended list of Braille contractions to be incorporated into the revised literary code. It is important that the members of Committee II decide which Braille contractions promote rapid and accurate Braille reading and writing in light of contemporary pedagogical issues. The author fervently hopes that this paper will stimulate an interest in documenting contemporary pedagogy and considering the opinions of leading educators in all English-speaking countries before establishing official code changes. A new Braille code should be both appropriate for the students of today and easy to implement.

## CURRENT TRENDS

The Braille literacy movement in the United States is expressed by the actions of two major groups. There is an establishment movement whose members represent various governmental agencies, private agencies, Braille code specialists, Braille transcribers, and Braille embossing houses. Their concerns often center on changing technology as it relates to Braille production using the present Braille codes. They continue to adhere to the official Braille codes during production but would welcome changes in the codes that result in a more consistent and reader-friendly product.

There is also a consumer/educator-driven movement whose members represent teachers, parents, and blind consumers of all ages. They support the efforts of teachers and consumers who for many years have quietly made changes in the Braille literary code and its uses. The changes relate directly to the use of certain Braille contractions and a greater use of letter-by-letter Grade I Braille. These deviations from the official code are occurring in an attempt to represent print formats used in regular classrooms more accurately. New technology allows the gradual introduction of contractions as each student reaches developmental milestones.

When is uncontracted Braille used? Which Braille contractions are being eliminated? The outstanding work of Committee II and its recommendations for changes in the Braille code highlight the most frequently requested code changes by both Braille literacy action groups. Committee II recommends the deletion of ble, com, dd, to, into, and by. There are also recommendations for certain changes regarding the use of specific short-form words.

A growing number of educators are eliminating four groups of contractions in addition to those recommended by Committee II:

- Whole-word lower contractions that are identical in configuration to upper single letter whole-word contractions. They include be, were, his, was, in, and enough. These lower contractions are not easily read by many students, even at advanced reading levels and even when contextual clues are plentiful.
- Double-letter lower contractions that are identical in configuration to single letters. They include bb, cc, dd, ff, and gg.
- Two-cell contractions that begin with the dots 5-6. They include ence, ong, ful, tion, ness, ment, and ity. Confusion between letters preceded by the letter sign and these contractions often occurs.
- The two-cell contractions that begin with dot 6, ation and ally. These contractions are often interpreted as capital letters rather than contractions.

All of the above contractions are somewhat difficult for beginning Braille readers to identify in short phrases, and many are extremely difficult to identify when isolated in word lists. I personally support the elimination of all of the above-mentioned problem contractions.

Many educators and consumers believe that unambiguous contractions that have unique configurations, for example, er, ar, ed, should be maintained and used when the students have reached upper elementary developmental milestones. Basic concepts of alliteration and phonetic word construction will have been mastered at this level.

## HOW IS A MODIFIED BRAILLE CODE BEING USED?

### Minnesota policy

An entire region of Minnesota has adopted a policy of Grade I Braille in the first year of school. Gradual introduction of Grade II contractions takes place during the subsequent years.

#### *Discussion:*

The teachers involved in the pilot program reported that after one year they have observed higher academic achievement scores in reading rates and reading accuracy in children using Grade I than was previously seen in children using Grade II in the first year of school. The grade I users showed greater interaction and participation with sighted children both academically and socially. Grade I can easily be incorporated in books, games, spelling competition, and life-skills labeling.

### Multiply Impaired Children

Multiply impaired blind children are being introduced to Grade I Braille first. Short-form words and Grade II contractions are introduced after thorough mastery of the alphabet and beginning reading has been achieved.

#### *Discussion:*

Multiply handicapped and learning-disabled students must have extensive practice at each level before being introduced to new symbols. The presentation in Grade I is consistent in configuration whenever used. The teachers report a reduction in Braille letter-reversal reading errors when Grade I is used for an extended period of time.

### Beginning Readers

Grade I is being used more with beginning readers of all ages.

#### *Discussion:*

Beginning reading exercises, spelling, and introduction of new vocabulary often show words in isolation. As the reading vocabulary increases, the majority of contracted words may be more easily understood in context.

### Contractions

Certain single-cell lower contractions and certain two-cell contractions appear to be difficult for many readers to interpret with confidence even at more advanced reading levels. The problem contractions, in addition to those identified by Committee II, are his, were, was, be, in, enough, bb, cc, dd, ff, gg, ful, ong, ment, ity, ation, and ally.

#### *Discussion:*

Undesirable hand movements have been observed as Braille readers frequently recheck these contractions in order to discern whether they are reading an upper- or a lower-cell contraction. It is almost impossible to identify single-cell lower contractions when they appear in columns. The overwhelming majority of educators with whom I speak want to see these contractions eliminated from the code. Until such a decision is made, the problem contractions are often being written in Grade I.

### New Technology and Braille

Grade I is required for the use of new technology. Voice-output and dynamic Braille-display devices frequently require the use of both Grade I and Grade II Braille when entering commands for operations.

#### *Discussion:*

We have many myths in education. For years it has been said that a student would become confused if presented with both Grade I and Grade II Braille. It was feared that the use of both codes would result in inaccurate writing and unacceptable practices. One need only observe a few of the thousands of capable blind children and adults who use

technology to produce papers and reports to see that a well trained individual can successfully use both codes interchangeably.

## **Grade I and Newly Blinded Individuals**

Grade I Braille is used for instruction of newly blinded youth and adults.

### *Discussion:*

New teaching methodologies use Braille labels in Grade I for an extended period of time before introducing books. The first books are in Grade I. Instructors believe that greater immediate success in using Braille to complete daily tasks and regain literacy skills increases self-confidence of newly blinded youth and adults.

## **Parents and Regular Classroom Teachers**

Parents and regular classroom teachers are learning and using Grade I Braille.

### *Discussion:*

Parents and regular classroom teachers are learning the Braille alphabet and numerals when their blind students are first introduced to Grade I Braille. They are correcting assignments, writing accurate examples in Braille for the students, and enjoying Braille themselves. Their enthusiasm encourages the students. They can provide immediate feedback to the children about their performance and quickly correct errors. Many blind students who are mainstreamed do not have the services of a vision teacher each day and often receive no feedback about the Braille they produce until several days have elapsed.

## **Beginning writing**

There is a rapidly growing trend to use Grade I Braille for writing at beginning levels.

### *Discussion:*

Teachers and sighted peers spell words to the blind child one letter at a time. The blind child writes the words one letter at a time. The presentation of Grade I in reading books provides an accurate model for the young child who is already writing Grade I. I believe that we will continue to see even greater use of Grade I Braille in the future.

## **A HISTORY OF CONTROVERSY**

A Braille literacy movement took place in France during the 1830's. No one wanted to change the traditional training for the blind. The raised-print letters used for classroom instruction were very difficult to produce and were read very slowly by touch. The resistance to change resulted from a belief that, because of the common typestyle, any sighted person could assist any blind child, which made education more accessible to the blind. Braille as an official educational medium was accepted only after blind high school students insisted on using the code because it allowed them to write for the first time. One brave teacher convinced the school board to adopt Braille as an official code after he observed improved interest and achievement among his students who were using Braille.

We need to listen to blind consumers today. They are demonstrating new uses for Braille and articulating unresolved needs. The blind adult population has demonstrated its immense ability to infuse new symbols into the official code and use technologies that require the mastery of both Grade I and Grade II Braille.

Our present code was never thoroughly researched when it was adopted early in this century. The practice of using Grade II only was a unilateral decision by Bob Irwin, then president of the American Foundation for the Blind. His main impetus was to provide a Braille reading code that would parallel the sight-reading approach used in regular classrooms during the 1930's. The U.S. was just recovering from an economic depression, and he showed that using Grade II could save money because it took less paper. His decision was opposed by the national organization of educators, to no avail.

From 1910 until 1950 there was a commonly used method for teaching Braille. Grade I Braille (alphabet only) was taught in the first three years of school. Grade 1-1/2 (alphabet plus 44 one-cell contractions) was taught during the next three years. Grade II Braille (alphabet plus 189 one-cell and two-cell contractions) was taught in year seven and used through year twelve. The most difficult contractions to learn were not introduced until the seventh year and were taught within an educational system that provided Braille instruction every hour of the school day.

The cognitive demands of young blind children are greater than those required of their sighted peers if all of the contractions are presented during the first year of school. The number of abstract symbols is much higher in Braille than in print. The correct application of many contractions requires discrete spatial interpretation that is difficult for most young learners.

The majority of blind people educated by the three-levels-of-contractions method were good Braille readers. They exhibited proficiency in writing, spelling, and grammar. The vast majority became independent and self-sufficient adults. These were blind students with average and above average academic abilities. They could probably have excelled with any code of Braille. Today's population of students is very different, and their learning needs must be addressed when selecting acceptable Braille contractions. The research by Troughton and Mangold supports the use of Grade I for certain purposes. The data indicate that applications for the use of Braille must be considered in the selection of the most appropriate code relative to a given purpose.

## RECOMMENDATIONS

- The deletion of certain contractions, as recommended by Committee II, is appropriate: ble, in, to, into, com, dd, and by. The additional contractions that should be eliminated are bb, cc, dd, gg, ful, ong, ence, ment, tion, ity, ally, and ation.
- Certain limitations on the use of short-form words are appropriate as recommended by Committee II.
- The code used to introduce Braille should be uniform as much as possible throughout the world so that materials may be shared and easily understood by blind learners of all ages and all nationalities.
- The beginning students reading Braille should have a one-to-one correspondence in Braille to print materials given to sighted peers so that they can interact more fully in the regular classroom.
- The introduction of two-cell contractions should be postponed until the blind learner has mastered basic reading and spelling.
- The members of Committee II should share information about the teaching practices in their countries.
- The final report for Committee II should include a description of teaching methodologies that contemporary societies consider sound educational practices.
- Tradition does not validate practice. "Now is the time to shake ourselves free of old ideas and traditions. We should not look back but rather go with youth, who always look toward tomorrow." Helen Keller, 1931

## REFERENCES

- Mangold, Sally S., "The Braille literacy movement: A dichotomy of action," *Getting in Touch with Literacy*, 1997, p. 9.
- Ryles, Ruby, "Early Braille Education Vital," *The National Braille Press Release*, Spring/Summer 1998, p. 3.
- Troughton, Marjorie, *One Is Fun*, Toronto: The Canadian National Institute for the Blind, 1992, p. 119.

# A Time to Embrace

## Parents of Special-Needs Children Find Respite in Night-Out Programs

By Laurie Fox / *The Dallas Morning News* Reporter

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*Editor's note: This article originally appeared in The Dallas Morning News. By going to their website at this link, Ministries for the Disabled, <[http://www.dallasnews.com/extra/292656\\_q\\_disabled\\_24rel.html](http://www.dallasnews.com/extra/292656_q_disabled_24rel.html)> you will find links to other resources such as the National Organization on Disability - Religion and Disability Program <<http://www.nod.org/acctallies.html>> and Joni and Friends <<http://www.joniandfriends.org/>>. Their address is P.O. Box 3333, Agoura Hills, CA 91376; phone: (818) 707-5664.*

As 8-year-old Sam Beller smiles, his blue eyes turn into crinkled slits and his eyebrows seem to dance on his forehead. He can't move much of the rest of his body, but a jaunty turn of the head or a gleeful gurgle can say a lot.

"You can tell by the sounds that he makes and his expressions what he's thinking," said Elizabeth Laird, a vocational nurse who spends her Friday nights caring for medically fragile and special needs children like Sam.

Sam, who has cerebral palsy and severe scoliosis, is a delight to almost everyone who meets him. He's also a lot of work. Every few weeks, his parents get some free help from Friday NITE Friends, an outreach ministry of Custer Road United Methodist Church in Plano. The parents' night out program for special needs kids is rare because it also takes in the children's well siblings. More than 80 families from throughout the area take part in the weekly, four-hour program, which is staffed by vocational and registered nurses as well as volunteers.

Three other local churches - Arapaho Road Baptist Church in Garland, First United Methodist Church in Denton and Highland Park United Methodist Church in Dallas - have started efforts, giving the area an unusually high number of programs that care for all the children in a family, regardless of whether they are disabled. The programs are all free and families do not have to be members of the congregation. And they are flourishing at a time when advocates are pressing places of worship to move beyond accommodating people with disabilities to welcoming and valuing them.

"A full life of faith is more than worship," said Ginny Thornburgh, director of the Religion and Disability Program of the National Organization on Disability in Washington, D.C. "Children and adults with disabilities have gifts and talents to bring to their congregations. The most important accommodation we can offer them is the gift of friendship."

The parents and workers at Friday NITE Friends agree. (NITE stands for Nursing Interventions in a Caring Environment). "There's a premium that you pay when you have a special needs child," said Kyla Prestwood, Friday NITE Friends director, who has a 17-year-old multiply handicapped daughter. "Time is the one thing that these parents need the most but they don't have. And for them to have an adult caregiver just take over for a little while is very expensive."

Ms. Prestwood tells tale after tale of initially hesitant parents who, when they finally admit that they need time away from their children, cry with relief. Some couples eat dinner and catch a movie. Others go shopping. They return home for a nap or, in the case of one mother, a bubble bath. The parents take a pager with them when they leave Custer Road at 6 p.m. and can call to check in. Most return before the 10 p.m. pick-up time, but even a few hours can make a big difference.

"Uninterrupted time is a treasure," said Darla Andrews of Plano after dining at a restaurant with her husband, Van. The couple's twins, 7-year-old Tom and Will, are autistic. Will is mentally retarded and visually impaired. Their brother, Jim, 5, is speech-delayed. Sister Katie, 9, is in an accelerated classroom at school and has no disabilities.

“We don’t know normal in our house,” Ms. Andrews said. “Friday NITE Friends is a real break for us. It’s really hard to put your faith in people to be able to leave your kids for a long period of time, but we have to. I hear horror stories of parents breaking up when they have all of these challenges.”

“Parents of special needs children can become very isolated and the stress can become overwhelming,” said Ms. Thornburgh, who helped launch a national effort to make churches more accessible to people with disabilities. “These types of programs allow parents and their children to get to know one another and their families,” she said. “That network is very important.”

The Rev. Mark Craig, pastor of Highland Park United Methodist Church, said the disabled community is underserved by churches. “These are the parents who aren’t in church anymore because they just can’t get away,” said Mr. Craig, who also was the pastor of Custer Road United Methodist Church for 15 years. “What these churches are doing for these parents doesn’t even come close to filling the need. If the churches don’t do it, who will?”

Melanie Lucido’s son, Joseph, is 18 months old but functions as a newborn because of hearing and visual impairments and severe motor delay. He suffers seizures and needs help sitting up and rolling over. She began attending the Night Owls program at Highland Park United Methodist Church, held the third Friday of every month, after she realized that she and her husband, Michael, needed time away but couldn’t afford it on their own.

“The last year and a half has been unbelievably stressful,” she said. “This gives our whole family a break. Our older son was able to be around others with special needs. It just seemed normal to him.”

Hilary Nelson coordinates the King’s Kids special needs ministry at Arapaho Road Baptist Church. She said the 2-year-old program, which includes a Sunday evening program, Sunday school and an adult special needs class, expanded into a Saturday evening parents’ night out program last year.

“For our church, it’s really opened people’s eyes and makes them more aware and comfortable with the disabled,” she said. “The parents involved, a lot of them haven’t had the time just to spend alone in so long they’ve forgotten how.”

Mr. Craig said many churches don’t start such efforts because they don’t see the need or they fear the expense of nurses and medical equipment. But, he said, with a congregation’s support, they pay for themselves.

At Custer Road, the Thanksgiving service gives the Friday NITE Friends group an opportunity to speak to the congregation and remind church members about those they’re helping. The collection from those services helps fund the group. The program costs about \$50,000 a year, and all the money comes from donations.

“People think about this ministry and really count their blessings,” said Carol Brady, a Friday NITE Friends coordinator at Custer Road. “Just helping these families makes you feel good.”

Organizers at Custer Road say they plan to start training other churches to launch similar programs. The church provided guidance and seed money to help First United Methodist Church in Denton get its weekly program, Friday’s Kids, off the ground.

“They [Custer Road] are inspiring other churches,” said Rhonda Clark, the program’s director. “Six years ago, there was only one program of this nature [in Texas], and now they’re cropping up locally and throughout the country.”

When Sam’s father, David Beller, arrives to pick him up at Custer Road, Sam grins and hums. Mr. Beller talks quietly with the nurses who have worked with him through the evening. The Bellers spent their evening away having dinner and shopping for tile flooring. They have to replace their carpet because of Sam’s allergies.

“If we had to hire a nurse and a babysitter for four hours, it would cost us more than \$100,” Mr. Beller said, lifting Sam into his wheelchair. “Sam enjoys it here. We spend so much time taking care of his physical needs. He has social needs as well.”

As the Bellers prepare to leave, Ms. Laird, the nurse, tidies up the playroom. “People will say to me, ‘This must be a depressing place,’” she said. “Are you kidding me? These kids fight [to get through] every day. They don’t complain, and their parents don’t either. It’s inspiring.”

Friday NITE Friends meets 6-10 p.m. each Friday at the Custer Road United Methodist Church, Plano, phone: (972) 618-3450 or link to <[www.crumc.org](http://www.crumc.org)>.

Friday’s Kids meets 6-10 p.m. each Friday at the First United Methodist Church in Denton, phone: (940) 382-5478.

Night OWLS meets 6-10 p.m. on the third Friday of each month at the Highland Park United Methodist Church in Dallas, phone: (214) 521-3111 or link to <<http://www.hpumc.org/missions>>.

King’s Kids Parents Night Out meets 6-9:30 p.m., the first Saturday of each month at the Arapaho Road Baptist Church in Garland, phone: (972) 495-2223, ext. 73.

## **I’m an Outreach Consultant Do I Really Want to Do Raised-Line Drawings?**

By Barbara L. DiFrancesco, Certified Braille Transcriber and Tactile Graphics Technician

*Editor’s note: The TSBVI VI Outreach team is actively exploring instructional strategies and products that might help students effectively learn through a wide variety of tactile graphics. We were excited to find Barbara DiFrancesco in New Mexico and are pleased to be able to share some of her wisdom in the article below.*

The theme for this year’s California Transcribers and Educators of the Visually Handicapped Conference was “Putting It All Together.” In the field of services to the visually impaired, teachers live this mandate on a daily basis. Stretched thin, expected to have answers and solve problems for everyone they meet, teachers of the visually impaired do just that. They make things happen and put things together for many people. With all their responsibilities, do they have to be involved in producing tactile graphics, a.k.a. raised-line drawings?

Last summer I had the opportunity to work with one of New Mexico School for the Visually Handicapped’s Outreach teachers. In addition to continuing his regular scheduled work of teaching braille, giving O&M lessons, doing assessments, providing information about eye conditions, contacting parents and school administrators, etc., this Outreach teacher organized in-service sessions for special education teachers, school braillists, and parents and students in his district.

Recognized needs: special education teachers -- more familiarity with braille materials. School braillists -- basic training in the Duxbury translation program. Parents and teachers -- a basic understanding of braille textbooks and raised-line drawings to help students with classwork and homework. He asked if I’d be willing to work with him. As a certified braillist with experience in transcribing textbooks and school materials, a Duxbury Braille Translator for Windows user, and tactile graphics technician, I had a contribution to make! Lucky for me: I was able to experience the joy of teaching a group of people so eager to learn, thanks to an Outreach teacher who “put it all together” for all of us.

## WHERE DO TACTILES FIT IN?

Raised-line drawings are hot! In spite of that, some people still feel they are extraneous, a bother, too much to deal with when there are so many more important things to do. Considering some of the “cute drawings” we’ve seen in demonstrations for producing raised-line drawings, they may be right. However, tactiles have their place and serve a purpose.

In a least restrictive environment, equal access to information is important. Students who are visually impaired are expected to perform at the same level as their peers. During test and assessment times, it can become evident that a student didn’t do well because of poor map reading skills or the inability to read a chart or a graph. The tactile graphics technician made the raised-line drawings correctly, but the student was unfamiliar with the material and didn’t know how to handle and read a raised-line drawing. The student had the mental ability to absorb the tactile form of gathering information, and the tactile readiness. But, the student was never taught how to use it, so it was useless under the fingertips.

### PROGRAMMING

The lack of certain tactile skills can bring a score down, and that is unfortunate. A bright college student taking her teacher certification exam was quite dismayed at the amount of graphs she was expected to handle in the test. She had a good grasp of the content, but her inability to deal with the material in a non-linear format affected her test score. A situation such as this shows the importance of developing in each student the basic tactile skills that demonstrate an ability to use information presented in various formats. This affects all subjects, and involves maps, charts, tables, graphs, diagrams, lists, schedules and figures.

The use of tactiles (a.k.a. raised-line drawings) must be incorporated into the overall print-to-braille adaptation of material in a reasonable manner. The purpose for using tactiles, like all braille material, is to produce literate braille readers. A transcriber must translate every word in the print text, but not every illustration needs to be rendered as a drawing. A note can suffice. The formatting of these notes is to block in cell 5 and begin the note in cell 7, to provide an easy location cue for the tactile reader.

To determine how to approach illustrations in transcribing a transcriber asks: Does the tactile reader just need to know there is a photograph and what it is? Then note that in braille. Does the picture caption or the text provide enough information about the illustration so that additional explanation is unnecessary? Then just use the caption and text. Is the illustration so complex that a written description is easier for the reader to grasp? Then you would write a description.

However, if there is a skill inherent in an illustration that a student is expected to master, then a raised-line drawing is needed. Also, if a drawing and its key organizes a lot of information so it can be easily absorbed and studied, a raised-line drawing is in order. But then, when the tactile is under the fingers of the tactile reader, that person needs direction for its proper use: the meaning of signifying objects with codes and symbols; help with tactile readiness issues and how to hand scan (read and organize) tactiles; the purpose of a key; how to use the key as a study guide; etc. It falls to the teachers to “put it all together” and make sure the necessary instruction takes place when using tactiles.

How can VI teachers keep track of this whole process? By becoming familiar with the basic skills required at each grade level. When a student who is visually impaired is expected to perform a task, incorporate the teaching of those skills into the goals of the educational plan. Work with a braille transcriber and/or tactile graphics technician to fulfill the directives of that educational plan.

For example: Johnny’s IEP evaluation at the end of second grade established that he did well in that grade and is expected to function as well in third grade. When preparing Johnny’s program for 3rd grade, look at the textbooks he will be using. Identify the basic skills he will be expected to master. Examine the braille textbook to assure that tactiles are present that will address those skills.

If third grade social studies is the time for learning map skills and beginning to read charts and graphs, then the braille

transcription of Johnny's social studies must contain enough examples of these types of tactiles for the teacher's use in teaching Johnny. If that is not the case, there is a need to find appropriate material and get the help of a local brailist/tactile graphics technician to produce the materials under your direction. Focus on the content and purpose of the tactile. Thus, the raised-line drawing becomes a powerful teaching aid. Johnny's whole class can benefit from his presentation at a show and tell.

## FORM FOLLOWS FUNCTION

There are various production techniques for raised-line drawings. Each serves a different purpose. A transcriber needs to prepare masters that are error-free as to content and production technique. The master must be able to hold up for making many copies. The necessary skills for textbook production are acquired with time and experience.

This is daunting for the teacher, but the good news is that a teacher's tactiles don't need to hold to the same standards. Here are a few teacher friendly techniques that are easy to learn and use, and serve the one-on-one teaching situation quite well.

1. Drawing boards. Use a soft mat with thin mylar, and a ball-point pen. Just draw on the mylar, pressing hard enough to crinkle it. Teachers can use tactile examples for explaining a point; students can make personal drawings with notes for later study; parents can discuss school work and work with their children at home. Mylar is available from Howe Press.
2. Puff paper. This has many names. Basically, you need either a printer, photocopy machine, or a Sharpie pen; swell-touch paper to draw on; and an image enhancer (a machine that uses a laser beam to "raise" the lines in your drawing). This technique is easy and serves well in classroom, home and work situations. Repro-Tronics produces the Tactile Image Enhancer and TIE Junior; HumanWare produces P.I.A.F. (Pictures In A Flash); and American Thermoform produces the Swell-Form Graphics Machine. They all have puff paper under different names: Swell-touch paper, Flexi-Paper, etc.

Obviously, this technique involves equipment, therefore, you need budgeting support from your district. This technique is well worth the expense because it is so easy for teachers and students to use, is so adaptable, and is appropriate for all ages. In addition, there are groups who produce excellent math and science diagrams. The material is downloadable online, so it is accessible to any teacher or visually impaired student who knows how to use the technology. This is an excellent option, especially for high school and college level students.

3. Tooling/embossing and collage: spur wheels and mirror image. A bit more technical but still workable, if you keep your drawings simple and uncluttered. Draw on the front; then the mirror image appears on the back. The design is raised by the use of serrated-edged spur wheels. For this technique (tooling and embossing) a tactile graphics kit is available from American Printing House for the Blind. Collage or another technique is often combined with tooling to complete the image.
4. Computer-Assisted Diagrams (CADs): The use of the Perkins or the computer can produce direct entry designs on braille paper, O&M maps, charts, graphs, etc. Collage or application of labels can complete the design. You can also use Wikki Stix, string, and so forth with glue.
5. Use of Overlays: If there is a tactile in a textbook, but it doesn't contain the information you need for a particular lesson, you can provide a drawing on a clear sheet of mylar to enhance the information in the tactile. No need to start from scratch. For overlays, the mylar needs to be a bit stiff, like the consistency of a transparency. Use flo-pens to draw designs, complete the design with spur wheels and/or point symbols to raise the image. You may use Wikki Stix and apply desired textures to your design.

Some of these techniques don't have much of a shelf life, and they are not intended for long-term use. They are intended to assist the teaching session, and serve as study tools for the student.

# Leber's Congenital Amaurosis

By Kate Moss, Family Specialist, TSBVI, Texas Deafblind Outreach

I have recently received a number of requests for information about Leber's Congenital Amaurosis, a degenerative disease that results in a severe loss of vision. This disease is thought to be caused by abnormal development of photoreceptor cells in the retina or perhaps the extremely premature degeneration of the retinal cells. Typically a baby with LCA will have very reduced vision at birth although the retina may appear normal when first examined. Within months, however, parents will usually notice nystagmus - an involuntary, rhythmical, repeated movement of the eyes. Children with LCA account for 10-18% of all cases of congenital blindness. Vision in individuals with LCA varies greatly from relatively mild acuity problems (20/70) to no light perception. (Leber's Links, 2001)

Occasionally LCA may be confused with other retinal problems such as retinitis pigmentosa, congenital and hereditary optic atrophy, cortical blindness, congenital stationary night blindness, flecked retinal syndrome, and achromatopsia. (Foundation Fighting Blindness, 2001) Some children originally diagnosed with LCA were later discovered to have Joubert Syndrome, Alstrom Syndrome, and Senior-Loken Syndrome. Although hearing loss is not an identified feature of LCA, some children with LCA in Texas also have hearing impairments. The 2000 Texas Deafblind Census identified ten such individuals and the 2001 Census identifies seven with both LCA and hearing loss. Some of these children were initially misdiagnosed as having Usher Syndrome.

LCA is genetically passed through families, and both parents must be carriers. Each parent has one gene with the disease, paired with one gene that is normal. When each child is conceived he will inherit genes in one of four ways. (1) If he gets the two healthy genes from his parents, he does not have LCA and is not a carrier. (2 & 3) If he gets a disease gene from one parent and not the other, he will be a carrier but not have the symptoms of LCA. (4) If he gets the two disease genes from his parents, he will have LCA. This is referred to as an autosomal recessive pattern of inheritance.

Children with LCA often have eyes that appear sunken or deep set. They may press on the eyes frequently; this is called oculo-digital reflex. Some children with LCA have cone-shaped corneas (Keratoconus) and cataracts that cause the corneas to become cloudy. By the time a child reaches adolescence, pigmentary changes occur in the retinal pigment epithelium (the supportive tissue underneath the retina). This is similar to changes that occur to the retina with retinitis pigmentosa, the vision condition associated with Usher Syndrome. This occurs because the blood vessels in the retinas become narrow and constricted. Unlike Usher Syndrome, where a progressive loss of vision is typical, vision loss in individuals with LCA usually remains stable through young adult life. Progression of vision loss later in life has not yet been clearly defined. Additionally, some individuals with LCA are very sensitive to light (photophobic). Children with some remaining vision are likely to be extremely farsighted as well. (Foundation Fighting Blindness, 2001)

In some cases, individuals with LCA also show central nervous system complications. They may be developmentally delayed, have seizure disorders, or motor impairments.

There is currently no treatment for LCA. However, there is a good deal of genetic research being done related to LCA. The Foundation Fighting Blindness notes that a gene for LCA has been isolated on chromosome 17. The Leber's Link website offers information from The Johns Hopkins Center for Hereditary Eye Diseases that indicates three genes associated with LCA: chromosome 17, a 65kD RPE protein, and CRX on chromosome 19. A fourth gene has recently been localized for this disease. In Texas, Dr. Richard Lewis with Baylor College of Medicine is doing ongoing research on LCA. Dr. Lewis is open to contact from families of children with LCA or who suspect their child of having LCA. Another contact at Johns Hopkins is Irene Maumenee. Contact information for both Dr. Lewis and Dr. Maumenee is listed below:

Dr. Richard Lewis, MD/MS  
Professor, Department of Ophthalmology, Pediatrics,  
Medicine and Molecular and Human Genetics  
Cullen Eye Institute, NC-206  
Baylor College of Medicine  
One Baylor Plaza  
Houston, TX 77030  
Phone: (713) 798-3030  
E-mail: rlewis@bcm.tmc.edu

Irene E. Maumenee, MD  
Professor of Ophthalmology, Medicine and Pediatrics  
Wilmer Eye Institute  
Maumenee Building, Suite 517  
The Johns Hopkins Hospital  
600 North Wolfe Street  
Baltimore, MD 21287-9237  
Phone: (410) 955-5214  
E-mail: jhched@welchlink.welch.jhu.edu

## REFERENCES/RESOURCES

If you are interested in connecting with other families concerned with LCA, there are a number of good websites available to help you with this. They also are a good resource for updates on research and general information about LCA.

### Leber's Links Website

This website has good information on Leber's, links to other websites, chatrooms, listservs, newsletter resource, research news, and more.

<<http://leberslinks.freeyellow.com/foundation.html>>

### The Foundation Fighting Blindness

<[www.blindness.org/leber.html](http://www.blindness.org/leber.html)>  
(888) 394-3937

## Meningitis

By Kate Moss, Family Specialist, TSBVI, Texas Deafblind Outreach

The 2001 Texas Deafblind Census data indicates that meningitis is one of the leading causes of deafblindness in our state. Recently in Texas there has been several scares related to outbreaks of meningitis. What is this disease and what are some of the concerns associated with it?

First of all, meningitis is not the same condition as encephalitis, although they both occur in the brain. Meningitis is the inflammation of the tissue lining of the brain and spinal cord, the meninges. Encephalitis is the inflammation of the brain itself. There are two broad categories of meningitis, viral and bacterial.

Bacterial meningitis is more uncommon, but it can be extremely serious. Often times it is fatal, especially if not treated immediately. Those who survive this type of meningitis often have a severe disability as a result. Brain injury and deafness are two common results of this type of meningitis. Babies in the USA are typically vaccinated for one type of bacteria that causes meningitis, the haemophilus influenzae type b (Hib) strain. Because of this vaccination program, this type of meningitis has practically disappeared in this country. The other two types of meningitis are meningococcal and pneumococcal. Both of these bacteria are very common. In fact, at any one time, around 10 to 25% of the population are carrying this bacteria, which lives on the back of the throat and nose. Usually these bacteria do not cause any real problems.

A person who becomes sick with bacterial meningitis needs immediate medical treatment. Antibiotics are used to treat bacterial meningitis. According to the Centers for Disease Control, high fever, headache, and stiff neck are common symptoms of meningitis in anyone over the age of 2 years. "Symptoms can develop over several hours, or

they may take 1 to 2 days. Other symptoms may include nausea, vomiting, discomfort looking into bright lights, confusion, and sleepiness. In newborns and small infants, the classic symptoms of fever, headache, and neck stiffness may be absent or difficult to detect, and the infant may only appear slow or inactive, or be irritable, have vomiting, or be feeding poorly. As the disease progresses, patients of any age may have seizures.” (CDC Website, 2001) A diagnosis is usually made with a spinal tap.

Viral meningitis is usually not as dangerous as bacterial meningitis although the symptoms often appear to be the same. About 90% of cases of viral meningitis are caused by a group of viruses known as enteroviruses. Herpes viruses and the mumps virus can also cause viral meningitis. There is no treatment for viral meningitis. People usually get well on their own with plenty of bedrest. They are simply given plenty of fluids and also medicine to treat the fever and headaches. Viral meningitis does usually not result in other disabling conditions and is rarely fatal.

A person may have meningitis more than one time, although this is rare. There are vaccines for some types of meningitis. Someone showing any symptoms of meningitis, should immediately see a doctor who can determine the type of meningitis present and begin treatment. Even with viral meningitis, severe problems can result from dehydration, especially in children and babies.

Both types of meningitis are spread through contact with respiratory and bodily secretions. That is why one of the best preventions for meningitis is regular and thorough hand washing. It is usually not spread through casual contact like sneezing or coughing.

When a person has meningitis, there is usually a long-term recovery period. There are also some problems which can be expected immediately following hospitalization for this illness and may disappear in time. In children we see many behavioral changes that may be due, in part, to the trauma of being in the hospital. These include babyish or clingy behavior, bed-wetting, temper tantrums, problems sleeping at night, and forgetting recently learned skills. There are other symptoms, however, that may last longer, or even be permanent. These include general fatigue, recurring headaches, problems concentrating, short-term memory loss, clumsiness, giddiness, balance problems, depression, violent temper outbursts, mood swings, bouts of aggression, learning difficulties, tinnitus (ringing in the ears), joint soreness or stiffness, visual problems such as double vision and cortical visual impairment, and the possibility of deafness, brain damage, or seizures as mentioned earlier. (Meningitis Foundation of American, 2001).

## REFERENCES/RESOURCES

Meningitis Foundation of America Inc.

7155 Shadeland Station, Suite 190

Indianapolis, Indiana 46256-3922

Telephone: (800) 668-1129

Outside North America: (317) 595-6383

Web: <<http://www.musa.org/>>

The Centers for Disease Control and Prevention

1600 Clifton Rd.

Atlanta, GA 30333

Telephone: (800) 311-3435

Web: <<http://www.cdc.gov/>>

The National Institute

of Neurological Disorders and Stroke

NIH Neurological Institute

P.O. Box 5801

Bethesda, MD 20824

Phone: (800) 352-9424

Web: <[http://www.ninds.nih.gov/health\\_and\\_medical/disorders/encmenin\\_doc.htm](http://www.ninds.nih.gov/health_and_medical/disorders/encmenin_doc.htm)>

## Attention: Individuals and Families with Usher Syndrome

Drs. Judith Willner and Seth Ness, with Mt. Sinai Hospital in New York, are conducting a study to find the genes responsible for Usher Syndrome (hearing loss and retinitis pigmentosa) in Ashkenazi Jews. If you or a member of your family are an Ashkenazi Jew or of Ashkenazic heritage and have Usher Syndrome, or both hearing loss and vision loss that has no other known cause, your family may be eligible to participate. The possible medical advances and greater understanding of Usher Syndrome that may result if causative genes are found are the primary benefits of participation. Involvement may be as simple as a phone call and giving blood locally or may involve spending a few hours at Mount Sinai Hospital in New York for vision and hearing tests at no cost to you. Call Drs. Ness or Willner at (212) 241-6947, Dept. of Human Genetics, Box 1497, Mount Sinai School of Medicine, 1 Gustave L. Levy Place, NY, NY 10029, e-mail to <nesss01@doc.mssm.edu>.

### Kate's Corner - continued from page 1

The Natalie Barraga Award for this year was presented to Sports Extravaganza (see the Winter 2001 *SEE/HEAR*) in recognition of excellence in public school programs for students with visual impairments. Yeah Kitra Gray and pals!

The Outstanding Parent of the Year Award was presented to Leslie Fansler of Amarillo in recognition of outstanding advocacy and dedication to the interest of people who are blind and visually impaired. Leslie, parent of two sons - one with deafblindness, is also a PPCD classroom teacher. Leslie serves as DBMAT Regional Coordinator for ESC Region 16 and is active in that organization along with her husband, Keith. Leslie was also recently awarded the Milken Family Foundation National Educator Award as an outstanding educator. We are very proud of you Leslie.

The Outstanding Student of the Year Award was presented to Will Conrad in recognition of outstanding achievement and performance in an academic career. Will graduates this Spring from Eanes ISD, near Austin. His former vision teacher, Ann Adkins, accepted the award on his behalf. He was at Rice University in Houston, attending freshman orientation, and unable to attend. Best wishes to you, Will, as you begin your college career!

The Virginia Bishop Award, presented in recognition of outstanding contributions to the field of early childhood for children who are blind and visually impaired, was awarded to my teammates, Gigi Newton and Stacy Shafer. You gals have long been considered the Dynamic Duo by your Outreach pals. Congratulations!

The Texas Chapter Award was presented to Blind and Visually Impaired Children's Program Coordinators of Texas Commission for the Blind, in recognition of outstanding contributions to the lives of persons who are blind and visually impaired. We all know about the hard work and dedication of these Coordinators. Bravo!

The Aubrey Boyd Tipps Memorial Award was presented this year to Angie Baird, TCB Vocational Counselor, in recognition of providing outstanding services in the field of placement of persons who are blind and visually impaired in competitive employment or sheltered workshops. Angie has placed fifty-one individuals in employment situations this year. That averages out to roughly one placement a week, excluding Christmas! Great job!

The Sammie K. Rankin Memorial (Outstanding Member) Award was presented to Debra Sewell, former Outreach staff member and current TSBVI Curriculum Director. This award was given in recognition of outstanding contributions to the field of services for persons who are blind and visually impaired, and in particular for her work in developing the *Assessment KIT* and the *Braille FUNDamentals Curriculum*. Congratulations Debra!

The Julia L. Young Award was presented to Melissa Whiddon in recognition of outstanding work with children who are blind and visually impaired. Melissa is the supervisor of the vision program in San Antonio ISD and a diagnostician who has worked hard to learn about the unique issues of children with visual impairments. We appreciate your dedication to this population.

# Interesting Facts from the Year 2001

## Annual Registration of Students with Visual Impairments

By Nick Necaie, APH Materials and VI Registration Coordinator, TSBVI Outreach

The Annual Registration of Students who are Visually Impaired (VI) is the count of eligible students who are visually impaired in each school district of Texas as of the first Monday in January. The “as of” date for this year’s Annual Registration was January 2, 2001. This count is done for a number of reasons. 1) It determines the amount of funding the state receives to get materials from the American Printing House for the Blind. 2) Each region’s State Supplemental Visually Impaired (SSVI) funds are portioned out according to the number of VI students they have. These SSVI funds can help pay for things like Vision Specialists at the Education Service Centers, salaries of VI teachers and O&M Specialists, training workshops, family support and other VI-unique needs as determined by plans within each region. 3) It is a tool for statewide and regional planning. 4) It is a federal requirement. Here are some interesting facts from the registry that give us a picture of students in Texas with visual impairments.

Total number of students registered - 6719 (One student in a non-public school)

Number of students who were on the 2000 registration but not on the 2001 - 1024

Number of new students added to the 2001 registration - 1142

Braille readers - 335

Number of infants - 555

Large print readers - 1215

Number of preschoolers - 784

Regular print readers - 1417

Number of kindergartners - 374

Auditory readers - 407

Number of districts with 1 or more VI students - 710

Non readers - 2475

Number of districts with only 1 VI student - 190

Number of legally blind students - 4502

Number of districts with 3 or less VI students - 393

Number of students whose primary handicapping condition is visually impaired (VI) - 3902. The first handicapping condition listed is VI. The students may or may not have additional handicapping conditions listed.

Number of students whose secondary handicapping condition is VI - 1586. The primary handicapping condition listed is other than VI.

Number of students whose third handicapping condition is VI - 1026. The first two handicapping conditions listed are other than VI.

Number of students who are VI only - 2815. No other handicapping conditions are listed.

Number of students with 2 or more handicapping conditions - 3903

Number of students who are AI/VI or DB (Auditorially Impaired/Visually Impaired or Deafblind) - 375  
*(Editor’s note: There is a sizeable discrepancy between the number of children who appear on the VI registry as AI/VI or DB and the number that are listed as deafblind on the Texas Deafblind Census - see page 27. We’re trying to determine why these numbers are different because we want ALL children with visual impairment have to access to services and resources.)*

The region with the most VI students registered is Region 4 (Houston area) with 1428 students on the Annual Registration.

The region with the least VI students registered is Region 9 (Wichita Falls area) with 79 students on the Annual Registration.

There are 42 Braille reading students at the Texas School for the Blind and Visually Impaired.

1573 or 23.82% of the students on the 2001 Annual Registration receive instruction in Orientation and Mobility.

## The 2001 Texas Deafblind Census

By Craig Axelrod, Teacher Trainer, TSBVI, Texas Deafblind Outreach

The 2001 Texas Deafblind Census, a federally required annual count of deafblind students in Texas, ages 0-21, was recently completed. In January, Dr. Roseanna Davidson's Census project staff at Texas Tech University sent materials to all local school districts in Texas. Someone in each district, often a Teacher of the Visually Impaired, reviewed and updated information about students who had been reported on the 2000 Census, and helped coordinate the completion of forms for newly identified eligible students. In February, districts returned the Census forms to the Regional Deafblind Specialist at their Education Service Center (ESC). Deafblind Specialists reviewed the forms, checking for completeness and accuracy, then submitted them to the Census project staff who compiled the information for inclusion in the Federal Deafblind Census. Each ESC recently received a final report of its regional data as well as a general statewide report.

Most of the data gathered through the Census process is required and requested by the federal government. Additional questions reflect the need for information about Texas-specific issues. Regional Census reports are now being analyzed by ESCs to help clarify regional needs and develop deafblind regional plans. Deafblind Outreach uses the reports to identify trends and training needs. Demographic information is also shared with other state agencies for their use in planning future services. Some facts and figures from the 2001 Texas Deafblind Census appear below.

### NUMBER OF DEAFBLIND STUDENTS IDENTIFIED ON 2001 CENSUS

ESC Region	2001 Count
1	22
2	13
3	11
4	103
5	6
6	23
7	21
8	10
9	6
10	49
11	70
12	17
13	31
14	10
15	30
16	16
17	36
18	31
19	25
20	48
TSBVI	17
TSD	11
State	606

### NUMBER OF DEAFBLIND STUDENTS IN 2001 COMPARED TO PREVIOUS YEARS

Year	Total	Male	Female
01	606	345	261
00	627	354	273
99	691	382	309
98	775	438	337
97	720	404	316
96	664	380	284
95	594	340	254
94	531	310	221
93	468	282	186

### AGES OF DEAFBLIND STUDENTS

Age	Total	Percentage of Population
0-2	25	4.1%
3-5	84	13.9%
6-11	200	33%
12-17	192	31.7%
18-21	94	15.5%
22	10	1.7%
over 22	1	0.2%

SYNDROMES/CONDITIONS

## MOST COMMON ETIOLOGIES

Etiology	Number
<i>CHARGE</i>	34
<i>Cornelia de Lange</i>	7
<i>Dandy Walker</i>	6
<i>Down Syndrome</i>	14
<i>Goldenhar Syndrome</i>	5
<i>Leber's Congenital Amaurosis</i>	7
<i>Usher I</i>	14
<i>Usher II</i>	13
<i>Congenital Rubella</i>	10
<i>Congenital Toxoplasmosis</i>	5
<i>Cytomegalovirus (CMV)</i>	27
<i>Hydrocephaly</i>	21
<i>Microcephaly</i>	19
<i>Asphyxia</i>	11
<i>Meningitis</i>	26
<i>Severe Head Injury</i>	14
<i>Stroke</i>	6
<i>Tumors</i>	9
<i>Complications of Prematurity</i>	97

## VISUAL IMPAIRMENT

Visual Status	Number
<i>Vision better than 20/70 in better eye with correction</i>	48
<i>Low Vision (visual acuity of 20/70-20/200 in better eye with correction)</i>	74
<i>Legally Blind (visual acuity of 20/200 or less or field restriction of 20 degrees or less)</i>	298
<i>Light Perception Only</i>	37
<i>Totally Blind</i>	65
<i>Further Testing Needed</i>	18
<i>Tested - Results Nonconclusive</i>	32
<i>Not Tested and At Risk (Documented hearing loss and at risk for VI)</i>	7
<i>Cortically Visually Impaired</i>	165
<i>Diagnosed Progressive Loss</i>	75
<i>Wears Glasses</i>	233

## HEARING IMPAIRMENT

Hearing Status	Number
<i>Very Mild (15-25 dB loss)</i>	13
<i>Mild (26-40 dB loss)</i>	45
<i>Moderate (41-55 dB loss)</i>	73
<i>Moderately Severe (56-70 dB loss)</i>	81
<i>Severe (71-90 dB loss)</i>	97
<i>Profound (91+ dB loss)</i>	106
<i>Further Testing Needed</i>	36
<i>Tested - Results Nonconclusive</i>	55
<i>Not Tested and At Risk (Documented VI and at risk for hearing loss)</i>	94
<i>Central Auditory Processing Disorder</i>	65
<i>Diagnosed Progressive Loss</i>	41
<i>Uses Amplification</i>	274

## ADDITIONAL DISABILITIES

Category	Number
<i>Physical Impairments</i>	381
<i>Cognitive Impairments</i>	399
<i>Behavior Disorders</i>	16
<i>Complex Health Needs</i>	253
<i>Other Impairments</i>	188

## LIVING SETTING

Residence	Number
<i>Birth/Adoptive Family</i>	540
<i>Extended Family</i>	19
<i>Foster Family</i>	17
<i>Group/Nursing Home, State/Private Facility</i>	23
<i>Other or Not Reported</i>	7

## HAS A DESIGNATED INTERVENER

Status	Number	Percentage
<i>Yes</i>	43	7.1%
<i>No</i>	389	64.2%
<i>Unknown</i>	174	28.7%

Here are some things the Census data tells us about identification of children and youth with deafblindness in Texas.

After a peak of 775 students were identified in 1998, the number has dropped every year, to 606 in 2001. While the decline may result in part from students being taken off the Census after assessments conclusively ruled out vision and hearing losses, this may not always be the case. Of the 62 students deleted from this year's Census who continue in special education, 31 have documented visual impairments with hearing classifications of "further testing needed to determine hearing impairment," "tested - results nonconclusive," or "not tested and at risk." How many of these students were tested for a hearing loss before being removed?

The federal government projects the number of deafblind students in a geographic area using a formula of 2 to 3 students with deafblindness per 1,000 students receiving special education services. According to TEA, 482,427 students received special education services in the 1999-2000 school year. If the federal projections are correct, there should be between 965 and 1447 deafblind students in Texas. Where are they?

There appears to be a significant, chronic undercount of 0-2 year olds. In response, representatives from several agencies will soon meet to discuss this issue. These will include the Texas Department of Health, Texas Commission for the Blind, Texas Education Agency, the Interagency Council on Early Childhood Intervention, the Three Low Incidence Disabilities Decentralized Function at Education Service Center Region 3, the Deafblind Census Project at Texas Tech University, and the Deafblind and VI Outreach Projects at Texas School for the Blind and Visually Impaired.

Usher Syndrome (Type I and II), a leading cause of deafblindness, is estimated by some to occur in 3-6% of the congenitally deaf or hard of hearing population. 2785 of the 4508 students reported on the 1999-2000 Texas State Survey of Deaf and Hard of Hearing Students were born deaf or hard of hearing. (This number does not include congenitally deaf or hard of hearing students who are in their local school districts and not being served by Regional Day School Programs for the Deaf.) 3% of 2785 is 83. There are currently only 27 students diagnosed with Usher Syndrome on the 2001 Texas Deafblind Census.

More optimistically, the number of students who are deafblind from Congenital Rubella Syndrome (CRS) decreased from 43 in 1994 to 10 in 2001, a possible result of both better immunization and graduation from the educational system of older students with CRS. The increase of students diagnosed with CHARGE, from 12 in 1993 to 34 in 2001, might indicate better identification and understanding of this syndrome.

The Texas Education Agency's newly adopted expanded definition of deafblindness (effective March 6, 2001) more closely reflects the federal definition, which qualifies a student to be counted on the Texas Deafblind Census. According to TEA, a student now qualifies as deafblind who "...has documented hearing and visual losses that, if considered individually, may not meet the requirements for auditory impairment or visual impairment, but the combination of such losses adversely affects the student's educational performance;" or "...has a documented medical diagnosis of a progressive medical condition that will result in concomitant hearing and visual losses that, without special education intervention, will adversely affect the student's educational performance." TEA's complete eligibility definition of deafblindness can be found on its website at <<http://www.tea.state.tx.us/rules/tac/chapter089/ch089aa.html>>, provision §89.1040. [Eligibility Criteria](#).

In light of these changes, will the number of students counted on the Texas Deafblind Census increase? We'll let you know in 2002. Meanwhile, if you have questions about whether or not a child should be included on the Texas Deafblind Census, please contact the Deafblind Specialist at your Education Service Center (below), Dr. Roseanna Davidson at Texas Tech University, (806) 742-2334, or any of the Texas Deafblind Outreach Staff. Students can be added to the Census at any time.

ESC Reg.	Specialist(s)	Phone	ESC Reg.	Specialist(s)	Phone
Region 1	Peter Graves	(956) 984-6165	Region 12	Tina Herzberg	(254) 666-0707
Region 2	Joyce West	(361) 561-8524	Region 13	Chrissy Cowan	(512) 919-5317
Region 3	Brian Jones	(361) 573-0731	Region 14	Billy Sealey	(915) 675-8636
Region 4	Susan Parker	(713) 744-6398	Region 15	Brenda Morris	(915) 658-6571
Region 5	Dion Potter	(409) 386-5514	Region 15	Debbie Louder	(915) 658-6571
Region 6	Nodya Thornton	(409) 435-2195	Region 16	Stormetta Stateler	(806) 376-5521
Region 7	Ann Phillips	(903) 984-3071	Region 17	Mary Jo Lovingier	(806) 792-4000
Region 8	Donna Clopton	(903) 572-8551	Region 17	Sharon Trusty	(806) 792-4000
Region 9	Tricia Lee	(940) 322-6928	Region 18	Bouneva Mayo	(912) 563-2380
Region 10	Heidi King	(972) 348-1598	Region 19	Olivia Schonberger	(915) 780-5344
Region 11	Peggy McNairn	(817) 740-7594	Region 20	Deborah Thompson	(210) 370-5453

SYNDROMES/CONDITIONS

## Look the World Straight in the Eye

Terry Murphy, Executive Director, Texas Commission for the Blind

The majority of the Commission's staff knows I'm big on inspirational quotes, so they appear from time to time in my mail. One such piece of paper recently caught my eye primarily because the sender had highlighted the name Helen Keller. From *The Book of Positive Quotations* by John Cook, Keller was quoted as saying:

“Never bend your head. Hold it high. Look the world straight in the eye.”

Wow, those simple words exude so much confidence! I was hooked, so I spent some time over the next few days reacquainting myself with this impressive woman.

I found that Keller was among “The 50 Most Famous People of the Century” in the December 1999 issue of *Biography Magazine*, which didn't surprise me. Although her life spanned two centuries (1880-1968), she left an indelible mark on the century in which you readers and I were born. Keller became the “poster person” for triumphant achievement in the face of physical disability in the 1900s. Blind, deaf, and unable to speak as a result of an unidentified ailment contracted when she was 19 months old, Keller nonetheless went on to graduate cum laude from Radcliffe. She traveled the globe, wrote 14 books, and lectured.

The person who helped Keller gain the confidence to “look the world straight in the eye” was her teacher, Annie Sullivan. Sullivan connected Helen to the world of possibilities at age 6. Once Keller realized from Sullivan that everything had a name, she was insatiable. Within six months, it is said, she had learned the manual alphabet and could read braille. One biography said that she went on to learn German, Latin, Greek, and French. All this says a lot about both the teacher and the student.

I venture a guess that there are few adults today who haven't seen, heard, or read one or more versions of “The Miracle Worker,” originally a play in which Sullivan and Keller were immortalized by William Gibson. The title itself says a lot about human nature. Back in the 1880s, Sullivan's ability to help Helen understand a world of sight and sound without seeing or hearing was indeed thought to be a “miracle.”

An even bigger “miracle” in the early to mid-1900s was that Keller went on to use her understanding and education to earn a living by writing and lecturing. Unfortunately, this type of miracle mindset about successful and productive people with visual and hearing losses still prevails today. I tend to think that Keller and Sullivan would say that being brought together as student and teacher may indeed have been a miracle, but that Helen's successful “employment and independent living outcomes,” as we would say in today's vocational rehabilitation field, were instead the result of a whole lot of hard work and perseverance on both their parts!

I couldn't help wondering as I read more about Keller what she and Annie Sullivan would have to say about the Commission's “Texas Confidence Builders” service model if they were here today. After wandering through a few more of her words, I'm pretty sure they would say it's nothing new to them. Consider these:

“We can do anything we want if we stick to it long enough.”

“One can never consent to creep when one feels an impulse to soar.”

And my favorite:

“The world is moved not only by the mighty shoves of the heroes, but also by the aggregate of the tiny pushes of each honest worker.”

I believe Sullivan thought of herself as an honest worker, not a hero. I think she would say that the way TCB provides services is similar to her approach in helping Helen - with tiny pushes of hope, optimism, determination, and honesty. From her background, Sullivan knew that if Keller could first learn alternative speech and communication techniques she would gain the confidence to tackle even more. I don't believe that Sullivan knew what Helen was fully capable of accomplishing. She just knew that with each step forward, a higher goal was possible. In those inevitable times when young Helen probably balked at something new or difficult, I can just see Sullivan pushing Helen gently forward even after adulthood because she knew Helen's self-confidence would grow as she learned and practiced new skills.

TCB workers are sometimes criticized for not giving up when individuals set their feet in concrete and refuse to learn alternate skills from which to choose in varying situations. We can't force a person to put forth the effort, but we don't give up as easily as we once did. From experience we learned that an individual who concludes vocational rehabilitation or independent living services after choosing to learn a minimum of skills will generally return time and again to the agency for assistance. When so many of these returning individuals said they found they lacked the self-confidence to resolve problems for themselves, *Texas Confidence Builders* was born.

We believe the "tiny pushes" Keller speaks about so eloquently are worth the potential criticism if we succeed in reaching individuals with the truth that living in a society primarily configured for sight and sound has enough barriers of its own without individuals limiting themselves. This last quote I came across pretty much sums up the lives of Sullivan and Keller, TCB workers, and the many individuals the Commission is challenging to be the best they can be. Helen Keller says:

"I am only one; but I am still one. I cannot do everything, but still I can do something. I will not refuse to do the something I can do."

## **A Vision for Texas Our Profession Determines Its Own Destiny**

By Dr. Phil Hatlen, Superintendent, Texas School for the Blind and Visually Impaired  
<PhilHatlen@tsbvi.edu>

*Editor's note: Dr. Hatlen gave this speech at the 2001 Texas Association of Education and Rehabilitation (TAER) Conference on April 20<sup>th</sup>.*

In recent months, and most certainly in the coming months and years, a common topic for conversation among educators has been TCB's Texas Confidence Builders. My own reaction to this change in service delivery has taken several turns over the past few months. Let me suggest one way of looking at it.

Unemployment and underemployment has been the primary issue among blind adults for as long as I have been in this profession. Despite advances in rehabilitation and education services, despite technology advances, despite changes in employer attitudes, the rate of unemployment has virtually remained the same for the past 50 years. TCB has looked at that fact, considered what to do about it, and taken a dramatic move in the manner in which it serves its customers. Whether you and I approve or not, the fact that TCB is willing to take risks, be bold, stretch the envelope, because nothing else has worked, is something that I, for one, can admire.

How are we, in education, doing these days? Very well, in many ways.

I think that local school districts, education service centers, and TSBVI have, over the years, developed a very

supportive, collaborative system that results in blind and visually impaired students receiving the best education in the most appropriate placement. “Appropriate” may change from time to time, and we have a flexible system in which that can happen.

But we have our chronic problems, too. Regarding unemployment, we must own this issue, too. What are we doing about it? About service delivery in rural areas, are we certain that students are receiving all the direct instruction from a Teacher of the Visually Impaired (TVI) that they need? And what of teaching the expanded core curriculum? Our profession clearly tells us that it is as important as the regular core curriculum. But are all TVIs finding the time and inclination to teach such subjects as social skills, living skills, and career education?

I’m not certain that you’ll all agree with me, but from my perspective, we in education are as much in need of evaluating our efforts and considering some new directions as was TCB.

I have a short list (five items) of concerns that I suggest to you are in need of immediate attention. And, like TCB, the solutions to some of these issues might very well require high-risk, bold efforts. My list consists of national issues, not unique to Texas. But my sincere hope is that professionals in Texas will take some of these concerns on as challenges to be overcome, and that once more Texas will take the lead in confronting issues and finding solutions.

## **1. INSTRUCTION IN THE EXPANDED CORE CURRICULUM**

The concept of an expanded core curriculum for blind and visually impaired learners had its origin in schools for the blind a century ago. It took a wrong turn for awhile in the middle of the 20<sup>th</sup> century when we became so obsessed with inclusion that we weren’t willing to admit that these students had unique needs, that vision loss in and of itself created learning needs.

This topic went through several name changes. It was first referred to as the “specialized needs of visually impaired students.” Soon we were using the term “unique needs,” the “disability-specific needs.” Finally, with the realization that all of education was moving toward the concept of “core curriculum,” the term “expanded core curriculum” was used and adopted.

The National Agenda movement ran it up the flagpole. Everyone saluted. Shortly thereafter, articles were written on the expanded core curriculum; our major professional organizations endorsed it; and there seemed few, if any, detractors. Therefore, I think it’s safe to assume now that most educators of blind and visually impaired students realize that all students must be assessed in all areas of the expanded core curriculum, and, based on assessment results, IEP goals must be written to address the areas needed by each student. (Years ago, when I stated that the learning of living skills should be of equal importance with learning to read, my educator friends would giggle or look at me aghast! Today, when I make that statement, I see heads nod in agreement.)

So, where are we today in implementing the expanded core curriculum? Are all students being assessed in all areas? Does the IEP reflect the outcome of assessment and provide for instruction in portions of the expanded core curriculum? Has the TVI been given the time to teach these vital skills? Sadly, in most areas of Texas, I think not. I think that dedicated, committed, well-meaning TVIs are not finding enough hours in the day to address the expanded core curriculum. I know there are many exceptions - some of you have told me of tremendous results in teaching the expanded core curriculum.

Perhaps we have not made our position clear enough. If the instructional day provides time to teach reading, it must also provide the time to teach living skills, social skills, career education, assistive technology, etc. If it doesn’t, our system is broken and needs to be fixed. I’m ready to help fix it; are you?

## 2. APPROPRIATE READING MEDIA

The question I feel compelled to ask today is this: Is there any visually impaired child, anywhere in Texas, whose reading medium was selected based on the amount of time the TVI could spend with her? You have heard me say this many times, and I'm going to say it again: A child who is in the early stages of learning to read and write braille will need his TVI for at least one hour per day. It is my sincere hope that no child in Texas is reading print because of the lack of time to teach braille.

If this is an issue in Texas, will you join me in addressing it?

## 3. CAREER EDUCATION

As I mentioned earlier, I believe that educators must own part of the dismal employment rate among blind adults in the U.S. Career education is a major curricular area in the expanded core curriculum. It is recognized as an educational need that most often will not be adequately addressed in the regular school curriculum. Consider the amount of career education that is incidentally learned by sighted students by visual observation, and then think about how these learning opportunities will be provided to blind and visually impaired students.

Some months ago, I was told by some of the leaders of our consumer organizations in Texas that most blind young people take at least ten years after high school graduation before they settle into a job - or, for the majority, settle for unemployment. My friends, it doesn't have to be that way. We, you and I, should commit to a career education program for our students that will prepare them for employment, for decision making, and for the dignity of work. Our graduates should have all the skills necessary to chart their own destiny, and not be dependent on TCB to give them direction in life.

Are all of you committed to teaching career education to all blind and visually impaired students in Texas? May I join you as we make this a goal for our Texas profession, and once more lead the nation in innovation?

## 4. TACTILE GRAPHICS

How's this for a topic that just won't go away? But, my friends, we are beginning to identify the real problem. For years our issue was a plethora of "raised pictures" coming from well-meaning, good-hearted people who truly believed that everything visual should be presented to blind students. When we finally got it straight between "pictures" and "graphics," and realized that tactile graphics make a lot of sense, but pictures with perspective are almost impossible to present tactually, we really thought we had achieved what we needed. When wonderfully creative people like Diane Spence and Bob Walling began to produce clear, sharp tactile graphics for geography, mathematics, and science textbooks, we really knew we had licked the problem of tactile graphics.

But, like peeling an onion, the more layers we took off the topic of tactile graphics, the more issues we found. At last, though, I think we have come to the core. Children need to be sequentially and systematically taught how to read tactile graphics. University preparation programs need to include "how to teach the reading of tactile graphics" to future TVIs. Then TVIs need to add this topic as a goal in the IEP of every blind student. How about it, universities, are you ready to do this? How about it, teachers, are you ready to commit instructional time to this vital area of learning?

Are there people we need to convince? How about TAER taking this on as a challenge? How about someone reporting back to TAER this time next year about the tremendous success in establishing programs to train teachers on how to teach tactile graphics, and in implementing programs in local schools that provide time for children to learn to read tactile graphics.

I'm ready; are you?

## 5. USE OF PARAPROFESSIONALS

The existence of paraprofessionals, or teacher assistants, is a given in our profession. After all, every profession, even Orientation and Mobility, uses them. But how are they used? Are they used to supplement and reinforce what the TVI has taught? Or, and ask yourself this question seriously, are they used to replace TVIs?

I could go on, but five topics for us to take on with commitment, dedication, and creativity, are enough. I know each of you could add to this list, and, because these are personal convictions, not fundamental truths, you might disagree with my list. My purpose in sharing these with you today is that I'd really like us educators in Texas to come together over chronic, serious issues, and collectively find solutions. We have led the country in many ways - let's do it again.

How about it, teachers, are you ready? How about it, TAER, is it time to tackle some tough issues?

### **Book Review: *What's Stopping You? Living Successfully with Disability***

By Gail Beukenkamp, Parent, Amarillo, Texas

*Editor's note: I want to thank Gail for graciously agreeing to write a book review for SEE/HEAR. We will be periodically including reviews on books and similar resources so that families and professionals can get an idea of what new materials are out there for them. We welcome the opportunity to publish other book reviews written by family members or professionals. If you are interested in doing one, please feel free to contact Edgenie Bellah, News & Views Section Editor.*

A disability can become a reality at any time in a person's life. It may be a gradual change or an overnight change in lifestyle caused by a sudden accident or illness. A disability not only effects the person who is disabled, but also has a major impact on other family members, caregivers, and friends.

*What's Stopping You? Living Successfully with Disability* is written by Mark Nagler, Ph.D. and Adam Nagler, father and son. Mark Nagler, Ph.D., was born with cerebral palsy and has triumphed over his disability. By living with a disability, he is able to give a personal view and help teach people how to cope with challenges. This book is about disabilities in general. It is divided into four parts.

Part one describes living with a disability. This part contains a very good section on advocacy and laws protecting the disabled. It explains the importance of advocacy and describes the different types. The author discusses the effect of a disability on family and friends and changes that take place in the home and at work.

Part two explains the role of caring for people with disabilities. Much like the individual who has the disability, caregivers have to go through an adjustment process. You have to accept that life has changed and make new arrangements. The authors emphasize throughout the book that a positive attitude is very important for the disabled person and the caregivers as well. They state that a positive attitude is necessary to triumph over a disability.

Part three gives advice about protecting the future of the disabled person. It describes the types of insurance, power of attorney, and the importance of financial planning. Advice is given on how to ensure your legal protection such as the necessity of having a will and information about filing a legal claim. The information is simplified to make it easy to understand.

Part four is a resource section. It explains how to search a disability on the Internet, and gives an extensive list of

health and disability related web site addresses. There is also a directory of numerous organizations, which includes addresses and telephone numbers that serve people with disabilities. Fourteen sample letters are included to help the disabled request the services they need.

*What's Stopping You?* is a very good resource if you are looking for information about disabilities in general. The book answers many questions about living with a disability or caring for an adult with a disability. There are many personal accounts throughout the book of adults living with disabilities. The book does not mention children specifically, but gives good advice for future planning.

## **Spanish-Language Low Vision Booklet Now Available!**

Reprinted with Permission from National Eye Health Education Program

We are excited to announce the arrival of the second booklet in our Ojo con su visión! (Watch out for your vision!) series. The Spanish-language adaptation of the low vision booklet, *Sepa qué hacer si tiene baja vision (What You Should Know About Low Vision)*, is now available for distribution. We would like to thank all of you who provided comments during its development. We are pleased with the final outcome and hope that you will be, too.

To receive a copy of the book, you may contact:

Low Vision at 20/20  
Low Vision Place  
Bethesda, MD  
20892-3655;  
Phone: (877) 569-8487  
Phone for Spanish speakers: (877) 569-8474  
Online at: <[http://www.nei.nih.gov/publications/LV\\_spanish.htm](http://www.nei.nih.gov/publications/LV_spanish.htm)>

## **Are You Still Looking for Summer Activities for Your Kids?? It MAY Not Be Too Late!**

Although most camps have already filled up, you might take a shot at contacting some camps to see if they still have openings. Remember, camp is an exciting, fun-filled way for kids to learn wonderful skills and to make great memories. To help with your search, we've updated the SUMMER CAMPS 2001 DIRECTORY on the TSBVI Website at <<http://www.tsbvi.edu/Education/camps.htm>>. If you don't have access to a computer or need some assistance, contact your local TCB office. They have the same list and will be happy to work with you!

Even if you don't have time to get signed up for this year's summer camp, it is not too soon to start thinking about next year. You may want to contact some of the camps to schedule a tour during their summer sessions and see if the program will meet your child's needs. This would also be a good time to get on the mailing list for next year's camp applications. Summer camp can be a wonderful opportunity for your child and for you.

# Short Classes at TSBVI

By Dr. Lauren Newton, Principal of Special Programs, TSBVI

## ABOUT SHORT CLASSES

A little over a year ago, TSBVI implemented an additional approach to serving academic students: **SHORT CLASSES**. Approximately 70 students, from all around the state, attended a short class during the 2000-2001 school year! The purpose of short classes is to serve students who are functioning close to grade level and whose basic needs are well met in the local school district, but who may need a short, intensive training boost in one or two disability-specific areas (e.g., O&M, independent living, technology, aspects of the braille code, math adaptations). While at TSBVI all students also have experiences developing social skills, interacting with other visually impaired students and professionals, and independent living. Most classes are one week long.

Students must be referred for a Short Class by their local school district. Students are requested to bring their week's school assignments (homework) with them. This serves two purposes: (1) the opportunity to teach new skills within the context of what students are learning at home, and (2) helping students keep up with their assignments while they are away. Before students come to a Short Class, their local VI teacher and TSBVI teachers discuss the student's current level of functioning in the IEP skills selected for instruction, to maximize effective instruction as soon as the students arrive.

## SHORT CLASSES FOR THE 2001-2002 SCHOOL YEAR

Below is a listing of Short Classes for next year. If you have an upcoming ARD, this could be a time to talk about a possible referral. Please call TSBVI if you have any questions about the programs. Notice that two different program options are provided to support local IEP objectives:

### 1. Disability-specific programs with a pre-determined curriculum

#### *Independent Living Skills*

Two programs - each scheduled for two 3-day weekends. Students must attend both weekends.

- High School (ages 16-22): September 6 - 9 and October 4 - 7, 2001
- Middle School (ages 12-15): March 21 - 24 and April 25 - 28, 2002

#### *Technology (secondary students)*

Each program is one week in length.

- Fall: November 11 - 16, 2001 - Braille 'n Speak
- Spring: February 3 - 8, 2002 - JAWS for Internet

#### *Math Adaptations (for students going into algebra or geometry)*

- November 25 - 30, 2001

### 2. Individualized Instruction on any Disability-Specific IEP Objectives

*Students will work on objectives jointly selected by LEA & TSBVI*

- High School: September 16 - 21, 2001
- Middle School: October 21-26, 2001
- Elementary School: December 9-14, 2001
- High School: January 13 - 18, 2002
- Middle School: February 24 - March 1, 2002
- Elementary School: April 7 - 12, 2002

## SHORT TIME AWAY FROM HOME

There are many reasons students and families may want to consider a short program at TSBVI. Here are just a few:

- All students return to their local school at end of a short program
- Participation in special programs is not a change in placement
- Students are not counted absent from their local schools
- LEAs provide transportation costs

For more information about these programs call, e-mail or visit our website at <www.tsbvi.edu>, or contact Dr. Lauren Newton, Principal of Special Programs; Phone: (512) 206-9119, E-mail: <NewtonL@tsbvi.edu>.

## Finding Wheels listserv

There is a new listserv called *finding\_wheels* that is a discussion venue for people to talk about transportation issues for children and young adults with vision impairments and strategies to assist young people in exploring their transportation options. The listserv is an extension of the curriculum *Finding Wheels* which Dr. Penny Rosenblum and Dr. Anne Corn co-authored. They wanted to set up a place where people who are using *Finding Wheels* or working with students on transportation issues could share ideas.

To join the listserv send a message to <listserv@listserv.arizona.edu>. In the message write “subscribe *finding\_wheels*, <your e-mail address First Name Last Name>.”

If you would prefer to send a message directly to Penny at <rosenblu@u.arizona.edu>, she would be happy to sign you up for the listserv.

## Survey Regarding Proposed Changes to the APH Tactile Graphics Kit

APH is considering some changes to the Tactile Graphics Kit (the larger kit used for diagramming foil masters for thermoforming). If you are a user of this kit, we would like your comments on the following questions - especially if you can give us compelling reasons NOT to make these changes!

1. We’re considering replacing the wooden rack that holds the tools with a vinyl pouch that holds each tool securely in its own pocket, folds to take up less room, and cuts about \$12 off the cost. Please comment.
2. We wonder if the pantograph is still a useful part of the kit. Are transcribers using it? If dropping this item would cut \$15 - \$20 from the cost of the kit, would you recommend keeping it or dropping it?
3. Any other comments or suggestions about the kit are welcome.

Thank you in advance for your help!

Fred Otto  
Department of Educational Research  
American Printing House for the Blind  
fotto@aph.org

# CLASSIFIED

Mail or e-mail your new classifieds to Jim Durkel at:

TSBVI Outreach, 1100 West 45th St., Austin, TX 78756, or [JimDurkel@tsbvi.edu](mailto:JimDurkel@tsbvi.edu).

An up-to-date Statewide Staff Development Calendar is posted on TSBVI's website at [www.tsbvi.edu](http://www.tsbvi.edu).

## **Texas Focus: Looking at Low Vision**

June 14 & 15, 2001

Radisson Plaza Hotel - Ft. Worth

This annual conference sponsored by the 20 Regional Education Service Centers, with help from Texas School for the Blind and Visually Impaired, will focus on topics related to the student with low vision. Topics include monocular and magnifier use, literacy issues for the student with low vision, services to infants and toddlers with low vision, and issues related to field loss.

For more information, contact Jim Durkel.

Phone: (512) 206-9270

E-mail: [JimDurkel@tsbvi.edu](mailto:JimDurkel@tsbvi.edu).

## **Visions 2001: The National Conference of The Foundation Fighting Blindness**

September 13-15, 2001

Westin Galleria Hotel in Dallas, Texas

Each year, Foundation researchers, staff and volunteers gather to share information about the latest scientific advances, assistive technologies, orientation and mobility resources, and coping strategies with attendees from across the United States. For more information, contact The Foundation Fighting Blindness at (888) 394-3937 or [www.blindness.org](http://www.blindness.org).

## **Virginia Murray Sowell Distinguished Lecturer Series**

September 28 & 29, 2001

Lubbock, Texas

Dr. Jan van Dijk will be the featured speaker at this year's Virginia Sowell Distinguished Lecturer Series, sharing his wealth of experience working with people who are deafblind. For more information, contact:

The Virginia Murray Sowell Center  
(806) 742-2320 or [sheila.dowling@ttu.edu](mailto:sheila.dowling@ttu.edu).

## **TSBVI Technology Institute**

September 21 & 22, 2001

Sheraton Four Points in Austin, Texas

This training is designed for education professionals working with students who have visual impairments. Sessions will include introduction to the Braille 'n Speak, introduction to Duxbury Braille Translation software, and introduction to screen readers. This is not general technology training. Parents interested in attending are encouraged to learn more about the relevance to them and their child by contacting Jim Durkel or Sharon Nichols before registering for this event.

For more information, contact:

Jim Durkel at (512) 206-9270,

[JimDurkel@tsbvi.edu](mailto:JimDurkel@tsbvi.edu)

or

Sharon Nichols at (512) 206-9388,

[SharonNichols@tsbvi.edu](mailto:SharonNichols@tsbvi.edu)

## **SWOMA: (Southwest Orientation & Mobility Association Annual Conference)**

October 12-14, 2001

Sheraton Four-Points in Austin, Texas

For more information, contact: Ruth Ann Marsh  
(512) 206-9203 or [RuthAnnMarsh@tsbvi.edu](mailto:RuthAnnMarsh@tsbvi.edu).

**INSITE Training:  
A Home-Based Model For Infants,  
Toddlers, and Preschoolers Who Are  
Multiply Disabled Sensory Impaired**

Part 1 - September 27 & 28, 2001

Part 2 - October 24 & 25, 2001

Part 3 - November 29 & 30, 2001

Bryan, Texas

This is a 6-day training for school and ECI professionals working with families, who have children, birth to 5 years, with multiple impairments, including an impairment in at least one of the sensory systems. Topics include information on vision loss, hearing loss, communication development, motor development, active learning, and working with families. For more information, contact Gigi Newton at TSBVI. Phone: (512) 206-9272; E-mail: GigiNewton@tsbvi.edu

**The Third Annual  
Sports Extravaganza for Blind  
and Visually Impaired Students**

Nimitz High School in Irving, Texas

October 26 & 27, 2001

Children with visual impairments often need confidence-building experiences, so they can participate in their regular school sports programs. This event provides the opportunity to do just that. For more information, contact Kitra Hill Gray at (972) 348-1580.

**Mark Your Calendars for the  
DBMAT Family Weekend  
October 12-14, 2001!**

It's not too early to mark your calendars for the DBMAT (Deafblind Multihandicapped Association of Texas) Family Conference, which will take place at Camp John Marc in Meridian, Texas. This annual fall retreat and learning weekend for families and service providers is a time of renewal and reunion for all who attend.

For more information, call (972) 287-1904 or e-mail DBMATorg@aol.com.

**CHARGE at the Crossroads:  
5th International  
CHARGE Syndrome Conference**

July 20-22, 2001

Indianapolis, Indiana

Indianapolis Marriott Hotel

This conference is for families with a member who has CHARGE Association. Friday sessions focus on medical issues and include presentations on adolescence, cochlear implants, dental issues, endocrinology, plastics, gastro-intestinal issues, neurology, vestibular function, balance, and oral feeding. Presenters will be Dr. Kim Blake, Dr. Udi Shah, Dr. Rod Lusk, James Thelin, Dr. Rebecca Slayton, Dr. Jeremy Kirk, Dr. Jeffrey Marsh, Dr. Jules Constantino, Dr. Sandra Davenport, Sara Johnson and staff from Riley Hospital for Children.

Saturday session topics include Circle of Friends, hearing issues, communication, interveners, deafblind simulations, SibShop, recreation/therapy (ice skating, adaptive skiing hippotherapy/therapeutic riding) and a grandparents get-together. A video entitled "Then and Now" will also be shown. Presenters will be Nancy Hartshorne with Jacob's Circle Participants, Susan Appell, Linda Alsop, Kim Lauger, Dick and Liz Young, Judith Bluestone, James Thelin, Kara Heide, Penny Clark, Mary Siebolt, Diane Hazel-Jones, Rob Last and Michigan Deaf-Blind Project Coordinators.

For more information, contact  
Marion Norbury at (573) 499-4694.

**Golf Fore Sight**

Are you a golfer and a person who wants to prevent blindness in Texas? Consider a "Golf Fore Sight" card! Purchase of this card entitles the holder to golf one round of golf at each course - free or discounted (cart rental required), and supports Prevent Blindness Texas. Nearly 100 golf courses around the state of Texas are participating in this event. You can purchase one card for \$35, two for \$60 or four cards for \$100.

For more information about this program, contact  
Prevent Blindness at (888) 987-4448.

## SEE/HEAR

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**If you no longer wish to receive this newsletter,  
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