

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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I Love My Life, Swimming, and Texas Longhorns!

By Alberto Gonzales, Austin, TX

Editor's Note: Alberto, a keynote speaker at the Deafblind Symposium held February 7-8, 2003 in Austin, wanted to share some of his thoughts with SEE/HEAR readers as well.

My name is Alberto Gonzales. I was born in San Antonio Texas in 1973. I was born deafblind due to Congenital Rubella Syndrome, but had some useful vision as a child. I can remember seeing leaves falling from trees, grass, and cars going by. I used to love swinging at the playground and running around my mother's yard. By the time I was nineteen, I lost all usable vision.

I attended Japhet Elementary where I began learning sign language, Grade I Braille, and how to use a cane. In the sixth grade, I attended Martin Luther King Middle School and began learning Grade II Braille. As a mainstreamed student at Sam Houston High School, I studied English, P.E., Biology, Homemaking, Health, Math, Computer Skills, and Government. I also benefited from "Vision Class." My teacher, Gail, helped me develop my mobility skills, learn to cook, and oriented me to fun activities that I could participate in. We played Scrabble, Poker, Dominoes, and Uno.

After I graduated from high school in 1995, I came to Austin to get training at the Criss Cole Rehabilitation Center. I continued Orientation and Mobility training to improve and maintain my skills, as well as become familiar with a new city. In addition, I received technology training, career guidance, and worked on communication skills. I participated in CCRC's apartment experience to help me with my transition to the Deafblind Apartment Program. I attended training for eight months, then moved to the Deafblind Apartment Program. I was 21 when I moved into my first apartment. My family was scared about me living alone at first, but now they know that I can be independent and safe. My mother still wants to hear from me every week, though.

I really enjoy Austin, living in my own apartment, and all my friends at the Deafblind Apartment Program. In the summer time, I love to go swimming with my friends in the apartment pool. Sometimes we barbecue, too. I know the UT Longhorns are a very good football team. They beat the Aggies 50 to 20. The Aggies are not good, thumbs down.

I can do many things myself. My personal alert system lets me know when someone is at my door, when the telephone rings, or even if my fire alarm sounds. I arrange my own transportation to work, church, and to visit my friends. I can call anyone I want by using my braille-TTY and Relay Texas. Staff is there to assist me with things like reading mail, budgeting, doctor appointments, and employment.

I attended classes at Austin Community College and currently work at Chuy's Mexican Restaurant. It was necessary to continue with O&M training at ACC to become oriented to the campus and at Chuy's so I could find my way around the restaurant with minimal assistance.

I know it is important to maintain good mobility skills to continue an independent life-style. In July, 2001, I flew to Michigan and stayed at the Leader Dog School for one month. My leader dog's name is Kersey. She is a female black lab and is three years old. She knows sign language like sit, laying down, right, left, etc.

I am a very experienced traveler. I have traveled to Dallas, San Antonio, and Seattle by myself. My mobility and communication skills allow me the freedom to take the bus or fly anywhere I want. In the summer of 2000, I went to Mexico with my family. I love deafblind camps like the Deafblind Retreat at Seabeck in Washington and Pineville Louisiana. Also, I am trying to save money for the next AADB (Ameri-

can Association of the Deaf-Blind) Conference in San Diego this July. I have also heard there will be a TBDA (Texas Deaf-Blind Association) meeting soon.

I have a new church. My church is Westover Hills Church of Christ. I was baptized on November 17 and became a new member November 24. It is a very, very pretty church. I go to church every Wednesday and Sunday. I read the Bible and have a deaf interpreter there.

My girlfriend Mary Ellen lives here. We have been together for 4 1/2 years. Mary Ellen is blind. Now she knows sign language, which I taught her a long time ago. Mary Ellen and I went to the Holiday Inn for her prom on May 9, 1998. My dream for the future is to be married, live in a nice house, and to have a good job.

Journeys Through the Land of Oz: Parents' Top Twenty Strategies for Managing Life

By Kate Scorgie, Ph.D., Associate Professor of Graduate Education, Azusa Pacific Univ.
and Lorraine Wilgosh, Ph.D., Dept. of Educational Psychology, University of Alberta
Reprinted with permission from *Exceptional Parent*, November 2002

In her book *When the Heart Waits*, Sue Monk Kidd portrays Dorothy's journey in *The Wizard of Oz* as an allegory for overcoming life crises. Until the tornado came, all Dorothy had ever known was her simple life in Kansas with Toto, Aunt Em and Uncle Henry. When the devastating event occurred, Dorothy was catapulted from her familiar surroundings to the often-bewildering Land of Oz.

The remainder of the book was the story of Dorothy's profound longing for her home and her subsequent wanderings through Oz in order to find it. Dorothy was told that the way home would involve a very long journey, "through a country that is sometimes pleasant and sometimes dark and terrible." Kidd reminds us that at some time in our lives, each of us will encounter a "tornado" experience and, like Dorothy, we may find ourselves in a strange land with no road map and a few recognizable landmarks, longing for our former familiar lives.

Dorothy navigated her way through Oz with the assistance of three new friends she met along the way: a Scarecrow who needed a brain, a Tin Man looking for his heart and a Lion seeking courage. Kidd claims that these characters are sent to remind us that in the midst of any life crisis, what each of us needs for safe navigation "home" is a new way of thinking, a new way of feeling and a resolve to persevere.

For the past several years we have been talking to parents about their journeys in parenting a child with a disability. We began by conducting extensive interviews with 15 parents whose children have a variety of conditions. As they narrated their journey from the initial diagnosis to the present, we asked them to share specific strategies they found effective for managing their personal and family lives. We then developed a survey instrument that we sent to two larger groups of parents. We asked them to indicate how important each of the strategies mentioned by the first group of parents had been to them as they parented their children. In particular, we were interested in documenting life management strategies that were deemed effective by the large majority of parents, regardless of child age and disability.

We have collected information from more than 200 parents. They described how the diagnosis of disability catapulted them into a bewildering new world. They shared the things that both helped and hindered them along the way. And they spoke powerfully of how, though the years, they have developed new ways of thinking, new ways of feeling and a determination to stay the course.

After analyzing these stories, we were able to document a number of strategies that parents held in common. We call these the Top Twenty Strategies for Effective Life Management, and would like to share them with you through the words of parents.

CELEBRATE YOUR CHILD

“My advice to a parent of a child newly diagnosed is, first of all, just to celebrate the birth of this child. Just to enjoy the child...because everyone else will try to give him a label.” [mother of a nine-year-old son with severe multiple disabilities]

CHOOSE TO FOCUS ON WHAT’S GOING RIGHT

“I dwell so much on the positive that you would think Ryan was actually pretty high functioning {though} he’s very, very limited in what he can do. But I don’t look at those things. I think it’s much easier to celebrate the little successes and sometimes they’re minuscule. You have to look at the positives and the little successes and dwell on those.” [mother of a nine-year-old son with autism]

GET BEYOND THE “WHY?” TO THE “HOW?”

“If we could all just accept our kids and teach them they’re pretty great just the way they are...the sooner you do it the better it is. Pretending like they’re gonna get well later – oh, I went through that phase. It was always some miracle that was going to happen. But that’s all dead time, all ‘no growth’ time for you and your child. So the sooner you can say ‘This is how it is. Let’s go forward from here,’ the better it is for everyone!” [mother of an adult son with profound hearing impairment]

APPRECIATE WHAT YOUR CHILD CONTRIBUTES TO OTHERS

“Last year one of Jana’s friends wouldn’t go to Brownie camp unless Jana went. This friend’s mother phoned me, desperate, weeks before camp: ‘Jana’s not getting sick, is she? She’s still going to go, isn’t she? Because my daughter will not go without Jana.’ And so we learned that Jana is a support to her friends, she does contribute. And those are the things we need to start looking at.” [mother of a nine-year-old daughter with Down syndrome]

TRUST YOUR INSTINCTS

“After two years [of preschool] I felt very frustrated. I used to leave there crying, thinking, ‘Why are you letting them do that to him and treat him like that and talk to him like that?’ But slowly I developed the confidence to decide I don’t have to be this way any more! Now I think there’s nothing that I couldn’t do if I set my mind to it.” [mother of a nine-year-old son with autism]

DON’T GO IT ALONE: ASK FOR HELP

“I needed to take my daughter to another city for treatment and we didn’t have the money to pay for the airline tickets. I was moved to phone our minister – I’d never ever asked for help from this church before, but I called and explained our situation. They were able to give us some financial help. And the minister phoned down to some families in that city and asked if someone could meet us. So a couple met us at the airport. They put their arms around us and kept them around us six whole weeks. And when we came home I realized that it wasn’t Mandy who had had the healing, it was me. And it sort of turned my thinking around: I learned that you don’t get help unless you ask for it. As long as people think you’re okay, they leave you alone.” [mother of a 17-year-old daughter with moderate developmental delay]

REASSESS SUCCESS

“You have to learn to come up with your own definition of what a successful child is, and not bow to the theory that the successful child is going to grow up, get married, have a good job and do this and that. You have

to say, ‘Well, for our child, it will be different. For him success might be something else.’ You have to throw out the old definitions. As long as he’s happy at what he’s doing, why should we define [what] happiness [is]?’ [father of an eight-year-old son with pervasive developmental delay]

UTILIZE PLANNED PERSEVERANCE

“I spoke with a resource person and she said, ‘Every year you’re going to have to address these same issues: Who’s going to be the teacher? What kind of support is there going to be and will that be sufficient for my child? Every year you’re going to have to address this. Just put it on the calendar.’” [mother of a six-year-old son with an undiagnosed genetic condition]

BE A PARENT FIRST

“There’s one thing I’d do differently now. When we found out Jeremy was hearing impaired, I signed up for a course, ‘How to work with your hearing-impaired child.’ And all of a sudden I turned into his teacher instead of his mother. But finally, a few years ago, I just woke up and said, ‘I’m sorry. I’m not doing this. I’m not going to sit across from the table and force him to do this. I’m just going to practice being his mother.’ And I’m much happier. I feel it was like a weight lifted off me.” [mother of an 11-year-old son with cerebral palsy and profound hearing impairment]

KEEP YOUR SENSE OF HUMOR

“The stories about Nathan have become family tradition. Lots of families have stories that they tell and retell. But the Nathan stories in our family are the funniest – he’s just hilarious. Oh, there have been lots of stressful times. For every funny story there are probably 10 or 20 difficult stories – stories of challenges and trials. But it’s the funny stories that keep you going.” [mother of an 11-year-old son with Down syndrome]

BE FLEXIBLE DAY TO DAY

“Because of her illness, how Laura feels fluctuates a great deal. So I wrote a list called White Days, Gray Days and Black Days. On ‘white days’ [the good days] I might go to the park, go out, cook dinner, make the most of a day when Laura’s feeling well and has some energy. ‘Gray days’ [in-between days] I still put things on my list, like cook supper—but it’s more like sit and watch a video with Laura, read books, or go to work, as she can still go to the babysitter on gray days. On ‘black days’ when she’s really ill, we might order pizza or, if there are plans, change them.” [mother of a seven-year-old daughter with degenerative metabolic disorder]

GIVE YOURSELF A “TIME OUT”

“I have one night a week and it’s mine. I need it. I always have something to look forward to and that’s what gets me by. I forget about everything for an evening and go out with my girlfriends. I know none of them can relate to what I go through. They have stress and they have so-called ‘normal’ kids. If they need one night out a week, I probably need three. But, yes, I just go out and try not to worry about it that night, and somehow the next day it doesn’t seem that bad.” [mother of seven-year-old triplets with moderate to severe developmental disabilities]

ALLOW YOURSELF “UPS” AND “DOWNS”

“Even though I say I have accepted everything that has happened with Jason—yes, I have accepted it. But there are always times when I will hear a song on the radio and all of a sudden it will hit me, ‘he’s never going to hear that exactly like I do.’ I will go through the grieving process again, and I will cry. And then away I go and I’m okay. I think this is just a life-long thing. He’s going to be my baby even when I’m 80 years old. And I think it’s okay to give yourself permission to keep feeling.” [mother of an 11-year-old son with cerebral palsy and profound hearing impairment]

REMEMBER TO NURTURE YOUR MARRIAGE

“Court your wife. You know she’s going to be stressed out, and so will you, and you will need each other. Do what you need to find time to be with each other. Go to dinner – go to a movie – do whatever you want to. Find time when you can be away from the demands and just be together.” [father of a 12-year-old daughter with severe developmental delay]

BE A FAMILY

“As a parent, you have to set an expectation to make things happen. One thing we do is go to a lodge in the mountains. The whole family goes, and you think, ‘Yes, we can still do things as a family.’ And we’ve always insisted that we eat breakfast as a family. Sometimes our kids complain, but I think it’s important to be together as a family.” [mother of a nine-year-old son with severe multiple disabilities]

BALANCE TIME TOGETHER WITH EACH OF YOUR CHILDREN

“My son once said, ‘You really do like Tommy much better than us, don’t you?’ I asked why, and he said, ‘You’re always spending time with him and you’re always holding him.’ Well, one thing a experience like this does to you is make you think consciously about a lot of things you never thought about before, like spending time with your other children. And I guess it’s not being afraid to talk to your kids about the situation, either.” [mother of a nine-year-old son with multiple disabilities]

KNOW WHAT YOU WANT AND GO FOR IT

“I think the ability to problem-solve is very valuable. Don’t take ‘no’ as a final answer; take it as a definite ‘maybe’ and go from there. A lot of times they say ‘no’ because they think you’re going to go away. What you need to do is try to analyze the situation. If you do your homework, are well prepared, and make a legitimate argument, oftentimes people will listen.” [mother of a 25-year-old son with Coffin-Lowry syndrome]

BE RESOURCEFUL: FIND WAYS TO BE UNDERSTOOD

“A neighbor came in one morning and we spent a morning taping Rachel in spasm, just to show the work that was involved in caring for her. We did it for the medical profession, because they couldn’t understand my story. So I have it on video. I have shown it to social workers, too, and I think it would be a good tool for group homes so they can be prepared for the kind of help needed.” [mother of a 17-year-old daughter with moderate developmental delay]

CONNECT WITH OTHER PARENTS

“I feel it is extremely important that parents of children with disabilities make contact with each other, because there’s nothing like speaking with somebody who’s in the same boat. There’s something that draws us all together. If I’m having difficulty with something, I will not call the professionals. Other parents are the first people that I will call. I will ask another parent, ‘Did you have to deal with this? How did you handle it?’” [mother of 11-year old son with cerebral palsy and profound hearing impairment]

VALUE THE JOURNEY

“When I look back I realize my son has been a wonderful teacher to me. He’s had an impact on so many lives – that’s the wonderful part. When Chris was young I used to think I had to know [right now] everything he’d need to know. In time I learned that as Chris grows, I will grow. And I will have the knowledge needed to meet his challenges. It was very important for me to recognize that.” [mother of a 15-year-old boy with Down syndrome]

These are twenty of the life-management strategies most often mentioned by parents in our studies. Every family that participated in our study was diverse, complex and unique, and each employed the strategies in a way that was unique to their family situation. It seems that there are many paths through the Land of Oz and through working together parents can create useful roadmaps and identify familiar landmarks.

Gifts from my Sister

By Susannah Kenley, age 19, San Francisco

Reprinted with permission from *reSources*, Vol. 10, No. 14 (California Deaf-Blind Services).

Growing up as Laura's older sister hasn't always been easy, and without laughter I hardly think I could make it through. Tears and laughter, pain and happiness, embarrassment and pride, and thousands of other emotions have all been a part of the adventure of being an older sister to a sibling born with CHARGE Syndrome. Being born with CHARGE, Laura does not hear, is extremely vision impaired, and has heart defects. But besides all of that, Laura is a goofy teenager with lots of personality, strong likes and dislikes, a very smart and pranky sense of humor, and a little attitude to go along with her age of seventeen. Laura is an extremely complex girl. And living with her has been no less if not more complex than Laura herself. Laura has made me feel thousands of different ways. She has made me want to crawl under the table at a restaurant and hide from people staring, scream out in frustration, punch a wall, slam doors and cry. But Laura can also make me laugh like no one else can.

Just like any other relationship between family members, Laura and my relationship has gone through many phases, both good and bad. The one thing I can say for sure is that over the years, being Laura's sister has become a lot easier. I can't ever remember a time in my life when Laura was not my little sister; she was born when I was only two years old so she is a part of nearly all my childhood memories. I even went to preschool with Laura at the San Francisco Hearing and Speech center for a few years. I loved going to school there because I could not only hang out with my baby sister, but I learned how to sing kids' songs using sign language and hang out with kids like myself and like my sister. Although I was not aware of it then, being in an environment like that let me know that I was not alone and that there were other kids like me who were siblings of deaf children. Trips to PAAVI—an early intervention family training project—and Easter Seals to play were also wonderful experiences for the same reasons. Going to summer camps that focused on families of children with disabilities were always exciting places to play, relax, and also to spend time with people who were dealing with the same life experiences that I was. I will always be thankful for the opportunities my parents gave me to get involved in the deaf-blind community at such an early age. Spending lots of time with Laura when I was very young is probably the reason why the two of us have stayed so close over the years. Having fun with Laura when I was young set the tone for the type of relationship I have with her now. Laura's life is full of doctors, teachers, therapists and caretakers. Being involved in Laura's social life from the start has let me know that I do not have to be another doctor or teacher of Laura's, and it is okay for me to just be her sister and friend.

It is easy to feel responsible for a sibling with disabilities, especially if you are older than they are. My parents have helped me work through that by explaining that I am not now and never will be the only one responsible for Laura. Although I know I do need to help out with her, I also know that my parents are doing the best that they can to support Laura, even in case something should happen to either of them. Wills and future living situations and dreams for Laura have all been explained to me, so I have never been left worrying whether or not I will be spending my time as an adult caring for Laura. Communication about these real-life,

real-world issues has made me feel comfortable about being Laura’s sister in the future. Having Laura as my little sister has undoubtedly changed the way I look at myself and at the rest of the world. It has taught me how not to get embarrassed so easily, how to deal with the unexpected, and how to appreciate the little things in life (like the fact that dinner has not been thrown all over the kitchen for once, or that no one threw a fit in the middle of the shopping mall). But more than that, Laura has taught me that lots of people out there need help (myself often included). Because of Laura I have chosen Sociology as my area of study in college, and have spent spare time volunteering in California and Louisiana. But most importantly, because of Laura I am able to look at life in an extremely positive way and with a sense of humor, and although that may sound cliché it is the truth. Not many people can or ever will be able to appreciate life and its blessings the way that I can and my sister Laura is the person I have to thank for those gifts.

Brothers and Sisters: Strategies for Supporting Siblings of Children who are Deaf-Blind

by Jackie Kenley and Myrna Medina, CDBS Family Specialists

Reprinted with permission from *reSources*, Vol. 10, No. 14 (California Deaf-Blind Services).

Brothers and sisters who have siblings with combined hearing and vision problems are first of all people and important members of the family. Siblings will probably want to know why this happened to their brother or sister and how it will affect them personally. This is especially important at the time the family is dealing with a new diagnosis; siblings need to be remembered at these times and have their questions answered and their concerns addressed. It will be helpful for siblings to understand exactly what and how much their sibling may see and hear, and about additional disabilities the sibling may have. Being open and actively listening to siblings may be tough for parents as they deal with a child who is deaf-blind, but these conversations are likely to be as healing for the parents as they are for the siblings.

THINGS TO CONSIDER:

Emotional Stages. Learning to live with a child who is deaf-blind requires going through all kinds of emotional stages—anger, grief, sadness, hope and acceptance. To help deal with these emotions, it’s a good idea to meet other parents of children with disabilities, share stories with them, and attend family support groups. Many times these various emotions come up at different times for individual family members. Birthdays and holidays are often tough on families, and this should be remembered and worked through as a family. For birthdays, sometimes it is very nice to celebrate each member of the family separately, if financially possible; if not, do not feel guilty about celebrating the siblings in a special way, or siblings might think there is a preference for the child who is deaf-blind.

Take a break! Giving the family a break from the responsibilities of caring for a child who is deaf-blind may be helpful, and provides family members the time to concentrate on other relationships in the family. Respite care or camps are a good idea for parents and siblings. Each child in the family has a need for individual care and attention, and giving this attention may require special effort and energy from parents. It is important for professionals working with the child who is deaf-blind to let the family know that it is okay for them to say we are tired, or we need help, and also emphasize that they are there to serve the entire family, not only the child who is deaf-blind.

There are positives as well as negatives. Having a sibling who is deaf-blind can have both positive and negative effects on the family. Different “behaviors”, surgeries, and illnesses are tough on all family.

Becoming Your Child's Best Advocate

By Mary Zabelski, President, National Association for Parents
of Children with Visual Impairments (NAPVI)

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Editor's Note: Awareness is published quarterly by The National Association for Parents of Children with Visual Impairments, Inc. To become a member or to order any of NAPVI's publications, contact them at P.O. Box 317, Watertown, MA, 02471-0317, 1-800-562-6265, <www.napvi.org> or <napvi@perkins.org>.

As your child passes through the educational system, you will need to acquire knowledge and information about the educational issues facing him or her. As a matter of fact, you will need to become your child's "best" advocate. You will find yourself working on behalf of your child, to make sure that the specialized educational services, guaranteed in the federal laws, are actually available in your state or local school district. We want our children to reach their full potential. To do this, they much have equal access to the classroom materials like their sighted peers. In a perfect world, all of the specialized services that the educational and civil rights laws entitle our children to receive, would always be available and easily obtainable. In this real world of ours, the full range of necessary services may not be available unless you actively work on acquiring them or "advocating" for them.

As your child's advocate, you may have to deal or bargain with your child's school district or local school to acquire the necessary services. Services mean the specialized teaching from the special education teacher, vision teacher, orientation and mobility instructor, and other related therapies (e.g., occupational therapy, physical therapy, speech therapy). You may find that you need to arrange for or "negotiate" for services through discussion and settlement of terms with the local educational personnel. Sometimes the services are not readily available and you will have to present your request in writing or through meetings with the educational staff, special education administrator of the district or the principal. The parents' role becomes critical to the success and positive educational experiences that can occur. More importantly, your involvement in decision-making is the key to developing a positive and meaningful educational program for your child.

You may think that the professionally trained teaching staff automatically knows what is best for your child. This is not necessarily the case. Remember, most pre-school, elementary and high school teachers have no training that helps them to understand what modifications and accommodations students who are blind or visually impaired, deaf-blind or multi-disabled, might need to properly access their textbooks and materials like their classmates. Remember that you have more information about your child's medical issues and the visual/medical diagnosis than the school personnel do.

It is important to recognize that the regular classroom teacher may not be familiar with your child's visual disability and how to provide the specialized services your child needs. When discussing the need for specialized services, the regular classroom teacher and the special education or vision teacher should be present. You may want to ask for a meeting to discuss these issues before the formal IEP meeting.

If your child has problems in school because of the lack of specialized services or a need for a change in services, you will need to speak up and negotiate for them. IEPs should be developed jointly, between school personnel, service providers and parents.

When my blind daughter was in the lower grades, I wanted her to develop the skills that would help her to be independent as she got older. I knew that she had to learn how to travel independently, learn to take care of her belongings, dress appropriately and develop friendships with the other students. I wondered what kind of job she could hold as an adult, considering she was “blind”. You as the parent, may be thinking about these issues, but the regular classroom teacher is generally not trained to look ahead. Many skills that are necessary will not be taught in the school your child attends. You should discuss these skills with the special education teacher and other therapy staff, so that you can work toward these objectives in school and at home. Each one of our children has a different area of strength and need. We can help them if we think about what skills they need to develop for future success in the real world, and advocate for the services to help them attain these skills.

Leading the Way to Success

By Will Conrad, Student, Rice University, Houston, TX

With forward by Ann Adkins, TSBVI Outreach Consultant and Will’s former TVI

Forward: Will Conrad, a sophomore at Rice University, is often asked about his experiences as a visually impaired student. Will was one of ten Rice freshmen featured in the spring, 2002 edition of *The Sallyport*, the Rice alumni magazine, and will be followed by the publication for the next four years. A former TAER Student of the Year Award winner and member of the Texas Commission for the Blind LITE (Leadership in Transition with Excellence) Committee, Will’s extracurricular activities are as extensive in college as they were as a student at Westlake High School in Austin (Class of 2001). They now include more activities to help prepare him for a career in law. For two summers, he has served as an intern with the State Office of Risk Management (SORM), General Council Division, and he plans to study in Scotland next fall. We have also included some excerpts from a personal letter he wrote for a scholarship application that tell a lot about this young man.

While these articles show some of Will’s accomplishments and his “academic side,” they can’t convey his personality and sense of humor. For example, when he walked off the stage into the orchestra pit after being inducted into the National Junior Honor Society, seventh-grade Will responded to the gasps from the audience with, “Guess I should have used a cane, huh.” He refers to his fall off the stage as “his swan dive.” As his TVI for five years, I enjoy sharing “Will stories” with my colleagues and other students and parents. One year, on a mission trip to Mexico, he helped the youth group of his church build a fence. Unfortunately, he hammered the arm of the girl working next to him instead of the fence. When I learned that he was taking a girl from his church to the prom, I couldn’t resist asking him if he used a hammer to convince her to be his date. It wasn’t the same girl, but Will was prepared for my questions, just as he continues to prepare himself for his studies at Rice and his life as a young adult who is visually impaired. His challenges include making the transition from print to Braille, using a cane, mastering complex technology, and learning to be his own advocate—the same challenges faced by many visually impaired students. Being visually impaired is only one aspect of Will’s life, however, and only one component of his success. He moves ahead with a sense of humor, as well as excellent skills, and is truly “leading the way to success.”

Excerpt from *The Sallyport* article, “All Roads Lead to Texas”:

Will Conrad is truly Texas proud. When another freshman was asked why he decided to come to Texas from the East Coast to attend college, Will piped up, “Because everybody comes to Texas. It’s the greatest state. You can’t deny it—you’re all here!” And Texas isn’t the only thing Will’s

crazy about. “My first semester has been a blast, and I’m really excited about my major, political science.”

Will’s enthusiasm, confidence, and determination don’t necessarily set him apart at Rice – most Rice students are very involved and passionate about their education and their futures. But Will, who is legally blind, has to work just a little bit harder at everything he does, which is what makes his accomplishments – and genuine zeal – so remarkable. From navigating the Rice campus to making sure he gets his books on tape well before each semester begins, Will’s got his hands full. But it’s not his visual impairment that is posing a challenge this semester – he’s been dealing with that since birth – instead, it’s the 15 credit hours, 35-page papers, and busy extracurricular schedule.

Will is involved in the Rice College Republican, Reform University Fellowship, the Baker Associate Committee, Campus Crusade for Christ, and the Intervarsity Christian Fellowship – activities that reflect the strong influence his faith has on his life. He credits a high school mission trip to Juarez, Mexico, with shaping the person he’s become. The trip, which included running a vacation Bible school, put his faith into action and established an identity that, he says, “has carried into my groups and friends at Rice.”

Will also has put his interest in practicing law into action by serving on University Court, which he says “allows me to get some experience with law while learning about the Rice judicial system and helping the university with discipline.” Sounds perfect for someone whose enthusiasm for justice is as big as the state of Texas.

Will wrote the following as a response to a question on a scholarship application:

With my first year at Rice University just completed, I have experienced and learned many new things. Navigating the campus proved no challenge after my first week when I became lost once. Using the knowledge that the cars travel one-way around the intercampus loop, I was able to resolve the situation quickly and return to my dorm. After this experience I had the confidence to not only travel around campus myself, but to provide visitors with directions. The rigorous academics at Rice challenged and stimulated me to seek new knowledge. I have chosen to study the field of political science stemming from courses in high school, and my passion for the subject has only expanded. This excitement about my studies results from the professors and their willingness to spend time with all students. The professors not only invite students to their offices during office hours; they will usually eat lunch in a college where any student may join them. I have had lunch with several professors and we discussed everything from college life to politics. This relationship with my professors promotes self-advocacy for necessary adaptations.

Even though I have made A’s at Rice, I have really learned more outside the classroom through participation in extracurricular service activities. Rice University Court represents an activity that I have particularly enjoyed. The Rice U-Court assesses punishment for violations of the code of student conduct, the alcohol policy, and criminal law. We use community service as a means of constructive sentencing. I serve on the court as the vice chair who investigates the different cases. I have worked with the chair of the court to purchase a computer with scanning features so that I can independently read the police reports. I have also served the Rice community by my involvement in the variety of campus ministries. One Tuesday each month I accompany other members of Intervarsity Christian Fellowship to the Palmer Way Station to serve breakfast to the homeless. With Reformed University Fellowship, I plan to take a weeklong mission trip to Prague in the Czech Republic. While on this trip, I will serve not only the Rice community, but also the international community.

I have experienced three major benefits from helping others: it makes me feel good, it accomplishes something for the other person, and it helps me grow in my relationship with God.

I have tried to prove to professors, fellow students, and particularly to other handicapped persons, that a blind student can be a leader in academics, school service work, and other community services activities. I believe that I have succeeded. (*Editor's Note: We believe you have too, Will!*)

Key Elements for Effective Assessment of Children who are Deafblind

Prepared by Evelyn P. Kelso, M.A., Educational Consultant,
ATECH/ASSETT, New Hampshire

Reprinted with permission from *in touch*, Summer 2002,
the Newsletter of the New England Center Deafblind Project

Children with deafblindness or multiple disabilities tend to experience the world as it exists within their immediate reach (Miles, 2000). Many of these children may have some residual vision and/or hearing. However, the combination of this dual sensory impairment limits the extent of interaction they have with people, access to information about events and objects at a distance, incidental learning acquired just by seeing and hearing, and development of meaningful concepts about home, school, and community. School teams must assess these children differently from other students to effectively address their unique learning needs.

Successful assessments should include:

#1: FAMILY PARTICIPATION

- Incorporate active family involvement throughout the assessment process.
- Interview the family regarding their priorities, immediate goals, and long term dreams.
- Include family input in planning assessment activities.
- Use family members to facilitate some assessment activities, as they are familiar and trusted by the child.
- Give attention to any family concerns that remain following assessment.

#2: TRANSDISCIPLINARY ASSESSMENT GUIDELINES

- Assessment of the child across natural settings (i.e. home, classroom).
- Selection of a variety of familiar, everyday activities where different skills can be assessed.
- Use of a transdisciplinary team approach in which educational team members share knowledge from their areas of expertise for other team members to incorporate in their practice.
- Follow-up team assessment by using information to plan the educational program.
- Focus IEP goals and short-term objectives on behavioral skills to be developed or expanded.
- Conduct ongoing assessment throughout the school year, with changes to the IEP made as the child masters critical skills (short-term objectives).

#3: ASSESSMENT STRATEGIES

- Base interactions on data in most recent vision and hearing reports. Select toys or other objects that use the child's preferred colors, textures, and sounds. Present the objects in the positions where the child has the best vision and hearing. After the child is engaged, move the toys to varying positions to assess any response.
- Use the child's current communication program if one exists. Interpret the child's changes in behavior as communication, and prolong the exchange to learn more about how the child communicates.
- Select a single team member to act as activity facilitator to decrease the number of people with whom the child will interact.
- Choose activities based on family routines.
- Include components that apply to classroom instruction and appropriate age level activities.
- Ask the child to make choices, follow steps in a routine, or indicate what comes next in an activity.
- Embed critical skills within activities to assess the child's level of understanding and response. Does the child initiate activity? What level of support or prompts are needed? What is the child's response if the routine is changed or sabotaged? What kind of choice-making is shown?
- Create a report in which team members contribute to one comprehensive final document based on areas assessed. The report should include ideas for planning and educational programming.

#4: ESSENTIAL ASSESSMENT DOMAINS

- *Social/Communication:* (Vocalizations, gestures, eye gaze, changes in movement, alertness, verbalizations, signing.) What methods does the child use for receptive and/or expressive communication? How does the child use these? How does the child respond to the assessment facilitator, parent, peer? i.e. cues, verbal requests, pauses for turn-taking.
- *Sensory/Motor:* What are the child's likes/dislikes? tolerance for different types of sensory input? willingness to explore new, unfamiliar sensory input? How does muscle tone affect the child's ability to participate in activities? (Motor planning? Stamina? Reach and grasp?) What supports and physical modifications are used and what are the results of each? What positioning works best for stabilization, comfort and greatest range of motion?
- *Functional Vision:* Does the child appear to have useful remaining vision? What focusing and tracking patterns are present? How does the child use near vision? distance vision? What is observed about the visual field—use of central or peripheral viewing? Do visual fields appear to be intact? Does the child look at an object while interacting with it or look away, and then act? Does the child show color preferences? preference for movement rather than still objects? Are eyeglasses or low vision aids recommended? tolerated? in use? What is the child's preferred learning mode: visual, auditory, or tactual?
- *Functional Hearing:* Is the child aware of sound? Does s/he alert to sound, orient to sound, localize sound, isolate a specific sound in the presence of other sounds? Does the child respond to a selected sound among other sounds? Does the child appear to use hearing to respond during the assessment—to voice? music? speech? Are hearing aids recommended? tolerated? in use?

All of these areas need to be assessed because they are interrelated in their influence on the child's ability to make sense of the world. Accurate functional data on vision and hearing is particularly critical since it is the combined effect of the dual sensory impairment that requires instructional approaches differing from either vision or hearing strategies. Only when the child is assessed in settings where s/he is familiar with the facilitators, routines, and materials will s/he have the opportunity to respond in a way that gives a true indication of developmental/cognitive level. The child will demonstrate competencies and areas where skills are emerging or as yet undeveloped. The more accurate the assessment of the child, the more effective will be the next steps toward greater meaning and participation at home, school and in the community.

Miles, B. (2000) *Overview of Deaf-Blindness*, DBLink, Revised July 2000.

This article was prepared as a partial requirement of the New England Center Deafblind Project/Summer Institute 2001. The information compiled here represents an outline of the information presented by Dr. Jennifer Grisham-Brown (University of Kentucky), Patty Mason (South Shore Educational Collaborative), Debbie Gleason (Perkins School for the Blind), Vicki Wilson (Perkins), and Darick Wright (Perkins).

Planning Your Child's Individualized Education Program (IEP): Some Suggestions to Consider

Reprinted with permission from Families and Advocates Partnership for Education (FAPE)
Coordinating Office: PACER Center, Inc., September, 2001

BEFORE THE IEP TEAM MEETING:

- Consider the vision you have for your child for the future as well as for the next school year.
- List your child's strengths, needs, and interests and your major concerns about his or her education.
- Consider how your child's disability affects his or her education.
- Think about your child's educational progress. What has been working and what has not?
- Request a written copy of your child's evaluation results or a meeting with school staff to discuss the evaluation before the IEP meeting. This gives you an opportunity to understand the evaluation before the IEP team meeting for your child.
- Consider the evaluation results. Do these results fit with what you know about your child? Is the evaluation complete and accurate? If you disagree with the school's evaluation, you may request, in writing, an independent educational evaluation (IEE) at no cost to you. The school must pay for the evaluation or show the due process hearing officer that its evaluation is appropriate. The results of an IEE must be considered by the IEP team in planning your child's IEP.
- Consider a variety of ways to involve your child in developing his or her IEP, starting at a young age if appropriate. Self-advocacy skills are important to develop.
- If needed, plan to bring someone with you to the meeting with knowledge or special expertise regarding the child, such as a spouse, relative, friend, related service personnel, or representative from a local disability organization.

AT THE IEP TEAM MEETING:

The IEP meeting is very important. You, the school personnel, and other IEP team members attending the meeting will review and discuss information about your child to develop the IEP. It provides an excellent opportunity to ask questions and share important insights about your child, whom you know better than anyone else does. The school needs to know what your child is like at home and in the community, as well as what your child's interests and activities are.

- Make sure others at the IEP meeting never forget that the meeting is about a real child - your child.
- Share your visions for your child, both short-term and long term.
- Discuss your child's strengths and needs and any concerns about your child's education.
- Remember that diagnostic tests and assessments do not present the total picture.
- When you believe that the teacher and school personnel are doing a good job, tell them so. Praise, when deserved, is a great thing.
- Be a good listener. Ask questions.
- Make sure you understand. If you don't understand something, ask to have it explained in a way that you can understand.
- Expect that what you know about your child will be used in making decisions.
- Use school data, your child's progress reports, and other information you know about your child to make decisions.
- You may not want to agree to a proposed IEP at the end of the meeting. Review the proposed IEP document at home. If you disagree with what is being proposed in the IEP document, you must notify the school as soon as possible to resolve the disagreement.

AFTER THE IEP TEAM MEETING:

- Your child's IEP must be reviewed at least once a year to determine whether the annual goals have been achieved and to revise the IEP if necessary.
- Your child's school must inform you regularly about your child's progress, at least as often as parents who have children without disabilities are informed about the progress their children are making. Schools can do this by providing periodic report cards. You will be informed about whether your child is making progress toward meeting the annual IEP goals, and whether the progress is enough to reach the goals. If your child is not making adequate progress, an IEP meeting should be held to review the IEP and make needed changes.
- You may request an IEP meeting at any time during the year if you believe it is important to consider changes in your child's IEP.

The information above is a product of the PACER Center, Inc., the coordinating office for Families and Advocates Partnership for Education (FAPE)

8161 Normandale Blvd., Minneapolis, MN 55437

952-838-9000 voice – 952-838-1090 TTY – 1-888-248-0822 toll-free

Website: www.fape.org

Notice: New Special Education Documents from TEA

By Jenny Lace, Education Specialist, Texas Deafblind Outreach

The Texas Education Agency has released two new special education documents which can be found on the TEA website at <www.tea.state.tx.us/special.ed>.

A GUIDE TO THE ADMISSION, REVIEW, AND DISMISSAL PROCESS

This document contains information a parent needs to effectively participate in the ARD committee meeting for their child. This guide was produced with the expert guidance of a stakeholder group of parents, educators, other professional service providers, advocates, and information compiled from statewide public meetings. The table of contents includes:

- Timelines in the Child-Centered Educational Process
- Special Education Introduction
- Terms and Definitions
- Special Education Process (referral, evaluation, eligibility, individualized education program, annual review)
- Parent Rights and Responsibilities in the Process
- Additional Issues Related to the ARD Process (behavior intervention plans, discipline, early childhood intervention, extended school year services, graduation, state assessment, transition)
- Eligibility Categories for Special Education
- Texas Special Education Resources

PROGRAMMING

All parents of students with disabilities currently receiving special education services should receive a copy of the guide from their school district by February 28, 2003. This guide will be updated as changes to federal regulations, state law and/or Commissioner's rules occur. The hard copy version of the document will always denote a print date. The most current version of the guide will reside on the TEA website at: <<http://www.tea.state.tx.us/special.ed/>> The guide is available in English, Spanish, and Braille.

NOTICE OF PROCEDURAL SAFEGUARDS: RIGHTS OF PARENTS OF STUDENTS WITH DISABILITIES

The Procedural Safeguards document explains the specific rights and responsibilities of the parent in the special education process. The table of contents includes:

- What Are Your Rights Related to Identification and Referral?
- What Are Your Rights Related to Evaluation and Reevaluation?
- What Are Your Rights Related to ARD Committee Meetings?
- What Are Your Rights Related to Discipline?
- What Are Your Rights Related to Accessing Your Child's Records?
- What Are Your Rights if You Choose to Send Your Child to a Private School?
- What Are Your Rights for Public Reimbursement if You Choose to Send Your Child to a Private School?

- What Are Your Rights When Your Child Turns 18?
- What Are Your Rights if You Are a Surrogate Parent?
- Resolving Disagreements
- Contact Information

Public schools, which include district and charter schools, must provide parents of students with disabilities and adult students with disabilities a copy of the procedural safeguards, at a minimum, upon:

1. Initial referral for evaluation;
2. Each notification of an ARD committee meeting;
3. Reevaluation of the child; and
4. Receipt of a request for due process hearing under 34 CFR Section 300.507.

Schools must no longer distribute the outdated 1997 version of the notice, and immediately begin to issue the new edition on the occasions listed above. Each school is responsible for downloading, printing, and distributing the Notice of Procedural Safeguards: *Rights of Parents of Students with Disabilities*, available online at: < <http://www.tea.state.tx.us/special.ed/>>. Each school must ensure that the notice is provided in the native language of the parent, or other mode of communication, unless clearly not feasible to do so. English, Spanish, and Braille versions are available from the TEA website. If the native language or other mode of communication is not a written language, the school must translate the notice orally or by other means so that it is understood by the parent.

Assistive Listening Devices

By Jim Durkel, Coordinator of Statewide Staff Development, TSBVI Outreach

Noise and distance make listening hard for anyone. The more background noise there is, the harder it is to hear. The farther away a speaker is, the harder it is to hear. For people with auditory impairments, noise and distance are additional problems on top of the impaired hearing.

Hearing aids don't amplify just speech, they amplify everything. This includes the background noise. Ideally, what you want to hear (called the signal) should be louder than background noise. This relationship is called the signal-to-noise ratio. A good signal-to-noise ratio is 20 dB. That is, the signal is 20 decibels louder than any noise. A more usual listening situation is a signal-to-noise ratio of 10 or 0. That is, the signal may be only 10 decibels louder than the noise or the signal and noise may be of equal loudness. In many classrooms, the signal-to-noise ratio can be 10 or 0. Rustling papers, children moving in their seats, the air conditioner running – all of these normal background noises can overwhelm a teacher's voice.

In many classrooms, the teacher does not stay within 3 feet of the child. Sometimes the teacher may turn his or her back to the child (as when talking while writing on the blackboard). These actions decrease the intensity of the signal, making it harder for the child to understand what is being said.

A group of devices, called assistive listening devices (ALD), were designed to help a person with a hearing impairment better cope with the problems of noise and distance. An ALD works by having the speaker wear a microphone connected to a receiver, worn by the listener. The speaker's voice is then sent directly to the listener's ear. No matter where the speaker is in the room, his or her voice is as far from the listener as the microphone is from his or her lips. Background noise is not picked up by the microphone and so its effects are decreased.

ALD's vary in how the microphone and receiver are connected to each other. In schools, the most common type of ALD is the FM unit. The microphone broadcasts the speaker's voice on an FM radio channel. The listener's receiver is tuned to that special frequency and picks up the radio signal. Many movie theaters, large churches, and public auditoriums use an ALD that sends the speaker's voice to the receiver by way of infrared light (kind of like your TV remote control). Some very inexpensive units connect the microphone to the receiver with a wire (these are called "hardwired"). This type of device is fine when the speaker and listener are not going to be very far apart, such as when they are sitting at a table together. If you have used headphones to listen to a stereo, you have used a hardwired ALD. There are infrared and hardwired devices for use at home for watching TV or listening to music without driving everyone in the house nuts with fights over the volume control!

ALD's also vary in how the receiver is hooked up to the listener's ear. The receiver may be connected to a set of headphones. There may be a wire running from the receiver to a "button" that snaps into a special earmold. The receiver may be connected by a special wire plugged into the listener's hearing aid. This is called a "boot". Finally, the listener may use a "loop". In this set up, the hearing aid on/off switch is set to "T". "T" stands for telecoil. This is a setting for the hearing aid to use electromagnetic energy instead of sound energy coming through the air. The listener has a special loop of wire, connected to the ALD receiver, that he or she wears around his or her neck. The receiver transforms the sound energy into electromagnetic impulses that the hearing aid picks up. Sometimes, auditoriums have giant loops running around their walls. Anything a speaker says through the microphone on stage can then be picked up through a hearing aid without the listener needing to wear any other type of receiver. There are new behind-the-ear hearing aids with small FM receivers built into the hearing aid. With this device, the speaker wears a microphone and the signal is sent directly to the hearing aid. This is the wave of the future and may soon become the most common ALD. When an ALD can be connected to a listener's hearing aid, there is less fuss, more consistent hearing aid use, and the sound will be amplified in a way that is most appropriate for that listener.

There is research showing that all children, with and without auditory impairments, benefit from good signal-to-noise ratios. As a result, there is another type of ALD starting to be used in some classrooms. With this device, the teacher wears a microphone. However, his or her voice is sent through speakers located around the classroom. This works like a small PA system. Now, the teacher's voice is louder than the classroom noise and his or her voice stays constantly loud, regardless of how far away the teacher is from the child.

Children with central auditory processing disorders and children with hearing loss only in one ear may have more troubles with noise and distance than listeners with no impairments. These people may not wear hearing aids or need amplification but may benefit from the use of an ALD.

There are some problems with ALD's. If they are set so that all background noise is blocked and only sound from the microphone is received, comments from fellow classmates may not be heard by the ALD user. The teacher needs to be sensitive to this and either repeat all comments made by classmates, or pass the microphone to the classmate before allowing him or her to speak. This can be cumbersome. ALD's can be set to allow some background sound in. This allows for hearing comments from speakers without a microphone, but

decreases the effectiveness of the ALD in providing the best signal-to-noise ratio. Many adolescents do not like to wear ALD's because they make them stand out from their peers. Some teachers feel uncomfortable with wearing a microphone. Some ALD's require a belt to hook the microphone on, limiting a teacher's wardrobe. Some teachers complain that the cords get in the way of movement. The microphone may fall in a water fountain and cords get tangled around hands while trying to cook. Wearing a microphone takes some getting used to and once you forget you are wearing it is right when you leave it turned on while taking a restroom break! ALD's need to be recharged every night and checked at the beginning of every day. There needs to be a process for handling repairs and maintenance in a timely fashion. Finally there is the issue of who will pay. An FM unit typically used in the schools can easily cost \$1,000.

If you feel your child may benefit from an ALD, contact your district's teacher for students with auditory impairments, your district's assistive technology team, or visit an audiologist. If you can show that your child is in situations where his or her ability to listen is adversely affected by noise and distance, you would have a good case for the use of an ALD. The ALD may not be needed all day. For example, if reading instruction occurs in a very small group in the library, an ALD may not be needed then. However, for your child to hear instructions from the coach during PE in a large, noisy gym, an ALD may be quite helpful. Visit the various settings your child is in during the day. Think about how much background noise was present. How far away from the student is the teacher? Are there times when an ALD would improve the student's safety? An ALD can keep a child in touch with the teacher's voice out in the community and on job sites. This may increase the likelihood that the child would hear the teacher's voice giving an alarm. However, a student wearing an ALD set to block background noise may not hear traffic sounds. You can see there is no simple answer to whether and when a child should wear an ALD. This why a team approach usually yields the best results. If possible, include the child on that team to get a commitment to care for and use the ALD. Once everyone understands the benefit of using these devices, any problems will seem worth the effort.

Teaching a Blind Student How to Graph on a Coordinate Plane: No Tech, Low Tech, and High Tech Tools

Susan Osterhaus, Secondary Mathematics Teacher, TSBVI

Editor's Note: In the author's words, "Although graphing calculators are mainstays of most secondary math classrooms, it is important for all students to understand the concept of graphing on a coordinate plane before they move to the graphing calculator." This is especially important for visually impaired students, and Susan Osterhaus, math teacher at TSBVI, ensures that her students learn to do so manually – they must physically plot points, graph lines, and find slope. Below are her answers to questions about how to teach this skill, and her suggestions for students, teachers, and parents.

1. HOW CAN BLIND STUDENTS GRAPH LINEAR EQUATIONS, INEQUALITIES, AND SYSTEMS OF INEQUALITIES INDEPENDENTLY AND EFFICIENTLY? OR IS THIS THE TIME WHEN THE VI STUDENT DOESN'T PARTICIPATE BECAUSE OF THE VISUAL NATURE OF THE TASK?

Most academic blind students, even those with spatial orientation problems, are quite capable of graphing, and as one of my students exclaimed, "Not only can we do it, it's fun!" There are several tools they can use to do so:

The Graphic Aid for Mathematics, from the American Printing House for the Blind (APH), is excellent for graphing algebraic equations. It can also be used in geometry, trigonometry, etc. It consists of a cork

composition board mounted with a rubber mat, which has been embossed with a grid of 1/2-inch squares. Two perpendicular rubber bands, held down by thumbtacks, can create the x- and y-axes. Points are plotted with pushpins at the appropriate coordinates. Points are connected with rubber bands (for lines), flat spring wires (for conic sections), or string (for polynomial functions). I like for my students to graph extensively, and they can do so incredibly fast on the APH Graphic Aid. In fact, many print students also like using it because it is fast, fun, and allows them to learn graphing skills in another modality. You can make your own graph board by affixing a piece of raised line graph paper (also available from APH) to a **cork board** and proceeding as described for the Graphic Aid.

If a student needs to turn in copies of graphs for homework, he can use **Wikki Stix** and **High Dots** on **APH graph paper**. This method can be quite expensive, however, and is very time consuming. It also tends to be more of a test of artistic ability than a demonstration of understanding of graphing concepts.

The **ORION TI-34** talking scientific calculator (from Orbit Research) and the **Accessible Graphing Calculator** (from ViewPlus Technologies) are examples of more high tech solutions for graphing activities. I described them in a previous *See/Hear* article (Winter, 2002), but strongly recommend that students be able to graph manually as well. It is important for visually impaired students to be able to use a variety of tools, and know when to use each of them. For example, a former student decided to graph a quadratic function manually because it was “too easy to bother with the computer.” Yet, he will use the AGC to graph an exponential function.

2. HOW DO STUDENTS REPRESENT INEQUALITIES THAT REQUIRE A SOLID LINE OR A DOTTED LINE ON THE GRAPH?

The APH Graphic Aid described above works well. Plot the points with pushpins and connect them with a rubber band when the boundary line is to be included in the solution (a solid line in print). Leave off the rubber band when the boundary line is not included in the solution (dotted or dashed line in print).

3. HOW CAN VI STUDENTS SHOW SHADED PARTS ON A GRAPH?

When graphing one inequality in two variables, I simply have my students place their hand on the shaded side. I check each graph as my students complete them. When graphing a system of two inequalities, the student places one hand on the shaded side of the first inequality. Then they place the other hand on the shaded side of the second inequality. Where the two hands overlap (including the boundary lines where applicable) is the solution. Pretty soon most of my students are able to handle three or more inequalities without multiple overlapping of hands. We even progress to linear programming problems involving four or more inequalities. In these problems, a bounded area with vertices is often found, and it is pretty obvious where the shaded portion (the solution) is located.

4. IS THERE A WAY FOR THEM TO DO MULTIPLE PROBLEMS ON A PIECE OF PAPER? WHAT IF THEY NEED TO BE TURNED IN TO ANOTHER TEACHER, OR YOU CAN'T CHECK EACH GRAPH AS IT'S COMPLETED?

If a student-made, manually produced paper copy is required, the student could use APH graph paper attached to a corkboard. She could plot her points using stick-on high dots, puff paint, etc. and could form solid lines using Wikki Stix. She could actually use a colored pen, pencil, or crayon to color the shaded area of the solution. This would take much longer, however, and would be very labor intensive. It will be important to know the purpose of the assignment and the concept(s) being taught. A paper copy of a single function can be created on the AGC (it can't graph multiple functions on the same graph). Often, it is possible for a sighted

person (teacher, peer, parent, teaching assistant) to make a print copy of the student's graph – the visually impaired student graphs on the Graphic Aid and someone copies it exactly onto a piece of paper to turn in. You can also divide the Graphic Aid into 4 to 6 small, separate coordinate planes for multiple problems. If you have a digital camera, you could even e-mail or print a picture of the student's graphs. Better yet, have the student take her own photos!

Please be sure that visually impaired students are allowed to participate in all kinds of graphing activities and that they are supplied with the proper tools. I would rather see them become proficient using a rubber graph board because they will learn so much more with this method, and they can do so independently. Creative exploration should begin in the early grades and allowed to blossom. Remember, the beauty of a tactile graphic is found in the fingertips of the beholder. And there can be no more beautiful and meaningful graphic than one created by those very same fingertips.

SOURCES FOR MATERIALS DESCRIBED IN THIS ARTICLE:

- APH Graphic Aid for Mathematics and APH Graph Paper: www.aph.org
- Wikki Stix: www.wikkistix.com
- High Dots: www.exceptionalteaching.com
- ORION TI-34 Talking Scientific Calculator: www.orbitresearch.com
- Accessible Graphing Calculator (AGC): www.ViewPlusSoft.com

Distance Education

Holly Cooper, Ph.D., Technology Consultant, TSBVI Outreach

In Outreach, we do a lot of training for teachers, parents, and others who spend time with students with visual impairments. We do the big conferences like Texas Focus and the Texas Deaf/Blind Symposium, as well as smaller sessions at Education Service Centers, and individual training when we do consultation visits. In spite of that, we often get requests for training from people who couldn't get to, or didn't know about, the sessions we offered. We can only be in one place at a time. Or can we? Well, through the magic of technology, we can and routinely are, in many places at once!

Last year, Outreach math and technology consultants, as well as others, did training over an interactive video system. Some vision teachers are familiar with this training medium since they took vision teacher certification courses this way. While it's not as engaging as real live face-to-face interaction and communication with colleagues, it's a good way to get information to people who need it.

GETTING CONNECTED

Do you want to find out what is scheduled for the remainder of this year? Math and Tech Outreach staff are both doing presentations once a month on Wednesday afternoons. You can see the list of topics and dates at: www.tsbvi.edu/technology/de-pres-out.htm for technology, and www.tsbvi.edu/Outreach/math-de.htm for math. To view the presentation, contact your local Education Service Center. Currently, about half of the ESC's are connecting and participating. Many local school districts also have the capability of connecting. In the Dallas area, Region 10 has researched and found a variety of sites in high schools and other local campuses that have connected and viewed our presentations live.

Audiences have included teachers, parents, and students, all of whom have had questions and needed information about how to use a specific device, or how to make the device more useful in the educational environment. If your ESC is not making this service available, contact them, and ask others to contact them and request these distance education sessions.

BE PREPARED

To get the most out of a distance education session, it is crucial to come prepared. If the training is on a particular device, such as a notetaker, bring the device with you to the training. If it is on a computer application such as JAWS, bring a computer with JAWS installed on it. Many computer applications for people with visual impairments are available as downloadable demo versions from the manufacturer's websites. A demo version is a great way to familiarize yourself with a product. So bring your computer with the software installed on it to the training session. Bring along user's manuals and other materials that you have on the device.

PROGRAMMING

If your student or child is mature enough to participate, try to arrange to have them come with you. Two heads are better than one. It's a lot of information at one time, and impossible to remember it all when you get back in the classroom. If you can have another vision teacher or paraprofessional come along with you to take notes, that can be a great help. Before coming to the session, spend a little time trying to use the device or software and exploring its features. Make a list of the questions you have, and features you would like to ask about. The strength of interactive video conferencing is in the interactivity, so come prepared to ask, and don't be afraid to speak up during the session.

As presenters, we really appreciate questions and comments from the audience, especially feedback sharing ideas about how others have used a device or software application. If you have a question, chances are the other people do also. If you plan to come to a session, you can send us an email to ask us in advance to spend time really explaining a particular aspect of the topic. We want to give our viewers the information they need!

We send the preliminary version of the handouts to the ESC's by the Friday prior to the session. Typically we email them, and the local people furnish print copies. Often we will have a list of web resources that will help you with tutorials, lesson plans, user's guides, and other supporting material. We are doing training both on specific devices and computer applications as well as about instructional strategies and general overviews of topics. In the spring we will be planning for next year, so send us an email about training sessions you would like to have in the 2003-2004 school year. Tell us what you want; we aim to please!

WHY COME TO A DISTANCE EDUCATION BROADCAST?

- Save travel time and expense; stay in your area and learn in a statewide workshop.
- Use the opportunity to ask questions and troubleshoot the device.
- Watch as we plug cords and flip switches to make devices work together.
- Work along with us and make sure you can use the devices and understand the instructions.
- Hear about on-line lesson plans, tutorials, web sites and other resources.
- Talk to the trainers and other teachers of students with visual impairments, and sometimes parents and students, about issues and questions of concern to you.

The Early Braille Readers Project

Holly Cooper, Ph.D., Technology Consultant, TSBVI Outreach

We in Outreach Technology are pleased to announce the launching of a new project: the Written Communication Technology for Early Braille Readers Project. This project will provide electronic braille equipment for a limited number of students who apply and are selected as participants. For more information about the project and how to apply, parents should contact their child's vision teacher. Teachers can contact the regional Education Service Center specialist for students with visual impairments.

WHAT'S IT ALL ABOUT?

The Early Braille Readers Project was designed to explore the potential of electronic braillewriter technology for very young students. We believe putting braille technology into the hands of students and their teachers in the primary grades will give students access to a virtually unlimited supply of written material. With such expanded access to materials, students will have more opportunities to learn literacy skills in a variety of contexts, increasing their learning opportunities. They will be able to participate in classroom activities more fully because the technology can receive input from a standard computer keyboard and output it in braille! General education classroom teachers and students can enter information in print, and the braillewriter can immediately emboss it into braille. No longer will all printed matter have to go to the vision teacher for the braille reading student to have access. The braille reading student also will be able to write in braille and output materials in print with a computer printer.

So what is this braille technology, and why haven't we been using it already? We have! It's a new version of a device that is familiar to many who work with visually impaired students: the Mountbatten Pro braillewriter! The exciting thing about the Mountbatten that led us to choose it for this project is its ability to interface with a computer. Pulse Data has released a new version of the Mountbatten with a multitude of ports and connectivity features. They have revised some of the function keys, so students will be much less likely to access the internal menus of the device, and unintentionally store or delete files.

NOT JUST GADGETS!

Equipment is great, but practical use of equipment in classrooms with children is another matter. We in Outreach Technology know that just having a piece of equipment doesn't necessarily help the student. We believe in support! An important feature of our project is training and support for the vision teacher, other teachers, support staff, and interested people who will be assisting the student, or using the electronic braillewriter themselves to produce accessible materials. We will do a series of initial face-to-face trainings, and scheduled trainings and trouble shooting sessions on interactive video or web-based interactive video. We will have a supporting listserv for users to ask questions and share ideas. Our project will have the capacity to add other supports as participants have needs.

WE'RE LOOKING FOR A FEW GOOD KIDS

To take part in this project, the vision teacher must complete an application, and the student must fall within the parameters we defined in our grant application. Included in these requirements are the following:

- The student must be an early or emerging braille reader who already is learning to read and write some braille letters (standard size braille);
- The student must be in kindergarten or first grade in the first year in which they participate in the project;

PROGRAMMING

- The student must be educated in the general education environment for the majority of the school day;
- The vision teacher and classroom teacher must be willing to take part in training and the use of the equipment.

We realize there are many other students who would benefit from the use of equipment like this who are older or who are educated in other class settings. Our project only includes young students who are ready to read. Probably most will not have other disabilities. We plan to collect information on students' progress in reading and writing, and feedback from teachers about how increased access to braille has made a difference in skill acquisition, social interactions with peers, and other aspect of the educational experience. With this project as a source of information, we will write and do presentations about (what we expect will be) the benefits of having access to braille through the use of technology. In this way, we hope to give teachers and parents the information they need to advocate for the use of technology and increased availability of materials in braille for younger students, and students who are early braille readers regardless of their age.

Do you think you know a student who would be a good prospect for participation in the Early Braille Literacy Project? We want to know about them. Contact your vision teacher or ESC vision specialist to start the process.

FDA Public Health Web Notification:

Cochlear Implant Recipients May Be at Greater Risk for Meningitis

Reprinted with permission from the U. S. Food and Drug Administration
Center for Devices and Radiological Health

Originally issued July 24, 2002 - Updated: October 17, 2002

SYNDROMES/CONDITIONS

The Food and Drug Administration (FDA) has become aware of a possible association between cochlear implants and the occurrence of bacterial meningitis. Worldwide, we know of 91 reports of meningitis in patients implanted with the three FDA-approved cochlear implant devices: Advanced Bionics Corporation devices (56 cases), Cochlear Limited devices (33 cases) and MED-EL Corporation devices (1 case). A total of 17 deaths have resulted from these meningitis cases.

Within the U.S., the FDA is aware of 52 cases of post-implant meningitis: Advanced Bionics Corporation devices (29 cases), Cochlear Limited devices (22 cases), and MED-EL Corporation device (1). Five cases resulted in death. Cochlear Limited, Advanced Bionics, and MED-EL devices were approved in 1985, 1996, and 2001, respectively. All cases are currently being investigated. According to information supplied by the manufacturers, the one MED-EL Corporation case and the majority of the Cochlear Limited cases had predisposing factors for meningitis unrelated to the implant (e.g., Mondini inner ear deformity, pre-implantation history of meningitis—see Predisposing Factors section below).

CASE INFORMATION

The ages of the U.S. meningitis patients ranged from 18 months to 84 years but most (33) of the patients were under 7 years of age at the time they developed meningitis.

Patients in the U.S. had onset of meningitis symptoms from less than 24 hours to greater than 6 years after implant. Thirty-two U.S. patients developed meningitis within one year post implantation, many within the first few weeks of surgery.

We have received cerebrospinal fluid (CSF) culture results in 23 cases in the United States. The organisms identified are: *Streptococcus pneumoniae* (pneumococcus) (16), *Haemophilus influenzae* (4), *Streptococcus viridans* (2), and *Escherichia coli* (1). Although vaccination is usually protective against both pneumococcus and H. influenzae, 2 cases of pneumococcal meningitis and 2 cases of H. influenza meningitis developed after the patient had received the appropriate vaccine.

PREDISPOSING FACTORS

The cause of meningitis in the cochlear implant recipients has not been established. Some deaf people may have congenital abnormalities of the cochlea which predispose them to meningitis even prior to implantation. People who become deaf as a result of meningitis are also at increased risk of subsequent episodes of meningitis compared to the general population. Other predisposing factors may include young age (< 5 years), otitis media, immunodeficiency, and surgical technique. The cochlear implant, because it is a foreign body, may act as a nidus for infection when patients have bacterial illnesses.

Design of the electrode is also being considered as a possible predisposing factor. Advanced Bionics electrodes with positioners (HiFocus I and HiFocus II) have been withdrawn from the market. The HighFocus I without positioner has been approved for use in the U.S. No Cochlear Limited or MedEl Corporation electrodes have a positioner.

SIGNIFICANT EVENTS AND GOVERNMENT ACTIONS TO DATE

In early July, European and U.S. cochlear implant surgeons and experts met to discuss the incidence of meningitis occurring after cochlear implantation. That group concluded that there were more cases of meningitis with the CLARION device with the electrode positioner than with other cochlear implants. The organizers of that meeting recommended discontinuing use of the positioner, and the regulatory authorities of several European countries (e.g., France, Germany, and Spain) accepted those recommendations. Consequently, Advanced Bionics agreed to discontinue use of the positioner in those countries and is marketing one of their current electrode systems (HiFocus I) without the positioner. The company also initiated a voluntary recall of any unimplanted CLARION devices in the United States, but subsequently has received FDA approval for marketing the HiFocus I electrode without the positioner.

Drs. Noel Cohen (New York University) and Thomas Balkany (University of Miami) conducted a survey to ascertain additional cases of meningitis in cochlear implant recipients. They surveyed all North American implant centers. Their survey helped FDA identify cases of meningitis during the early course of this investigation.

The Centers for Disease Control and Prevention (CDC) and the FDA, in partnership with State Health Departments, are presently conducting a formal, comprehensive investigation into the apparent association between meningitis and cochlear implantation. The purpose of this investigation is to gather information that may help determine risk factors that lead to meningitis in this implant population and help to develop strategies to prevent meningitis in cochlear implant patients. This investigation focuses on implant recipients who were under the age of six at the time of implant.

MENINGITIS

Meningitis is an infection of the lining of the surface of the brain. Early symptoms of meningitis include fever, irritability, lethargy and loss of appetite in infants and young children. Older children and adults may also manifest headache, stiff neck, nausea and vomiting, and confusion or alteration in consciousness. Physi-

cians are encouraged to consider a diagnosis of meningitis in cochlear implant patients when such symptoms exist and to begin appropriate diagnostic testing and treatment as soon as possible.

The younger patient population (< 5 yr) and the elderly are most vulnerable to meningitis.

COCHLEAR IMPLANTS AND OTITIS MEDIA

In some of the reported cases of meningitis in cochlear implant recipients, patients may have had overt or sub-clinical otitis media prior to surgery or before the meningitis developed. Physicians are encouraged to consider appropriate prophylactic perioperative antibiotic treatment, and to diagnose and treat otitis media promptly in patients with cochlear implants.

USE OF PNEUMOCOCCAL VACCINATIONS FOR COCHLEAR IMPLANT RECIPIENTS

Persons **less than 2 years** with cochlear implants should receive the pneumococcal conjugate vaccine according to the high risk pneumococcal conjugate vaccination schedule. This schedule is the same as the pre-shortage routine immunization schedule used for children less than age 2 years. For high risk infants who start the series before age 6 months, this means they would get four doses, given at 2 months, 4 months, 6 months and 12-15 months.

Persons who are **age 2 years and older** with cochlear implants should receive pneumococcal vaccines, according to the following schedule:

- High risk children age 2 years and older who have completed the pneumococcal conjugate vaccine (Prevnar®) series should receive one dose of the pneumococcal polysaccharide vaccine (Pneumovax® 23 or Pnu-Imune® 23). If they have recently received pneumococcal conjugate vaccine, they should wait at least two months after completing the pneumococcal conjugate vaccine series before receiving pneumococcal polysaccharide vaccine.
- High risk children between the ages of 24 and 59 months, who have never received either pneumococcal conjugate vaccine or pneumococcal polysaccharide vaccine, should receive two doses of pneumococcal conjugate vaccine two or more months apart and then receive one dose of pneumococcal polysaccharide vaccine at least two months later.
- High risk persons age 5 years and older should receive one dose of pneumococcal polysaccharide vaccine. Pneumococcal conjugate vaccine is not routinely recommended for persons age 5 years and older. If pneumococcal conjugate vaccine has recently been given, then polysaccharide vaccine should be administered 2 or more months after pneumococcal conjugate vaccine.

USE OF HIB VACCINATION IN COCHLEAR IMPLANT RECIPIENTS

Most children born after 1990 will have received the Hib vaccine when they were infants. <<http://www.cdc.gov/mmwr/preview/mmwrhtml/00041736.htm>> Those who did not receive Hib vaccine and who are younger than five years should receive the vaccine. For those age 5 years and older, Hib vaccine is not routinely recommended.

The CDC National Immunization Program (NIP) has set up a hotline that will advise persons with cochlear implants to receive age-appropriate high-risk pneumococcal vaccinations. In addition, they will be able to answer questions related to immunization issues or refer calls to immunization experts at NIP if needed.

The Hotline numbers are:
English 1-800-232-2522 (M-F, 8a -11p)
Spanish 1-800-232-0233 (M-F, 8a-11p)
TTY 1-800-243-7889 (M-F 10a-10p)
The hotline is closed on weekends and federal holidays.

REPORTING CASES OF MENINGITIS IN COCHLEAR IMPLANT RECIPIENTS

We encourage you to report cases of meningitis in cochlear implant recipients. Please call 1-877-CDC-HEAR to report cases so that they can be included in the CDC-FDA study. You can also report cases directly to the device manufacturer or you can report them to MedWatch, the FDA's voluntary reporting program. You may submit reports to MedWatch one of four ways: online at <<http://www.accessdata.fda.gov/scripts/medwatch/>> by telephone at 1-800-FDA-1088; by FAX at 1-800-FDA-0178; or by mail to MedWatch, Food and Drug Administration, HF-2, 5600 Fishers Lane, Rockville, MD 20857.

FDA Contact: Nancy Pressly
Office of Surveillance and Biometrics (HFZ-510)
1350 Piccard Drive, Rockville, Maryland, 20850
Fax at 301-594-2968, or by e-mail at <phann@cdrh.fda.gov>

Additionally, a voice mail message may be left at 301-594-0650 and your call will be returned as soon as possible.

Meningitis

By Kate Moss, Family Specialist, TSBVI, Texas Deafblind Outreach
Originally printed in the Spring 2001 SEE/HEAR

The 2001 Texas Deafblind Census data indicates that meningitis is one of the leading causes of deafblindness in our state. Recently in Texas, there have 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 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, this bacteria is carried at any one time by around 10-25% of the population. It 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 look-

ing 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 if they get plenty of bed rest. They are simply given plenty of fluids and also medicine to treat the fever and headaches. Viral meningitis usually does 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 that 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 remain permanently. 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. “It cannot be emphasized enough that some patients may not experience any of these complications and will make a fast and problem free recovery. However, it must be recognized that meningitis can cause many after effects which MAY affect some sufferers.” (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 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

The Centers for Disease Control and Prevention

1600 Clifton Rd.

Atlanta, GA 30333

Telephone: (800) 311-3435

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

Bacterial meningitis information: http://www.cdc.gov/ncidod/dbmd/diseaseinfo/meningococcal_g.htm

Viral meningitis information: http://www.cdc.gov/ncidod/dvrd/revb/enterovirus/viral_meningitis.htm

TCB and Other State Agencies Await 2004-2005 Budget

By Terry Murphy, Executive Director, Texas Commission for the Blind

The 78th Texas Legislature is underway. Predictions of a tight budget and potential cutbacks are now hard facts, and the Texas Commission for the Blind and other state agencies are busy providing information to the state's decision-makers about our budget requests. The Commission's legislative appropriations request for the 2004-2005 biennium reflects the agency's dual responsibility of putting together a budget that recognizes the state's limited financial resources yet honestly speaks to the cost and benefits of the vital services we provide. We asked for a technical change in TCB's method of finance to ensure that Texas receives and maintains its full share of federal dollars allotted to the Vocational Rehabilitation Program; a conservative increase in general revenue for the Blind Children's Vocational Discovery and Development Program; and a small but essential increase in the number of authorized employees for the Children's and Independent Living Programs.

We've been busy explaining to legislators that the state's program for children with visual disabilities is still a critically needed resource. No other program in Texas works with children who are blind and their families like we do on a one-to-one basis to help parents understand blindness and explore how it relates to their child's individual capabilities now and in the future. The number of children with severe visual impairments is expected to increase through the next budget cycle, and based on population data and the Texas Education Agency Registration Report for students receiving special education services because of a visual impairment, more than 650 additional children could benefit from comprehensive vocational discovery and development services this coming year.

It will be difficult for the agency to serve more children without the four additional blind children's specialists we've included in the budget. At this point, it appears that adding more personnel to state government for increased services is not a legislative priority, but we are hopeful that the benefits of being able to serve more children who are blind will become clear to legislators as we move forward in the session.

At the time the last *See/Hear* newsletter was written, we had not yet completed the 2002 fiscal year. The Commission once again achieved all its major goals. We provided transition services to 1,167 blind students out of our vocational rehabilitation budget, and provided habilitation services to 7,294 children with state funds during the year. Our Vocational Rehabilitation Program served 9,985 individuals, and we provided independent living services to 4,523 individuals, most of whom were senior citizens. In round numbers, we were directly involved with approximately 23,000 Texans last year in various ways as they moved, with our assistance, toward more fulfilling and independent lives. This number doesn't include the more than 17,000 people who received screening services and 211 people who received treatment services for potentially blinding eye conditions with funds allocated to the agency for its Blindness Education, Screening, and Treatment Program from donations to the Texas Department of Transportation during drivers license renewals.

Although these statistics are a regular and necessary part of our reporting responsibilities every year, the actual results of our services are far more exciting and meaningful to talk about than numbers. I'm still smiling about some of the comments made during a recent "graduation" ceremony at Criss Cole Rehabilitation Center. One young woman thanked the staff for their constant encouragement at a time when she lacked confidence in herself that she could read braille. Another thanked the staff for the adaptive office skills she had learned, which had already landed her a new job. These and thousands of others just like them are the real stories behind our budget request.

It will be a while before we know what resources we will have for the next two years to provide services. I can promise you right now, however, that we'll spend wisely every penny we do receive in our mission to work in partnership with blind and visually impaired Texans to reach their goals.

The National Agenda

(Continued from Fall, 2002 *SEE/HEAR*)

Introduction by Phil Hatlen, Superintendent,
Texas School for the Blind and Visually Impaired

One of the wonderful blessings of my chosen career has been the opportunity to work as a partner with parents of blind or visually impaired children. When I first began as a teacher, it took me several years and some difficult experiences before I came to realize that, without parents as partners, my efforts with their children were not very effective. But when I came to realize that no one knows children better than their parents, that their experiences and knowledge bring an invaluable component to the process of children's learning and growing—only then was I able to embrace the concept of partnerships with parents.

The National Agenda (NA) originated with the concept that parents and professionals must work together to improve educational opportunities for blind or visually impaired students. And thus did Donna Stryker (a very wise and gifted parent) and I become co-chairs of the National Agenda.

As the NA gained momentum, as its impact began to be felt throughout the country, as Donna and I found ourselves working closely together on many occasions, my commitment to the partnership of professionals and parents was significantly strengthened. Together, Donna and I accomplished much more than we might have been able to do individually. I found myself learning something new from her on every occasion we were together, and Donna's passion for the role of parents in education was (and is) a powerful thing to behold.

Please read on as Donna Stryker describes her role and commitment to the National Agenda.

The National Agenda – A Parent's Perspective

By Donna Stryker, Parent, Las Cruces, NM

For the past 8 years or so since Phil Hatlen asked me to co-chair the National Agenda I have had the opportunity to watch miracles happen.

Miracles are not always fishes and loaves, or the parting of a large body of water. Miracles occur when everyday folks work on great plans and bring them to a reality.

The miracles I have seen as a parent are a set of goals that a group of dedicated people actually agreed upon that would affect forever the way a child who is visually impaired or blind, including those with multiple impairments, would be able to learn.

The miracle of a number of states across this county that embraced the notion that students with visual impairments learn differently and need “equal yet different” services in order to learn to the best of their ability.

The miracle of parents and professionals operating as true partners within the National Agenda to such a degree that many of the existing projects within AFB (American Foundation for the Blind), AER (Association for Education and Rehabilitation of the Blind & Visually Impaired), APH (American Printing House for the Blind) are as a result of the belief that the National Agenda is the change agent in educating children with visual impairments. Goals that address training teachers of the visually impaired, ensuring the right of full participation and partnership of parents, early referral, on-going professional development, full array of placement options, access to materials (The Instructional Materials Accessibility Act is a direct result of the National Agenda), expanded core curricula, etc., are all miracles in progress as the impact of the National Agenda results in dramatic changes.

As a parent of a college student, I have seen my son benefit from the “miracle” of the National Agenda. When the National Association of State Directors of Special Education collaborated with parents, professionals, and consumers to produce a set of guidelines for administrators who may or may not have had experience with a blind or visually impaired student I had the document I needed to help my local district understand the differences in the way my son learned.

There are many more pages of examples I could share about how the National Agenda is a miracle to me, but suffice it to say that in this time of fear from outside sources, in this time of rethinking of our personal and professional priorities, in this time of getting back to basics within our families, whether that be our sons and daughters or extended families of friends, teachers, professionals that touch our lives daily and the lives of our children...The National Agenda has made a difference, is a miracle of people working together toward a common goal that they believe in their heart of hearts to be of great importance. And is of great importance—just ask a parent who is able to help a teacher understand why a book in their child’s hands at the same time as their sighted peers is important. That is the miracle of the National Agenda.

What’s Looming Ahead? A Legislative Update

By Colleen Horton, Texas Center for Disability Studies

Reprinted with permission from *Texas Parent to Parent Newsletter*,
Fall, 2002 (Vol. 1, Issue 1).

It’s hard to believe, but in a few short months, Texas legislators will be meeting in Austin to contemplate again the myriad of issues that come before them. Included in that massive bundle will be issues that directly affect the lives of our children with disabilities. Some of the legislation that will be proposed will be good and could help to improve the lives of our children. Other legislation could further reduce a family’s ability to access services. All of the legislation that involves our children requires our attention.

Adequate funding for community services is the critical component in supporting families, yet many legislators do not consider this a priority. This isn't necessarily due to a lack of concern, but is often due to a lack of awareness. Think of our lives before we had children with disabilities. Funding Medicaid waiver services was not something that kept us awake at night...I would venture to guess that most of us never knew Medicaid waivers existed.

Legislators often don't know the reality and the urgency of the need to support families caring for children with disabilities. Most have never had any personal experience that would make them aware. It is our responsibility – yours and mine – to invest time and energy to make them understand our strong commitment to care for our children at home and the challenges that commitment often presents. It is our responsibility to talk to them about our lives and the lives of our children. It is up to us to make sure they understand that not supporting children in families only costs the state more when families are forced to institutionalize their children because they can't get the help they need.

Legislators will make many decisions that will affect the course of the lives of our kids. They have a lot to learn and we are the experts that must teach them. Now is the time to start gearing up to do your part to improve the way our state supports children and families. Here are some things that you can do:

- Connect with other parents in your local community – advocacy work is always easier when not done alone.
- Get connected with disability organizations that can keep you up-to-date on the issues.
- Get some advocacy training for your local network to help alleviate some of the discomfort that often accompanies new adventures.
- Find out who your representative and senator are and contact their staff.
- Make an appointment to visit them and let them know that you will be keeping in touch throughout the legislative session. Remember, they work for you.

When action alerts are sent out requesting that families contact legislators on an issue, the need is very real. Make a commitment that you will respond. Every letter, every phone call, every email, and every fax is counted when legislators make their decisions. If they don't hear from us, we have no right to complain about their decisions.

Announcing SibKids and SibNet Listservs

The Sibling Support Project of the Arc of the US is pleased to announce SibNet and SibKids. SibNet and SibKids are the Internet's only listservs for and about brothers and sisters of people with special health, developmental, and emotional needs.

Both SibKids (for younger brothers and sisters) and SibNet (for older siblings) allow brothers and sisters an opportunity to connect with their peers from around the world. Both listservs have members from the US, Canada, Australia, England, Japan and elsewhere. SibNet (started in 1996) and SibKids (started in 1997) are remarkably warm, thoughtful, and informative communities where young and adult brothers and sisters share information and discuss issues of common interest.

Anyone who has email can subscribe to SibKids and SibNet. For a no-cost subscription and to learn more about SibKids and SibNet, please visit the Sibling Support Project's Web Page: <<http://www.thearc.org/siblingsupport/>>.

Finally, if you have further questions about SibKids, SibNet, and our Sibshops or the work of the Sibling Support Project, please contact:

Don Meyer, Director
Sibling Support Project of the Arc of the US
6512 23rd Ave. NW, #213
Seattle, WA 98117
206-297-6368

Providing Hope and Encouragement for Parents of Child with Disability Goal of New Book

Press Release reprinted with permission by Kensington Publishing Corp. and Dr. Klein

From the time a pregnancy is identified, most parents begin building hopes, dreams, and expectations for their new baby. These dreams can be suddenly shattered when a child is diagnosed with a disability or special health care need, noted Stanley D. Klein, Ph.D., co-editor with Kim Schive, of *You Will Dream New Dreams: Inspiring personal stories by parents of children with disabilities* (Kensington, \$13.00).

“Although compassionate physicians, nurses, social workers, and other health care professionals may try to provide emotional support and useful information,” Klein said, “most parents describe feeling terribly alone with feelings they can find hard to put into words. Many parents and professionals have suggested that the diagnosis of a child’s disability initiates a mourning process in parents, much like the grief felt when a child dies. Yet the child is alive and parenting must proceed.”

“Our book,” stated Klein, “is all about human connections - ‘veteran’ parents reaching out to parents who have recently learned that their child has a disability or a special health care need. The compassion and caring of these very special connections can be healing at a critical time in the life of a family.”

“To create this book, we asked ‘veteran’ parents of children with disabilities to tell the stories they wish they could have heard at that emotionally difficult time, to share words of validation, affirmation, support, and encouragement. Although the authors of these essays have had very different experiences—differences that are reflected in the stories they tell — similar messages of hope and encouragement come through in each essay,” Klein stated. The basic messages of the essays include:

- You are not alone.
- The wide range of difficult feelings you are experiencing are a normal part of the human experience. We, too, have been there when everything seemed hopeless; yet we have survived, and our lives have continued. You can go on and grow.
- Although there are no easy answers, you will find ways to cope. You are likely to discover inner resources you did not know existed.
- There is sadness; some dreams are lost. You will mourn, but you can heal. You will be happy again; you will dream new dreams.

FROM THE FOREWORD OF *YOU WILL DREAM NEW DREAMS*

You are not alone. My wife and I have been there and we have learned to dream new dreams. On July 1, 1960, our son, Peter, then an infant only four months old, was involved in a terrible automobile accident which took the life of his mother, my first wife. For a considerable period of time, his very survival was in doubt. He had multiple skull fractures and serious brain injuries which resulted in his having mental retardation.

...While in the hospital with tubes running in and out of his tiny body, he was baptized. He returned home just before Christmas and our family life began anew...After spending three years as a single parent to Peter and his two older brothers, God sent me Ginny Judson, a schoolteacher who I met and married in 1963. In 1966, Ginny and I added a fourth son to our family.

...it has always been very special for us to meet and talk with other parents who have shared similar experiences. We have been comforted and nourished by other parents; we have wept together and we have laughed together. We never perceived one another as superstars or martyrs; we were mothers and fathers discovering our gifts while trying to be the best parents we could be.

I have also been uniquely blessed with opportunities to apply the lessons I have learned as a parent in public life. In 1978, I ran successfully for governor of Pennsylvania and served two four-year terms. Peter was a fine campaigner, a popular subject for campaign photos and a frequent participant in official activities after I was elected. Our feeling was one of pride in Peter's accomplishments, not reluctance to share his shortcomings. Everyone in Pennsylvania knew that the governor had a son with a serious disability...

Later when I served in Washington, D.C., as Attorney General of the United States, one of my principal tasks for President Bush was to spearhead the effort to obtain congressional passage of the Americans With Disabilities Act (ADA), the civil rights law designed to end discrimination against persons with disabilities and remove barriers to their participation in all aspects of community life. Once again, it was parents, parent organizations and organizations of people with disabilities who helped develop bipartisan support for this legislation.

When I served at the United Nations, I had an opportunity to observe how the needs of some 500 million persons with disabilities around the world are beginning to be met — through the UN's own program of action and in many nations that are using our ADA as a model. Today determined advocates throughout the world, including many parents, are stimulating new thinking about how persons with disabilities can best serve and be served in their societies...

In this book, more than 60 parents who have "been there" reach out to new parents by sharing their stories and their wisdom. They describe their deepest emotions and reflect on how they have become seasoned, veteran parents. Because of their sons and daughters, their lives and their values changed. They have become informed experts about their children and have found new ways to grow and serve. As veteran parents ourselves, Ginny and I know firsthand that parents' strongest allies will always be other parents and we count ourselves fortunate to have been able to share our experiences with others.

To new parents, grandparents and other family members reading these fine essays, we say with special feelings of respect: "Welcome to a wonderful worldwide community! Keep this book nearby and share it with your family and friends. You are not alone."

*Dick Thornburgh
Washington, DC*

Applicants Wanted for Weeklong Youth Leadership Program Next Summer

Press Release from Children's Association for Maximum Potential (C.A.M.P.)

The Children's Association for Maximum Potential (C.A.M.P.) is looking for future community leaders to participate in an exciting leadership training program – the 2003 C.A.M.P. Youth Leadership Forum (YLF) for students with disabilities. The YLF, which will be held at a Hill Country Conference Center in Center Point, Texas, is a fun, educational, vocational awareness program that enables young people to learn from each other and from successful adults with disabilities who are recognized leaders and role models. The leadership forum, which is being developed under a Council grant, is *free* for individuals who are selected to participate. Applications for the YLF are due April 1, 2003.

Modeled after a national youth leadership program that originated in California 12 years ago, the YLF will target 30 young people with disabilities from across Texas. Forum participants are selected by C.A.M.P. through an application and interview process and include applicants that want to be leaders in the community who have demonstrated academic success, community involvement, leadership potential, and an ability to interact effectively with other students.

The weeklong summer program for youth from across the state will be held Sunday - Friday, July 27 to August 1, 2003. During this forum, participants will develop a "personal leadership plan." This plan will help them identify and deal with barriers to personal and professional success. Participants will also collaborate with other young people who have leadership qualities, learn more about assistive technology, work on building self-esteem, and learn about the history of disability as a culture.

WHAT WILL HAPPEN AT THE FORUM?

The forum will:

- Bring together young people with disabilities (ages 16 to 22) who demonstrate potential leadership qualities and provide an opportunity for them to share information with each other.
- Offer educational programs including the history of disability as a culture, assistive technology, developing leadership/self-esteem and other areas. Presenters will include leaders with disabilities.
- Identify existing barriers to personal and professional success, and develop plans to deal with those barriers.
- Assist each participant in developing a "Personal Leadership Plan," which will include specific actions plans to implement in their communities.
- Include a day at the Texas State Capitol and an opportunity to get to know some of our state lawmakers.

If you know a young person with disabilities who would benefit from this program, please encourage him/her to call for an application. For more information or to request an application, call Jennifer Murphy or Sandie Gonzalez at (210) 292-3566 or (210) 292-3574, or email at: <jenniferm@c-a-m-p.org>.

Financial Support for CAMP Youth Leadership is provided by the Texas Council for Developmental Disabilities, with Federal funds made available by the United States Department of Health and Human Services, Administration on Developmental Disabilities.

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.
An up-to-date Statewide Staff Development Calendar is posted on TSBVI's website at <www.tsbvi.edu>.

March 5, 2003

Literacy for the Student Who Is Deafblind

Location: Region VIII ESC, Mount Pleasant, Texas

Presenter: Barbara Miles

Contact: Donna Clopton at (903) 572-8551 or dclopton@reg8net

Note: This workshop is from 9:00 A.M. – 3:00 P.M.

March 7, 2003

Auditory Learning Series:

**Hand-On Strategies to Encourage Listening Development
Across the Curriculum for Students who are Deaf and Hard of Hearing**

Location: TETN network broadcast available at all ESCs

Contact: John Bond at (210) 370-5418

March 7-9 2003

**California Transcribers and Educators
of the Visually Handicapped's (CTEVH) Annual Conference**

Location: San Francisco Marriott Hotel in Burlingame, CA.

Contact for packet and information: Christy Cutting 206-417-4945 or cecquilter@attbi.com.

March 17-22, 2003

**CSUN's 18th Annual International Conference:
Technology and Persons with Disabilities**

Location: Los Angeles, CA

Contact: Center on Disabilities at (818) 677-2578 or www.csun.edu/cod/

April 3-5, 2003

Texas Speech and Hearing Association (TSHA) Conference

Location: Adams Mark Hotel, Dallas, TX

Contact: <http://www.txsha.org/>

**Texas Association for the Education and Rehabilitation
for the Blind and Visually Impaired (TAER):
Shared Visions-United Voice
April 24-26, 2003**

Featuring keynote speakers:

Don Meyer, senior author of “Sibshops: Workshops for Brothers and Sisters of Children with Special Needs,” “The Fathers Program,” and “Grandparent Workshops.”

Elaine Sveen, mother of a child with visual impairments, teacher of students with visual impairments, superintendent of the Minnesota State Academy for the Blind and current president for AER.

Location: Omni Hotel, Austin, TX
Contact: Edgenie Bellah at edgeniebellah@tsbvi.edu

**May 1-3 2003
National Braille Association’s
27th National Conference and Workshops**

Location: Middleburg Heights, OH
Contact: National Braille Association 3 Townline Circle, Rochester, NY 14623;
Phone: 585-427-8260; Fax: 585-427-0263;
Email: nbaoffice@compuserve.com

**May 9, 2003
Auditory Learning Series:
Auditory Learning-It’s More Than Listening!**

Location: TETN network broadcast
available at all ESCs
Contact: John Bond at (210) 370-5418

**June 8-11, 2003
Early Childhood Intervention (ECI) Conference**

Location: Hotel Intercontinental, Dallas, TX
Contact: Kristen Hamlett at (512) 424-6791
or Kristen.Hamlett@eci.state.tx.us

Texas Focus 2003: Focus on Tactile Learning

June 12 & 13, 2003

Featured Keynote Speaker: Dr. Sally Mangold
Location: Gunter Hotel, San Antonio, TX
Contact: Jim Durkel at JimDurkel@tsbvi.edu or
(512) 206-9270

Assessment of Students With Visual and Multiple Impairments

June 24-25, 2003

Location: Region IV ESC, Houston, TX.
Presenter: Millie Smith
Contact: Karen Crone, kcrone@esc4.net

National Federation of the Blind's 2003 National Convention

June 28-July 4

Location: Louisville, KY
Contact: National Federation of the Blind
1800 Johnson Street, Baltimore, MD 21230
Phone: 410-659-9314

American Council of the Blind's 2003 National Convention

July 5-12 2003

Location: Pittsburgh, PA
Contact: American Council of the Blind
1155 15th Street NW, Suite 1004
Washington, DC 20005
Phone: 800-424-8666 or 202-467-5081
Web site: www.abc.org

Students With Visual and Multiple Disabilities, Including Autism

July 9-10, 2003

Location: Region IV ESC, Houston, TX.
Presenter: Marilyn and Jay Gense, Oregon
Contact: Karen Crone, kcrone@esc4.net
Cost: \$60.00, Open to 200 people and we would love to have people from around the state.

O&M for Students with Deafblindness

July 11, 2003

Location: Region IV ESC, Houston, TX.
Presenter: Marilyn and Jay Gense
Contact: Karen Crone, kcrone@esc4.net
Cost: \$30.00

2003 American Association of the Deaf-Blind Convention

July 12-18, 2003

Location: San Diego State University,
San Diego, CA
Contact: American Association of the Deaf-Blind
814 Thayer Ave., Suite 302, Silver Spring, MD
20910; Phone: 800-735-2258;
email: info@aadb.org

6th International CHARGE Syndrome Conference

July 25-27, 2003

Location: Cleveland, Ohio
Contact: Dennis O'Toole at
conference@chargesyndrome.org

**Advocacy-Everyone's Responsibility:
A fieldwide conference
in the nation's capital,
sponsored by AER**

July 25-29, 2003

Location: Wyndham Hotel, Washington DC
Contact: www.aerbvi.org

**The American Society of Deaf Children
(ASDC) 18th Conference
July 26-30, 2003**

Campference: part camp and part conference, there's something for everyone! While children take part in camp-like activities, parents attend educational workshops. Evening events bring everyone back together for family-focused activities.

Location: Texas School for the Deaf
Contact: TSD Educational Resource Center
on Deafness
1102 South Congress Avenue,
Austin, Texas 78764
Email: ERCOD@tsd.state.tx.us or
Phone: (512) 462-5329

**13th DbI:
World Conference on Deafblindness
August 5-10, 2003**

Location: The Delta Conference Centre,
Mississauga, Ontario, Canada
Contact: www.dbiconferencenanada.com

**Technology
Distance Ed Presentations
for 2002-2003**

By Sharon Nichols and Holly Cooper

- 3/5 Integrating Note Takers Into the General Ed Curriculum
- 4/16 Routines and Technology: Activities to Make it Work
- 5/7 Matching Technology to the Student

**Math
Distance Ed Presentations
for 2002-2003**

- 2/26: Preparing Nemeth with the Scientific Notebook
- 3/26: Using tangibles in middle school math

All broadcasts will be held
from 1:30-3:30 PM Central Time.
Questions? Karen Scanlon at (512) 206-9314 or
Karensanlon@tsbvi.edu

**TSBVI Short-Term Programs
Spring 2003**

Special Programs were developed to serve academic students from Texas who can benefit from a short period of intensive instruction in some area of the expanded core curriculum for visually impaired students. Referrals must come from the local school district (usually the VI teacher). Interested parents should confer with their school district about objectives for their child, and work together to make a referral.

- Mar.23-28 Secondary IEP #2 (same as above)
- *Apr. 5-8 A Capitol Experience (visit & learn about legislature)
- Apr.13-17 Elementary IEP #2 (same as above)
- *May 1-4 Elementary Austin Experience (social enrichment)

* Asterisks mark Thursday - Sunday events.
Contact: Dr. Lauren Newton, principal
(512) 206 - 9119 or <newtonl@tsbvi.edu>

SEE/HEAR

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June 1st for the Summer edition
September 1st for the Fall edition

Production Staff

Editor-in-Chief - David Wiley (512) 206-9219;
DavidWiley@tsbvi.edu
Layout Editor - Carolyn Perkins (512) 206-9434;
CarolynPerkins@tsbvi.edu
TCB Editor - Jennifer Kocyan (512) 377-0579;
Jennifer.Kocyan@tcb.state.tx.us
Website Editor - Jim Allan (512) 206-9315;
JimAllan@tsbvi.edu
Spanish Edition Editor - Jean Robinson (512) 206-9418);
JeanRobinson@tsbvi.edu
Production Assistant - Jeannie LaCrosse-Mojica
(512) 206-9268; JeannieLaCrosse@tsbvi.edu
TCB Braille Transcriber - B. J. Cepeda
(512) 377-0665; BJ.Cepeda@tcb.state.tx.us

Section Editors

Family - Edgenie Bellah (512) 206-9423;
EdgenieBellah@tsbvi.edu
Programming - Ann Adkins (512) 206-9301;
AnnAdkins@tsbvi.edu
Jenny Lace (512) 206-9389;
JennyLace@tsbvi.edu
Holly Cooper (512) 206-9217;
HollyCooper@tsbvi.edu
Syndromes/Conditions - Kate Moss (512) 206-9224;
KateMoss@tsbvi.edu
News and Views - Jennifer Kocyan (512) 377-0579;
Jennifer.Kocyan@tcb.state.tx.us
Classified - Jim Durkel (512) 206-9270;
JimDurkel@tsbvi.edu

The audio version of *SEE/HEAR* is provided by
Recording for the Blind and Dyslexic, Austin, TX.

**If you no longer wish to receive this newsletter, please call
Beth Rees at (512) 206-9103
or e-mail her at BethRees@tsbvi.edu.**



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