

# 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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## The Angel in My Life

By Honey S. Hastings, Sister and Future Teacher, Hondo, Texas

*Editor's note: I first met Honey a little more than ten years ago when I connected to her parents, Mel and Richard Dugosh, and her brother, Chris. Now all grown up, Honey is a senior at Sul Ross State University in Alpine, Texas and preparing to become a teacher. She will graduate in December of 2002 with a degree in Elementary Education and hopes to move back to Central Texas, to live and teach closer to Chris. When she contacted me recently about sharing this article, I was delighted. I think you will enjoy it. It is always exciting to see the children we meet with deafblindness or visual impairments grow up and watch what they do as adults. It is also exciting to see what their sisters and brothers do. Honey, I know that you have made your mom, dad and Chris very proud. Honey can be reached at P.O. Box 5003, Alpine, Texas 79832. Her phone number is (915) 837-1603.*

I was very young when he came into my life, the small brown-haired, hazel-eyed boy who fit in the palm of my Daddy's hand. Even though he had been carried to term he weighed only four pounds, which, of course, is not ideal for a healthy baby. The thing is, he was not healthy, according to my Daddy's voice on the other end of the phone that night, when he called to tell me I had a new baby brother. "What do you mean by not healthy, Daddy?" I asked, sitting on the lap of my elderly neighbor as a tear rolled down her age-worn face. A tear even I could tell was not sprung from joy.

You see, I was only four when Chris was born. I did not understand the technical diagnosis that the doctor had given. I could not even pronounce Cornelia de Lange Syndrome to save my life, let alone know what it meant. I did know, however, that I had a baby brother all to myself, to love in only the way a big sister could.

It is difficult to describe Cornelia de Lange Syndrome (CdLS), to those who have never seen an individual with this uncommon genetic disorder. There is no known cause, except an irregularity on the third chromosome, but that tiny error left my brother legally blind, deaf, mentally retarded, and physically disabled. It also placed my mom in a state of shock, especially while waiting for the doctor to do research to identify his syndrome. My brother has already lived past the day the doctor direly predicted his life would expire. He is now sixteen, thirteen years longer than the doctor said he would ever live.

Chris, even with all of his disabilities, really put that doctor in his place. He just simply survived. Since he has so many different disabilities, it's remarkable that he even has the ability to grasp a daily routine or interact with those around him. Nevertheless, from the time he came home from the hospital, he has had a constant smile on his face that could touch anyone's heart. His body, though tiny and disfigured, reminds me of an angel, with arms bent at the elbow and only one tiny finger to resemble a pair of wings. His eyebrows join in the middle to define beautiful hazel eyes that slowly gaze out on the world, only to catch shadows of life as it hurriedly passes him by.

Now as a teenager he is quite grown up. Although still petite in size, he is steadfastly approaching adulthood. I grew up with a fearsome devotion to my brother as I watched those around me recoil in his presence. I spent those early years attending school and playing with my brother at home. Big sisters love having someone around to play dress up with. It never occurred to me that not participating in the extracurricular activities for school, such as sports and what not, was out of the ordinary. My brother and I were inseparable. I was everywhere he tended to be. It always surprised me when we were out in public and everyone would stare. I remember asking my Mom, "What are they staring at? I don't see anything." Mom would just laugh and tell me that not everyone could see an angel. He was special, and we were blessed.

In my reluctant teenage years I began to resent that, having Chris as my brother, I had to give up quite a bit. My senior year of high school, I was needed to put Chris on the school bus, drive myself to school, get out early in time to

get him off the bus, make dinner, clean the house, do my homework, and go to bed. Anything extra that I wanted to do for myself, I had to make time for. All of this was necessary, so my parents could work to make ends meet. It was my duty to help out, despite feeling that it was extremely unfair. I was only seventeen, and had done nothing to deserve this, so why did I have to sacrifice so much? Why did I have to give up the presumed best year of my life? Everyone else was out creating graduation year memories. Why couldn't I?

I am now only beginning to understand. I really did not give up much at all. The lessons I learned from my brother have made me the person I am today. I will be graduating from college early with a degree in Elementary Education. That will allow me to play with children and teach the things they need to know, in order to move on through their lives, outside of their homes and beyond the stars. I only hope I can teach these children as much as my brother has taught me about determination, life, love and devotion. I want to share with them just how important life is, and the role that each and every individual has. He is here to remind me that I can touch the hearts of children as they grow, and hopefully point them in the direction of happiness. I can change a life, just like he changed mine. He is my angel.

*Honey and Chris*

## **When I Start Skiing I Never Want to Stop**

By Rebecca Soto, Student and Paralympic Hopeful, San Antonio, Texas

*Editor's note: You are about to meet an amazing young woman. In her own words, Rebecca will describe her experiences about learning how to ski, and how important this activity is in her life. You will be inspired by her story. If you want to know more about Rebecca's skiing experiences or her plans to participate in the 2006 Paralympics in Italy, you can contact her at <rebeccaskier@killamail.com>. Rebecca will also be speaking at next year's TAER State Conference, April 24-26, 2003. If you would like to help Rebecca meet her goal of getting to Italy by contributing to her ski fund, please make your check payable to: Rebecca Soto, Paralympic Ski Fund c/o Patrick Peranteau at Goldstein, Goldstein & Hilley, 310 S. St. Mary's St., Suite 2900, San Antonio, TX 78205.*

My name is Rebecca Soto. I am 18 years old and a junior at Jefferson High School in San Antonio, Texas. I live with my foster mom, Jan Peranteau.

I was born with retinopathy of prematurity. I remember seeing light when I was younger, but now I am totally blind. I have always been very active. I love jumping on my trampoline, riding a tandem bike with a partner and climbing on monkey bars. So, I was very excited the day my parents, Jan and Pat, told me they had found out about a skiing program that worked with people with disabilities. I wondered if I would ever get a chance to learn how to ski.

A few weeks later, my parents announced that I would be going skiing in March. The adaptive ski program, Challenge Aspen, had given me a scholarship. I would travel with one of the secretaries at my dad's office, and stay with Christine and Gerry Goldstein, my dad's boss. I couldn't believe I was going to learn how to ski.

There were ski clothes to buy...a new ski jacket, gloves, long underwear, ski goggles, snow boots. Mom and I shopped and shopped. Finally, the day came for me to leave. I remember getting on the airplane and thinking, "Is this really happening? Am I really going to get to ski?" On my way to Aspen, Colorado, I kept thinking about the days ahead. Who would ski with me, and how could I do it? When the plane touched down in Aspen, I stepped onto the icy stairway leading down to the ground. I could feel the cold wind blowing in my face and hear the sound of snow crunching under my feet. I put out my hand to feel the soft snowflakes falling. I opened my mouth and let some flakes drop on my tongue. They were wet and fresh. We hurried inside, and there, waiting to greet us was Houston Cowan, the director of Challenge Aspen. He was tall and warm and gave me a big hug. He had this very southern accent, and I immediately felt right at home with him.

The next day I woke up in a cozy log house. Everyone was up early, and talk at the breakfast table centered around me and my first day of skiing. We rushed to put on our clothes and stuffed ourselves into the van. "This is it," I kept saying. I wondered who my instructor would be.

*Rebecca and Case Ronde, her ski guide*

We arrived at Buttermilk Mountain and my stomach churned. I began to wonder if I should still do this. I remember waiting in the ski rental line and listening for the first time to the calm voice of my instructor, Johnny Klein. He told me he would call out commands like "Left turn," "Right turn," and "Stop." He also had a bamboo pole that I could hold onto at first. Still, I thought, "How can I ski if I can't see?" His assuring voice told me that we would go slowly and attempt new things as I felt comfortable. He also said that it is very important to trust the instructor and do exactly as he commanded.

My first big step was getting on the chair lift. The chair lift is slowed down for handicapped skiers. And so I began – first down bunny slopes, then halfway up the mountain, and then, by the end of the day, the top of the mountain. I felt so proud, skiing from the top of Buttermilk to the bottom of the mountain on the very first day. As my skiing improved, I learned to use ski poles. I also had a chance to free ski. Free skiing is skiing when no commands are called and the skier decides when to make turns. I can pretend that nobody is with me. I feel like a sighted person when I free ski.

From that first day, I have loved skiing and know that I will always want to ski. When I ski I get a feeling of forever and a feeling of not wanting to stop. I feel like I am floating and almost weightless. Most of all, I feel like a river flowing and like a bird flying.

Skiing totally blind takes a lot of trust, confidence and concentration. A totally blind skier has to be able to trust the guide and have confidence in that person. That is why I like to really get to know my guide before we ski together. If I am not comfortable with that person, I ask for another guide.

This is my seventh year skiing with Challenge Aspen. I know I will always return because I love it so. Even though I have come back every year, I did not expect Houston Cowan to ask me to start training for the Paralympics. He told me a couple of years ago that he wanted me to try out for the U.S. Disabled Ski Team. I would compete with other blind skiers on the same course that the Olympic skiers will use. After much consideration, I said yes. The 2006 Olympics will be held in Italy, and I plan to be there.

Last April I competed with ten other blind skiers in a downhill race at Lake Tahoe, and beat the top male blind skier by six seconds. I almost came in first place, but I fell and came in second with a silver medal.

After two years of training, I am beginning to understand the commitment it will take to get to the Paralympics in 2006. It will require not only numerous trips to Aspen for training, but I must also work out at home to gain strength and endurance. I will need to speak before groups, explain my goals and raise money to attempt these goals. But I believe with hard work, I will make my dreams come true.

## **The Morning Sun Rising**

By Terry Boisot, Parent, Santa Barbara, California

TheArcLink News, October 2001

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Ben has been in junior high school for a little more than a month now. He is in a new school district at a new school with hundreds of kids he didn't know at first. He has seven new teachers and four people providing him program supports in his seven classes. He receives additional support from a speech therapist, a teacher of students with visual impairments, a teacher of students who are hard of hearing, an occupational therapist, a physical therapist and an inclusion teacher who pulls this all together at a school that has never fully included kids with severe disabilities in the regular classroom before.

This is a big investment of time and money, requiring plenty of planning and organizing. Teamwork must be in its highest form. All for one kid who has little formal communication skills, uses a wheelchair, wears contact lenses, glasses, leg braces, hearing aids and uses an Assistive Listening Device.

At first, school was very confusing and scary to Ben. He cried a lot, quit eating and had to take a lot of breaks. There are so many adults and kids, so many different places to go. I worried if he was unable to see or hear well enough to assimilate what on earth was happening.

But no one gave up. Not a teacher, not a specialist, not the principal, and not one of the 895 kids that go to Goleta Valley Junior High. Despite Ben's confusion and fear, expectations for his learning and successful participation at school never decreased. I noticed a stronger determination amongst his educational team and his fellow students to learn about Ben and what he was trying to convey with his use of numerous informal communications.

Then one day, precisely two weeks after school started, Ben suddenly understood. He didn't cry anymore at school, and he couldn't sleep Sunday night because of the excitement he felt in anticipation of the school day to come on Monday. He started making more choices in what he wanted to wear, eat and do, as well as attentively listening to the teachers during the day and responding to "yes" and "no" questions on tests. Last week he received his first **real** C+ on his Progress Report.

I couldn't have been more proud.

The kids all started becoming more familiar to him, and he learned to recognize the voices and touch of teachers.

In technology class Ben is learning about electronics, computer technology, and machinery. In turn, he teaches his class partners about the technologies he uses to access his environment and participate in class and in society.

Ben hits the pavement in P.E. on his bike, alongside his 60 classmates as they run the mile. In art class, he uses his electric scissors to cut out pictures. He sketched a tennis shoe with his vibrating pencil. In keyboarding class he activates numerous computer programs using switches. As an aide in the cafeteria he is becoming more and more the cook as he uses his electric peeler.

In theater arts Ben has become part of the curriculum. Most of the students raise their hands when the teacher asks who would like to be in Ben's group, and then she challenges them to think creatively how Ben can be included in their class assignment.

Last week, through dance and movement, the students performed a vignette of the morning sun rising. Using the toggle on his wheelchair, Ben slowly rose to standing, smiling as if he were the morning sun, as his classmates danced around him celebrating his arrival.

I attended Back-to-School Night almost two weeks ago. The theatre arts teacher announced to the parents in her room, "This is the most loving and caring group of students I have ever taught."

I knew why.

The keyboarding teacher spoke of diversity and the gifts of all children. Ben's art teacher was thrilled to report that once she started wearing the microphone to Ben's Assistive Listening Device, he started to laugh at her jokes.

Recently, I e-mailed the principal to tell her how much I appreciated the way the school embraced Ben, and she responded by saying how proud she was to have him there. When I told Ben what the principal of such a big school said, he smiled from ear to ear.

Not a day goes by without Ben's inclusion teacher reporting of all the kids Ben helped that day. Kids whose lives are otherwise dysfunctional at home - who have never found self-esteem - seem to find it with Ben.

These are kids whose learning disabilities are not visible to the naked eye, with trouble concentrating, reading or getting their computer started. Because Ben is there, so are those who support him, always willing to lend other students a hand and the support they need.

This is what inclusion is all about.

On Thursday I picked up Ben a little early from school. As we were leaving, 7th period P.E. class came ripping around the corner and in stampede form headed in our direction. We had no choice but to stand still and wait as one by one the kids stopped only long enough to say, "Hey, Ben!"

There wasn't one patronizing pat on the head. Just the respect for a fellow student who has brought something to them that often gets lost in the pressure to excel academically. Something priceless that only successful lives include.

Humanity.

*Terry Boisot is the parent of a child with disabilities, serves on the board of directors of Alpha Resource Center of Santa Barbara and The Arc of the United States. She is concerned about all disability matters and welcomes comments at <tboisot@thearclink.org>.*

## Beating Blindisms

By Sarah J. Blake, Freelance Writer and Educational Consultant

*Editor's note: Sarah J. Blake is a freelance writer and has published many articles about blindness online and in print. She also writes about additional health topics, disabilities, and inspirational/devotional topics. To see more of her work, visit <[www.growingstrong.org](http://www.growingstrong.org)>.*

*Fabulous fact sheets about blindisms and other related topics are available at the Royal National Institute of the Blind (RNIB) <<http://www.rnib.org.uk/multidis/stereo.htm>> and at V. I. Guide: A guide to internet resources about visual impairments for parents and teachers <<http://www.viguide.com/vsnsocial.htm>>.*

*The following e-mail discussion lists have parent, student, and professional comments on this issue. Send your e-mail to <[bvi-parents-subscribe@associate.com](mailto:bvi-parents-subscribe@associate.com)> or <[LCA@yahoogroups.com](mailto:LCA@yahoogroups.com)>.*

Twenty-five times I had written it... “I will not put my hand in my eye.” I had 475 more times to go. That was nineteen more pages. I was going to be there all night.

I put another piece of paper in and wrote twenty-five more sentences. Anger welled up in me. I would figure out a way to stop this habit which I had had since I was too young to remember.

By the end of the fourth page, I had begun to cry. I was not a fast writer; and besides wanting to be finished with this horrible chore, I was ashamed. I was being punished for something I couldn't control, no matter how much I wanted to. My parents didn't know how many times a day I rebuked myself for this behavior. “You're doing it again, stupid,” I would tell myself. “You said you were going to stop.”

I don't remember the end of that night. I think my mother gave in and allowed me to stop shortly after I reached that one hundredth sentence. Seventeen years would pass before I would conquer the habit.

The habit is commonly known as “eye pressing.” I have lost count of how many times I have seen parents ask the same questions on e-mail lists. “How can I get my child to stop pressing her eyes? Is it dangerous?” Less often, I see similar questions about other behaviors.

Blind children often exhibit a number of behaviors which provide them some kind of stimulation or enable them to communicate somehow. These behaviors are so common that they have been labeled with the term “blindisms.” In this article I will discuss some strategies for helping children to modify these behaviors; however, I also want to emphasize another fact. Not every behavior that a blind child exhibits can be classified correctly as a “blindism.” Some behaviors, such as biting and tantrums, are commonly seen in children of a certain developmental level. When addressing any child's behavior problems, it is important to think about what the behavior is accomplishing as well as the cause for it.

### EYE PRESSING

Opinions differ regarding the effects of eye pressing. It often causes the eyes to appear sunken, but as a person who did it for many years I am not convinced that it is dangerous to the eyes. That probably depends on the force the person uses. I never used much force, and there are no studies to prove whether the same things would happen to my eyes if I had never pressed. It is possible that a person could get an infection in the eye from rubbing or pressing with unclean hands; however, I have never known this to happen to any of my acquaintances.

The biggest problem with eye pressing is that it is considered “socially unacceptable.” It is not something most people do, even though it is probably as “normal” for a blind person as biting one's nails is for anyone else. This is the reason that stopping is so difficult.

Many children who press their eyes begin doing so shortly before their first birthdays. Eye pressing may have a number of causes. I have read about children who did it because their eyes hurt. A popular explanation is that pressing on the eye causes the retina to be stimulated so that the child sees flashes of light. I do not recall having this experience. Like many people, I am unable to identify or explain the reason for the behavior.

Many children press their eyes more when they are tired or upset. I recommend that parents and caregivers not choose these times to discourage the behavior. It is important for the child to be able to work through other things at these times; adding eye pressing to the agenda can be overwhelming emotionally.

My advice for discouraging eye pressing is to help the child become aware of her body parts and their relationship to one another. One family has had success with using verbal reminders, at first accompanied by physical prompts. “Hands down” is the verbal cue which they use. I have suggested to other families that use of a cue such as “Where are your hands?” might encourage the child to think more often about what his hands are doing and whether or not it is an appropriate activity. The advantage of a question like this is that it can be used at other times, when the hands are engaged in appropriate activities, and will help the child build a healthy sense of self to use the question as a monitor rather than as a reprimand. Furthermore, “Where are your hands?” can also be used to address other behaviors which may occur in addition to, or as a replacement for, eye pressing.

## **ROCKING AND BOUNCING**

Rocking and bouncing are other behaviors common to blind children. Some researchers propose that rocking develops as a response to a need for vestibular stimulation and an inability to move freely in the environment because of overprotection, failure of caregivers to encourage movement, or restricted movement which is the result of medical problems. As with eye pressing, body awareness is essential for enabling a child or adult to successfully eliminate the behavior. In addition, the person will also need to replace the eliminated behavior with an appropriate form of vestibular stimulation.

## **SPINNING**

Spinning is another behavior often seen in blind children. Spinning may accomplish a number of things. As a former spinner, I can recall enjoying the experience of watching things “go by” as I spun. I can also recall enjoying the experience of feeling “wind” if I held my arms out.

Spinning is an activity enjoyed by young sighted children as well. The difference between the experience of the blind and sighted child is that sighted children are more able to use appropriate means of satisfying their desire for spinning. These same means may be just as useful for blind children, but the blind child is unable to seek out appropriate means so uses what is readily available: his own body. Examples of appropriate outlets for spinning include merry-go-rounds, sit ‘n spins, tire swings, etc. Blind children also need the same kind of vigorous exercise which sighted children get by running, jumping and climbing, and can participate in these activities with or without modifications, depending on their individual abilities and the safety of a given environment.

## **HEADBANGING**

Many parents have written about their children headbanging. Most of these children were beginning to develop communication skills but did not yet have the ability to ask for what they wanted or needed. This behavior is analogous to tantrums which are common in sighted children of the same age. A growing number of parents are finding that teaching their children some signs to use for making requests not only helps to eliminate the problem behaviors but also promotes the development of verbal communication.

## THE IMPORTANCE OF TEACHING APPROPRIATE BEHAVIORS

When eliminating any behavior which is socially inappropriate, parents and other caregivers should remember that the behavior serves a purpose for the child and must be replaced by an acceptable behavior which serves the same purpose or eliminates the need for the problem behavior. In the case of eye pressing, keeping hold of the child's hands may or may not serve to decrease the child's desire to eye press.

## CHOOSING YOUR BATTLES

When a behavior is persistent, caregivers might be wise to choose their battles carefully. Addressing the behavior at a later time or waiting until the child is old enough to participate in developing strategies to address the problem might make the attempt more successful.

## Family Vacation, a Perfect Opportunity for Skill Building and Fun

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

It's that time of year in Texas... school's almost out, the temperature is rising, and everyone's thoughts turn to the great escape. Vacation! While many of us will choose a quiet time at home, others will choose to travel. Vacationing with a child who is visually impaired or deafblind, and perhaps has other disabilities, can require some special planning. For those of you who have been reluctant to launch out on a trip with your child, I hope to persuade you to give it a try. For those of you who are seasoned travelers, maybe this will give you some ideas about how to make the trip more meaningful to your child with visual impairments or deafblindness.

## ADVENTURES REQUIRE SOME PLANNING

The first step in planning is to pick your destination. Though the world is open to you, it helps to pick a destination that matches the amount of time you have, the amount of money you can spend, and the kinds of things you want to do. Many trips have been doomed from the start because the group of travelers were not in agreement about their expectations for their time away. If this is a family vacation, take time to discuss what types of things each of you would enjoy doing. It is probably better initially to think of activities, rather than focus on a place. Make a list of the kinds of activities each person finds relaxing and enjoyable. Don't forget to include activities that your child with disabilities might enjoy if he/she is not able to speak for himself/herself. Consider a range of activities, including those things that you have never done before but always wanted to try.

You can also get your child involved in planning the trip. If your child is learning how to use the internet, help her research possible travel destinations. For example, a search using keywords "Texas" and "vacation" turns up many links to various websites about places to go in Texas. Depending on your child's computer skills, she may be able to search by state or city names to identify potential sites of interest. Of course, some websites are more accessible to people with visual impairments than others.

Visit your local library for books about travel. Ask your educational staff to have your child do some "research" as part of his or her literacy activities. If you know where you will be going while on vacation, ask them to help your child find books about the animals, historical events, or points of interest related to these destinations. Begin to work on concepts that your child might need to know about some of these destinations. For example, if you are going to the ocean, start learning about "salt water," "sand," and "sunburn."

If you are going to travel by car, think about the reliability of your family vehicle, its size related to comfortable travel and luggage storage, and suitability of the vehicle for the terrain you are traveling through. There is nothing more miserable than being crammed in a car that breaks down on the side of the road in the middle of nowhere. If the family car is too small or not particularly reliable, it might be a good idea to consider other modes of travel such as rental cars,

the bus, the train, or a plane. If your budget won't allow for that expense, you might want to consider traveling to a place close-by, or building a vacation around fun activities near your home.

Vacations can be incredibly stressful if you feel overwhelmed by your schedule of activities. My personal experience is that I always overestimate the amount of driving I can do and the number of activities I can participate in each day. Have your child help you choose from a list of possible activities, to make the most of the time available. Each day, give her opportunities to select preferred activities. If possible, build some flexibility into your plans, in case family members want to extend or shorten an activity.

It is also wise to set a budget for your trip. What are the limits on your spending? What will food, lodging, entertainment and souvenirs cost? Knowing what you can afford to spend, and sticking to it, can make for a vacation that won't stress you out after you come home and see the travel bills. Talk to your visually impaired child about the costs of the trip. This is a great opportunity to learn budgeting skills. There are many ways to keep down the trip's cost. For example, you can bring food from home for at least one meal each day, or travel with a cooler so you can pick up items from grocery stores along the way. Your child can participate by making a list and helping you find things in the grocery store. Food in restaurants and fast foods are much more expensive. Many hotels and motels offer free breakfast buffets or special rates for families. Be sure to ask about these possibilities when you make reservations or check in. Camping, especially at state and national parks, can often reduce the cost of lodging. Discuss these options with your child to help them learn how budgeting decisions get made.

### **MAKING THE JOURNEY FUN**

If there are family members who don't do well sitting in a car for more than an hour, think about the value of making them do that. Ultimately, you may decide that's just the way it has to be. However, planning shorter segments of travel, with brief activities interspersed along the way, might make everyone's journey much more enjoyable.

Games and activities for small spaces are always a good idea when traveling with children. There are a variety of books with simple car games and activities for children that can be found at major bookstores and/or your library. There are also a variety of specially designed travel board games at most toy stores. Many of these games can be adapted, so that your child with disabilities can be included in the play.

An easy thing to do is to make a lap board of thin plywood and glue Lego-type blocks on to the board to make a building grid. This makes a secure base for building or stacking activities with the Lego-type blocks while traveling in the car. If two or more children share the activity, you may want to place the base in the lap of the child with the disability so the activity will center around him and provide more opportunities for interaction.

Another option is to make a lap tray with a 1/2 inch raised lip around the edge. A variety of insert boards can be designed using poster board or cardboard for building blocks, marble maze games, felt board art, drawing, etc. These can be placed inside the tray and changed as the activity changes. The tray will help secure the surface and also prevent crayons and other items from rolling off onto the floor.

A metal cookie sheet also makes a great play surface for magnet letters and shapes. When the magnets get dropped or spilled, the tray can be used to quickly retrieve the magnets from the floor or seat. You could even let the child collect different magnets from the places you visit. Have a conversation about each one, where you got it, what you did in that place, who you met there, and so forth.

Portable tape players with cassettes of music or stories can make a long trip pass quickly. Be sure to get the tape players with headphones; this can make your journey much more enjoyable. There are many good book and tape packages, as well as music of all kinds available, to purchase at most toy stores or borrow from your public library.

A travel scrapbook is a nice idea for the child who is using an object or picture calendar. Objects and/or pictures (depending on the individual needs of the child) collected from the day's journey can be saved and placed on pages of the book, separated by dividers, to represent each day of the trip. Brothers and sisters can help with the book and/or make a book of their own. As much as possible, let the child pick the objects or pictures. Drawings can also be added. If the child has a good deal of usable vision, postcards purchased from previous visits, or pictures from travel brochures depicting travel destinations, can be used to represent "tomorrow's travel itinerary." Each evening the calendar book can be discussed as a part of the bedtime story routine. In addition to filling time in the car and helping the child better understand what's coming up, this book will serve as a great reminder of the trip that you and your child can talk about throughout the rest of the year. It may also become a cherished keepsake as your child or children grow older.

You might also use symbols or pictures to represent and discuss certain types of "stops" in your travel. For example, if you pull into a roadside park just to use the restroom, you might have a picture or bathroom symbol to help your child with disabilities and his siblings understand in advance that this will be a short stop. A timer could be used if returning to the car is difficult for some of your passengers. When you are ready to stop for lunch, a different picture or symbol would be given to your child. Once again, establishing a limit on the amount of time you will be stopped may help the transition back to the road. You can also kill some travel time by discussing what kind of stop will happen next. Symbols like this can also help kids anticipate end of the day favorites like a dip in the pool.

It may be a good idea to rotate seating. Letting each kid take a turn in the front seat can help break up potential conflicts. Of course, the age of the child may eliminate front seat travel if they need to be in a car seat. Sometimes vacations can bring families together a little too much for everyone's individual happiness. Revolving seating, prior to an argument, distributes the togetherness so that it remains a positive thing. While you are at it, you can teach concepts like "first," "next," "front," "back," and "now."

If you have a very young child (birth to four or five), go to your local library or favorite book store and check out books on travel games for children. *Travel Games*, by Julie Hagstrom, has many games and travel tips to help keep a squirmy baby occupied on those long rides, and many are easily adapted for the child with deafblindness or visual impairments. This particular book also offers good suggestions, such as buying low-sugar snacks to avoid having children who are contained in a car all day with no way to burn off their "sugar charge."

When packing for the trip, especially if the journey is a long one, place some favorite books and toys in a special bag or box that the kids don't know about. This gives you the advantage of surprise when the kids are bored with the play things they brought. Doling out these little surprise packages gives the kids something to look forward to each day. This toy-box-in-the-trunk trick also lets you exercise some control over the amount of junk you have inside the car.

## WHAT SHOULD WE PACK?

Everyone tends to pack too many clothes when they travel. Summer travel makes things easier because many items are lightweight and require less space to pack. Limit your wardrobe. Pack things that can be handwashed in a basin and hung overnight to dry. Remember, if you aren't in the same place for more than two or three days in a row, people won't realize you have worn the same shirt three times that week. Pack one pair of comfortable walking shoes and one pair of dress shoes (if you need to pack any at all). Take a sweater, even in the summer. Air-conditioned buildings can be a chilling experience, and fun places like caves and mountains don't have climate control.

Purchase travel size containers or (if everyone doesn't share the same product) transfer items such as shampoo, lotion and mouth wash to small tightly sealed containers. Include some basic medicinal supplies such as bandaids, antibiotic ointment, sunscreen, aspirin and cotton swabs, or consider purchasing a first aid kit. To prevent spills, place messy items inside plastic bags or plastic containers with tightly fitting lids. Be sure to pack prescriptions of important medications and make sure the amount of medications will not run out before you return home.

If you are planning your excursion so that you will be spending time in the great outdoors, consider packing some of your goodies into a small plastic washtub that has sturdy handles. This tub can be used for hauling water, carrying wood, washing out clothes, bathing children, and so forth. Add disposable clean up cloths (e.g., Wet-Nap, Towelettes, Wet Ones) or dampen cloth rags placed in plastic bags or containers to take care of sticky fingers and faces. These also come in handy when you are feeling hot and tired. Wiping your face, neck, and hands can really help you perk up.

### **LET YOUR CHILD TAKE RESPONSIBILITY**

As your children are able, give them more responsibility for packing and keeping up with their own clothing, toys, and snacks. For some children this may mean taking time to help them generate a list they can tuck in their bag. Some children can make their list in braille or large print. Some children may need to inventory their suitcase using pictures of shirts, shoes, underwear, swimsuits and so forth. The child can use it to make sure everything is packed or returned to the suitcase. Of course, you will still probably have to do a check to make sure things don't get left behind, but you may want to have your child help with that. Let her search the closet in the hotel for shoes on the floor or clothes on hangers. Have her "look over" the sink area to make sure toothbrushes haven't been left behind. These skills can come in handy later, when the child needs to be an independent traveler in a future job.

Some children with more multiple disabilities may not be able to take on this much responsibility. Still, they can practice some independence by simply identifying a particular box where toys or snacks are located in the car. They can practice finding the item they want and returning it to its proper place when they are finished. Another great way a child can help is by folding some of their clothes before you pack or repack each day of the trip. Most children, even those with some mobility issues, can help by carrying their backpack or favorite toy to and from the car.

Identify several favorite activities with your child, and organize the materials they will need for each activity. For example, if they like to play with magnets you can have a conversation about the things they will need, such as a cookie sheet to work on, magnets, and a container for carrying the magnets. Once you have helped them identify the materials, have them help you get the materials together for the trip.

Preparing for a trip and packing up your belongings is a great opportunity for working on independent living skills, recreation and leisure skills, and organizational skills. You may want to visit with your Teacher of the Visually Impaired, to get help making materials accessible for your child and for developing ideas about how to work on specific skills.

### **SPECIAL PROGRAMS FOR INDIVIDUALS WITH DISABILITIES**

For some families of individuals who are older and interested in traveling on their own, investigate some of the special travel organizations for individuals with disabilities. Some of these organizations offer very exotic vacations with a lot of one-on-one support for a price. One of the brochures I received from this type of organization had trips ranging in price from \$895 for a six-day trip to central Oregon up to \$3,145 for a ten-day trip to Rome, Italy. Some of these organizations can be found on the Internet at Family Village, <<http://www.familyvillage.wisc.edu/recreat.htm>>.

If you are planning to visit amusement parks (e.g., Fiesta Texas, Six Flags), zoos or museums, find out about special accommodations they may offer for people with disabilities. Sometimes these locations can provide special access for children with disabilities, if you notify them of your visit ahead of time. One mom told me that they were able to avoid the long lines in a theme park once the park staff knew her child had a disability.

There are many wonderful places to visit and exciting adventures waiting just outside your door. Even a trip to visit Grandma and Grandpa can be a rich learning experience for your child. Take advantage of these summer opportunities to focus on practicing skills that will help your child throughout his or her life. Most of all enjoy spending time with your child building memories that will last a lifetime.

# Are We There Yet? or How I Spent My Summer Vacation

By Jim Durkel, Statewide Staff Development Coordinator, TSBVI, Outreach  
(with many thanks to Barbara DiFrancesco, Lucia Hasty and Ike Presley)

Like many families, my family traveled for summer vacations. I remember two things I especially liked about these trips: souvenirs and maps. I want to talk about how families can help their children with visual impairments enjoy these same two parts of summer vacation.

Tactile graphics are a way to give people with visual impairments a kind of “touch picture.” Tactile graphics use raised lines, various textures, and raised points to create graphs and maps. Tactile graphics have also been used to represent science diagrams, such as the bones in the human hand.

Tactiles are different from models, as they are more 2-dimensional than 3-dimensional. Tactiles are representations, and people who use them need to be taught how to read and interpret them just as people who are sighted need to be taught how to read and interpret visual graphs, maps, and diagrams.

One way to start helping children learn to use tactiles is through the creation of remnant books. During a family vacation, this is similar to collecting souvenirs.

The point of the remnant book is to help the child remember people, places, or activities encountered during the vacation. When I was a child, I collected (among other things) postcards, photographs, books, rocks, pine cones, and knickknacks from souvenir shops. Each one of these “treasures” helped me remember my family’s trip.

A remnant book can start with a scrapbook. Instead of photographs, things or pieces of things can be attached to the pages. Did you stop at McDonald’s for lunch one day? Then glue in the empty french fry box. Did you stop to soak your feet in a brook? How about a small pebble picked up from the bank?

The important thing to keep in mind about a remnant book is that the objects or pieces of objects should be meaningful to the child. Each remnant should also feel differently from any other remnant. By attaching these “souvenirs” to pages and then reviewing the book with the child, you can start to help your child learn that these tactiles stand for, or represent, an experience.

If your child is starting to use braille, simple sentences can be added to the pages either with a slate and stylus or through the use of a braille writer or labeler. If you are unsure about how to do this, ask your child’s Teacher of the Visually Impaired or your Texas Commission for the Blind Children’s Specialist.

Maps are more sophisticated tactile graphics. A map is just a representation of space and the relationship of two or more points in that space. The simplest map would be a line from one point to another. The direction of movement, and maybe the distance between the two points, could be represented on this map. For example, I want a map that represents a trip from Austin to Dallas. I could have a point at the bottom of the page represent Austin, then draw a line up towards the top of the page (to indicate movement to the north). I could then use a second, different point to indicate Dallas. Midway between these two points I could add a third point to indicate Waco, which lies midway between Austin and Dallas. How do I know the top of the page is north? I put a key or a compass rose on the page to let the reader know that. How do I know the circle point is Austin, the square is Dallas and the triangle is Waco? Again, I have a key that explains this to the person using the map.

How would I make these points and lines? Points are the easiest. A point can be made on a piece of braille paper using a slate and stylus. Or I can use a push pin on the back of the paper to make a raised bump on the front. I can use

a brass brad pushed through the paper to serve as a dot or use a paper punch to cut a dot out of cork, cardboard, or fabric. I could use a small bead as one point. Again, remember that if I want two points to represent different things I need to make each point feel differently from all the others.

Lines don't have to be tricky either. I can create a line by gluing string or ribbon on the braille paper. I can use puff paint or white glue to draw a line. Pipe cleaners or candle wicking (with a metal interior) can also be used to make lines.

One easy way to make more elaborate maps is to put a piece of thin writing paper on a piece of wire screen. For example, using a crayon, draw an outline of a state. The crayon wax will now be raised slightly and have a bumpy feel. Points and lines inside the map can then be added.

Of course, the outline of a state can be raised by gluing string or ribbon over a tracing.

Great lines can be made by taking a piece of braille paper, placing it on a piece of carbon paper with the copy side up, then tracing the map on the top of the braille paper. A reverse image will appear on the back of the braille paper. Put the braille paper on a rubber mat (a vinyl place mat works well) with the reversed image side up. Now trace the reverse image using an embossing wheel (or tracing wheel from a sewing kit). A raised line will be formed on the braille paper.

You could also use a common screw driver and a hammer to add lines. Again, work on the back side of the braille paper. Place your mat under the paper and then place the screw driver on the line you want to raise. Gently hit the screw driver with the hammer, lift the screw driver up, move it over, and repeat. This gives you a kind of dashed line on the front side of the braille paper.

If your child can't bring home any braille paper from school, use a manila file folder.

Do you want your map to represent the coastline of a state along the ocean? Cut the state's outline from a piece of cardboard and glue it onto a piece of paper. The ocean will be the low space and the state will be the raised space. Add points for cities and lines for roads.

Here are some general things to think about when making a map. First, everything that is on a visual map might not go on a tactile map. A good tactile will only use 4 or 5 different types of lines and no more than 4 or 5 different kinds of points. Adding more can be confusing for the person reading a tactile map.

Put only important information on the map. If you never use farm-to-market roads, don't put them on the map; stick with the Interstate highways. Ask your child what she or he would like to have on the map. Are they interested in the cities? The rivers you will cross? Campgrounds in which you will stay?

Maps need to start out simple. Add more details only as your child develops the necessary tactile skills and an understanding of maps. For example, a child's first map may only show a few main cities with one or two connecting roads. Other information, such as rivers, other cities, and other roads can be added over time. It may be better to have several different maps, such as one with rivers and another with highways. This way no single map becomes unreadable because of too much information.

Making maps is just as much fun as reading them. Have your child help. This is the best way to find out what kind of lines and points feel different to your child, and if they are far enough apart to be easily read. Your child can practice using a slate and stylus to put labels on the map.

If something unplanned but exciting happens, be prepared to add a special point to the map during the trip to help your child remember this event later. (Trust me, something unplanned but exciting happens on every trip!)

If you know ahead of time where you will be going, you may want to ask your child's Teacher of the Visually Impaired or Orientation and Mobility Specialist for some help. These professionals may have access to machines that can make raised line drawings using special paper. They may also be able to order a map for your child from the American Printing House for the Blind (APH).

Your child's Orientation and Mobility Specialist may be able to lend your child a braille compass, to find the direction you are traveling and then compare that to the directions on the map.

Maybe your child can't use a tactile map. How about an auditory map? You and your child can record the major information onto a cassette tape. This could be as simple as "First we drove to Dallas. In Dallas we visited Grandma. Then we went to Six Flags." Or as elaborate as "We left Austin on IH 35 traveling north. We went through Temple and Waco. We stopped for kolaches in West. We arrived at Grandma's house in Dallas 4 hours after leaving home." This kind of recording, together with any souvenirs that were collected, will help your child remember the trip.

Students with low vision may be able to use existing maps, or they may benefit from maps which have been enlarged and/or which have had irrelevant information taken out. Have you ever seen the trip maps created by AAA? These maps break down a trip into several pieces with each piece having its own page. This modification may help a child with low vision find and interpret important information more easily. Breaking a map into pieces could also benefit a child learning to read a tactile map.

Of course, magnifiers are great to use with maps. In addition to reading maps, a small hand held magnifier is good for exploring leaves or stones, or other objects encountered on the vacation. Monocular or telescope use can be encouraged by having the child watch for highway exits or billboards. Monoculars and telescopes can also be used to play "license plate lotto." Whoever spots the most license plates from different states is the winner.

Many children with low vision enjoy taking photographs. Before you buy film, find out if your child sees black and white pictures better than color pictures. Disposable cameras have become so inexpensive that families may be able to afford to have several photographers!

This summer, help your child create memories while reinforcing important skills!

## **Art: A Great Tool for Teaching Students with Visual Impairments**

By Holly Cooper, Technology Specialist, TSBVI, Outreach

Art is something most children enjoy doing, and it does not necessarily require great vision or motor skills. There are a lot of quick and easy ways to make art activities easier for kids with visual impairments, even those who have other disabilities. When developing ideas for activities, look for things that involve more than just coloring and drawing with pencils or markers. Consider materials that emphasize texture and dimension or teach concepts and skills. Many of the traditional arts activities are appropriate if you keep some things in mind.

### **Make work easy to access**

- Use trays (cafeteria type, cookie sheets, or APH work/play trays) to keep materials from rolling or sliding away. Trays also can be used to help contain wet materials.
- Attach paper to the work surface with masking tape. Remember, don't remove them until they are dry or the paper might tear!

## Make backgrounds high contrast

- Make sure that background papers contrast highly with the materials being used.
- Dark colors such as black or dark blue generally work best for backgrounds, and brighter, more intense colors make better foreground figures. If the work calls for more colorful backgrounds, consider medium blues, purples, and greens. Red, orange, and yellow are backgrounds that contrast well with each other and most other colors.
- Use a light box, overhead projector, or other suitable light source to help provide contrast. Tape a thin-ply paper such as typing or copy paper to the overhead and use water color markers alone or with stencils. **DO NOT** use wet materials such as fingerpaints or watercolor paints with overheads or light boxes! This can lead to a nasty shock!!

## Consider tactile issues

Finger painting or play dough can be a great activity for many children who are not able to hold paint brushes easily. However, if they are tactilely defensive, you may need to prepare them for touching the medium with their hands.

- Before these activities, take time to wash or bathe the child's hands in a tub of warm water with a little soap. Massage the fingers gently and encourage the child to rub his hands together. Scrub gently with a brush or washcloth. Wipe them with a towel to dry and rub a little lotion on them.
- Never put the child's hands into a substance without telling him/her what he/she is going to touch. If language is an issue, take time to let the child explore the substance using other senses such as smell.
- If possible, warm the substance a little before he touches it. You can put a jar of finger paint directly into a tub of warm water or put playdough-like substances in a ziplock bag, then into warm water. **DON'T MICROWAVE**, as this tends to produce hotspots that may burn the child! You want to get the substance just close to body temperature. Touch it yourself before offering it to the child.
- Lead the child's hand to the substance using a hand-under-hand technique. Let him experience you working with the material first before expecting him to move his hands into the paint or dough.

## Utilize "themes" to help build concepts

Each season generally has colors, shapes, and objects associated with it. For example, around Valentine's Day there are heart shapes, "X"s and "O"s for hugs and kisses, and the colors of red, pink, and white. A summer theme might teach concepts about water and animals that live in the water, round sand dollars and star-shaped fish, the colors blue, green, yellow and white, gritty sand and fuzzy beach towels, one fish and many fish. By repeating these colors, shapes, textures, and concepts in a variety of art activities during the season, you can help the child learn some specific concepts while they are exercising their creative muscles.

## Utilize a variety of materials that emphasize different skills

You can work on developing motor skills by choosing specific materials. If the child needs to practice grasping, try using sponges or a bottle with a sponge applicator. If drawing small circles with a crayon is too difficult a task, she might be able to grasp the extra large chalk and draw bigger circles on the sidewalk. She can work on head control, reaching and grasping while lying on a therapy ball or wedge, using a potato half or corncob to stamp or roll on paint. If your child does not have enough vision to draw shapes with a pencil, can she glue macaroni, cloth, or other materials inside a raised outline made from glue that forms different shapes and patterns? If she can't use her hands to fingerpaint, can she do some painting with her feet? Practice cane skills by walking around and collecting things to make a collage. Build concepts and practice having conversations as you discuss the items you find together.

Art is a great way to keep children entertained, but it is also a great way to teach concepts and skills. As those summer days set in, make some plans to be creative with your child. You both will benefit from the experience. Invite the neighborhood children to join in as well. Creative activities done together can help build fast friendships and provide opportunities to work on important social skills.

## IDEA on O&M

By Grace V. Ambrose, Ed.D., Project Coordinator, RT/O&M & VRA  
Hunter College & Lighthouse International

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Recently, I had the good fortune to be sitting around the table with a group of well-respected O&M instructors and a nice bottle of wine. Conversation turned to a discussion of the difficulties associated with trying to provide O&M services to students within the confines of the school day. This discussion led to a disclosure by some of the new instructors in the group to the fact that they were unclear of what their rights were as O&M professionals.

What followed was an insightful discussion led by some of the more, shall we say, seasoned instructors. I took the opportunity to record this conversation and organize the information that came out of it, into the form of a true/false quiz. The good thing is that there are no losers in this exam.

### **1. True or False - Orientation and Mobility (O&M) is specifically named in the (1997) Individuals with Disabilities Education Act Reauthorization (IDEA Reauthorization).**

*True.*

O&M services have been a bona fide related service since 1975 (when PL 94-142, Education of All Handicapped Children the precursor to IDEA, was enacted). O&M services are specifically named in the (1997) Individuals with Disabilities Education Act Reauthorization (IDEA Reauthorization).

O&M services are named as an example of a related service in the section of the Act that addresses the requirement under IDEA for schools to provide related services to students in special education programs.

Additionally, O&M as a related service is defined in the definitions section of the regulations issued on March 12, 1999 by the United States Department of Education to implement IDEA. The definition appears below.

*Definition of O&M from the IDEA regulations.*

It appears in the definition section of the regulations and is found in paragraph 6b of Related Services Definition, Section 300.24. 300.24 Related services.

*(a) General.*

As used in this part, the term *related services* means transportation and such developmental, corrective, and other support services as are required to assist a child with a disability to benefit from special education, and includes speech-language pathology and audiology services, psychological services, physical and occupational therapy, recreation, including therapeutic recreation, early identification and assessment of disabilities in children, counseling services, including rehabilitation counseling, orientation and mobility services, and medical services for diagnostic or evaluation purposes. The term also includes school health services, social work services in school, and parent counseling and training.

(b) *Individual terms defined.*

The terms used in this definition are defined as follows:

(6) *Orientation and mobility services -*

- (i) means services provided to blind or visually impaired students by qualified personnel to enable those students to attain systematic orientation to and safe movement within their environments in school, home, and community; and
- (ii) includes teaching students the following, as appropriate:
  - (A) Spatial and environmental concepts and use of information received by the senses (such as sound, temperature and vibrations) to establish, maintain, or regain orientation and line of travel (e.g., using sound at a traffic light to cross the street);
  - (B) To use the long cane to supplement visual travel skills or as a tool for safely negotiating the environment for students with no available travel vision;
  - (C) To understand and use remaining vision and distance low vision aids; and
  - (D) Other concepts, techniques, and tools.

*300.14 Include*

As used in this part, the term *include* means that the items named are not all of the possible items that are covered, whether like or unlike the ones named.

*300.23 Qualified personnel*

As used in this part, the term *qualified personnel* means personnel who have met SEA-approved or SEA-recognized (SEA = State Education Agency) certification, licensing, registration, or other comparable requirements that apply to the area in which the individuals are providing special education or related services.

**2. True or False - The Academy for Certifying Vision Rehabilitation and Education Professionals (ACVREP) is specifically named in IDEA as the certifying body for O&M instructors.**

*False.*

The ACVREP is not named in IDEA as the certifying body for O&M instructors.

Under the United States' governmental system known as Federalism, there are specific powers rendered to the Federal government, and specific powers reserved for states. The Federal government retains the right to require states to establish special education programs, and to establish the framework under which these programs function.

The operation and administration of public education within the context of this framework is a power rendered to states. This includes, among many things, the certification of teachers and other school personnel.

Since IDEA is a Federal statute, it does not address how states administer teacher certification programs. It does, however, reinforce the obligation of states to establish procedures for the preparation and retention of personnel in schools. In most states, and specifically in New York State, procedures have not been established subsequent to the passage of the 1997 IDEA amendments that specifically address the retention of teachers who provide O&M as a related service. In New York State, and in other states, personnel retained by schools to teach O&M only are required to hold valid teaching credentials.

Some local school systems in New York State have established their own teacher credentialing systems. These credentialing systems must be consistent with IDEA and with State Education Laws and regulations, and may not serve

to weaken the implementation of Federal and State law. Within these restrictions, local school districts, therefore, are able to set teacher credentialing requirements that may differ from those required by the state.

This is where ACVREP comes in. By establishing a credible and rigorous structure for credentialing teachers of O&M, the Academy is benchmarking a certification standard and procedure for those who would provide O&M instruction --- in any setting --- but, in this case, specifically in schools. Modeled on longstanding professional certification standards and procedures, the Academy’s protocol for certifying teachers of O&M is one that could be adopted, or adopted by reference, by state or local education teacher credentialing bodies.

**3. True or False - The P.E. teacher could, in theory, be allowed to teach O&M to a student in New York State.**

*True.*

In theory, this is true if school districts followed only the New York State certification requirements. School districts where additional requirements are established by the local education agency for related service providers who teach O&M prevents this from happening in those districts. *(Editor’s note: Grace adds that this is true in all states where the law does not define qualifications of an O&M instructor. Currently in Texas, an O&M instructor must be certified by the Academy for Certification of Vision Rehabilitation and Education Professionals [ACVREP] or by the Association for Education and Rehabilitation of the Blind and Visually Impaired [AER].)*

**4. True or False - All O&M instruction must take place during the instructional hour (45 minutes).**

*False.*

When O&M is provided as an IEP mandated related service, the frequency, duration, and location of the service must be specified on the student’s IEP. Committees on Special Education are free to set the frequency, duration, and location of services as appropriate to meet student need, based on assessment.

When the O&M assessment demonstrates the need for age-appropriate O&M instruction such as learning concepts of travel in residential areas by age 6 (Ambrose & Corn, 1997) or concepts of travel in complex, unfamiliar areas by age 12 (Ambrose, 1999), O&M instructors have the responsibility to set the frequency, duration and location of services to meet this instructional mandate.

**5. True or False - O&M instructors who are providing IEP mandated O&M services are prohibited legally from taking students off campus.**

*False.*

O&M services, as defined in IDEA - “means services provided to blind or visually impaired students by qualified personnel to enable those students to attain systematic orientation to and safe movement within the environments in school, home, and community;...”

It is important to remember that O&M services, when provided as a related service, must fulfill the IEP mandate. According to the IDEA definition of O&M as a related service, *IEP mandates for O&M must be written to enable students to achieve skills for travel at school, at home, and in the community, as appropriate, based on assessment.*

IEP mandates for O&M can specify the school campus, the home, and the community as the location of services.

*When IEP mandates specify the location of service as “off campus,” it is, therefore, not illegal to take the student “off campus” - in fact, it would be required.*

On the other hand, it would not be appropriate to take a student “off-campus” for O&M instruction, if this is not consistent with the student’s IEP O&M mandate and goals.

...When IEP goals specify instructional settings, schools are out of compliance with the IEP if the student is not taught in those settings. This means it is necessary to complete assessments and determine whether students are functioning at age-appropriate levels off campus. If discrepancies are found, it is necessary to write age-appropriate instructional goals for O&M that are then taught in functional settings.

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## Mitochondrial Diseases

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the United Mitochondrial Disease Foundation, Inc.

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

*SEE/HEAR Editor's note: A number of children in Texas who are visually impaired or deafblind have as the cause of their sensory loss, Mitochondrial diseases. In order to understand more about these diseases, I visited the United Mitochondrial Disease Foundation website. I learned that we have a great opportunity in Texas to learn more about these diseases because their 5th International Conference on Mitochondrial Diseases will be held this year in Dallas. I want to thank the UMDF for letting me excerpt portions of the wealth of information they provide on their website to share with our SEE/HEAR readers. I encourage you to visit this website if you have a child with a Mitochondrial disease or if you are a teacher working with one of these children.*

### BASIS OF THE DISEASE

Mitochondrial diseases result from failures of the mitochondria, specialized compartments present in every cell of the body except red blood cells. Mitochondria are responsible for creating more than 90% of the energy needed by the body to sustain life and support growth. When they fail, less and less energy is generated within the cell. Cell injury and even cell death follow. If this process is repeated throughout the body, whole systems begin to fail, and the life of the person in whom this is happening is severely compromised. The disease primarily affects children, but adult onset is becoming more and more common.

Diseases of the mitochondria appear to cause the most damage to cells of the brain, heart, liver, skeletal muscles, kidney and the endocrine and respiratory systems.

Depending on which cells are affected, symptoms may include loss of motor control, muscle weakness and pain, gastro-intestinal disorders and swallowing difficulties, poor growth, cardiac disease, liver disease, diabetes, respiratory complications, seizures, visual/hearing problems, lactic acidosis, developmental delays and susceptibility to infection.

### WHEN TO SUSPECT MITOCHONDRIAL DYSFUNCTION

There is no one identifying feature of mitochondrial disease. Patients can have combinations of problems whose onset may occur from before birth to late adult life. Think mitochondria when:

- A "common disease" has atypical features that set it apart from the pack.
- Three or more organ systems are involved.
- Recurrent setbacks or flare ups in a chronic disease occur with infections.

Mitochondrial diseases, or cytopathies, should be considered in the differential diagnosis when there are these unexplained features, especially when these occur in combination:

### Symptoms

- Encephalopathy
  - √ Seizures
  - √ Developmental Delay or Regression (including early and late-onset dementia)
  - √ Myoclonus
  - √ Movement Disorders (dystonia, dyskinesias, chorea, etc.)
  - √ Complicated Migraine
  - √ Stroke
- Neuropathy
- Cardiac Conduction Defects or Cardiomyopathy
- Hearing Deficits
- Short Stature
- Disorders of Extraocular Muscles
  - √ ptosis
  - √ acquired strabismus
  - √ ophthalmoplegia
- Diabetes
- Renal Tubular Disease
- Visual Loss
  - √ retinitis pigmentosa
  - √ optic atrophy
- Lactic Acidosis (may be mild)

### Problems Associated with Mitochondrial Cytopathies

ORGAN SYSTEM	POSSIBLE PROBLEMS
Brain	Developmental delays, mental retardation, dementia, seizures, neuro-psychiatric disturbances, atypical cerebral palsy, migraines, strokes
Nerves	Weakness (which may be intermittent), neuropathic pain, absent reflexes, gastrointestinal problem (gastroesophageal reflux, delayed gastric emptying, constipation, pseudo-obstruction), fainting, absent or excessive sweating resulting in temperature regulation problems
Muscles	Weakness, hypotonia, cramping, muscle pain
Kidneys	Proximal renal tubular wasting resulting in loss of protein, magnesium, phosphorous, calcium and other electrolytes
Heart	Cardiac conduction defects (heart blocks), cardiomyopathy
Liver	Hypoglycemia (low blood sugar), liver failure
Eyes	Visual loss and blindness
Ears	Hearing loss and deafness
Pancreas	Diabetes and exocrine pancreatic failure (inability to make digestive enzymes)
Systemic	Failure to gain weight, short stature, fatigue, respiratory problems including intermittent air hunger

SYNDROMES/CONDITIONS

### Mitochondrial diseases with associated vision and hearing losses and descriptions

There are quite a large number of Mitochondrial diseases listed on the United Mitochondrial Disease Foundation website. Some of these have various visual conditions and hearing loss associated with them. Some of the ones listed include:

*Alpers Disease*

Long name: Progressive Infantile Poliiodystrophy.

Symptoms: seizures, dementia, spasticity, blindness, liver dysfunction, and cerebral degeneration.

*Complex I Deficiency*

Long Name: NADH dehydrogenase (NADH-CoQ reductase) deficiency.

Symptoms: Three major forms:

1. Fatal infantile multisystem disorder, characterized by developmental delay, muscle weakness, heart disease, congenital lactic acidosis, and respiratory failure.
2. Myopathy beginning in childhood or in adult life, manifesting as exercise intolerance or weakness. Elevated lactic acid common.
3. Mitochondrial encephalomyopathy (including MELAS), which may begin in childhood or adult life and consists of variable combinations of symptoms and signs, including ophthalmoplegia, seizures, dementia, ataxia, hearing loss, pigmentary retinopathy, sensory neuropathy, and uncontrollable movements. May cause Leigh Syndrome.

*Complex III Deficiency*

Long Name: Ubiquinone-cytochrome c oxidoreductase deficiency.

Symptoms: Four major forms:

1. Fatal infantile encephalomyopathy, congenital lactic acidosis, hypotonia, dystrophic posturing, seizures, and coma. Ragged-red fibers common.
2. Encephalomyopathies of later onset (childhood to adult life): various combinations of weakness, short stature, ataxia, dementia, hearing loss, sensory neuropathy, pigmentary retinopathy, and pyramidal signs. Ragged-red fibers common. Possible lactic acidosis.
3. Myopathy, with exercise intolerance evolving into fixed weakness. Ragged-red fibers common. Possible lactic acidosis.
4. Infantile histiocytoid cardiomyopathy.

*Complex IV Deficiency / COX Deficiency*

Long Name: Cytochrome c oxidase deficiency is caused by a defect in Complex IV of the respiratory chain.

Symptoms: Two major forms:

1. Encephalomyopathy: Typically normal for the first 6 to 12 months of life and then show developmental regression, ataxia, lactic acidosis, optic atrophy, ophthalmoplegia, nystagmus, dystonia, pyramidal signs, and respiratory problems. Frequent seizures. May cause Leigh Syndrome.
2. Myopathy: Two main variants:
  - a) Fatal infantile myopathy: may begin soon after birth and accompanied by hypotonia, weakness, lactic acidosis, ragged-red fibers, respiratory failure, and kidney problems.
  - b) Benign infantile myopathy: may begin soon after birth and accompanied by hypotonia, weakness, lactic acidosis, ragged-red fibers, respiratory problems, but (if the child survives) followed by spontaneous improvement.

*CPEO*

Long Name: Chronic Progressive External Ophthalmoplegia Syndrome.

Symptoms: Similar to those of KSS plus: visual myopathy, retinitis pigmentosa, dysfunction of the central nervous system.

### *KSS*

Long name: Kearns-Sayre Syndrome.

Symptoms: Progressive external ophthalmoplegia, pigmentary retinopathy, heart block, and high cerebrospinal protein.

### *LCHAD*

Long name: Long-Chain Hydroxyacyl-CoA Dehydrogenase.

Symptoms: Encephalopathy, liver dysfunction, cardiomyopathy, and myopathy. Also pigmentary retinopathy and peripheral neuropathy.

### *LHON*

Long Name: Leber Hereditary Optic Neuropathy.

Symptoms: Primarily blindness in young men. Less common symptoms: mild dementia, ataxia, spasticity, peripheral neuropathy, and heart conduction defects.

### *MERRF*

Long Name: Myoclonic Epilepsy and Ragged-Red Fiber Disease.

Symptoms: Myoclonus, epilepsy, progressive ataxia, muscle weakness and degeneration, deafness, and dementia.

### *NARP*

Long Name: Neuropathy, Ataxia, and Retinitis Pigmentosa.

## **HEADING TO TEXAS IN JUNE 2002**

The mission statement for UMDF is “to promote research for cures and treatments of mitochondrial disorders and to provide support to affected families.” One activity that supports this mission is their international symposium. The 5th International UMDF Symposium on Mitochondrial Disease for Mitochondrial Specialists, Clinicians, and Families will take place this summer at the Westin Galleria, in Dallas, Texas. Meetings are planned for everyone’s needs and families will have the opportunity to attend the medical meeting for clinicians. Also new this year will be a special session for affected adults. A special tract will be offered for newcomers to learn the basics of mitochondrial disease before the detailed medical sessions. Other topics include insurance, legal issues, estate planning, and practical tools for couples and non-affected siblings. There are three different tracks offered at this event:

Scientific Meeting - “Mechanisms of Mitochondrial Function and Disease”

June 6-7, 2002

Meeting for Clinicians - “Troubleshooting Difficult Cases in the Clinical Setting”

June 8, 2002

Family Meetings

June 7-9, 2002

For registration information about the Family Meetings, please contact the UMDF office by phone (412) 793-8077 or e-mail [info@umdf.org](mailto:info@umdf.org), or visit the UMDF website at [www.umdf.org](http://www.umdf.org). For medical professionals seeking information about the Scientific Meetings or Meetings for Clinicians, contact the University of Texas Southwestern Medical Center at Dallas by phone (800) 688-8678 or e-mail [Misti.fitzner@utsouthwestern.edu](mailto:Misti.fitzner@utsouthwestern.edu), or access their website at [www.utsouthern.edu](http://www.utsouthern.edu).

# Early Hearing Detection and Intervention

By Karl R. White, Utah State University, Logan, Utah

*Editor's note: In Texas we have made great strides implementing newborn infant hearing screening as a result of The Newborn Infant Hearing Screening and Intervention Act of 1999. We thought you might be interested in knowing more about the importance of early hearing loss detection and intervention, as this program, like many others, will be scrutinized when budgets are drawn up in Washington DC and in Texas. If you have questions or would like to know more about this issue, please contact Karl White in Logan, Utah, at <KWHITE@coe.usu.edu>.*

## BACKGROUND

Hearing loss continues to be the most common birth defect in America. The Newborn Infant Hearing Screening and Intervention Act of 1999 (as introduced by Representative James Walsh), was incorporated as Title VI of the Labor, HHS and Education Appropriations Act of 1999, and signed into law. This law has enabled federal funds for state grants to develop infant hearing screening and intervention programs. Congress also identified several specific goals to address the problem of hearing loss in children through the Children's Health Act of 2000 (P.L. 106-310), including early hearing screening and evaluation of all newborns, coordinated intervention and rehabilitation services, and ongoing applied research to better understand the learning and developmental needs of deaf or hard-of-hearing children.

Since 1999, the number of states requiring statewide newborn hearing screening by law or voluntary compliance has increased from 11 to 41 states and the District of Columbia. While progress is being made, there is still a long way to go. Only 67% of babies are now screened for hearing loss before 1 month of age (up from only 20% in 1999). To date, over half of the newborns who do not pass the hearing screening are lost to follow-up. Moreover, over half of the infants diagnosed with hearing loss are not enrolled in early intervention programs by 6 months of age.

Over the last three years, there has been more grant applications than funding available, which underscores the need to extend federal funding. Currently, 44 states and 3 territories (out of 50 states and 9 territories) have received HRSA competitive grants for the purpose of implementing statewide EHDI programs. Since these grants have only been operational for 6 months to 2 years, a dedicated source of funding is critical at this time to ensure that state programs become fully operational, successful and properly link screening programs with diagnosis, early intervention and the child's medical home.

Only 30 states have received CDC cooperate agreement grants over the last two years (15 states in FY2000 and another 15 states in FY2001) to assist them in developing strong surveillance and tracking systems. These systems are needed to ensure follow-up and coordination of early intervention services for young children identified with hearing loss. States also face multiple challenges in transferring information about children diagnosed with hearing loss among service providers, the state EHDI programs and early intervention programs.

## FACTS ON HEARING LOSS IN CHILDREN

Everyday in the United States, approximately 1 in 1,000 newborns (or 33 babies every day) is born profoundly deaf with another 2-3 out of 1,000 babies born with partial hearing loss, making hearing loss the number one birth defect in America. (National Center on Hearing Assessment & Management website 2002, Centers for Disease Control website, 2002)

Newborn hearing loss is 20 times more prevalent than phenylketonuria (PKU), a condition for which all newborns are currently screened. (Grosse, 2001)

Of the 12,000 babies in the United States born annually with some form of hearing loss, only half exhibit a risk factor – meaning that if only high-risk infants are screened, half of the infants with some form of hearing loss will not be tested and identified. (Harrison & Roush, 1996) In actual implementation, risk-based newborn hearing screening programs identify only 10-20% of infants with hearing loss. (Elssmann, Matkin, & Sabo, 1987) When hearing loss is detected beyond the first few months of life, the most critical time for stimulating the auditory pathways to hearing centers of the brain is lost, significantly delaying speech and language development.

Only 67% of babies are now screened for hearing loss before 1 month of age (up from only 20% in 1999). Of the babies screened, only 56% who needed diagnostic evaluations actually receive them by 3 months of age. Moreover, only 53% of those diagnosed with hearing loss are enrolled in early intervention programs by 6 months of age. (National Center on Hearing Assessment website, 2002) As a result, these children tend to later re-emerge in our schools' special education (IDEA, Part B) programs.

When children are not identified and do not receive early intervention, special education for a child with hearing loss costs schools an additional \$420,000, and has a lifetime cost of approximately \$1 million per individual. (Johnson et al, 1993)

## **NATIONAL RECOMMENDATIONS ON EARLY HEARING DETECTION & INTERVENTION**

The Joint Committee on Infant Hearing (Joint Committee on Infant Hearing, 2000) and U.S. Public Health Service's Healthy People 2010 health objectives (Healthy People 2010 website, 2002) recommend that all newborns be screened for hearing loss by 1 month of age, have diagnostic follow-up by 3 months, and receive appropriate intervention services by 6 months of age.

A National Institutes of Health (NIH) Consensus Panel in 1993 recommended hearing screening of all newborns. The consensus report concluded that the best opportunity for achieving this goal is provided by the development of hearing screening programs for newborns in hospital nurseries or in birthing centers, prior to discharge. (National Institutes of Health, 1993)

The U.S. Preventive Services Task Force in 2001 concluded that universal newborn hearing screening does lead to earlier identification and treatment. However, there were not enough clinical studies of sufficient size and strength to evaluate long-term outcomes. While the preponderance of anecdotal evidence and clinical research indicates that EHDI provides substantial benefit, additional clinical outcome studies and clinical trials are needed. (Agency for Healthcare Research and Quality website, 2002)

## **METHODS AND COSTS FOR NEWBORN HEARING SCREENING**

Advances in technology for newborn hearing screening at most birthing hospitals have allowed for cost containment, with current charges ranging from \$25 to \$60. The cost of identifying a newborn with hearing loss is less than one-tenth the cost of identifying newborns with PKU, hypothyroidism, or sickle cell anemia, which are screened for in nearly every state. (Grosse, 2001)

Two types of electrophysiologic procedures are used to screen newborns singly or in combination:

- Auditory brainstem responses (ABR) are measured by placing sensors on the baby's head. Sound is then introduced to the baby's ears through tiny earphones while the child sleeps. A computer allows brainwave activity to be recorded to indicate whether the ear and auditory brainstem pathway are responding to sound. This test is painless and takes only about 5 minutes.
- Otoacoustic emissions (OAE) are faint sounds produced by most normal inner ears. The sounds cannot be heard by people, but can be detected by very sensitive microphones that are placed in the ear canal. During testing, a tiny flexible plug is inserted into the baby's ear and sound is then projected into the ear through the

plug. A microphone inside the plug records the otoacoustic emissions that the normal ear produces in response to the incoming sound. Testing is also painless, takes about 5 minutes to complete, and can be done while the baby sleeps.

## **BENEFITS OF EARLY HEARING DETECTION AND INTERVENTION**

Infants identified with hearing loss can be fit with amplification by as young as 4 weeks of age. With appropriate early intervention, children with hearing loss can be mainstreamed in regular elementary and secondary education classrooms. (Joint Committee on Infant Hearing, 2000) Recent research has concluded that children born with a hearing loss who are identified and given appropriate intervention before 6 months of age demonstrated significantly better speech and reading comprehension than children identified after 6 months of age. (Yoshinaga-Itano & Apuzzo, 1998 and Yoshinaga-Itano et al, 1998)

Even mild hearing loss can significantly interfere with the reception of spoken language and education performance. Research indicates that children with unilateral hearing loss (in one ear) are ten times as likely to be held back at least one grade compared to children with normal hearing. (Bess, 1985, Bess, 1998, and Oyler et al, 1988) Similar academic achievement lags have been reported for children with even slight hearing loss. (Quigley, 1978) Children with mild hearing loss miss 25-50% of speech in the classroom and may be inappropriately labeled as having a behavior problem. (Flexer, 1994)

Recent clinical studies indicate that early detection of hearing loss followed with appropriate intervention minimizes the need for extensive habilitation during the school years and therefore reduces the burden on the IDEA Part B program. (Centers for Disease Control and Prevention website 2002 and Ross 2001) In contrast, a 30-year Gallaudet study revealed that half of the children with hearing loss graduate from high school with a 4th grade reading level or less. (Gallaudet Research Institute website, 2002)

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## What's in a Name?

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

In the last issue of *See/Hear* I let the readership know that the Texas Commission for the Blind was considering a new name for its children's program. The agency's Board voted in its March meeting to rename the program the **Blind Children's Vocational Discovery and Development Program**. This is the second name change in the program's history. Initially known as the Visually Handicapped Children's Program in concert with our enabling statutes, the name changed to Blind and Visually Impaired Children's Program in the early 1980s. The change was made to bring the name "blind" into the language of our service programs. In addition, the word "handicapped" was losing favor in the disability field, so we changed along with the times.

Why another change now? Much has happened in 20 years in state government. We've been struggling for a couple of years with an external identity crisis in the children's program. A new program name that clearly defines our specific role in state government will place us in a better position to educate the public and legislators. We need to insure that our services are understood as unique and separate from educational, health, and welfare services.

In a memo we sent to our staff about the name change, we asked them to look at the new name chosen by the Board and set their vision on what it says. I'm taking this opportunity of sharing this vision with our *See/Hear* partners.

**Blind Children's...** Straight up and up front. Although we still serve children with visual impairments and they are very important to us, we are best known for our specialized knowledge about blindness - no other agency in Texas does what we do for blind children. To reinforce that message, our caseworkers are being retitled "Blind Children's Specialists."

**Vocational...** The word vocational is important because it clearly sets us apart from education, health and welfare services. The word vocational may mean full-fledged competitive employment to a lot of people; to us it is a broader, less restrictive term when you're talking about children. Too many children are labeled too soon in their lives as having no vocational potential. Vocational to us means working toward a purposeful existence. We believe all blind children, regardless of a child's medical prognosis or severity of disabilities, have the potential for developing in a vocational direction. Depending on the individual blind child, success could be any one or more of a wide range of accomplishments - from learning to have meaningful interactions with loved ones to eventual paid work experience.

**Discovery...** A child's life is all about discovery. Discovery is an action word. It's a positive force. It's an all-inclusive term. The moment all children are born they begin to discover the world around them, their interests, their differences, and their passions. The Commission is right there to help the child and family discover the many possibilities they never thought existed for someone who is blind. When the time is right, we'll be there to help children and families discover successful role models who are themselves blind and once walked the same path their child is now on.

**Development...** Development is also an action and all-inclusive word. This is where our staff really shines. No other agency professionals in Texas have the blindness-specific expertise to recommend the appropriate developmental training that will make each tomorrow a little bit better for blind children and their families.

**Program.** We have a comprehensive, fully developed, statewide system of services ready to help parents and children who are blind.

Well, that's it. We've received a few comments since the change - most of them positive. One concerned parent questioned the need for "vocational" in the name, stating that not all children we serve have vocational potential. The parent was concerned that the word would throw some parents off and they would not know the program was available to them if their child was visually impaired or had multiple disabilities and future vocational possibilities looked bleak to them. I reassured that parent, as I want to assure you, that we'll do our best to promote our services to parents of all children with visual impairments, regardless of the severity of their other disabilities.

The concern expressed about children with no "vocational" potential made me think about an e-mail recently sent around by our Lubbock regional director that I want to share with you. It speaks volumes about our vision for all of the agency's programs, including our children's program and the name change. She reminded us of words used by President George W. Bush in 1999 in a campaign speech and later again in his nomination acceptance speech. In talking about his domestic policy for educational reform, he used the phrase, "Some say it is unfair to hold disadvantaged children to rigorous standards. I say it is discrimination to require anything less - the soft bigotry of low expectations."

What compelling words! "The soft bigotry of low expectations." Her e-mail went on to say that the soft bigotry of low expectations applies not only to public education but also to the habilitation and rehabilitation of blind consumers. She gave the examples of the blind student who is allowed to get out of gym class whenever she wants, or the college disabled students office that intervenes on behalf of the blind student with a professor, or the employer who allows the blind employee to skip a special employee meeting because he'd have to report to work an hour early. Low expectations; learned dependence. To foster independence, she said that the Commission should expect of our consumers what we expect of everyone else and offer consumers the same courtesies we offer to everyone else - nothing more, nothing less. I agree.

Our Blind Children's Vocational Discovery and Development Program promises to have high expectations of every child. We promise parents we will have those same high expectations of them as we help them to learn about the special qualities and needs of their child with visual loss and how to help their child develop to their full potential. As President Bush said, to expect less would be a form of soft bigotry on our part.

## “Where Airplanes Fly”

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

What follows is a story with as many versions as there are teachers of the visually impaired. A good friend of mine was a resource teacher for the visually impaired at a senior high school. Among his students was a very bright, competent totally blind 11th grader. My friend was concerned about the concepts and social skills of this student who excelled in academic learning. One day he had the student climb up a ladder and touch the ceiling of the classroom. My friend said, “Do you know what that is?” The student responded, “This is where airplanes fly.”

While this little story seems to illustrate a lack of concept development, not social skills development, I contend that it is a classic illustration of why we need to be teaching social interaction skills.

Over the years that I’ve been involved in education of the visually impaired, it’s been interesting, frustrating, and tragic that my colleagues and I have paid so little attention to the systematic, sequential teaching of social skills. I recall that among the original reasons given for “mainstreaming” were to give blind and visually impaired students opportunities to grow up socially with their sighted classmates and neighbors. So we placed them in regular classrooms and thought proximity would do the rest. When questioned about teaching social skills, we would say that we corrected inappropriate social behavior (rocking, eye-poking, etc.) as needed. What that meant was that we intervened when children were being socially inappropriate and tried to extinguish the behavior. It did not mean, at least in my case, that we replaced inappropriate behavior by teaching what would be socially acceptable. We also did not share with students information about which behaviors were permissible with different audiences, and which behaviors were permissible only in the privacy of their own homes or their own rooms.

In a former life, when I taught future teachers of the visually impaired at a university, I offered a course entitled “Social and Psychological Implications of Blindness.” Almost every semester, the students and I would begin this course with a fascinating discussion. We would consider the possibility that, for the adventitiously blinded adult, the major issues of blindness would probably be psychological, while for the congenitally blind child, most issues would be social. The child, who knows no other condition than blindness, may not have any psychological reaction to being blind. On the other hand, every social skill that is incidentally, casually learned through vision will need to be taught to blind children. What happens to these skills if we have no social skills curriculum?

As a result of our rather feeble and innocently ignorant attempts with social skill training in the early years of mainstreaming, too many blind and visually impaired young people entered the adult world with few skills for social interaction. Thus, the very reasons we mainstreamed students led to many socially inept young adults.

Are we doing better now? I hope so - we have curriculum for assessing and teaching social interaction, we have an expanded core curriculum that stresses the teaching of social skills, and our universities are paying much more attention to the preparation of teachers who know how to teach non-academic skills.

Ann MacCuspie wrote a book entitled *Promoting Acceptance of Children with Disabilities: From Tolerance to Inclusion* (Atlantic Provinces Special Education Authority, 1996) that every professional in education of the visually impaired should read. Ann describes what she calls “Pupil Culture,” and warns us that this characteristic of adolescents is learned through the visual observation of peers, and is essential for a healthy social life in school and the community.

According to MacCuspie, pupil culture has several functions:

1. It is a defense resource for pupils against teachers and other adults.
2. It determines who belongs and who does not.

3. It provides special benefits for group members.
4. It legitimizes children's perceptions of their world.

MacCuspie goes on to illustrate, through her research, why it is difficult, if not impossible, for visually impaired children to be a part of the "pupil culture."

*"...many sources of incompatibility became apparent. Classmates of these (visually impaired) students were often perplexed as to how to interact with a student who was visually impaired or how to respond to her/his atypical behaviors or mannerisms. Students with a visual impairment, frequently uninformed of the negotiated rules of school culture, behaved inappropriately... The social environment itself was often a hostile one for children with disabilities integrated in the regular classroom. Competence, verified in competitive settings or judged on inequitable criteria, routinely placed the student with a visual impairment at a disadvantage..."*

I've been very conscious of this emphasis in Ann's book because I am the father of a teenager. Lucas, my son, is 13 years old, soon to be 14. Throughout his life, he has been a kind, sensitive, loving and fun-loving young man. He, and his mother, are the joys of my life. Yet, I am very aware of his beginning to identify with his pupil culture now. The changes are subtle, for Lucas still has a deep and abiding love of his family, and is committed to being a loving member of our circle. But there is a normal and growing dimension of him in which we, my wife and I, are not included. He has friends with whom he shares interests, even passionate interests, and his parents can only look on and approve. He is growing up, becoming his own person, not just an extension of us. I have yet to hear or see Lucas deliberately defy his parents, and I attribute that to the 13 years of love, caring, and gentle discipline he received.

Why am I telling you this story? Because most of what Lucas knows about his pupil culture has been learned casually and visually. He "fits" with a certain crowd at school because they share interests, have very animated conversations, and laugh a lot together. His identity with his pupil culture will grow over the next few years, and his parents only hope and pray that his solid foundation will help him remember honesty, integrity, and what is right.

Lucas first became a member of a pupil culture because of the common interests he and his friends share. As the months and years go by, that bond will strengthen through shared experiences and relationships. Hopefully, his friends today will be his lifetime friends.

What are some of the prerequisites children must learn in order to be a member of a pupil culture? What are the characteristics of pupil culture that blind and visually impaired children may need to be taught? This is what Ann MacCuspie has to say:

- *unwritten rules of pupil culture, such as those things to tell teachers and those things which are shared only by children*
- *activities which are popular on the playground and the rules which guide participation*
- *the opportunities which exist for interaction with peers outside the classroom, such as debating club, choral groups, school newspaper, and recreational pursuits*
- *the types of problems other students are experiencing as they proceed through school (e.g., peer pressure, belonging, understanding others)*
- *common knowledge items such as the current fashions in clothing, hairstyles, television programs, music, and recreational and leisure pursuits*

- *popular games (e.g., board games, card games, video games) and how to play them*
- *how to participate and what to do on playground equipment, how to participate in run and chase games, how to play in a group*
- *information which is displayed on classroom walls, bulletin boards, overhead projectors, film screens, and television monitors*

How can we help these students develop a pupil culture? I'm not certain, and many of you readers have done more than I have in this regard. But I can't help thinking about spending some time every day, or several times a week, helping the pre-teen on your caseload learn socially appropriate dress, socially acceptable mannerisms, develop interests common to other students, learn conversational skills (don't interrupt, how to feign interest, etc.), appropriate relationships with adults, etc.

Because, after all, social skills are just as important as learning to read, aren't they?

## **Stipends Available for Training as Teachers of the Visually Impaired, Orientation and Mobility Specialists, and Deafblind Professionals**

The collaborative visual impairment (VI) preparation project in Texas provides stipend money to students wanting to become teachers of the visually impaired (TVI), orientation and mobility (O&M) specialists, and deafblind professionals in Texas. The stipends cover tuition, fees, books, and in some cases travel and living expenses. You must be a Texas resident to qualify.

TVIs are specially certified teachers who help visually impaired children (birth - 22 years) achieve their educational goals. They work as part of the educational team, to provide instruction in skills which are unique to visual impairments. Their goal is to help students achieve independence. TVIs work with children with visual impairments (low vision and blind), their parents, other educators, O&M specialists and community agencies.

A TVI's day might include:

- Teaching a toddler to enjoy playing with a variety of toys
- Teaching a young child how to read and write braille
- Teaching students how to make a favorite snack
- Modifying materials with other educators and paraeducators to address the impact of a visual impairment

Orientation and mobility (O&M) specialists train students how to travel independently, safely and efficiently in their home, school and community. As part of the educational team, O&M specialists help students know where they are in space, where they want to go, and how to get there. O&M specialists work with individuals who have visual impairments, birth through adulthood, in both educational and rehabilitation settings.

An O&M specialist's day might include:

- Teaching a young blind baby how to move towards her mother's voice
- Teaching a child with low vision how to interpret the sounds of traffic
- Teaching a teenager how to use a cane when traveling in a crowded mall
- Coordinating with parents and educational team members to teach a visually impaired child how to participate in a sporting event

Deafblind professionals work with students who are deafblind. As part of the educational team, deafblind professionals provide educational programming for these very unique children and adults.

## **TRAINING INFORMATION**

University-based courses are offered either entirely over the web or in combination with interactive television systems at regional education service centers. Students usually take two classes each semester, including the summer. It is possible to attend Stephen F. Austin State University and take traditional on-campus classes. Full-time students can finish the program in one year and have part of their living expenses covered by the stipend.

Interested future TVIs in the Corpus Christi area may also participate in an alternative certification program. This program can be completed within a calendar year.

### **No degree?**

Applicants without an undergraduate degree can get a bachelor's degree and certification as either a TVI or O&M specialist at Stephen F. Austin State University. This is the only undergraduate program in the state.

### **Bachelor's or Master's degree?**

With at least a bachelor's degree, a person can complete certification as an O&M specialist, by taking courses through distance learning methods and spending one summer in a university training program at Texas Tech University or Stephen F. Austin State University.

Future O&M specialists take eight courses and complete an internship/practicum. It is necessary to plan on spending one summer on the university campus to complete six credit hours of instruction. It may also be necessary to travel to complete some of the internship/practicum. Stipends are available to help offset the cost of the required travel.

Future TVIs must have a classroom teaching certificate *before* completing Visually Impaired certification. Visually Impaired certification is available through Stephen F. Austin, Texas Tech University, or Region II Education Service Center's Teacher Preparation Program.

Future TVIs must either complete six courses and an internship or attend the Teacher Certification Program at Region II Education Service Center. TVIs may get emergency certified after completing Braille and one other course.

## **WHO DO I CONTACT FOR MORE INFORMATION?**

### **Program-specific information**

#### *Region II Education Service Center*

Ms. Joyce West  
Phone: (361) 561-8524  
E-mail: [jwest@esc2.net](mailto:jwest@esc2.net)

#### *Texas Tech University*

Dr. Nora Griffin-Shirley  
Phone: (806) 742-2345  
E-mail: [ibngs@ttu.edu](mailto:ibngs@ttu.edu)

#### *Stephen F. Austin State University*

Dr. Dixie Mercer  
Phone: (936) 468-1142  
E-mail: [dmerc@sfasu.edu](mailto:dmerc@sfasu.edu)

### **General professional information**

Dr. KC Dignan  
Phone: (512) 206-9156  
E-mail: [kcd@tsbvi.edu](mailto:kcd@tsbvi.edu)

## TSBVI Short-Term Programs for School Year 2002-2003

Spring ARDs are a good time to think about an upcoming TSBVI short-term program for your student. Learn more about these programs on TSBVI's website at <[www.tsbvi.edu](http://www.tsbvi.edu)>, or contact Lauren Newton, Principal of Special Programs, by e-mail at [newtonl@tsbvi.edu](mailto:newtonl@tsbvi.edu) or by phone at (512) 206-9119.

### FALL SEMESTER 2002

September 8-13:	Technology Week (electronic notetakers, speech access for Windows)
Sept. 29-Oct. 4:	Elementary IEP #1 (you pick the objectives)
October 20-25:	Middle School IEP #1 (you pick the objectives)
November 10-15:	High School IEP #1 (you pick the objectives)
December 1-6:	Math (adapted tools & technology)
December 1-6:	Practical Academics (students below grade level)
*December 12-15:	Middle School Holiday Gift Making

### SPRING SEMESTER 2003

January 12-17:	High School IEP #2 (same as above)
*January 23-26:	Low Vision Weekend (modifications & adaptations)
February 9-14:	Middle School IEP #2 (same as above)
*February 20-23:	Teen Getaway (social enrichment)
March 23-28:	Secondary IEP #2 (same as above)
*April 5-8:	A Capitol Experience (visit & learn about legislature)
April 13-17:	Elementary IEP #2 (same as above)
*May 1-4:	Elementary Austin Experience (social enrichment)
*Weekend Program	

### **KASA (Kids As Self Advocates)**

Reprinted with permission from Family Voices  
Friday's Child News, April 5, 2002

KASA (Kids As Self Advocates) is very HAPPY to announce... FORUMS! This is your opportunity to SPEAK OUT and make your voices heard. These are not your parent's forums. The forums work like bulletin boards, you can write back to subjects that are already there, or start your own. Tell us what is on your mind, take part in research and surveys to help people who work with youth hear from youth and find support and encouragement from your peers. Make some friends, have "virtual" conversations, have fun! Visit <[www.fvkasa.org](http://www.fvkasa.org)> to register, read and write! Thanks to Joshua Keys at Motion Medium for all his hard work getting these up and looking great.

KASA has a listserv. If you would like to join it, send an e-mail to <[kasa-subscribe@yahoogroups.com](mailto:kasa-subscribe@yahoogroups.com)> or join KASA through our website at <[www.fvkasa.org](http://www.fvkasa.org)>.

## **IDEA Rapid Response Network**

Reprinted with permission from Family Voices  
Friday's Child News, April 12, 2002

The Disability Rights Education And Defense Fund (DREDF) has launched the IDEA Rapid Response Network. Comprised of parents of children with disabilities, advocates and supporters, the Network is:

- Building a cadre of parents and supporters nationwide who can be called on to respond to proposed amendments or concepts for changes to IDEA that might weaken, eliminate or in any way compromise the civil rights of children with disabilities during the upcoming Congressional reauthorization process; and,
- Educating and informing parents about proposals to amend IDEA.

If you wish to receive e-mail information about reauthorization activities and/or participate in the Network, please send an e-mail to [preserveIDEA@dredf.org](mailto:preserveIDEA@dredf.org). Include your name, contact information (postal address, telephone number, and e-mail) and whether you only want updates or would also like to participate in the Network. For more on IDEA and Family Voices, contact Bridget Via, FAPE Project Coordinator at the National Office, [bvia@familyvoices.org](mailto:bvia@familyvoices.org), (505) 872-4774.

## **Medicaid Simplification Bill (Senate Bill 43)**

Reprinted with permission from  
March/April 2002 Texas Medicaid Bulletin, No. 161

*Editor's note: Although this article was written for health care professionals, the information is also relevant to parents whose children utilize Medicaid funds.*

On January 1, 2002, Senate Bill 43, the Medicaid Simplification bill, went into effect. The bill's purpose is to remove barriers to children's enrollment into and continued participation in Texas Medicaid. Key features of interest to health care providers include:

- The simpler three-page application for children's Medicaid includes easier verification requirements.
- Face-to-face application and renewal appointments in DHS offices are no longer required.
- Changes have been made to the system so that children moving between Medicaid and CHIP do not experience a gap in coverage.
- The eligibility period lasts a continuous six months. Children newly enrolled after January 1 will begin a six-month continuous eligibility term; that is, they will not lose Medicaid coverage due to changes in family income or size. However, children certified for Medicaid coverage before January 1, 2002, only will begin a six-month eligibility period at the time of their first Medicaid renewal event in 2002.

The Medicaid ID system will not change in the short-term, despite the six-month eligibility terms. Clients will continue to receive updated monthly ID cards. The Medicaid ID cards contain many other kinds of information for and about Medicaid children. Therefore, the cards will continue to be issued monthly.

Two important aspects of the legislation include:

- Caretakers of newly enrolling Medicaid children are required to participate in a health care orientation.
- Caretakers of all Medicaid children are required to keep their children up-to-date on their medical Texas Health Steps (THSteps) checkups.

If caretakers do not comply with these requirements, they will need to go to a DHS office for a face-to-face renewal with a DHS worker. Caretakers who comply with these two requirements will be allowed to complete their children's renewal process through the mail.

It is important for THSteps and Medicaid providers to understand the following determination made by the state.

A caretaker may claim to be compliant with the health care orientation and checkup requirements if he or she:

- Takes a child to a THSteps checkup or to a Medicaid provider for a medical visit of any kind, or
- Completes the act of scheduling a checkup or medical visit (no matter how far into the future the appointment must be made).

Therefore, health care providers are encouraged to allow as many Medicaid caretakers as possible to call and schedule checkups and medical visits.

To access other articles in the March/April bulletin, go to <<http://www.eds-nhic.com/downloads/m161.pdf>>.

## **Children with Special Health Care Needs Program (CSHCN) at Texas Department of Health Anticipates Changes**

Reprinted with permission of the CSHCN Division, TDH, April, 2001

The Board of Health adopted new rules for the CSHCN program in April 2001. Those changes were a big step on the road to improved care for Texas children with special health care needs. However, CSHCN has a limited budget for 2002 and 2003. At present, the need for services is larger than the amount of money CSHCN has to spend.

The hard task facing us now is figuring out the best ways to serve children and families with the money we have. We will have to take a new look at whom we serve and do not serve, what services we offer, and how we administer all aspects of the CSHCN program. As you can imagine, making the best decisions will be a challenge, and it is not yet certain when final decisions will be made. At this point, CSHCN is already making cuts in staff and administrative expenses. We are also looking at possible changes to CSHCN services, contracts and other aspects of the program.

It is very important to us to base decisions on input from the people whom the decisions will most strongly affect. Various groups and individuals have already made some suggestions. TDH and the CSHCN Advisory Committee are currently discussing issues and possibilities for the future of the CSHCN program. (The Advisory Committee includes 9 parents of children with special health care needs.) We believe that parents and families of children with special health care needs are an important source of guidance. Your input can help us make intelligent, caring, well-considered program changes, so that CSHCN can work within its budget to be the best program it can be.

CSHCN plans to gather a great deal of input from providers, clients and families in the coming weeks. We hope you will be willing to let us know what you think. CSHCN will provide a number of opportunities for you to comment, including public hearings (to be announced on the CSHCN website and in the Texas Register). Please feel free to call, fax, e-mail or write to us with your questions, comments and input. You may also want to check future issues of the CSHCN Parent Newsletter for updates on the program review process. Thank you for partnering with us to do the very best we can for Texas children with special health care needs.

Contact Children with Special Health Care Needs Division - Attention CSHCN Implementation Team, 1100 W. 49th Street, Austin, Texas 78756, E-mail: [cshcn@tdh.state.tx.us](mailto:cshcn@tdh.state.tx.us), Phone: (800) 252-8023, ext. 3110, or (512) 458-7111, ext. 3110; or Fax: (800) 441-5133.

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# 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>.

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## **Fifth Biannual Usher Syndrome Family Retreat** **June 7-9, 2002** **Austin, TX**

Usher Syndrome is a leading cause of deafblindness. People with Usher Syndrome are usually born with a hearing impairment, then begin losing vision later as a result of retinitis pigmentosa. This pattern of deafblindness creates some unique issues for children with Usher Syndrome and their families.

Families from all over Texas come to this event year after year. The experience of meeting other families and adult mentors with Usher Syndrome, and simply having time together, makes this a very special weekend. Topics of this year's retreat will include recreation and leisure, planning for college and post-secondary life, and strategies for living a rich full life while coping with the challenges of Usher Syndrome. Information will also be shared about the supports and resources available to school-aged children with Usher Syndrome, their siblings, and their parents.

Travel assistance from Texas Deafblind Outreach is available for families interested in attending.

**Registration deadline is May 21, 2002.**

## **Mental Health Issues Associated with Usher Syndrome** **A special day of training for** **Counselors, Teachers, Rehabilitation Professionals and Parents** **June 7, 2002** **TSBVI Conference Center - Austin, TX**

Michael Brennan, currently the Mid-Atlantic Regional Representative for the Helen Keller National Center, will be the featured speaker at this one-day training. Michael brings a unique perspective to this topic. He has Usher Syndrome (Type II). After completing his Masters Degree from Gallaudet University, he established the Mental Health Counseling Program at Deaf Community Services of San Diego, California. Michael was also Coordinator of Research and Training on Mental Health and Deaf-Blindness, under a grant at Alliant University. He is a licensed Marriage and Family Therapist (MFT), has extensive knowledge and experience in the field of psychosocial issues and deafblindness, and is well-versed in the emotional adjustment challenges caused by dual hearing and vision loss.

The registration fee of \$50 includes the cost of lunch and materials.

Checks or agency purchase orders should be made out to Texas School for the Blind & Visually Impaired.

**Registration deadline is May 21, 2002.**

**For more information about the retreat or one-day training,**  
**or to request registration flyers for these events,**

contact Beth Rees

Phone: (512) 206-9103 or E-mail: BethRees@tsbvi.edu

**Motor, Vision & Travel:  
Working as a Team to Address  
the Motor and O&M Issues of the  
Young Child with a Visual Impairment**

Movement and exploration of the environment play important roles in the development of concepts, strategies for interacting with objects, and body awareness. Vision loss can significantly impact these areas. This workshop will share fun ideas for working on orientation and mobility, motor and sensory skills. The importance of teamwork will be emphasized, and roles of the OT, PT and O&M Specialist will be discussed.

This workshop will be offered to families and professionals at these locations:

- Monday, June 3, 2002 - Huntsville, TX
- Thursday, June 6, 2002 - Mt. Pleasant, TX
- Saturday, June 8, 2002 - Abilene, TX
- Tuesday, June 18, 2002 - Lubbock, TX
- Friday, June 21, 2002 - New Braunfels, TX
- Thursday, June 27, 2002 - Kilgore, TX

For information, contact Karen Scanlon  
Phone: (512) 206-9314 or  
E-mail: KarenScanlon@tsbvi.edu

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

INSITE is a 6-day training for school and ECI professionals working with families who have children (birth to 5) with multiple impairments, including sensory impairment.

- Silsbee** - Region V Education Service Center  
Part I - June 4 & 5, 2002  
Part II - August 19 & 20, 2002  
Part III - September 17 & 18, 2002

For more information, contact Kathy Williams  
at Region V ESC  
Phone: (409) 386-5507  
E-mail: kmwilliams@esc5.net

**Texas Focus 2002:  
Looking for Access**

June 13-14, 2002  
Renaissance Hotel, Houston, TX

This conference is for people involved in the education of children with visual impairments, including those with multiple impairments and deafblindness.

This year's theme, "Looking for Access," will draw our attention to ways students with visual impairments can be given more and better access to the school curriculum, their community, and the world in general.

For more information, contact Jim Durkel  
Phone: (512) 206-9270  
E-mail: JimDurkel@tsbvi.edu  
or Mindy Carroll  
Phone: (512) 206-9344  
E-mail: MindyCarroll@tsbvi.edu

**5th International UMDF  
Symposium on  
Mitochondrial Disease**

June 6-9, 2002  
The Westin Galleria in Dallas, TX

The 5th International United Mitochondrial Disease Foundation (UMDF) Symposium on Mitochondrial Disease for Mitochondrial Specialists, Clinicians, and Families will take place this summer at the Westin Galleria, in Dallas, Texas. Meetings are planned for everyone's needs and families will have the opportunity to attend the medical meeting for clinicians. Also new this year will be a special session for affected adults. A special tract will be offered for newcomers to learn the basics of mitochondrial disease before the detailed medical sessions. Other topics include insurance, legal issues, estate planning, and practical tools for couples and non-affected siblings.

For family registration information, please contact the UMDF office by phone at (412) 793-8077 or e-mail at [info@umdf.org](mailto:info@umdf.org), or visit the UMDF website at [www.umdf.org](http://www.umdf.org). Medical professionals seeking information on the Scientific Meetings or Meetings for Clinicians, contact the UT Southwestern Medical Center at Dallas by phone at (800) 688-8678 or e-mail at [Misti.fitzner@utsouthwestern.edu](mailto:Misti.fitzner@utsouthwestern.edu), or look on their website at [www.utsouthwestern.edu](http://www.utsouthwestern.edu).

**Third Mid-Atlantic  
CHARGE Syndrome Conference**

June 21-23, 2002

Four Points Sheraton - Aberdeen, Maryland

Any individual who is interested in learning more about this rare and complicated syndrome should attend, including family members, medical and educational professionals, therapists, medical interns/residents, education/special education students. All are invited to participate in this event. For more information contact:

CHARGE Syndrome Foundation, Inc.  
2004 Parkade Boulevard  
Columbia, MO 65202-3121  
Phone: (800) 442-7604 or (573) 499-4694  
Contact: Marion Norbury  
E-mail: marion@chargesyndrome.org

**American Council of the Blind  
Annual Convention**

June 29 - July 6, 2002

Adam's Mark Hotel in West Houston, TX

For information contact the ACB at:

1155 15th Street, NW, Suite 1004  
Washington, DC, 20005

Phone: (800) 424-8666 or FAX: (202) 467-5085  
Website: <<http://www.acb.org/convention/index.html>>

**Braille Revival League's  
Annual Convention**

June 30 - July 3, 2002

Location: Houston, TX

Contact: Kim Charlson  
Phone: (617) 926-9198  
E-mail: kcharlson@acb.org

**10th Biennial Statewide Conference  
on Education of the Deaf**

**Sailing Together Toward New Horizons**

July 24-26, 2002

The Omni Bayfront & Marina Towers Hotels  
Corpus Christi, TX

Contact: Ruth Hicks at (281) 396-6378  
E-mail: rhicks@wmjh.katy.isd.tenet.edu

**National Federation of the Blind  
NFB Convention 2002**

July 3, 2002 (Seminars)

July 4-9, 2002 (Formal Convention)

Location: The Galt House Hotel, Louisville, KY

For information, visit the NFB website at

<<http://www.nfb.org/coming.htm>>

Phone: (410) 659-9314

E-mail: nfb@nfb.org

**Association for Education and  
Rehabilitation of the  
Blind and Visually Impaired  
International Conference**

July 17-21, 2002

Toronto, Canada

Please contact AER for additional information.

Executive Director, Mark Richert

P.O. Box 22397, Alexandria, VA 22304

Phone: (877) 492-2708 or FAX: (703) 823-9695

E-mail: aernet@aerbvi.org

Website: <<http://www.aerbvi.org>>

**Foundation Fighting Blindness  
Annual Low Vision Conference**

**Seeing the Light**

August 22-24, 2002

Chicago, Illinois

For information, contact the FFB at

<<http://www.blindness.org/html/annual/w2002inf.html>>

11435 Cronhill Drive

Owings Mills, MD 21117-2220

Phone: (410) 568-0150

**Cortical Visual Impairment:  
Further Pathways To Intervention**

August 27-29, 2002

Braille Institute of America, Los Angeles, CA

Presenter: Dr. Chris Roman

Contact: Janie Humphries

Phone: (800) 223-1839, ext. 367

E-mail: jhumphries@aph.org

**Virginia Murray Sowell Center  
2002 Distinguished Lecturer Series  
“Providing Quality Instruction in the  
Expanded Core Curriculum”**

with Dr. Phil Hatlen

Superintendent, TSBVI  
& Other Guest Speakers

September 27 & 28, 2002

Texas Tech University - Lubbock  
Contact: Virginia Murray Sowell Center  
for Research and Education in Visual Impairment  
(806) 742-2345 or (806) 742-2326 FAX  
Website: <[http://www.educ.ttu.edu/sowell/  
VSC\\_Pages/Lecture/lecturerseries.html](http://www.educ.ttu.edu/sowell/VSC_Pages/Lecture/lecturerseries.html)>

**Closing the Gap Conference**

October 17-19, 2002

The Radisson South Hotel  
Bloomington, Minnesota

Contact: Sarah Anderson, Administrative Assistant  
Closing The Gap, Inc.

P.O. Box 68, Henderson, MN 56044

Phone: (507) 248-3294 or FAX: (507) 248-3810

E-mail: [sanderson@closingthegap.com](mailto:sanderson@closingthegap.com)

Website: <<http://www.closingthegap.com>>

**American Speech and Hearing  
Association Annual Convention**

November 15-18, 2002

New Orleans, LA

Please contact ASHA for additional information.

10801 Rockville Pike, Rockville, MD 20852

Phone: (800) 498-2071 or TTY: (301) 897-5700

FAX: (301) 571-0457

E-mail: [actioncenter@asha.org](mailto:actioncenter@asha.org)

Website: <[http://professional.asha.org/  
events/index.cfm](http://professional.asha.org/events/index.cfm)>

**Coming in February 2003!**

**Texas Symposium on Deafblindness**

Look for more information about this event  
in the summer edition of *SEE/HEAR* and  
on the Statewide Staff Development Calendar  
for Professionals in Visual Impairment at  
<<http://www.tsbvi.edu/Outreach/vi.htm>>.

**American Association of the  
Deaf-Blind 2003 Conference**

July 12-18, 2003

San Diego State University - San Diego, CA

Please contact AADB at

814 Thayer Ave, Ste 302, Silver Spring, MD 20910

FAX: (310) 588-8705 or TTY: (510)797-3213

E-mail: [tomjill@juno.com](mailto:tomjill@juno.com)

**American Society for Deaf Children  
18th Biennial Conference**

July 26-30, 2003

Texas School for the Deaf, Austin, TX

This conference is scheduled for the summer of 2003  
in Austin, Texas. Please contact Ken Silverstein, ASDC:

P.O. Box 3355, Gettysburg, PA 17325

Phone: (800) 942-2732 (Parent Hotline)

TTY: (717) 334-7922 or FAX: (717) 334-7922

E-mail: [asdc1@aol.com](mailto:asdc1@aol.com)

Website: <<http://deafchildren.org/>>

**Children Who Are  
Medically Complex  
or Technology Dependent:  
Building Relationships,  
Respecting Diversity**

March 31, April 1 and April 2, 2003

Lowes Hotel in Philadelphia, PA

Ken-Crest Children & Family Services

3132 Midvale Avenue, Philadelphia, PA 19129

Phone: (215) 844-4620, ext. 134

FAX: (215) 844-4610

E-mail: [kencrest@kencrest.org](mailto:kencrest@kencrest.org)

Website: <[www.kencrest.org/medfrag/conf.html](http://www.kencrest.org/medfrag/conf.html)>

**Deafblind International Conference**

August 5-10, 2003

Delta Meadowvale Hotel & Conference Centre

Mississauga, Ontario

To request more information on the conference,  
and to be on the mailing list, contact Stan Munroe  
Phone: (519) 372-0887 or FAX: (519) 372-0312

E-mail: [stan.munroe@sympatico.ca](mailto:stan.munroe@sympatico.ca)

Website: <[http://www.dbiconferencecanada.com/  
index2.htm](http://www.dbiconferencecanada.com/index2.htm)>

## **SEE/HEAR**

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**Contributions to the newsletter can be mailed or e-mailed to section editors at:**

**TSBVI Outreach**  
**1100 West 45th St.**  
**Austin, TX 78756**

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March 1st for the Spring edition

June 1st for the Summer edition

September 1st for the Fall edition

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The audio version of *SEE/HEAR* is provided by  
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**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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**Austin, Texas 78756**

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