

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

Summer 2001

Volume 6, No. 3

Table of Contents

FAMILY

A Tale of Two Children.....	2
Out of the Mouths of Babes.....	7

PROGRAMMING

Helping You and Your Child Get a Good Night's Sleep.....	8
A "Cheat Sheet" for New Teachers of the Visually Impaired Working with Infants.....	15
Q & A with Marty.....	17
Almost 100 Motor Activities for Infants and Toddlers.....	19
Reading for Everyone: Expanding Literacy Options.....	22

SYNDROMES/CONDITIONS

Early Identification of Hearing and Vision Loss is Critical to a Child's Development.....	27
---	----

NEWS & VIEWS

Off to a Good Start.....	31
Help and Hope, One Child at a Time.....	32
ECI Provider Network: Champions of Service.....	33
Creative Thinking Maximizes Parent Training Opportunities.....	34
Update About Jeff.....	37
CORRECTION! CORRECTION!.....	37
Classified.....	38

Kate's Corner

Things are momentarily quiet here at TSBVI Outreach with many of the staff out on much deserved vacations. The spring wrapped up with a flurry of activity that slide into the early part of June with Texas Focus in Ft. Worth. All reports from folks who were able to attend the conference indicate that this was another very informative event for both the families and professionals who attended and a welcome focus on students with low vision.

Outreach staff have been working on a number of other projects as well. One in particular that I am happy to report on is a project we did in collaboration with DB-Link, the National Information Clearinghouse on Children with Deaf-Blindness. My colleague, Robbie Blaha, and I have written a book, *Introduction to Sexuality Education for Individuals Who Are Deaf-Blind and Significantly Developmentally Delayed*, which DB-Link will publish. We anticipate this book becoming available in the Fall of 2001. You may contact DB-Link at (800) 438-9376 or email <dblink@tr.wou.edu> to get more information about receiving a copy. We very much appreciate DB-Link giving us an opportunity to make this happen. We hope that families and professionals in Texas and other parts of the country will find the information useful.

Robbie will also have another publication coming out soon through the TSBVI Curriculum Department. The book, *Calendars for Students with Multiple Impairments Including Deafblindness*, provides detailed information on determining which type of calendar to use with a child, designing the calendar, and transitioning a student to the next

Kate's Corner - continued on page 21

A Tale of Two Children

By Pauletta Feldman and Mary Ann Reynolds

Reprinted with permission from: *Future Reflections*, Volume 19, Number 4
published by the National Federation of the Blind, <www.nfb.org>

Note from Barbara Cheadle, Editor of Future Reflections: The following article, co-written by Pauletta and Mary Ann, was originally published in 1995 in the VIPS Parents' Newsletter, a publication of the Visually Impaired Preschool Services in Louisville, Kentucky. I was curious about what had happened in the five years since they wrote it, so I asked them if they would do an update. They graciously agreed, and their updates conclude the article. Here now, is Pauletta's and Mary Ann's A Tale of Two Children.

Pauletta: On the surface, Mary Ann and I may seem very different in that we have chosen what appears to be two diametrically opposed school placements for our blind children. But we are not very different at all in the hopes and dreams we have for our children - we have just chosen different paths to help our children achieve them. The existence of placement options expands the current and potential opportunities our children have available to them, and we have taken advantage of these options.

Mary Ann's daughter Ashley and my son Jamie have been at two opposite ends of a continuum of services that exists for the education of blind children. Ashley, who is eight and in third grade, has been in a fully inclusive, public school classroom since kindergarten. Jamie, who is ten and in fourth grade, has attended the Kentucky School for the Blind since kindergarten as a day student and this year is in a half-day placement at our neighborhood school.

Parents often ask Mary Ann and I about our children, their schools, and why we've made the decisions we have. That's the purpose of this article - to share with all of you who are, or will be, struggling with the same decisions we have faced. But as a prologue, we want to say that nothing is written in stone. What works one year for your child may not work the next. The important thing is that parents are aware of the options and know that we may choose from any of a variety of combinations to produce the best educational situations for our children. We need to know our children, their strengths and needs, and to know what's out there in order to make good decisions.

OUR DREAMS

Mary Ann: Our dreams for Ashley are the same as for our other two children: to grow up to be somebody special and unique, whether that is to be a homemaker, a teacher, a doctor, or whatever. We both want her to be happy. Some people hope and dream for jobs, independence, etc. I guess I expect that to come. When Ashley was born, she had a severe heart defect. Two years and three surgeries later, the worries of various abnormalities, the fear of hearing problems, and the diagnosis of "blindness" all but shattered our normal dreams. As sadness and abnormality crept in, we longed for happiness and normalcy. I guess I'm still developing those dreams as she grows. She wants to be a preschool teacher. If she dreams about being a teacher, that's what I dream for her. I want her to grow up, go to school, have friends, go to college, fall in love, marry, and have her 2.5 kids. That's my dream.

Pauletta: It's hard to describe all of the dreams I've had for Jamie. Some of them have remained the same and some of them have changed over time. (For instance, I don't think he'll turn out be a classical violinist - he wants to be a rock star!) As a matter of fact, Jamie has lots of careers in mind and wishes he could do them all at once - be a librarian (like his Dad), a writer, a cook in a restaurant, a teacher, an actor, a disc jockey, and a musician. When he was five he wanted to be a fireman (I could see the headlines, "Blind Fireman Rescues Woman from Burning Building!") and a policeman. Mainly, I want a happy and productive life for Jamie. I want him to be employed and on his own someday. I'd like for him to be able to go to college. But most of all, I want him to believe in himself so that he will have the gumption to pursue his own dreams, whatever they may be.

PRESCHOOL PLACEMENTS

Mary Ann: Ashley began attending preschool when she was four. Options were limited five years ago, more so than they are today. I looked for a regular preschool that would allow her to be around other children. I looked for over a year, honest! I found TWO places available. People actually hung up on me when I mentioned “blind.” People wouldn’t return my calls. I was hurt. I loved my child and wanted others to love her, too. I wanted her to enjoy preschool and learn things that I could not provide in the home. VIPS had provided intervention in the early years and through Melinda, an intervention worker, we got hooked up with Tully Preschool. We were welcomed with open arms. When we visited, the other children walked Ashley around to show her the room. After that, I knew this was the place.

Pauletta: Jamie started out at Christ the King Montessori Preschool two days a week when he was two-and-one-half years old. When he was three we switched to Kenwood Montessori, which was closer to home and where my older children had attended. There were new teachers and directors at Kenwood who wanted to build the school. They learned about us through a consultant teacher at Christ the King, and they came to us to recruit Jamie! That was wonderfully refreshing, since I had felt that I had to “sell” him just to get anyone else to give him a try! I ended up working at his preschool as a teacher’s aide, so I got to see firsthand the great things he was doing and learning. The school offered lots of hands-on multisensory learning experiences. It was an environment in which Jamie was cherished.

PREPARING TO MAKE A KINDERGARTEN PLACEMENT DECISION

Mary Ann: Ashley’s preschool years were great. Tully had an all-day program and offered kindergarten in the afternoon. Because of that, she automatically remained another year. As time went by Ashley learned the school building inside and out (she started cane training at age four). Before using the cane, Ashley would run through the halls, never worrying about bumping into other children. I soon learned that Ashley, being half the other kids’ size, needed her own independence so she could get on with learning. Because Tully is all on one level (not to mention its educational benefits) and Ashley was tiny, had heart disease, and was too brave for her own good, we decided after much thought that it was in her best interest to remain there. Our neighborhood school where my older children attended had turned Ashley down for preschool. After that, I realized that it was up to me to find and give her the best possible option.

Pauletta: I talked to a lot of professionals. I talked to lots of blind people. I tried to find out everything I could about all the special adaptations a blind child would need to succeed in life. I tried to come to grips with what were Jamie’s greatest areas of need and what were his particular strengths. I believed that learning the skills of blindness would be key to his future success. And then I visited schools to compare program strengths with Jamie’s needs. Jamie could have stayed for kindergarten at Kenwood Montessori, where there was a very strong mutual attachment. But I wanted to know what else was out there. I visited public school programs, one where there was a resource teacher and resource room for visually impaired children. I visited the kindergarten at the Kentucky School for the Blind (KSB), and knew immediately, in my gut, that this was where Jamie needed to be. (To enroll at KSB vision must be a child’s primary disability, and the child must possess communication and basic self-help skills.)

WHY WE CHOSE THE SCHOOLS WE DID

Mary Ann: Because our neighborhood school would not take Ashley during her early training years, it really was not in her best interest to move her two years later. At Tully, she knew her way around and could independently move to where she needed to go - art, music, PE, lunch, etc. Now she could concentrate on academics and not just learning a new building. I taught elementary school and knew how important those early learning years were. I felt it’s going to be hard enough - let’s not make it any more difficult than it has to be. I thank God it worked out. She is at Tully to this day and will remain until she graduates from the fifth grade.

Pauletta: There were many reasons we chose KSB. Jamie is almost totally blind with just a little light perception.

I was very concerned that he develop good Braille skills. Jamie was also physically delayed and had poor upper body strength and fine motor skills. At KSB, he could participate in adapted PE daily, and the kindergarten program focused on fine motor development and pre-Braille skills. While Jamie was in preschool, his social skills had not progressed as I had hoped. He was a very passive child. I was afraid that he would not do well in a large class - not come out of himself and not stand up for himself - so the smaller class sizes at KSB were attractive to me. I also thought it was important to his developing self-image for him to have blind friends and role models. He has been at KSB for almost six years now. However, we have begun easing him into our neighborhood school. That has been a wonderful process that could be the subject of a whole different story!

WHAT THEIR PLACEMENTS HAVE BEEN LIKE

Mary Ann: Ashley is a popular girl and has numerous friends. Because many of the Tully children live in the community, she is able to meet with them on the ball field, in the grocery store, etc. The variety of activities in our community help others to see Ashley leading a normal life, and the kids know she is part of their broader world, too, not just a part of the school. This creates friendships. Ashley has always had the help of an itinerant teacher of the visually impaired (TVI). In the early years, the TVI would Braille stories in Grade I Braille (alphabet letters with no contractions) because the American Printing House for the Blind (APH) only produced early reading materials in Grade II Braille (with contractions). Even her preschool teachers helped her with Braille, and she had Braille labels for just about everything, even the fish tank! Ashley has kept many of her friends from preschool, often recognizing their voices in the hall. When she was younger, she enjoyed stopping and talking to all the teachers. She learned so much about those around her. Because many of the children already knew Ashley, they did not over-help her, but knew when to help and when not to. They still do this. Ashley is learning how to request help and hopefully how to give it back. Her teachers have been wonderful. Her primary teachers' classes have been right next door to each other. She has had the same locker for three years. How's that for consistency! Finally, I can drop her off at the side door, and, like everyone else, she walks to her locker, puts her things up, and goes about her business. People at Tully are warm and caring. There is always a friendly welcome when she enters the door every morning. Ashley has had to miss some things occasionally to fit her special classes in. One year she fussed at me every morning because she had to miss PE to have her cane lesson. Her sister even informed me that PE was Ashley's favorite class. I told Ashley I remembered when I taught, and all the kids said their favorite classes were PE and lunch, and at least she didn't have to miss lunch! We soon learned that for every loss there was usually a gain. Her TVI has been wonderful. I am so thankful for her patient endurance and sense of humor. She has communicated regularly with us over the years and helped Ashley learn so much. She has provided extra tutoring, daily balancing of hours for Ashley between resource room and classroom, and even helped Ashley get a computer system from the Lions Club. She has been a real source of support for me. Her specialized training in vision and experience with integrating other blind children has given us confidence and hope.

Pauletta: Jamie started cane training in preschool and was able to continue with the same O&M instructor at KSB. Since kindergarten, he has received regular O&M instruction from three times each week for individual lessons to group classes with his other classmates to work on residential travel and quiet street crossings. There has been a lot of class changing at KSB, so there are lots of opportunities for Jamie to practice travel! He must travel to different buildings to participate in music, PE, and to go to lunch. Each year, his O&M instructor has worked with him on his schedule and routes. Through third grade, Jamie had adapted PE and instrumental music daily. Daily living skills have been built into the curriculum. Jamie worked on the *Patterns* series for learning to read and write Braille. *Patterns*, available from the American Printing House for the Blind (APH) is a systematic and sequential process of introducing the 178 Braille contractions. Jamie was introduced to the slate and stylus, abacus, and computer in first grade. However, it is only this year that he has finally become proficient with them. He is using the computer more and more for writing, learning the basics of word processing, and getting introduced to computer bulletin boards. He has gotten to be in three full-costume, musical productions - last year he was Gepetto in the primary grades' production of Pinocchio! Seeing the kids act on stage was such a gift. It was something I had never imagined blind children would be so good at doing! KSB has been a real support system for me. Jamie's teachers have always been accessible and

welcomed my input. They have been almost another extended family! Jamie spent a second year in third grade last year to hone some skills and to do some maturing. It also seemed a good time to explore new possibilities. We were feeling that his skills were now strong enough to move into a more integrated educational placement. Last year, after Christmas, he started attending our neighborhood school, Semple Elementary, one day each week. Our primary objective for this little experiment was social. We wanted Jamie to begin to adapt to a different learning environment and to make more friends in our neighborhood. There was mutual visitation between schools and a truly wonderful collaboration between the Jefferson County Vision Program (JCPS), KSB, and Semple administrators and teachers to make sure Jamie had what he needed. I think this easing-in process really paid off for both ourselves and Semple, giving all of us the support and time we needed to work into a comfortable relationship. This year, Jamie is going half-day, each day, to both schools. I couldn't be more proud or appreciative of my little neighborhood school, which has taken my little interloper and made him one of their own! Plans are for him to do the same for fifth grade. He has a long day, getting on the bus at 6:30 a.m. to KSB, where school starts at 7:30 a.m. for language arts and math, then back on the bus at 11:30 a.m. to Semple, where he has lunch and spends the afternoon for science and social studies until 3:20 p.m. He has music, PE, and computer at both schools. His JCPS itinerant teacher of the visually impaired has been wonderful and works with him three to four afternoons each week. His O&M instructor from KSB has worked with him on learning his way around Semple and is now working on walking between school and home.

HAVE THERE BEEN DISADVANTAGES?

Mary Ann: I've talked about the advantages. The disadvantages are that Ashley has little opportunity to meet and get to know other blind children. We sent her to KSB summer school, and she enjoyed that experience and enjoys meeting VIPS children. I am sure she has many questions she will ask another blind child when given the opportunity. We all need someone who understands. Ashley is attracted to many of the children and people in our church who have special needs and enjoys getting to know them.

Pauletta: There are always trade-offs. The main disadvantage of Jamie's placement has been that he hasn't gotten to know many children in the neighborhood and hasn't had to deal with typical classroom situations where there are many students and distractions. But I think we are working on these with the dual-placement.

FILLING IN THE GAPS

Mary Ann: Because some things may need extra attention or explanation, we all try very hard to provide as much information as possible to help Ashley understand and experience things in life. Instead of talking about the park, we go. We make cookies a lot and talk about measurements. When they are talking about specific subjects in school, we try to find opportunities to increase her understanding. We provide as many "real" experiences as possible. She has a "preschool" in the basement with real cubbies and activities and she, her sister, and their friends learn a lot in "their classroom." I try to buy tapes and allow more music than usual and know that it is important to her. It is scary living on a busy street and having a daughter who is too brave for her own good. But hopefully, she will grow up and learn to be wise in her independence.

Pauletta: Will we ever be able to fill in the gaps? There just don't seem to be enough hours in the day! I couldn't ask for more from the education that Jamie is receiving in school! He's getting all the academics plus working on many blindness-specific skills. Jamie has to master writing in three forms (Braillewriter, slate, and keyboard). He needs to work on handwriting so he can sign his name. But there are still so many gaps in his knowledge and skills. We spend three times the amount of time another sighted child would spend on science and social studies - talking while we read, creating impromptu models to build on his concepts. Homework can take a lot of time each day, especially now that he's in fourth grade. With KIRIS testing coming up, he will be staying for extended school days to practice open response tests and performance events. He also needs down time, time for friends, time to learn to do things for himself. We fit in everything we can, but we also keep in mind that he needs time to be just a kid. And we need time to be just a family!

HAPPY NOW?

Mary Ann: Maybe we all just appreciate the little things more and that makes us all smile a lot. Yes, we are very happy.

Pauletta: Jamie's a great kid, he has fantastic educational services, and we have wonderfully supportive teachers. How could we ask for more? The only ones who can really determine what will be best for your child is you and your child with the help of supportive professionals. There are creative solutions to problems. There are combinations of services that can be developed to meet your child's unique needs. The best advice we can offer about pursuing service options for your child and making them work is this: Don't be afraid to dream. Don't be afraid to look at many possible paths to the same end. Be creative. Be flexible. Be willing to compromise. Know which battles are worth fighting, and save your energy for those. Try to solve problems at the school level without alienating your support base - fragile relationships can become strong ones when they are given time to grow. Your child's teachers can be your strongest allies.

2000 UPDATE

Mary Ann: Well, after 14 years in our local public school system, we have decided to make a huge change - Ashley will attend the Kentucky School for the Blind this fall. Over the past two years she has spent many days after school just hanging out with the other kids at KSB, while attending the local school in her area. Over the years I have been intrigued with the changes that children go through once they become teen-agers. Boy, do they change! Ashley's teen-age personality is blossoming, and she is beginning to have a mind of her own. Part of her growing out of her cocoon is dealing with her blindness and all of the issues involved with it - accepting blindness as part of yourself and being proud of who you are. At KSB Ashley will meet other students who share the same challenges. She has never had this opportunity in an integrated setting. Don't get me wrong. I am not comparing the two settings. I am not advocating for or against either setting. I am merely sharing the experiences of my child. She is changing, and her needs are changing. My dream for Ashley is that she will grow strong wings and fly like a butterfly into the world as a happy and productive individual. But, right now, being in school with other blind peers will enable her to share common experiences at the academic and recreational levels. She is enjoying the conversations with the other students on issues related to their blindness. This is a new experience. We are excited to see how it will progress. For now, we are just going to take it one day at a time and see what happens. Each year is a new adventure. Looking over the horizon, I see Ashley on the road to independence.

Pauletta: A lot has happened in the five-and-one-half years since originally writing about Jamie's school placement in the VIPS Parents Newsletter. Jamie is now a sophomore in high school! Just to update, Jamie continued in a dual placement through eighth grade with KSB and our public schools, first at Semple Elementary and then at Barret Traditional Middle School. Sixth grade was rough - Barret had never had a blind student and was not accustomed to making accommodations. Their motto was, "Students adapt to us, we do not adapt to students." We knew that going in and believed that only minor adaptations would be required. Probably the hardest adaptation, which was also the biggest help, was for classroom teachers to learn how to team-teach with Jamie's vision itinerant. Barret teachers were not used to working with itinerant teachers. However, by seventh grade, things were running very smoothly. And by eighth grade, when Jamie graduated, the principal and teachers told me that one of the hardest things about losing Jamie (they had come to LOVE him) was losing his vision itinerant! The experience turned out to be a wonderful opportunity for growth for Jamie and for students and staff at Barret. While Jamie had EXEMPLARY services from our public school system, we continued to be a KSB family, too. Over the years, Jamie had made so many wonderful friends there. A disappointing aspect of his public school experience was that friendships at school did not transfer to after school hours. Jamie tried and we tried, but with the exception of one young man, Barret friends stayed at school. So, for his freshman year, Jamie went back to KSB full-time. He stayed part-time in the dorm to have more of a social life after school. That worked very well. This year he is living at school through the school week. That's been really rough for us. We've had to let go big time - let go of overseeing schoolwork on a daily basis, let go of having our youngest child at home! But Jamie is making us let go as he moves toward greater independence. He now has the active after

school life that all teen-agers want. He does jazz band after school; he's on the track team and has daily practice; he broadcasts and trains other students for the school radio station; and somewhere in there, he fits time to study and just hang out! The path we are taking in raising Jamie and ensuring that he receives a good education will continue to be one with many forks and detours. Our resolve is to continue to be open to, and flexible in, making whatever adaptations are required to meet his changing needs.

Out of the Mouths of Babes

By Paige Parrish, Parent, Tyler, Texas, <MAXBITES@prodigy.net>
and Jean Robinson, Family Specialist, TSBVI, VI Outreach

Paige, mom of Alexandria (Alex), has been gracious enough to share her experiences raising a child with blindness. Alex who is almost 9 years of age is losing what vision she has due to Leber's Congenital Amaurosis. Her mom has been diligent and creative about teaching her concepts that sighted folks take for granted. Alex, who attends Andy Woods Elementary School in the Tyler I.S.D., had been reading about different kinds of animals along with her classmates. Paige knew that even though Alex was acing the tests she didn't really have the big picture. This savvy mom called the Caldwell Zoo in Tyler to request a "hands on" tour. When the public relations director discouraged her, Paige persisted. Eventually the owner not only agreed to the tour, but personally showed Alex around the zoo. He asked that they come in the morning, before the zoo opened to the public, when the animals were just waking up and still in their private areas. Alex, her mom, and vision teacher were able to feel the ear and horn of a rhino with the help of the animal trainer. Alex explored a giraffe and trailed along its tall neck! Her face lit up when she connected the words that she previously had read to the real thing! This "aha moment" brought tears to the owner's eyes.

This experience led to another opportunity. Alex's unique way of learning made a profound impact on the veterinarian for exotic animals. He plans to contact Paige the next time they have to anesthetize a large animal; Alex hopes it will be an elephant!

Once again, Paige has paved the way for Alex to have the same opportunities as her classmates, by encouraging her to enter a local essay-writing contest. The Kimberly Clark Company, in conjunction with Brookshire Brothers grocery store, sponsored the contest. The theme was "My Favorite Teacher." Alex entered and won! One winner was chosen from each grade level for the entire district. She selected her V.I. teacher as the subject. Here is Alex's essay.

My favorite teacher is Mrs. Elsie Rao. She is my visually impaired teacher. I think that she should be selected as Brookshire's favorite teacher because she works very hard to teach me other ways to read, write and do math. But she is so much more than that. She helps me learn that my vision loss will not stop me from becoming a successful person. She believes in me even when I do not, and she has a very special way of describing the world to me. Once, I asked her why some cars did not have roofs? She said, "They are called convertibles." She just happened to own one, so she let me feel the roof go down. She said, "You really can not understand this unless you ride with the wind blowing through your hair. (Editor's note: Of course they took a ride.) My mom says that Mrs. Rao always starts with a firm foundation. I really did not understand this until I asked Mrs. Rao what concrete was. She went out and bought a bag of concrete for us to make just so I could understand. She has a big impact on my life and she also lets me teach her about being blind so together we keep on learning.

Paige reminded me that these success stories would not be possible without the support of their local school district. Connie Moore, the principal of Andy Woods Elementary, believes in "teachable moments" and understands the importance of release time for her vision teacher. Paige believes that Alex is exposed to the expanded core curriculum because Mrs. Rao not only answers Alex's many questions but involves her in finding the answer. If at all possible, Alex hears about it, reads about it, and does it. This approach pays off; the first place prize for her essay was a \$1500 gift certificate from Circuit City.

Helping You and Your Child Get a Good Night's Sleep

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

A version of this article appeared in the April 1994 edition of *P.S. News!!!*

Editor's note: This article is based on information presented by Ray Condon at a workshop in July 1993.

“Oh those sleepless nights will break my heart in two.” Truer words have ne'er been spoken, particularly by parents of children with disabilities. While anyone might find a night of restful sleep elusive, it can be a unique challenge for children with disabilities, and their families.

When looking for causes and solutions to a problem like this, parents and school staff should work together as a team. A team will be best able to develop an intervention plan that succeeds. The kinds of stimulation provided at school during the day influence a student's ability to sleep at night, and a sleepy student has difficulty learning. A child's sleep problem is everyone's problem.

PROGRAMMING

WHAT IS SLEEP?

Identifying some common facts about sleep will help distinguish general characteristics that most people experience from problems unique to children with disabilities.

1. The function of sleep is controversial. Some people believe sleep is an internally controlled period of non-responding, during a phase of the circadian cycle, that promotes energy conservation. Others think sleep is a restorative or balancing process that occurs after energy consumption. Everyone agrees that sleep is a state of consciousness.

2. Sleep occurs in repeating 70 to 100 minute cycles of two states, REM and nonREM. In the REM state, when dreaming happens, the brain is active but the body is effectively paralyzed. In the nonREM state, muscles are relaxed but can move. This state (in 4 stages from drowsy to deep sleep) may serve a restorative function, and is most typically identified as sleep.

3. Circadian cycles are repeating biological cycles approximately 25 hours long, in which sleep, waking, alertness, activity, rest, changes in body temperature, hormone release and many other body functions take place. This cycle is reset daily to the 24 hour clock by internal processes and external cues such as daylight and darkness, mealtimes, social structures, bedtime and especially time of waking. Daily routines are critical for resetting the biological clock, because external cues influence a body's internal processes. Chronically delayed sleep can lead to reversal of a person's daily schedule.

4. Wakings and arousals, typically 3 to 7 per night, are normal for children and adults. They're most likely to happen at the end of a REM state and, among other things, enable us to change positions in bed. Usually we're unaware of them and resume sleeping within a few seconds. Problems can arise when a person has difficulty going back to sleep after an arousal.

5. People require varying amounts of sleep and generally need less sleep with age. Fragmented or fitful sleep is more common after age 7, and especially for people over 45.

6. Most children sleep deeply during the first and last few hours of night, and more lightly between those times.

7. Sleep/wake cycles can be easily disrupted in people sensitive to change. Irregular sleep/wake patterns lead to significant alterations in a person's mood, energy level, sense of well being and ability to learn new information. A tired child may not act tired, but be irritable, inattentive, impulsive, aggressive, hyperactive or socially withdrawn. Behavioral indicators like these might suggest a sleep problem.

8. Causes of disrupted sleep differ between people. An individual's sleep history can be looked at to help identify patterns of problems.

SLEEP PROBLEMS OF CHILDREN WITH DISABILITIES

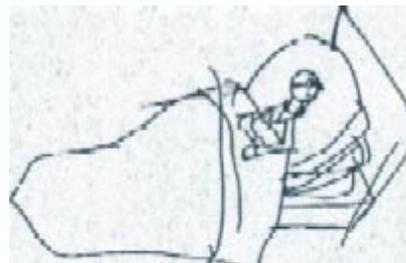
Though much has been published about the sleep and sleep problems of adults and children, there's little information about sleep-related issues of children who are visually impaired or deafblind. A review of several studies, however, indicates that children with disabilities are more likely than those without disabilities to have sleep problems.

Our environment provides many cues that help us wake up, stay awake during the day and go to sleep at night. The communication difficulties often experienced by a child with multiple disabilities make understanding and appropriately responding to these cues more challenging. Other factors can also effect sleep. For example, the medication a child is taking may cause daytime drowsiness. A child with high or low muscle tone might be unable to independently change positions in bed, which is important for a good night's sleep. Some children with profound disabilities have difficulty intentionally regulating their levels of wakefulness and move through sleep, drowsiness, alertness and agitation, independent of environmental cues. Individuals who are totally blind experience a high incidence of sleep phase disorder (where days and nights are gradually reversed), in part because they don't receive the light cues that influence their circadian rhythms.

Some of the sleep concerns often identified by parents of children with deafblindness include night wakings, reversed schedules (sleeping in the day), whether or not to use medication, irregular and fragmented sleep, difficulty falling asleep, short durations of sleep, night wandering, extensive screaming or crying at night, and sleeping with parents.

Children may never outgrow their sleep problems, but many situations can be improved with intervention. It's important to see a sleep problem as symptomatic of one or more other problems, then identify and address those problems. Often there are no easy answers, but regular contact between the parents and professionals trying to resolve a persistent sleep disturbance helps everyone on the team stay energetic and optimistic. An outside consultant can contribute objectivity and perspective to a team's overall game plan. In some cases, this may be all that's needed to solve a child's sleep problem. When seeking assistance from the medical profession, it's difficult to find a person with both an understanding of sleep disorders and experience helping children who have multiple disabilities. A knowledgeable professional, with the interest and willingness to work as part of a team, can be a valuable resource. The American Academy of Sleep Medicine has information about sleep disorder clinics in Texas, and can be contacted at:

American Academy of Sleep Medicine
6301 Bandel Rd., Suite 101
Rochester, MN 55901
Phone: (507) 287-6006
Website: <www.AASMnet.org>



“Sleep is Boy”

by
Wendy Haynes
1975

EXPLORING SLEEP BEHAVIORS

Sleep disorders are behaviors, triggered and maintained for specific reasons. After the possible causes for a behavior have been identified, intervention strategies can be designed.

Sleep Hygiene

As mentioned earlier, sleep patterns are influenced by external conditions and events. Setting up and maintaining good “sleep hygiene” is the first step in addressing a child's sleep problem. Factors that will improve sleep include good health, exercise, a meaningful and consistent daily schedule, a balanced diet and appropriate amounts of food, a bedtime environment that encourages sleep, and a pleasant, relaxing sequence of activities in the hour before bedtime.

Collecting Information

In addition to establishing conditions that make sleep more likely, it's helpful to systematically collect information about a child's sleep behaviors. Doing this will help indicate tendencies and patterns that might not be seen if memory alone is relied upon. Clearer understanding of a sleep problem's causes will make successful intervention more likely. Since improvement and change can be slow, documentation also charts progress. In addition, this information will highlight the severity of a child's sleep problem. A child who is routinely awake at night, and sleeping during significant portions of most school days, is not learning very much. An intervention strategy coordinated between school and home will improve the quality of this student's education. A "Daily Sleep Diary," completed over a period of time, can help provide a picture of current and changing sleep behaviors.

PROGRAMMING

Daily Sleep Diary			
Name: _____		Date: _____	
Planned Bedtime: _____		Actual Bedtime: _____	
	cooperated	resisted	strongly resisted
Cooperation going to bed:			
Cooperation staying in bed:			
Night wakings:	begin	end	total time
#1			
#2			
#3			
#4			
#5			
#6			
Total time of all night wakings:			
End of sleep - Wake-up time: _____			
Total amount of night sleep (minus night wakings): _____			
Child's mood upon final awakening: _____			
Naps:	begin	end	total time
#1			
#2			
#3			
#4			
#5			
#6			
Total time slept (naps and night sleep):			
Comments and observations: _____			

Children generally sleep less as they become older, but each child’s sleep requirements are unique. Knowing the total amount of time that your child sleeps in a day will have implications for intervention. For example, because naps taken during the day count toward the total number of sleep hours, eliminating daytime naps may help some children sleep better at night. Or, moving naps from 4:00 p.m. to 2:00 p.m. might improve sleep onset at bedtime.

The time a child is awakened is one variable that can be externally controlled and followed consistently. A routine weekday wake up time that changes over the weekend may make adjustment to Monday mornings more difficult.

A child’s mood upon final awakening in the morning will be one measure of the previous night’s quality of sleep.

Interpreting Information

Now that sleep information has been collected, the “ABC Record of Sleep Problems” can help pinpoint possible reasons for the problem behavior or behaviors. In some cases, an event occurring prior to a sleep problem could be causing the problem sleep behavior. Changing one or more preceding events may make the behavior less likely to occur. A child who roughhouses with siblings before going to bed (antecedent), then remains awake for several hours (behavior), might fall asleep more easily if activities before bedtime are less energetic. In other situations, reinforcing consequences may motivate a child to repeat a behavior. A child who is given a snack (consequence) after getting out of bed (behavior) might learn to get out of bed more frequently. Behaviors won’t appear as often when their consequences are less rewarding, especially if effective, more appropriate alternative behaviors are taught.

ABC Record of Sleep Problems			
Name: _____		Date: _____	
Antecedents	Behavior	Consequences	Reason
Describe what happened before the behavior occurred (what, who, where and when).	Describe the behavior (include how it began, as well as its intensity, how long it lasted and how many times it occurred).	Describe what happened after the behavior occurred (any change in the environment or reactions from people).	Why did my child behave in this way? What did the behavior accomplish?

INTERVENTION TECHNIQUES

Sleep problems have traditionally been addressed differently by the medical and behavioral communities. Recently though, these approaches have become more consolidated.

Behavioral Intervention

Information collected in the “Daily Sleep Diary” and “ABC Record of Sleep Problems,” will help the team identify patterns of problems and possible interventions. Any program that’s implemented must be individualized for each child’s needs and circumstances. Several intervention plans are described below. Each has a different goal and procedure for addressing a particular sleep problem. A mix and match approach might be helpful. When teaching a child new behaviors, the positive attitude of parents, teachers and other team members is crucial for success. An intervention plan should be implemented at a pace that’s comfortable for all participants.

PROGRAMMING

1. *Positive Bedtime Routine*

Problem: Bedtime resistance

Goal: To teach a child bedtime cooperation

Procedure:

1. Determine child’s natural bedtime
2. Develop a 20 minute fixed sequence of enjoyable, calming pre-bed activities (warm bath, lotion rub, story time in a rocking chair, etc.)
3. Begin the sequence 20 minutes before child’s natural bedtime
4. Follow the sequence and praise child for completing each activity, including going to bed

Things to consider: Pre-bedtime routines will prepare a child physiologically and behaviorally for bed. Calming activities can be identified and learned at school, then practiced at home during the bedtime sequence and at other times.

2. *Graduated Extinction*

Problem: Bedtime resistance and night wakings

Goal: To gradually withdraw the consequences maintaining a problem behavior and help a child accept change calmly through “progressive learning.”

Procedure:

1. Implement good sleep hygiene practices
2. Determine when child should go to bed
3. Put child to bed; if tantrums persist after 1 to 2 minutes, provide neutral reassurance; repeat as often as necessary
4. Over time, ignore tantrums for increasingly longer intervals, up to a maximum of 20 minutes
5. Respond consistently within each episode

Things to consider: A calm child will return to sleep more easily than one who becomes upset.

3. *Extinction*

Problem: Bedtime resistance and night wakings

Goal: To totally withdraw the consequences that maintain a problem behavior through “planned ignoring”

Procedure:

1. Implement good sleep hygiene practices
2. Determine when child should go to bed
3. Put child to bed and ignore tantrums
4. If child gets out of bed, direct child to return with minimal attention or interaction
5. Respond consistently in every episode

Things to consider: Extinction may work with some children, especially those who are younger, nonambulatory, and/or not “fighters.” Other children might continue struggling, then become physiologically agitated and difficult to calm.

4. *Scheduled Awakening*

Problem: Night arousals and night wakings

Goal: To retrain a child who regularly wakes up spontaneously to awaken under new conditions

Procedure:

1. Determine time(s) child routinely wakes up
2. Awaken child 15 to 30 minutes earlier
3. Follow a routine procedure with awakened child (hold, console, change diaper, etc.)
4. Return sleepy child to bed

Things to consider: A child who associates waking up with reinforcing consequences (parents come, play, snack, etc.) is conditioned to be awakened by parents. After the initial retraining, time intervals between awakenings are gradually increased.

5. *Bedtime Fading*

Problem: Bedtime resistance and night arousals

Goal: To shift a child’s natural bedtime to a more acceptable time and reduce night arousals

Procedure:

1. Eliminate all daytime sleep (sleep restriction)
2. Determine child’s natural bedtime within 15 minutes
3. Follow positive bedtime routine sequence. Begin the sequence 20 minutes before child’s natural bedtime
4. If child falls asleep within 15 minutes, begin the sequence 15 to 30 minutes earlier the following night
5. If child does not fall asleep within 15 minutes, begin the sequence 15 to 30 minutes later the following night, then return to step 4 when child begins sleeping

Things to consider: External circumstances and habits can help build associations about going to sleep. It’s important to continue increasing the percentage of successful bedtime experiences.

Whatever intervention strategy is attempted, it's important to negotiate a level of cooperation acceptable to both child and adult, then slowly increase expectations. Mutual support between adults is also essential for maintaining perspective, confidence and calm.

Medication and Chemical Intervention

If all other attempts at finding a solution through behavioral intervention have been unsuccessful, the use of medication may be appropriate as a final resort. Medication alone is of limited benefit. It might be a short term solution that provides temporary or intermittent relief from insomnia, or may be used in combination with a more permanent behavioral retraining approach that changes a persistent pattern. When administered over a long period of time, medication can sometimes actually be counterproductive to sleep. It may cause "rebound" insomnia, impede or impair the quality of a person's sleep, and/or produce adverse side effects. Tolerance to medication might also develop, making increased dosages necessary for achieving desired results. Before experimenting with medications or nutritional approaches such as vitamins and herbal remedies, consult with a neurologist, psychiatrist, or physician familiar with sleep disorders.

CONCLUSION

While learning to get a good night's sleep may be a slow, labor intensive process for you and your child, the results will be well worth the effort. Good luck, good night and sweet dreams!

REFERENCES

- Adams, L. A. & Rickert, V. I. (1989) Reducing bedtime tantrums: comparison between positive routines and graduated extinction. *Pediatrics*, 84, 756-761.
- Durand, V. M. & Mindell, J. A. (1990) Behavioral treatment of multiple childhood sleep disorders. *Behavior Modification*, 14, 37-49.
- Ferber, R. (1985) *Solve Your Child's Sleep Problems*. New York: Simon and Schuster.
- Finnie, N. R. (1975) *Handling the Young Cerebral Palsied Child at Home*. 2nd Edition. New York: E. P. Dutton.
- Nakagawa, H. Sack, R. L. & Lewy, A. J. (1992) Sleep propensity free-runs with the temperature, melatonin, and cortisol rhythms in a totally blind person. *Sleep*, 15(4), 330-336.
- Palm, L., Blennow, G. & Wetteberg, L. (1991) Correction of non-24-hour sleep/wake cycle by melatonin in blind retarded boy. *Annals of Neurology*, 29(3), 336-339.
- Piazza, C. C. & Fisher, W. (1991) A faded bedtime response cost protocol for treatment of multiple sleep problems in children. *Journal of Behavioral Analysis*, 24, 129-140.
- Rickert, V. I. & Johnson, M. C. (1988) Reducing nocturnal awakening and crying episodes in infants and young children: A comparison between scheduled awakenings and systematic ignoring. *Pediatrics*, 81, 203-212.
- Stores, G. (1992) Annotation: sleep studies in children with a mental handicap. *Journal of Psychology and Psychiatry*, 33, 1303-1317.
- Tzischinsky, O., Skene, D., Epstein, R. & Lavie, P. (1991) Circadian rhythms in 6-sulphatoxymelatonin and nocturnal sleep in blind children. *Chronobiology International*, 8(3), 168-175.

A “Cheat Sheet” for New Teachers of the Visually Impaired Working with Infants

By Nancy Toelle, Coordinator, Quality Programs for Students with Visual Impairments
and Ann Rash, Teacher Trainer, TSBVI, VI Outreach

One of the factors that makes working with students with visual impairments an interesting undertaking is the range of ages we serve in Texas. With the help of the animal trainer, Teacher of the Visually Impaired’s (TVI) work with visually impaired students from birth to age 22. Each age has its own considerations, rewards, and concerns. This article will outline a beginning approach to providing services for infants.

The first step in providing educational services for any student is determining eligibility. Eligibility criteria differ for infants. They are eligible based on the existence of a documented eye condition and suspicion of future VI needs rather than on current demonstrated needs. Eligibility is decided by the Individualized Family Service Plan (IFSP) team based on assessments and the wishes of the family. IFSP = Individualized Family Service Plan and is equivalent to the IEP, but differs radically in content. If an infant is eligible for vision services, be sure to go through the typical enrollment procedure for your district. It is important for your district’s funding that they are included in PEIMS and are on the TEA Annual Registration of Students who are Visually Impaired.

The TVI’s role in determining eligibility

- Receive the screening for visual impairment and current eye exam report from ECI.
- Perform the FVE and LMA (Functional Vision Exam and Learning Media Assessment), address the need for an O&M evaluation, functional blindness, a low vision evaluation, assistive technology and devices, other services, and identify appropriate learning media.
- Assist with developmental assessment and share with the ECI assessment staff information about the impact blindness/low vision has on normal development.
- Ensure that screening for deafness is performed by ECI staff.
- Ensure that a Texas Commission for the Blind children’s caseworker is involved with the family.
- Maintain an eligibility folder in the district.

Working in coordination with ECI agencies, TVIs participate in the referral process, and are part of the IFSP team. We work within their system as an adjunct to their services.

How the role of the TVI working with infants differ from the role with students aged 3-22

- Time considerations: The calendar for this process moves very quickly. Service cannot be interrupted for more than 2 weeks at a time during the course of a calendar year, unless parent requests it.
- Year-round service: service continues at the same frequency decided upon at the annual IFSP meeting through the summer months unless a change is requested by parents.
- Documentation: Service must be documented according to ECI requirements, with copies provided to ECI and the parent.
- Transition: The process for transitioning to post ECI programming goes according to a fixed schedule and sequence and starts 90 days before the child’s third birthday. The child may or may not transition to a PPCD program (Preschool Program for Children with Disabilities - a public school program). The program that’s selected should best meet the child’s needs.

The TVI's role in developing an IFSP

- The TVI helps analyze and share the results of the child's FVE and LMA with ECI staff.
- It's important to provide ECI staff with information on early intervention related to vision.
- The TVI must attend all IFSP meetings.
- In an IFSP meeting, parents select and prioritize what they want for their child. The IFSP is not based solely on assessed educational needs.

The TVI's role in providing services to family and infant

- Bring in information and resources related to the child's visual impairment, act as part of the instructional team to implement IFSP, enable parents and other caregivers to follow through with child by "role releasing."
- Observe child with caregivers to see what's currently being done.
- Stress from the beginning that change/learning occurs in direct relation to the frequency of the infant's instruction/opportunity to learn and use new information and skills.
- Share with the team members the relationship between concept development and opportunities to move and actively interact with the environment and community.
- Work as a team with ECI staff serving the student, including the occupational therapist, physical therapist, speech therapist, instructional staff and case manager. Provide them with your expertise and learn from theirs.
- Coordinating team time can be difficult, but working together will promote a holistic approach to the child's needs. This should include anything from feeding issues to problems with sleep habits and growth.
- Research the child's eye condition if it is unfamiliar, so you can inform the team of current or future educational or medical implications.
- As needed, attend eye medical appointments and/or low vision clinical visits to learn more and help parents understand their child's eye condition.

Resources helpful to TVIs

- INSITE Developmental Checklist Instructional Manual: This checklist assesses all areas of development. It contains illustrations based on normal development with adaptations for children with sensory impairments and multiple disabilities. The checklist can be used by teachers and caregivers to develop appropriate goals and activities for the parent. Call Hope, Inc. at (435) 245-2888 or check their website at <www.hopepubl.com>.
- Blind Children's Center Publications: These educational booklets are written for teachers and parents. They cover topics on nurturing, feeding, movement, etc. Call them at (800) 222-3566 or check their website at <www.blindcntr.org/bcc/pubs.htm>.
- Visit the TSBVI website, <www.tsbvi.edu>, and conduct searches for topics you need. From there, you can access links that contain pertinent, infant-specific information. You may also want to search the archives of the *SEE/HEAR* Newsletter for topics such as potty training, communication, Little Rooms, and concept development.

Tips from old teachers to new ones

- Hold and play with the baby so the two of you can bond. Make your time with the child pleasurable. You will be a more effective service provider and might give parents some useful ideas about bonding with their baby.
- Stress that you are providing parent-infant training as a team: the parents with expert knowledge of their child and you with expert knowledge of visual impairments.
- Shoot for the stars with every infant; maintain an “anything is possible” attitude.
- Visit the child often enough to make a difference.
- If the child is not responding as much as you would like, become a detective and search out possible reasons (time of day you visit, previous therapies that day, seizure activity, medications, etc.).
- Be reliable about appointments and encourage your parents to do the same.
- Assist parents in developing self-advocacy skills by providing resource information to them.
- Play an active role in the child’s transition to public school. Coach parents about the ARD/IEP process.

If this is the first infant you’ve become involved with, seek assistance from a mentor teacher. If one is not available, keep in mind that every TVI has a long list of firsts in his or her career: first braille student, first student with severe multiple disabilities, first gifted low vision student, first adaptive technology user, AND first infant. You will feel inadequate, but competency will develop over time. One of the hallmarks of successful TVIs is that we seek out resources, conduct research to find answers to pressing questions, and feel comfortable taking responsibility for jumping in and doing things we’ve never done before. The determination to willingly accept that responsibility is critical to developing the array of skills needed by a typical itinerant TVI.

Q & A with Marty

By Marty Murrell, VI Program Administrator, Texas Education Agency

Editor’s note: Marty recently received some e-mailed questions about issues related to vision services for young children. Here are the questions and her responses.

For children from birth through 2 years of age, who should make the referral for an orientation and mobility (O&M) evaluation? Can it come directly from one team member or should the referral be an IFSP team decision? What if the services are provided by the education service center?

Services to a child with a disability (birth-2) are provided as a result of a decision by the child’s IFSP team. Assessment is considered a service and therefore the IFSP team should determine the need for the assessment.

If the parent, the vision teacher, or anyone else on the team suspects there is a need for an O&M evaluation, then that should be discussed in an IFSP meeting. The team determines if there is, in fact, a need, who will do it, when it needs to occur, etc. If the IFSP team agrees that there is a need, then the ECI program provides the notice to the parents and obtains the parent’s consent according to IDEA-Part C requirements. Once the consent is obtained, ECI will follow the previously arranged logistical procedures to provide to the district the appropriate paperwork, including such things as copies of the notice and consent.

According to the ECI/TEA MOU, the district is responsible for providing orientation and mobility services, which include evaluation. If the district relies on O&M evaluation and instruction provided by an education service center (ESC), the district should forward appropriate referral information to the ESC, according to procedures set forth by the ESC.

Sometimes physicians are hesitant to estimate visual acuities for very young children. How should this be documented on the Texas Eye Examination Report?

For most infants, an eye doctor should be able to get a general idea of acuity from direct ophthalmoscopy. Reluctance to give an estimate may be a result of not knowing specifically how the information will be used. Sometimes this can be addressed by providing technical assistance to the doctor. If the doctor indicates that he/she was unable to test and does not give any estimation of visual abilities, then there may be a need for an evaluation by a doctor with more experience and skill with similar children.

If the doctor has had little experience with young children, especially those who are very difficult to assess, there are two excellent videos by Deborah Chen, Ph.D. and Deborah Orel-Bixler, Ph.D., O.D., that can be shared with the doctor to demonstrate effective diagnostic techniques to use with babies. The titles are “Vision Tests for Infants” and “What can Baby See? Vision Tests and Interventions for Infants with Multiple Disabilities.” These may be purchased from the American Foundation for the Blind or may be available on loan from your regional education service center or the TSBVI.

When referring children to the eye doctor, parents should be directed to doctors with the expertise to provide the information that is needed to make decisions about the needs of the child.

Sometimes it takes several weeks or even longer to obtain the eye report from the eye doctor. How should we document this? Do you have any suggestions?

For students 3 years or older who need eye reports as part of their special education evaluation, the district can use such things as logs or contact reports to document attempts to get copies of the reports. However, this documentation does not eliminate the district’s responsibility to adhere to the required timelines.

Since the cost of the eye doctor evaluation and report is a district responsibility, the district does have the option of choosing who will provide the evaluation and report. If a specific doctor does not respond to reasonable timelines, does not provide the information the district needs, and does not respond to efforts by the district to explain the critical need for timely and quality information, the district should identify doctors who will do these things, and refer students to them. The district may establish a contract with a specific doctor in order to meet its responsibilities under IDEA.

For children under 3 years, obtaining the eye doctor evaluation and report is the responsibility of the ECI program.

Timely eye reports may be an issue that can be addressed effectively through the Regional Plan for Students with Visual Impairments, since the planning group includes the agencies for which this is typically a problem (ECI, TCB, and districts.).

Some strategies that have been suggested by others include visiting with the doctors to share information; inviting doctors to a luncheon meeting; developing informational brochures/packets for the doctors; developing a cover letter to accompany the eye report form explaining the critical need for timely and complete information.

PROGRAMMING

Almost 100 Motor Activities for Infants and Toddlers

By Olga Uriegas, VI and O&M Specialist, Region 11 Education Service Center

Editor's note: This article first appeared in the Fall 1996 issue of SEE/HEAR, almost five years ago, but we thought it was worth reprinting for our readers who may not have received SEE/HEAR back then. Olga's ideas are pretty easy to implement. However, you may want to consult with your child's Orientation & Mobility Specialist about where to begin, given your child's current skills. She/He may also be able to demonstrate the best ways to support the baby's body as you help him/her with specific movements.

Initial orientation and mobility lessons should be with and for the parents of children with visual impairments. Here are some things you can do, Mom and Dad, with your infant or toddler.

Mom and Dad hold baby close to your body, let him/her hear your heart beat, smell your scent, bond with you, etc.

Say the baby's name as you touch him/her.

Mom and Dad, talk to your baby while you actively move the baby's body.

Mom call baby's name while Dad assists baby to turn from back to side.

Rattle toy and assist baby to turn from back to side to touch the noisy toy.

Dad or Mom assist baby to turn from back to left side and back to right side while in the crib, on the bed, or on the floor.

Mom or Dad assist baby to turn from stomach to right side or stomach to left side while in the crib, on the bed, or on the floor.

Mom or Dad assist baby to turn from stomach to back, from back to stomach.

Mom or Dad assist baby to turn from back to front using a blanket.

Say the baby's name as you touch him/her, talk to the baby, tell him/her what you are doing.

Lie the baby on his/her back and gently massage baby lotion on the baby's arms. (Talk to baby and tell him or her "This is your arm.")

Gently bring the baby's hands together and massage baby lotion on those little hands.

Lie baby on his/her back and gently massage baby lotion on his /her legs. (Talk to the baby and say, "This is your right leg.")

Lie baby on his/her back and gently massage baby lotion on the baby's tummy. (Talk to baby and tell him/her "This is your tummy.")

Perform body massage while offering consistent body part labeling, rhythm (sing!) and language.

Lie baby on his/her stomach on top of Dad's stomach, baby should be facing Dad's chest/neck area (Dad, talk to the baby).

Lie the baby on his/her stomach on your knees and rock calmly and slowly while talking or singing a lullaby.

Lie baby on his stomach, in your lap and gently rock him/her while singing, stop rocking when you pause in your singing.

Enjoy your baby!

Carry baby in front baby pack, let body awareness and bonding take place.

Lie baby on his/her stomach on favorite blanket and give the baby a ride across the bed.

Lie baby on his/her stomach on a favorite blanket and give the baby a ride across the carpet or the wooden floor or the grassy backyard.

Mom or Dad help baby to turn in the crib or the bed from stomach to back.

Dad and Mom assist the baby to turn to noisemaking toy that you are holding. Gently guide baby's hand toward the sound of the toy. Assist the baby with grasping a toy. Allow him/her plenty of time to explore the toy. Vary toys, but at first explore one or two toys which the baby prefers.

Gently guide baby's hand toward the crib slats. Then guide the hand to grasp and shake (attach noise makers to the top of the slats).

Assist baby to reach for a noisy mobile suspended from the crib.

Combat crawl (with stomach contact) in the crib, on the carpet, on the linoleum floor. Combat crawl in cross pattern (with stomach contact) on the wooden floor.

Straddle baby and assist him/her to creep across the surface moving arms, then moving arms and legs.

Straddle baby to assist him/her to creep across surface at least 5 feet in a cross pattern.

Assist baby to maintain sitting position for at least one minute.

Have the baby sit with the sofa as a support. Place a small beach ball (with rice inside) in your baby's lap.

Sit baby in the infant seat and explore a favorite toy.

Sit baby in the infant seat placed on the grocery cart, while Mom brings items to touch, smell, and feel before she places them in the cart.

Sit in a warm sandbox with pillow as support.

Sit in warm sudsy water in the bathtub with Mom as support.

Sit the baby in his/her high chair and explore a favorite toy.

Mom or Dad sit behind baby and with your hands move baby's hands to play patty cake.

Place baby on his/her tummy, assist baby to push up on hands.

Roll a beach ball from Mom to baby, from Dad to baby, etc.

Guide baby by the forearm (rather than a hand) to reach noisy toy.

Assist baby to pull self to standing positions using support.

Assist baby to stand and maintain his/her position with support.

Dad, stand baby on your lap, support baby at trunk and waist.

Allow baby to assume standing position without support.

Assist baby in grasping a toy by lightly guiding the arm from the shoulders.

Mom and Dad support baby to make walking movements.

Let the baby walk with the support of the sofa, table or bed.

Walk the baby without support from objects.

Walk without support of objects with his/her arms outstretched with a wide base at the feet.

Walk with weight evenly distributed, toes pointed in the direction he/she is headed.

Walk from Mom to Dad with arms swinging at his/her side.

Mom and Dad give baby the opportunity to walk on even and uneven surfaces . . . sloping hills, driveways, etc.

Ascend steps on all fours by creeping or scooting.

Make stair ascending movements with support from Mom or Dad.

Ascend steps alternating forward foot (one foot per step).

Descend back door steps on buttocks by scooting.

Make stair descending movements with support.

Descend front door steps one at a time (both feet on each step) then progress to using alternating forward foot (one foot per step).

Locate the top step.

Descend 5 step stairs.

Stop at the front/back door stair landing.

Make running movements, while holding his/her hand.

Run together, hand-in-hand.

Kate's Corner - continued from page 1

level of calendar usage. It also provides information about how a calendar can serve as a tool not only for scheduling, but more importantly for building receptive and expressive language and conversational skills. I am very excited about this book. I think parents will find it easy to understand and quite helpful in getting a calendar system going with their child.

Another event the gang here in Outreach is looking forward to is having Holly Cooper, our new Technology Specialist, join us in August. Holly has been an itinerant teacher of the visually impaired in Lewisville ISD and Dallas ISD, a classroom teacher of children with multiple disabilities in Ft. Worth, and has had experience with deaf and deafblind students as a teacher aide and interpreter in Mesquite and as a graduate assistant at Callier Center for Communication Disorders in Dallas. Holly has long had an interest in assistive technology and augmentative communication systems. She also served on the assistive technology team in Lewisville ISD. We are glad to have Holly join us and know that you will be glad to see her out and about in Texas this next school year.

Sharon Nichols, our other Technology Specialist, is thrilled to have a technology partner with Outreach next year. She is looking forward to working with Holly and having her support in meeting the technology needs of the staff and students in the local ISDs.

Please take time to complete the annual SEE/HEAR and Outreach survey included in this edition of SEE/HEAR. Your feedback on the newsletter and other Outreach activities is very important to us as we plan for the coming year. We really do read every one of them and many of the changes made to SEE/HEAR have come from the feedback you sent to us. We also utilize this information in planning new workshops and other training activities. So, before you sit down to read SEE/HEAR, please take a few minutes and fill out the survey.

Reading for Everyone: Expanding Literacy Options

By Cyral Miller, TSBVI, Director of Outreach
and Ann Rash, Teacher Trainer, TSBVI, VI Outreach

Instruction in the use of alphabetic braille has become a hot topic across the state and nation. Also known as uncontracted or Grade 1 Braille, the term refers to a braille code made up of the letters of the alphabet, punctuation symbols and the number sign. It has 180 rules. In contrast, contracted or Grade 2 Braille consists of the alphabet plus 189 one cell and two cell contractions representing various combinations of letters. Contracted braille, with 450 rules, is a more complex system of letters plus whole word and part word contractions. Grade 2 Braille is regarded as the standard form of literacy for blind individuals. It is endorsed for its space-saving properties and for increased reading speeds achieved by accomplished readers. Since the 1950s most published materials from the American Printing House for the Blind and other braille producing organizations have been produced in Grade 2 Braille, and most instruction provided to braille reading students in both local and specialized schools has been in the contracted form.

The VI Outreach Team at the TSBVI became interested in alphabetic braille as a way to increase literacy options for students with visual impairments. There is a national search for strategies to help more blind and visually impaired students develop competence in reading and a sense that many students who could and should be readers are not mastering braille. During on-site visits to schools and in conversations with teachers of the visually impaired (TVI's), we have encountered students who struggle for reading competency despite adequate levels of specialized services. Other students are not offered braille instruction because additional disabilities are thought to limit their ability to read braille contractions. We became familiar with *One is Fun: Guidelines for Better Braille Literacy*, by Marjorie Troughton, written in 1992. In that Canadian publication (available to download from the TSBVI website at <www.tsbvi.edu>), Ms. Troughton reviewed research on approaches to teaching braille literacy, comparing instruction in contracted and uncontracted braille. She put forth compelling arguments to reconsider the current practice of introducing braille with Grade 2 contractions. We invited Dr. Linda Mamer from British Columbia, Canada to present *One is Fun* materials at the Texas Focus conference in El Paso. She reinforced the idea that introducing braille with uncontracted systems may offer greater literacy opportunities for many of our students.

To further explore this issue, we surveyed selected professionals with expertise in braille literacy and looked for written documents. There were four questions on our survey:

1. Have you had experience teaching or observing the instruction of uncontracted braille?
2. What students, in your opinion, might be good candidates for short-term instruction in uncontracted braille (to be followed by instruction in contracted braille)? Why? Let us know how you define short-term.
3. What students, in your opinion, would be good candidates for long-term instruction in uncontracted braille (and won't switch over)? Why?
4. Please share with us your knowledge of research relevant to practitioners making decisions on which type of braille instruction is appropriate for specific students.

We received responses from 16 individuals, including Tanni Anthony, Dr. Anne Corn, Francis Mary D'Andrea, Dr. Cay Holbrook, Dr. Alan Koenig, Dr. Linda Mamer, Dr. Sally Mangold, Dr. Dixie Mercer, Debra Sewell, Anna Swenson, Nancy Toelle, and 5 TVIs from California and Colorado. All 16 respondents had experience teaching or observing instruction in uncontracted braille, thus confirming widespread use of this technique. We have included many of their survey comments below along with what we have learned from reading and discussions. In a presentation on this issue at the 2001 Texas AER conference, many participants acknowledged using this method with students. We

were interested to find that several admitted to feeling guilty at trying alphabetic braille, because they had been taught that *real* braille is Grade 2 (contracted) Braille.

There are a variety of students for whom the short-term teaching of alphabetic braille should be considered. Most survey respondents suggested that beginning readers and adventitiously blinded students in particular would benefit from learning braille introduced in uncontracted form.

Beginning readers in early elementary classrooms typically are taught with phonics-based instruction. In Texas, the Texas Reading Initiative, a research-based program developed in 1997 and implemented statewide, relies heavily on phonics for early instruction. Jennifer Dorwin, a home counselor with The Blind Babies Foundation in California noted, “Many young sighted readers use the method of phonics to decipher words and learn how to read. I think it is only fair that we do not deprive our braille readers of the same processes.” Other survey responses also highlighted the correspondence between alphabetic braille and regular print. For example, Debra Sewell said, “Students in a general education classroom using a skills-based phonetic approach to reading” would be good candidates for beginning with alphabetic braille. Alphabetic braille is a direct parallel to print, with letter-by-letter reading and writing, so phonetic rules are the same for both. In Grade 2 Braille, contractions frequently combine syllables and groups of letters into one sign.

Nancy Toelle shared an experience of teaching Grade 1 Braille to a kindergarten student, who learned to read and write at the same rate and using the same methods as her peers. In addition to direct instruction by her TVI, all other classroom activities throughout the day incorporating the language arts were performed alongside her classmates using the same materials in Grade 1 Braille.

Students who lost their vision in later years and needed to switch from print to braille were also seen as good candidates for learning alphabetic braille, at least initially. “Most adults who have read print need to experience successful reading in braille as quickly as possible in order to maintain the motivation to learn. Uncontracted braille allows them to read adult literature soon after learning the alphabet,” wrote Sally Mangold in her response to our survey. As Harley noted, “A most important factor in the braille reading program for the late newly blinded is the provision for success in reading since newly blinded persons are generally insecure and are very sensitive to failure.” (Harley et al, 1987)

Many survey responses also indicated that alphabetic braille is a good choice for a population of students who were described variously as having additional disabilities, learning disabilities, lower cognitive abilities, or as learning at a functional academic level. Carson Nolan concluded in 1974 that comprehension and reading speeds with contracted words were more difficult for students noted as “slow learners.” (Lowenfeld, 1969) Based on studies conducted with contracted braille, “the evidence of the study strongly suggests that for students whose IQ is below 85, braille is an extremely inefficient medium of communication and the necessity of mastering it may constitute an additional education handicap.” (Nolan & Kederis, 1969) The assumption seems to have been that because the complexity of contractions makes Grade 2 Braille hard to read, instruction in braille for students with additional disabilities should be limited. In *One is Fun*, Ms. Troughton stated that by removing most contractions and simplifying the necessary rules, these populations became more adept at reading and more successful in braille literacy.

Frances Mary D’Andrea described a student who had a brain tumor removed. “Prior to my trying uncontracted braille with her, she had been unsuccessful in learning to read, although she had memorized the alphabet. She had very good auditory and phonological skills. By the end of the school year, she was reading a number of little books that I had made up for her. She moved away at the end of that year, and called me the next year to tell me that she was now reading Grade 2 Braille books.”

In *Instructional Strategies for Braille Literacy* we found an example of a young student, Tony, who was having difficulties learning to read braille. His TVI had taught him the alphabet using the Mangold program. She used the

Patterns series, but he had problems remembering the vocabulary words from one day to the next and even from one hour to the next. The teacher tried numerous other strategies and then decided to consult with the teacher of students with learning disabilities (LD) in Tony's school.

The recommendation from the LD teacher was to use a linguistic approach. He guided the TVI teacher in using word families, such as the 'at' family (fat, cat, sat, and mat), to create stories that Tony could read. The TVI also created games and used other strategies that had been tried before, but this time with Grade 1 and the new reading strategies. Tony's self esteem improved and his reading level increased. He later became a Grade 2 reader and was on level with his peers by fourth grade. (Wormsley, 1997)

The Outreach survey asked for other categories of students who may initially need to use uncontracted braille. Students who are learning English as a second language were mentioned. These students rely on their knowledge of a written language they have already learned, and may become confused by needing to master new symbols and writing rules in addition to the new vocabulary. For some of these students, alphabetic braille was described as a gateway to literacy; a successful entry point from which they could move on to fully contracted Grade 2 Braille.

Some students may learn alphabetic braille and not switch to Grade 2. Debbie McCune from Colorado noted that this category includes students with "cognitive limitations and students who do not have a need for heavy reading." Tanni Anthony added, "There may be students with memory challenges who would need to stay on this type of system, or kids who need continual reinforcement of the braille code in their environment and as such, need to have everyday people around them understand the braille code." Dixie Mercer also identified students who are unmotivated to use braille and whose primary literacy need is for a functional labeling system. A simple alphabetic code might be the most successful system for this type of student. Frances Mary D' Andrea stated, "To me, the test would be: Is it functional? Is it practical? And does it contribute to the student's sense of accomplishment as a reader?"

Linda Mamer and others mentioned that students who are deafblind and learning many language codes, including finger spelling, might stay with alphabetic braille. All respondents stress ongoing assessment, keeping the possibility of Grade 2 Braille always in mind. Sally Mangold stated, "There may be students who learn slowly and have certain learning disabilities who may function best in uncontracted braille for years. The determination as to whether to keep them in uncontracted braille should be made on an evaluation of their level of success where they are."

Many educational practitioners rely more on folk art and instinct than formal studies. Alan Koenig and Cay Holbrook both noted that there is very limited research on the use of uncontracted braille other than *One Is Fun*. In many cases, instructional strategies may be based on what materials are available. Marjorie Troughton wrote, "When these decisions were made (to have all books published in Grade 2 Braille) it was not possible physically or financially to publish books in two different codes. However, with today's technology, computers, scanners and printers, it is no longer impractical. The reasons for only one code are no longer valid. The reasons for two codes are very evident. It is time that a larger percentage of possible braille users be given the opportunity to have a code that is useful to them." (Troughton, 1992).

Anna Swenson summed up our exploration of this topic well by stating, "I continue to feel that there is no 'right' way to teach braille, given the many variables involved. Teachers should select the approach that best meets the needs of an individual child in a specific educational setting. There are certainly anecdotal success stories on both sides of this debate. While further research may clarify best practice in certain situations, expanding, rather than narrowing, the range of options will enable teachers to make the best instructional decisions for their students."

Overall when we looked at texts commonly used by vision professionals, the international work on developing a Unified English Braille Code, the Texas Reading Initiative, survey responses and dialogue with teachers of the visually impaired, several questions kept surfacing:

1. *What are the most important skills young braille readers need to acquire reading in the braille medium?*

The Texas Reading Initiative has shown that young readers must make a connection between sounds and individual letters. They need to associate and manipulate sounds to form words. They need to write about their experiences and be able to read back that information. Reading consists of many skills, including letter discrimination and use of meaningful vocabulary. For many reasons, young braille readers often do not have adequate reading readiness skills in the early elementary years. Research has shown that the tactual discrimination skills of first grade blind children, and their recognition of common household objects by touch, may vary widely. (Nolan and Kederis, 1969) Early instruction must maximize successful movement from oral to written language experiences, focusing on connections between sounds, letters and real life experiences.

2. *Should we completely switch from contracted to uncontracted braille?*

All research we reviewed, ongoing discussions with practitioners, and our survey results point to adding alphabetic braille as an instructional strategy, rather than advocating taking away Grade 2 Braille. As in all decisions, careful consideration and assessment should determine the child's learning media. If a child is successfully progressing using contractions, clearly he/she is learning in the most appropriate medium. For most braille readers wishing to access published literature at the highest speed, the goal will be to master all of Grade 2 Braille. Currently, standardized tests such as the Texas Assessment of Academic Skills are produced in Grade 2 Braille, as are most other normed test materials. The alphabetic braille code can be an entry for many who, once hooked on the excitement of fluent reading, transition into more advanced literacy instruction. In some areas of Canada and a few American districts, braille readers move to contracted reading in upper elementary grades. Others will transition earlier or later, as appropriate to their learning styles. Uncontracted braille offers early successes with the mechanical challenges of braille reading.

3. *Could we increase the literacy options for our students with learning disabilities?*

All students are different, and no one method of teaching reading will work for all students. It is essential to have a variety of approaches to match individual student needs, especially for students with specialized learning challenges. Several reading strategies commonly used for students with learning disabilities are not recommended for braille readers because "of the contractions in the braille code that do not always provide for single letters." (Sacks & Silberman, 1998) Phonics-based reading, code-emphasis instruction, and the Orton-Gillingham methods all fall into this category. Rather than limiting the potential methodologies used to teach reading, alphabetic braille instruction for students with visual impairments and learning disabilities may expand the teacher's ability to individualize reading instruction.

4. *Could we increase the literacy options for our students with multiple disabilities?*

Sighted students who have cognitive disabilities read and write using print to their maximum abilities. The teachers working with these students are motivated to continue providing reading instruction because they see the importance of their students being able to read and write their names, write lists for shopping, read a menu, or write a short note to a friend. Our students with visual impairments and cognitive impairments should have the same opportunity and means to complete these functional tasks. If braille is their medium, they need sufficient practice in reading and writing. Uncontracted braille may be the strategy that allows them to acquire functional literacy. Using uncontracted braille, they could braille a list for the grocery store, read a braille menu at McDonald's, braille phone numbers of their friends and family, and read the signage in many public buildings. Uncontracted braille would also be easier for the teachers and staff working with the student to learn, and would allow them to give immediate feedback to the student.

Sighted students are able to use materials that pair words with pictures and symbols that help decode the print. Students with visual impairments and additional disabilities may also benefit from tactual symbols that are paired with uncontracted braille to support communication and literacy activities.

5. *How would using uncontracted braille impact the braille reader in the mainstream?*

Alphabetic braille in its simplicity allows everyone in the reader's life to become a participant in the reader's literacy.

General education staff, peers, and family can quickly learn the letter symbols and punctuation signs. Use of alphabetic braille in early learning allows the braille student to listen to and learn the same reading lessons as their peers in the classroom. The rules governing spelling of words is the same for all students, and the materials can be more easily checked by the general education teacher without waiting for a skilled braille reading TVI to arrive.

The certified TVI may need to explore available published resources to find alphabetic braille materials. Agencies such as APH are beginning to research the use of alphabetic braille and plan to produce some titles in this format in the future. The first sixteen clusters of *BRAILLE FUNDamentals*, a new TSBVI braille curriculum, teach the alphabetic code. The textbook division of the Texas Education Agency will consider requests for Grade 1 Braille texts and currently produces some titles that have been requested in that format. At this time, most existing publications are available in Grade 2 Braille; however, with electronic files, all formats can be produced. It is exciting that advances in technology for braille production have given our students more options for literacy.

After compiling the survey responses, examining some of the available resources and speaking with TVIs from around Texas, we are convinced that the use of alphabetic braille has potential to increase literacy options for many students with visual impairments in Texas. Have you had experiences teaching uncontracted braille? We would love to hear about them. Does this article spark your interest? Do you want to try this strategy with your students? We are very interested in teaming with districts or TVIs who want to explore instruction in alphabetic braille. To be hooked up with a member of our VI Outreach team, you can contact Ann Rash at (512) 206-9269 or <annrash@tsbvi.edu> or Cyral Miller at (512) 206-9224 or <cyralmiller@tsbvi.edu>.

REFERENCES AND READINGS

Beginning Reading Instruction: Components and Features of a Research-Based Reading Program (1997). Publication Number CU7 105 01. Texas Education Agency, Austin, Texas.

Harley, R. K., Truan, M. B., and Sanford, L. D., (1987). *Communication Skills for Visually Impaired Learners*. Charles C. Thomas, Publishers, Springfield, Ill. p. 233.

Lowenfeld, B., Abel, G.L. & Hatlen, P.H. (1969). *Blind Children Learn to Read*. Charles C. Thomas, Publishers, Springfield, Illinois, p.27.

Nolan, C.Y. & Kederis, C.J. (1969). *Perceptual Factors in Braille Word Recognition*. *Research Series No. 20*. American Foundation for the Blind, New York, NY, p.43.

Sacks, S.Z. & Silberman, R.K. (1998). *Educating Students who have Visual Impairments with Other Disabilities*. Paul Brookes Publishing Co., Baltimore, MD, p.171.

Troughton, M. (1992). *One is Fun: Guidelines for Better Braille Literacy*. Brantford, Ontario.

Wormsley, D.P. (2000). *Braille Literacy Curriculum*. Towers Press, Overbrook School for the Blind, Philadelphia, PA.

Wormsley, D.P. & D'Andrea, F.M., eds. (1997). *Instructional Strategies for Braille Literacy*. American Foundation for the Blind, New York, pp. 161-162.

Early Identification of Hearing and Vision Loss is Critical to a Child's Development

By Gigi Newton, INSITE Specialist
and Kate Moss, Family Specialist, TSBVI, Texas Deafblind Outreach

IMPORTANCE OF VISION AND HEARING TO DEVELOPMENT AND LEARNING

Although every one of our senses plays a role in early development, vision and hearing certainly seem to lead the way. Much of early parent/child bonding has to do with the child's ability to make eye contact and sustain a gaze with his parents, respond to their voices by gurgling and cooing, and to be comforted by the sight and sound of them. Much of the reason an infant tries to move is because he sees or hears something that intrigues him. He learns that things and people exist in the world primarily because he sees and hears them come and go. He visually tracks an object he pitches to the ground or hears it hit the floor. That tells him the object still exists, even though it is not in his hands any longer. When she cries she can hear Daddy calling to her or see Momma walk into the room. She can inspire her parents to linger and play with her by cooing and making eye contact, the earliest form of conversation. He learns about size, shape, color, functions of objects, social interactions, and so much more just by listening and looking at the world at work. Early development has critical links to a child having full use of his/her vision and hearing. When these senses don't work perfectly or not very well, everything is impacted.

IT'S HARD TO TELL A PARENT THERE MAY BE VISION AND HEARING ISSUES

Professionals working with infants and families may have a hard time suggesting that there is a problem with a child's vision or hearing. This is especially true when the family is already dealing with their child's other medical or disability issues. After all, a family can only deal with so much at one time. Because infants are much harder to test for vision and hearing loss, many mild impairments (or sometimes even major impairments) may not be diagnosed quickly. Subjecting the family to another round of testing is always a hard call.

LEARNING ABOUT HEARING AND VISION LOSS IMMEDIATELY IS CRITICAL

As we said earlier, much of the sensory information that is vital to children's development comes through the senses of vision and hearing. During the first three years of a child's life major neural networks are being formed in the brain. Much of this development comes from distance senses, i.e., vision and hearing, which allows us to know about things and people in the world even when we are not in physical contact with them. After the first three years, development of these neural networks becomes slower. Skills that may be gained in early intervention cannot be made as quickly when the child is older.

For these and other reasons, children should be regularly checked for vision and hearing problems. We know that even mild problems with these senses can have major impact on learning. A mild hearing loss in a noisy home or daycare center can result in a child who misses critical bits of information. He may miss sounds that let him develop normal language and speech patterns. He may miss instructions his parents or babysitter gave him and appear to be misbehaving. He may become withdrawn because he is not sure what is expected of him. If he has a visual field loss he may constantly be stumbling over things. This has great impact on self-concept. A child who is sensitive to light may not enjoy or feel secure playing out of doors.

Every child, with or without a disability, should have regular and periodic vision and hearing checks. If the child is severely disabled, this can be even more important since their other senses may not be as useful in compensating for what they miss visually and auditorially. In fact, this is so important that schools complete vision and hearing screenings at regular intervals throughout the remainder of the child's educational career. These types of screenings are even more critical from birth to age three.

PARENTS SHOULD TRUST THEIR INTUITION

Parents know more about their child than anyone else does. Often we meet parents who tell us that they knew something was wrong with their child’s vision and hearing before any of the doctors mentioned it. In fact, many have been told that they shouldn’t go looking for trouble or that their child would “grow out of it.”

Parents should trust themselves when they feel there is something wrong with the way their baby uses his vision or hearing. They should feel comfortable insisting that vision and hearing are tested, especially if their child is at high risk for vision and hearing loss.

RED FLAGS

There are many red flags associated with vision and hearing loss. Below are the syndromes, diseases and conditions, listed on the Texas Deafblind Census, that put a child at high risk for deafblindness. Children with these etiologies should be watched closely for vision and hearing problems.

Syndromes, Diseases and Conditions

Hereditary/Chromosomal

Aicardi
 Alport
 Alstrom
 Apert
 Bardet-Biedl
 Batten Disease
 CHARGE
 Chromosome 18, Ring 18
 Cockayne
 Cogan
 Cornelia de Lange
 Cri du Chat
 Crigler-Najjar
 Crouzon
 Dandy Walker
 Down
 Goldenhar
 Hand-Schuller-Christian
 Hallgren
 Herpes-Zoster (or Hunt)
 Hunter (MPS II)
 Hurler (MPS I-H)
 Kearns-Sayre
 Klippel-Feil Sequence
 Klippel-Trenaunay-Weber
 Kniest Dysplasia
 Leber’s Congenital Amaurosis
 Leigh Disease
 Marfan
 Marshall

Maroteaux-Lamy
 Moebius
 Monosomy 10p
 Morquio
 Norrie
 NF-Neurofibromatosis
 (von Recklinghausen Disease)
 NF2-Bilateral Acoustic
 Neurofibromatosis
 Optico-Cochleo-Dentate
 Degeneration
 Pfeiffer
 Prader-Willi
 Pierre-Robin
 Refsum
 Scheie (MPS I-S)
 Smith-Lemli-Opitz
 Stickler
 Sturge-Weber
 Treacher Collins
 Trisomy 13 (Trisomy 13-15, Patau)
 Trisomy 18 (Edwards)
 Turner
 Usher I
 Usher II
 Usher III
 Vogt-Koyanagi-Harada
 Waardenburg
 Wildervanck
 Wolf-Hirschhorn (Trisomy 4p)

Pre-Natal/Congenital

Congenital Rubella
 Congenital Syphilis
 Congenital Toxoplasmosis
 Cytomegalovirus
 Fetal Alcohol Syndrome
 Hydrocephaly
 Maternal Drug Use
 Microcephaly
 Neonatal Herpes Simplex

Post-Natal/Non-Congenital

Asphyxia
 Direct Trauma to the Eye and/or Ear
 Encephalitis
 Infections
 Meningitis
 Severe Head Injury
 Stroke
 Tumors
 Chemically Induced

Related to Prematurity

Complications of Prematurity

SYNDROMES/CONDITIONS

Sometimes the child's etiology is unknown or the child may have only one diagnosed sensory loss. Professionals working with infants and young babies, as well as parents, should be aware of the red flags that may indicate a problem with either vision or hearing.

Hearing Loss

At Risk Factors

- Malformation of the ear, nose, and throat
- Rubella during pregnancy
- Rh incompatibility
- Family history of hearing loss
- Apgar score from 0-3
- Severe neonatal infections
- Meningitis
- Low birth weight (under 3.3 lbs.)
- Hyperbilirubinemia
- Ototoxic medications
- Severe respiratory distress and/or prolonged mechanical ventilation (10 days or more)
- Neurodegenerative disorders
- Childhood infectious diseases such as mumps and measles

(Hearing, Speech and Deafness Center website, <www.hsdc.org>, June 2001)

Behavioral Indicators

- The child does not stop moving, does not quiet in response to speech, and/or does not arouse from light sleep to sudden loud noises.
- At about 4-7 months, the child does not turn to sounds and voices or give an indication of detecting a sound source by eyes widening or blinking, fussing or quieting, increasing or decreasing overall activity level, changes in breathing or sucking patterns.
- There is a lack of babbling, cooing, grunting, or the child stops these behaviors and does not progress to speech.
- The child does not respond to familiar sounds (such as mom's and dad's voices) by cooing/gurgling when he cannot see them.
- The child does not use speech at an age when most children are beginning to use speech (approximately 9-12 months).

(SKI-HI Institute, 1998)

Vision Loss

At Risk Factors

- Family history of vision loss (Retinoblastoma or Albinism)
- Malformation of the ear, nose, and throat
- Prematurity and low birth weight less than 3 lbs.

- Birth trauma/head trauma
- Anoxia
- Cerebral Palsy
- Congenital viral or bacterial infections (Rubella, CMV, Syphilis, Group B Streptococcus Infection, Toxoplasmosis, Chicken Pox, HIV)
- Meningitis, Encephalitis, Hyperthyroidism, Microcephaly

Behavioral Indicators

- The child does not have eyes or eyelids that look typical.
- The child does not recognize caregivers' faces or smile in response to their smiles around the age of 3 months.
- He does not get excited when he sees his bottle or other familiar objects he likes.
- At 4-6 months, the child's eyes do not seem to move together when following an object or person.
- The child may turn or tilt his head in unusual positions when looking at an object.
- The child may hold an object very close to his eyes.
- The child may over-reach or under-reach for objects (accurate reaching usually occurs around 6 months).

WHAT DO YOU DO?

If there is a concern about vision or hearing, your ECI program should make a referral to the appropriate medical professional. We would like to encourage ECI personnel to work closely with their Teacher of the Visually Impaired, Teacher of the Deaf and Hearing Impaired, and/or TCB Children's Caseworkers in helping the families prepare for the doctor visits. These professionals have much to offer to the process. They can usually share the names of doctors, audiologists, and vision specialists who have more experience working with disabled children. Often they can guide the ECI professional and parents in compiling a list of concerns related to the way the child uses his vision and hearing. More importantly, they can provide parents with information about the types of testing that may be done and how to help prepare the child for testing. This level of support can be provided before an actual vision or hearing referral has been made.

Parents and professionals must keep a close watch on a child's progress related to vision and hearing. Hearing and vision issues must not be ignored, especially if the child has other disabilities. When a problem is suspected, no time should be lost in following up on the concern. We owe it to our children not to lose that critical window of time between birth and age three. When early intervention can make such major differences in life-long functioning, they can't afford to wait.

REFERENCES AND RESOURCES

Hearing, Speech and Deafness Center website, <www.hsdcc.org>, June 2001. Early identification of hearing loss. From *Communication Update*, published on HSDC Website, copyright 1996-99.

Moss, Kate. *Syndromes which often result in combined vision and hearing loss*. Texas School for the Blind and Visually Impaired website, <www.tsbvi.edu/Outreach/archive/syndromes.html>, 2001.

SKI-HI Institute, 1998. Auditory development. *Understanding Deafblindness: Issues, Perspectives, and Strategies*. SKI-HI, Utah State University, Logan, Utah, p. 21.

Texas School for the Blind and Visually Impaired website, <www.tsbvi.edu/education/db-etiology.htm>, June 2001. *Primary identified etiology - deafblind*.

Off to a Good Start

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

I've "stolen" the title of this short paper from the Blind Babies Foundation in San Francisco. I was once their Executive Director, and I think they'll forgive me for using this title, which, I think, describes what we all want for our infants. Using such a descriptive title leaves me with the responsibility of providing some content that will be helpful to parents and teachers. This time, I want to talk directly to parents of babies and toddlers.

What do I want to say to parents of blind and visually impaired infants? First of all, I want to say to you that those of us who have not walked in your shoes have only the slightest idea of what it feels like, and what it is like, to be the parent of a blind child. It is, therefore, with much humbleness that I share with you the following thoughts:

- Love, cuddle, and completely enjoy your baby. He may not be what you expected and wanted, and you may still be grieving, or be in shock, but from the moment of birth your baby needs your body, your warmth, your love.
- Try to notice the wonderful attributes of your baby. It's easy and natural to dwell on the disability, but your joy in parenthood will really start growing when you begin to discover the many wonderful things about her.
- Seek out professional help as soon as possible after diagnosis. Pediatricians, ophthalmologists, social workers, and generalists in early childhood are all valuable allies, but the one person you really, really need is an experienced expert in the effects of visual impairment on early growth and development.
- Maintain close physical contact with your blind baby. For example, a back- or front-pack can be far better than a buggy or stroller, because, while the surroundings may hold no interest for your child, the warmth, contours, and movement of your body will.
- Have the same developmental expectations for your baby as you would for any child, but know that your direct involvement in her development will be essential.
- If your baby is blind or has severe visual impairment, remember that incidental learning through observation will not occur. When my son Lucas was a baby, I observed him laying prone on his tummy in our living room. He pulled himself up so his head was raised, his arms straight, and moved his head as far as he could in both directions. As I watched him, it became clear that what he was doing was visually organizing his environment. How do blind babies do this? It is not difficult, but it must be taught. Your "expert" in visual impairment will help you learn how to do this.
- The blind child's world is the length of her arm. This is essential and fundamental to remember as you begin to find ways to assist in your child's development. Sounds and smells beyond arm's reach cannot be identified by the blind child, so expansion of his world is up to you and the good advice and suggestions you receive.
- In order to creep, to crawl, to cruise, and to walk, there must be a reason for the blind child to move. Something must be beyond arm's reach that he wants. This sound or smell must be associated with a past pleasant experience. An enjoyable toy that makes a distinct sound, mother's voice that is out of reach, the smell of something good to eat - these are the experiences that motivate blind and visually impaired babies to walk.
- Be prepared for developmental differences between your child and a non-disabled child. Sometimes walking doesn't occur until the baby is 12-15 months old or older. If other areas of motor development seem okay, don't worry. Your baby is simply learning other things and postponing walking. Talk with your expert on visual impairments about differences in developmental patterns, how you might help, and whether you should be concerned.

- If your baby is likely be a braille reader, consider early introduction to braille as a system for pairing symbolic language with real objects. You may wish to put braille labels on every object in your home - the walls, the floor, the toilet bowl, the dresser, etc. When your baby encounters these strange dots, you don't need to begin reading instruction. Just tell him that the jumble of dots represents the word "wall" (or whatever), and "wall" is the object that the word is attached to. It seems to me a shame that some braille readers don't see their first word until formal school, while sighted infants and preschoolers are surrounded by print from the time they can remember.
- Teachers of visually impaired students have many stories to tell about blind and visually impaired children who were not ready to learn when they came to school because they lacked real, concrete experiences. These young children are lacking in *experiential learning*. What this means is that they arrived at school without the background of experiences with the real world that adds meaning to learning. Your baby and preschool child needs *direct, physical experience* with his environment in order to learn in a meaningful way. The story in the reading book about a brother and sister at the grocery store will have little or no meaning for the blind child who has not experienced "grocery store." This experience has to happen in a grocery store, and must include verbal information and first-hand tactual experiences. Your baby and preschooler must have a comprehensive exposure to the world, and information for understanding that world, if school is to be successful.

Well, I could go on, but I think I'll stop now. Babies are precious - they deserve the very best we can give them. They don't know what they need - parents must know and offer the experiences, the love, and the caring required by a blind or visually impaired child. Parents won't always know what to do - they need a competent, creative teacher of the visually impaired or early childhood caseworker who *knows* early childhood growth and development to help them. So you see, the parent/child/professional team must begin when the child is an infant. There are so many essential learning and developmental experiences required by the blind baby that this partnership must begin as soon after diagnosis as possible.

Parents: Don't delay - find yourselves a qualified and creative expert in visual impairment right away!!

Teachers: Don't delay - if you're not feeling qualified to help parents through the critical growth period of birth to five, then find classes and readings that will prepare you for this crucial role.

Parents and Teachers - have fun with babies, and help babies to have fun with you and others!!

Help and Hope, One Child at a Time

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

One of the hardest, but most rewarding, aspects of working at the Commission is calling on parents who have just learned that their long-awaited babies will never clearly see the loving faces holding them. It's hard, because this is an emotional time for everyone - even for those of us who have chosen the field of blindness and visual impairment as our life's work. It never gets easier seeing the initial fear in parents who are still trying to absorb the medical facts behind their baby's visual impairment when we are asked to call on them.

I think I speak for all of us at the Commission when I say I wouldn't mind losing my job for lack of customers. But, that's not likely to happen in my lifetime. Based on the 2001 Annual Registration for Students With Visual Impairments published by the Texas Education Agency, there are 6,719 students ages 0 to 21 in Texas today who fall within TEA's definition of visually impaired. We serve an even broader range of children, so there is much work to be done.

Our reward in calling on parents of newborns and young children comes from being able to plant early seeds of help and hope. Help first comes in the simple form of a caseworker's business card. Although a parent seldom reads the words Texas Commission for the Blind with enthusiasm, we're accustomed to the reaction. It's okay. This isn't the time to wow parents with all the great things individuals who are blind or visually impaired are doing today. Instead, it's the time to listen and answer questions. Hope is planted with just a few straightforward words: "The Blind and Visually Impaired Children's Program is here to help when you're ready."

Walter Anderson, the editor of Parade, the magazine insert in many U.S. Sunday newspapers, says in his book, *The Confidence Course: Sevens Steps to Self-Fulfillment*, "True hope dwells on the possible, even when life seems to be a plot written by someone who wants to see how much adversity we can overcome."

Although written for all ages, Anderson's words are especially appropriate for the parents we meet. When a baby is born with visual problems or a child acquires a severe visual impairment, the whole family begins a challenging journey. Because the primary source of information for most children is vision, family members of children with vision losses are immediately called into action to fill in some missing or incomplete information. This is unfamiliar territory for most parents. The Commission's job is to provide them with a map that ultimately leads to a fuller and richer life for their child. The map we draw is full of "possibility thinking" check points as we encourage parents to dwell on the possible for their child.

One line a lot of parents will hear from our caseworkers during their early meetings is, "I'm here to put your baby to work!" It is so important for parents to absorb the encouragement behind these words. We speak from decades of experience when we say we believe in their child's potential to adapt fully to life with a visual loss. We also believe in the parents' ability to add the roles of advocate, coordinator, and teacher to their family's résumé. The earlier the work begins for both family and child, the sooner everyone will be smiling with each newly-learned skill, and what started out as such an anxious time for the parents can ease into an everyday way of life.

The agency is making preparations for a celebration in November to commemorate 70 years since the Commission was created in 1931 and 30 years since Criss Cole Rehabilitation Center opened in 1971. In doing some research on services to children, I read in our archives where a Miss Ruth Siler, Preschool Blind Child Counselor, reported to the Agency's Board back in 1957 that she had just finished a pamphlet for parents of preschool children who were blind. I also noticed that the agency was asking for one additional preschool counselor. From these small roots, services have slowly grown into a statewide network of Blind and Visually Impaired Children's caseworkers. This past legislative session did not yield the funds we had hoped to use to expand the program, but we are fortunate to have 39 hard-working caseworkers across Texas who served 8,265 children last year, including permanently severely visually impaired children and children needing eye treatment.

Occasionally we still hear about parents who were unaware of our services. You can help by telling parents of young children with visual impairments about the Blind and Visually Impaired Children's Program. Tell them that a caseworker is nearby to deliver help and hope.

ECI Provider Network: Champions of Service

Twenty years ago, the Texas Interagency Council on Early Childhood Intervention or ECI was the state agency designated by the Texas Legislature to provide services to families with children with disabilities and/or developmental delays. Federally and state-funded, ECI supports families to help their children reach their potential through developmental services.

Over the years, the ECI Provider Network has become the backbone of ECI, putting ECI's values, mission, and goals into action and making sure each child receives the best start in life.

Beginning with a small handful of programs, ECI's Provider Network has grown to 65 statewide programs offering services in every Texas county. As a result, families have equal access to all services that ECI offers wherever they may reside in Texas. These services may include screening and assessments; physical, occupational and speech-language therapy; and special instruction, training and counseling services.

Since 1982, ECI awarded contracts to fund services at the local level contracting with agencies and organizations in Texas. Approximately half of the ECI programs are state or local mental health and mental retardation facilities, about one quarter are with school districts or regional educational service centers, and about one quarter are nonprofit organizations. Staff from these programs may include early intervention specialists, nurses, psychologists, dieticians, paraprofessionals, teachers, social workers, and physical, occupational, speech and language therapists.

Time and time again ECI families tell stories of how staff members of the provider network have given them support, found resources, and have become a valued member of the family. "I don't know what I'd do without the ECI professionals that help my child, especially my service coordinator. She has been so helpful," said an ECI Mom. "She's like a part of the family."

In FY 2000, local ECI programs conducted intake on 33,293 new children and families. They also provided service coordination to all enrolled children (including intake) and provided transition planning to 15,299 children who were leaving ECI services for their next service setting.

In addition to providing services to eligible families, ECI programs maintain connections with clinics, hospitals, and physicians. Local ECI programs conduct public awareness activities to locate and refer all eligible children born or receiving medical treatment in a service area.

If you have questions or concerns about your child's development, call your doctor. When it comes to your child's health, getting help early is best. For more information about ECI, a local program in your area, or to refer a child call the ECI Care Line at (800) 250-2246 or (512) 424-6800 (in the Austin area), or visit the ECI website at <www.eci.state.tx.us>.

Creative Thinking Maximizes Parent Training Opportunities

By Edgenie Bellah, BVICP Consultant, Texas Commission for the Blind
and Kate Moss, Family Specialist, TSBVI, Texas Deafblind Outreach

One of the simple truths in life is that parents are their children's first teachers and advocates. Parents of children with visual impairment, deafness, and deafblindness face unique challenges with these dual roles. To work confidently alongside their child's professional team members, whose expertise comes from years of education and ongoing training, parents need training opportunities themselves. They need opportunities to expand their own knowledge base about their child's medical and physical needs, special education law, transition, resources, communication, orientation and mobility, and much, much more.

We are fortunate in Texas to have many such training opportunities for parents. Some come from within the school system, local Texas Commission for the Blind offices, and Regional Education Service Centers. Others are offered on a statewide basis by TSBVI Outreach, DBMAT, and others, such as Texas Focus, the Texas Symposium on Deafblindness, DBMAT Family Conference, and the Technology Institute. Available training is sometimes specific, focusing on visual impairment or deafblindness. At other times it may address more generic issues such as special education laws, transition issues, and estate planning. Many parents will have opportunities to learn about the syndrome or medical condition that caused their child's disabilities through state and national conferences such as the CHARGE Syndrome Conference, the

Texas Usher Syndrome Family Retreat, the Shaken Baby Syndrome workshops, and other similar events.

There are so many available training opportunities that it is often hard for parents to choose among them each year. Unfortunately, many times the deciding factor has to do with whether or not they have the resources to pay for registration, travel, and child care expenses associated with the events. The majority of parents must depend totally on scholarships or training funds. In recent years funding for these activities has decreased and the number of people wanting to access training funds has increased. Event planners struggle to make sure all that the families who want to participate have the support they need to attend. Still, many times parents can't find the resources they need when they need them.

WHAT CAN BE DONE?

Event organizers

Get the word out early

Event organizers need to get the word out on training opportunities well in advance of the event. By sharing training event announcements with the ESCs, TSBVI, and TCB so they can be included in their training calendars and on their websites, parents know where to go to find out about training opportunities. This also helps families plan ahead about when and where to get funding. The TSBVI website maintains a statewide calendar of training opportunities for both families and professionals. We welcome any submissions to this calendar. To share your workshop announcements, contact Jim Durkel at (512) 206-9270, or through e-mail at <jimdurkel@tsbvi.edu>. This information is also published in the classified section of the *SEE/HEAR* newsletter.

Contact possible funding resources in the initial stages of planning

Learn about possible resources to help you offer travel and registration funding to families, and contact them in the initial stages of planning. The Texas Planning Council for Developmental Disabilities allows event organizers to write a request proposal for funding to help families attend training. Local Lions Clubs and other civic organizations often have funds they are willing to contribute to cover these types of costs. Some school districts and Education Service Centers may have limited dollars to help sponsor families, if they are notified of the event early enough.

Collaborate, collaborate, collaborate

Collaborate with local, regional, and state agencies and organizations to provide the support families need to participate in training. This might mean asking a local scout troop to help provide child care at the event, or seeing if a local grocery or restaurant will donate food. The agencies may not be able to pay for family travel, but might agree to share the cost of a speaker or other expense. The more contributors there are to an event for various individual costs, the more funding may be directed to help with travel and childcare needs.

Families

Register immediately and indicate an interest in funding assistance

Too often parents don't ask for help until it is too late to access available training funds. Training events typically have set budgets for assisting families with travel and registration costs. Decisions about who will receive available funds are often made shortly after the registration deadline. Parents who do not get their registration forms in ahead of deadlines often miss out.

Agencies such as Texas Commission for the Blind have state paperwork requirements that make last minute requests problematic. All TCB services, including training for parents, has to be part of plan that is developed with the family. Sometimes funds requested at the last minute can only be provided on a reimbursement basis. This means that parents will not be able to attend if they can't afford the upfront costs or wait a month for the processing of reimbursement checks.

Sometimes parents are hesitant about signing up for a workshop until the last minute because they are unsure of their ability

to attend due to a child's health, family work schedule, or other life event. Most conference planners can cancel a hotel reservation, airline tickets, and so forth at the last minute, but it is often very difficult to make these arrangements even a week before the event. Most hotels have special rates for reservations made during a set period of time. Airline tickets purchased very early tend to be cheaper than those purchased at the last minute. If parents think there is any chance they can attend a workshop, it is better to get the registration in on time and make travel plans early. Of course, parents should check with individual funding sources and conference or workshop planners to find out about cancellation policies.

Stay up-to-date on training opportunities and prioritize training needs

Parents and other interested family members should check these resources regularly to learn about training opportunities that are being planned. Make a list of any training events that seem useful, and contact the organizers to get registration information. Ask them about funding to assist with event costs and learn how these funds can be accessed. Prioritize the events based on training needs and your schedule. If you can select only one or two events each year, be sure it will meet your training needs and be held at a time and place you can access.

Contact funding sources well in advance

Contact funding resources well in advance of the event to let them know about your interest in attending. Find out if they anticipate having funds available. For example, TSBVI Outreach typically has a travel budget for each of its sponsored events. Outreach policy is to spread the funding out as far as it will go. Knowing how many families need to access these funds makes it easier to plan distribution.

Know what you will need before you ask

Think about the type of support you will need and be familiar with the approximate costs of these supports. This may mean prioritizing costs. What parts could you pay for if no other source was available? What items are less likely to find a different funding source? Not everyone can pay for airline tickets, but many people are able to pay for gas charges or meals. How much will the hotel room cost? Is the whole family flying to the event, or, if you must drive a long way, will you need an extra night of hotel costs? The clearer you can be about your exact needs, the easier it is for funding resources to identify how they can help.

Learn about various funding resources

Become familiar with local funding resources and other supports. Your local Lions Clubs, Soroptimist Clubs, Elks Clubs and other civic organizations may have money to help cover some of the cost of travel and registration. If you are receiving services from MHMR or through Texas Department of Health or Texas Department of Human Services, they may be able to assist with respite care, child care, or other costs associated with attending training. Generally your TCB caseworker can help you identify local and regional resources. Of course, both TCB and TSBVI Outreach are resources for families. Make a list of all the possible resources in your area so you know whom to call when you need help. This is something you can also share with other parents who may not know where to go for help.

Think of creative ways to get the support you need

Get creative! If you have friends or family members who might be able to help with some part of the expense, offer to trade favors. For example, baby sit their children in exchange for their baby sitting services while you are at the training. Help them with some needed task in exchange for gas money. Set aside a few dollars each month to use for incidental expenses at these events. Remember the pocket change jar your parents might have kept? Even if you only have ten dollars set aside when you want to go to training that can help pay for a meal or buy some gas. One family cleaned out their garage and had a garage sale to get money together to help with travel to a national conference.

Look for training that doesn't require a lot of funding

Check out training opportunities that don't require travel expenses. For example, is your local school district offering training? More training opportunities are now being offered through distance learning methods such as Internet courses,

correspondence courses, videotapes, etc. Sometimes just meeting with another parent to talk about issues and share ideas can be an incredibly beneficial training experience. Think about organizing a small “coffee klatch” of parents or plan a family picnic in the neighborhood park with several other families. Not all training has to involve going to a workshop or conference.

Address training needs as a part of your child's ARD

Look to your local school district for providing individualized training related to the implementation of your child's IEP. When you are having your child's ARD, talk about your training needs and the training needs of staff working with your child. Parent training is a related service as defined by IDEA. Some of your training needs may be met by school staff working with you at your school or in your home. In some cases, if they are asked, your Regional ESC or TSBVI Outreach may be able to bring training to your school program or at least to your community.

Don't forget that you may be able to provide training as well as receive it. This can be a help to members of your child's team who need to learn about the ways you have been successful in working with your child. Consider what you can offer to your team, to help them learn about the special ways you feed your child, how you communicate, what you do to comfort him when he is frightened or cranky. After all, you are an expert about your child.

The most important element is to get training needs spelled out in the IEP and discuss the resources for meeting these training needs as a regular part of your ARD meeting. Schools can then plan ahead and budget if they are trying to help pay for part of your training costs.

CONCLUSION

Parent and family training is an important part of helping a child with visual impairments and deafblindness. Unfortunately, not every parent who wants to access training will be able to do so. It is important to plan ahead and be familiar with the resources that are available to help in this effort. Please think about your family's training needs and start planning today for the 2001-2002 school year.

Update About Jeff

It was reported in the Spring issue of *SEE/HEAR* that Jeff Pruett had entered a national art contest for students with disabilities sponsored by the Helen Keller Foundation. Rather, the 2001 Helen Keller International Art Show was sponsored by the International Council for Exceptional Children Division on Visual Impairments, University of Alabama Birmingham Vision Science Research Center, University of Alabama Birmingham School of Optometry, University of Alabama Birmingham School of Education and Ivy Green Property Board.

From more than 150 entries, Jeff's drawing, “Eyes in the Night,” was one of only 30 pieces selected to tour at various galleries, conferences and universities across the United States, including the Virginia Murray Sowell Center at Texas Tech University in Lubbock and the Washington National Cathedral in Washington, DC. Jeff's accomplishment will be acknowledged during the Distinguished Lecturer Series featuring Dr. Jan van Dijk, September 26-29, 2001. The artwork of three other Texas students, Christina Farley, Shane Hill and Cameron Hebert was also selected for this prestigious national tour. Congratulations to you all!!!

CORRECTION! CORRECTION!

We want to apologize to our SEE/HEAR readers for the incorrect phone number listed under the Spring 2001 article, “Spanish-Language Low Vision Booklet Now Available!” and for any inconvenience it caused. To reach the National Eye Institute for the Spanish-Language information email to <neipub@aerie.com> or call (301) 496-5248 or go online to <<http://www.nei.nih.gov/publications/publications.htm>>.

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>.

**Visions 2001:
The National Conference of
The Foundation Fighting Blindness**
September 13-15, 2001
Westin Galleria Hotel in Dallas, Texas

Topics include the latest retinal research; coping with visual impairment; networking and support group opportunities and more. Condition and syndrome topics include: Usher and Bardet-Biedl Syndromes, RP, and Macular Degeneration.

For more information, contact The Foundation Fighting Blindness at (888) 394-3937 or <www.blindness.org>.

**Virginia Murray Sowell
Distinguished Lecturer Series**
September 26-29, 2001
Lubbock, Texas

Dr. Jan van Dijk will be the featured speaker at this year's Virginia Sowell Distinguished Lecturer Series, sharing his wealth of experience working with people who are deafblind. The 30 works of art selected to tour with the 2001 Helen Keller International Art Show will be on display throughout the Series. For more information, contact:

The Virginia Murray Sowell Center
(806) 742-2345 or sheila.dowling@ttu.edu.

A van Dijk Reader

A reader of classic and new articles by Dr. Jan van Dijk is now available on the DB-LINK website. This collection, written between 1965 and 2000, addresses a variety of issues related to the education of students with deafblindness. The articles can be found at <<http://www.tr.wou.edu/dblink/vandijkFT.htm>>.

TSBVI Technology Institute

September 21 & 22, 2001
Sheraton Four Points in Austin, Texas

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

For more information, contact:

Jim Durkel at (512) 206-9270,
JimDurkel@tsbvi.edu

or

Sharon Nichols at (512) 206-9388,
SharonNichols@tsbvi.edu

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

Part 1 - September 27 & 28, 2001
Part 2 - October 24 & 25, 2001
Part 3 - November 29 & 30, 2001
Bryan, Texas

A 6-day training for school and ECI professionals working with families who have children (birth to 5) with multiple impairments, including sensory impairment. Topics include information on vision loss, hearing loss, communication development, motor development, active learning, and working with families.

For more information, contact Gigi Newton at
TSBVI. Phone: (512) 206-9272;
E-mail: GigiNewton@tsbvi.edu

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

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

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

**Second International Conference
on Parents with Disabilities
and their Families**

October 11-14, 2001
Oakland Marriott Hotel
Oakland, California

In the U.S. alone, there are more than eight million families in which one or both parents have a disability. This will be the second international conference to focus on families in which one or both parents have a disability. The conference will be hosted by Through the Looking Glass, an internationally recognized disability community-based agency with expertise in research, advocacy and services to parents with disabilities and their families. This ground-breaking conference will feature international speakers addressing a wide variety of topics related to parents with disabilities including child custody, adoption, pregnancy and birth, legal rights and assistive technology. A National Task Force on Parents with Disabilities and their Families will reconvene at the conference. For further information, contact:

Through the Looking Glass

Phone: (800) 644-2666

International callers: (510) 848-1112, ext. 130

TTY users: (800) 804-1616

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

SWOMA:

**(Southwest Orientation & Mobility
Association Annual Conference)**

October 12-14, 2001

Sheraton Four Points in Austin, Texas

Topics will include: Global Positioning Systems, Wheelchair Mobility, Traumatic Brain Injury, Teaming with Occupational Therapists and Physical Therapists, Environmental Accessibility Issues and more!

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

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

Nimitz High School in Irving, Texas
October 26 & 27, 2001

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

**Ring the Bell for Literacy in 2001!
The Fifth Biennial
Getting In Touch With Literacy
Conference**

November 8-11, 2001

Philadelphia, PA

Wyndham Franklin Plaza Hotel

The GITWL Conference provides a forum for a discussion of literacy for people who are blind or visually impaired. Topics cover all aspects of literacy including low vision literacy, braille literacy, and use of technology, for all age ranges and ability levels.

For more information, contact:

Ellen Croucher at ellenc@mdschblind.org

Diane P. Wormsley at dwormsley@pco.edu

or call (215) 780-1366.

SEE/HEAR

published quarterly: February, May, August, and November

Available in Spanish and English on TSBVI's website at <www.tsbvi.edu>.

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

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

Deadlines for Articles

December 1st for the Winter edition

March 1st for the Spring edition

June 1st for the Summer edition

September 1st for the Fall edition

Production Staff

Editor-in-Chief - Kate Moss (512) 206-9224;

KateMoss@tsbvi.edu

Layout Editor - Craig Axelrod (512) 206-9435;

CraigAxelrod@tsbvi.edu

TCB Editor - Edgenie Bellah (512) 377-0578;

Edgenie.Bellah@tcb.state.tx.us

Website Editor - Jim Allan (512) 206-9315;

JimAllan@tsbvi.edu

Production Assistant - Jeannie LaCrosse-Mojica

(512) 206-9268; JeannieLaCrosse@tsbvi.edu

TCB Braille Transcriber - Ann Hill (512) 377-0654;

Ann.Hill@tcb.state.tx.us

Section Editors

Family - Jean Robinson (512) 206-9418;

JeanRobinson@tsbvi.edu

Programming - Ann Rash (512) 206-9269;

AnnRash@tsbvi.edu

and Gigi Newton (512) 206-9272;

GigiNewton@tsbvi.edu

Syndromes/Conditions - Kate Moss (512) 206-9224;

KateMoss@tsbvi.edu

News and Views - Edgenie Bellah (512) 377-0578;

Edgenie.Bellah@tcb.state.tx.us

Classified - Jim Durkel (512) 206-9270;

JimDurkel@tsbvi.edu

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

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

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

**Texas School for the Blind and Visually Impaired
Outreach Program
1100 West 45th St.
Austin, Texas 78756**

NON-PROFIT ORG.
U.S. POSTAGE PAID
AUSTIN, TEXAS
PERMIT NO. 467