

SEE/HEAR

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

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Editor's Corner

Have you noticed we've made changes in SEE/HEAR? We appreciate those of you who responded to the survey about the newsletter which appeared in the July edition. The changes you see are in response to your suggestions; we hope the rest of you like them. First of all you will see that we have four sections of the newsletter: Family, Programming, Syndromes/Conditions, and News & Views. The section markers will make it easier for you to home in on your favorite part of the newsletter. The Family section will include articles written by family members including children and adults with visual impairments and deafblindness, parents, brothers and sisters, grandparents, etc. The Programming section contains articles about educational and rehabilitative programming and best practices. The Syndromes/Conditions section includes information

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Food, Food, Food

By John Jackson, Parent, Nolanville, Texas

“I heard there were no calories in Atlanta,” our new friend Norma DiMartino stated as Treasa (my wife), Norma and I looked at what turned out to be the most delicious pie we have ever tasted. Norma could not have been more right. The whole week we got food. Food for the spirit, food for the mind, and food for our lives.

Treasa and I are the proud parents of Hunter, a wonderful 2½ year old boy with multiple disabilities. One of Hunter’s disabilities is legal blindness. Treasa, Hunter and I were in Atlanta for the International Conference of the Association for Education and Rehabilitation of the Blind and Visually Impaired (AER). We were able to attend the conference due to the combined efforts of Mollie O’Leary from the Texas Commission for the Blind, Jean Robinson from the Texas School for the Blind & Visually Impaired, and Brenda Frizzell from Child Team.

No amount of calories could have filled the 690 participants from around the world as they came together to share, learn and prepare ways to enhance the lives of the population of the world whose physical vision is impaired. As Treasa and I saw the passion and focus of the participants we were overwhelmed by the realization that we and our support staff (which many envy) are not alone, but just a small part of a worldwide effort to enhance the lives of others. It made us all but cry. To see professionals who volunteered their time to come and learn new ways to help, instruct, and liberate the lives of the clients was amazing. The power of concern, love, and focus could have no other effect but to feed the spirit.

While neither my wife nor I are professionals, the sessions were not so advanced that we couldn’t get something from them. The sessions on new research and methods gave us hope for the future. Sessions on ways we can work with our son at home to improve his vision added to our arsenal. Ideas, ideas, and more ideas were freely given. When people found out we were parents they were more than free with their time to answer questions and give us a fresh approach to methods they used. Each person we spoke with taught us there is so much being done and that can be done. Yes, the calories were rich and filling, but there was always room for more and more willing to give.

Food for our lives was given from the minute we walked in, and it is still being given. The conference was so much more than we expected while not knowing what to really expect. Being placed in an environment such as we were, we could walk away knowing everything is going to keep advancing in a positive direction. Sometimes I know that parents with children such as ours feel it is a never-ending struggle. Attending the conference taught me there is an end and it is success. One thing did surprise me, the lack of parents at the conference. I know that with the experience we had, we will be attending more in the future. You see, to Treasa and I the question is not how can we, but how can we not? If not us then who?

Good Days, So-So Days, and Bad Days

By Kenyetta Kinney, Student, Coolidge, Texas

Editor’s note: Ann Rash, VI Outreach Education Specialist and Programming Editor for SEE/HEAR brought this article to our attention. This article was written last year when Kenyetta was in a combined class of 2nd and 3rd graders. Her vision difficulty is secondary to her primary diagnosis of MS, multiple sclerosis. We appreciate Kenyetta’s willingness to share her feelings with the readers of SEE/HEAR.

Hi, my name is Kenyetta Kinney. I am a third grader at Coolidge Elementary School in Coolidge, Texas. I am in a 2/3 (second- and third- grade) class and I also go to special classes for Reading and Math. I go to P. E.,

Music, and Computers. We also have lunch, recess, and sometimes we have pep rallies. I like school.

Sometimes I have bad days and good days and so-so days. This is because I am not seeing so good. I have people who come see me. They help me and teach me to get around safe.

When I have a good day I can see very good, and I can get around good all by myself. When I have a so-so day I have somebody help me to get around safe. When I have bad days I use sighted guide to get around safe. Sighted guide is when I have to hold on to somebody's arm to get around.

In the classroom I use all kinds of things to help me on all my different days. On a good day the teachers blow up my work to make it bigger. On my so-so days I use my magnifying glass and my CCTV. A CCTV blows up my work, and I look at it on a TV screen. On my bad days my teachers help me practice getting around safe, and we talk through my work instead of writing. I work very hard on all my different days.

I have to take medicine every morning and at night, and I have to take a shot every Friday. The medicine has a bad taste, but the shot doesn't hurt. I don't like taking medicine, but the doctor says I have to take it. We have to go all the way to Fort Worth to see the doctor. My mom takes me, and we always stop and get chicken on the way home. Sometimes I have to go to another doctor for my eyes. He is in Corsicana. I think I have about forty doctors sometimes.

I have a bunch of special teachers who come and work with me. I go to Speech with Ms. Tooke. She reads books to me, and I talk to her. Mary Ann and Ms. Bunch come to see me. They help me work on feeling things and listening. Tonya and Rhonda come and work with me on sighted guide and asking for help when I need some. Debra comes to my house and is going to teach me how to cook spaghetti. She also brought me a talking clock so I can know what time it is. Sometimes people come and visit for only one day. They watch me and work with me for that day. I like it when all of them come to visit.

I'm really like everyone else. I just have trouble seeing sometimes, and I need some help. Most days I just like being with my class. Sometimes I think that everybody worries about me too much, but I know they love and care for me. All the attention bothers me sometimes, and I get embarrassed. That's OK. I have a lot of jobs. I'm a girl, a lady, a person, a big sister, a daughter, a student, and a kid...I just don't see good some time.

For Your Information:

Parents' Perspectives on . . . Behavior, Communication & Instructional Strategies

On July 30 - August 1, 1998, eighty parents and family members from across the country attended the national workshop "Going for the BEST: Building Excellence and Strength Together" in St. Louis, Missouri sponsored by the National Technical Assistance Consortium for Children and Young Adults with Deaf-Blindness (NTAC) and the National Family Association for Deaf-Blind (NFADB). The children of these 80 individuals represented the full diversity found in the deafblind population, as well as an age range from infant to young adult. The goal of the workshop was to generate a list of what the participants identified as the most important practices to parents in the areas of behavioral issues, communication, and instructional strategies in the education of their child who is deafblind.

Linda Carter, Keith Fansler, Sareth Garcia, Patricia McCallum, and Alison Rickerl are the parents from Texas who attended the St. Louis conference. Kate Moss from Texas Deafblind Outreach, and C. C. Davis, the Helen Keller National Center Regional Representative for Texas, also participated. We all greatly benefitted from our involvement, although we were sometimes uncomfortable with the process, since this workshop was

about the parents instructing the professionals instead of the professionals instructing the parents. It was also about parents teaching each other about their child's unique needs and learning how those needs were frequently the same and yet sometimes differed from another child with deafblindness.

In a large general session, Jerry Petroff (with help from a variety of staff from NFADB, NTAC, HKNC, and state deafblind projects) took the parents through a process of brainstorming the critical practices, from their perspectives, related to communication, behavior, and instruction. Then, through a series of smaller group activities, this list of practices was refined and ultimately prioritized by the entire group. There were many interesting discussions throughout the weekend. Parents representing older individuals, babies, children with additional disabilities, children who used ASL, individuals from minority cultures, each brought up issues from their unique perspectives. Persuasive arguments were made in favor of a particular wording. Everyone worked hard to listen openly to what each person offered to the discussion, to really "hear" each other. The sharing was tremendous. The final document contains only a portion of all the ideas that were put forth by the group. It does serve, however, as a valuable guide to the issues families want addressed by professionals in the field of deafblindness, education and rehabilitation, and the community in general.

Keith Fansler from Amarillo, Texas shared these thoughts about the gathering: "I always come away from these workshops and conferences with a lot of new ideas and information, sometimes it is an overwhelming amount. Parents always pull together, energizing each other to share their beliefs and concerns. One thing I have come to realize is that we all come from many different backgrounds and have many unique challenges, even though all of our children have some type of deafblindness. As I hear parents expressing their concerns, I start thinking how we all have the same common goal: the best education and jobs, heck, the best life that this world has to offer our specially challenged children. We are not different from any parent all over this great nation and around the world. We all want the best for our children; however, sometimes I think we try to impose what is best for our own child onto other children. We need to step back and hear where families are coming from sometimes. We need to make sure they feel heard, then honor and respect their beliefs."

What follows is the list of those practices developed by the parents in St. Louis.

PARENTS' PERSPECTIVES ON . . .

Important Practices in Communication

1. Families and professionals need to gain an understanding of various communication techniques, strategies and modes in order to give the child an individualized and appropriate communication system that reflects the child's assessed needs and respects the family's choice. Children should be provided with multiple communication approaches including total communication, sign language, pictures and augmentative communication methods in both home and school environments.
2. Teachers and service providers must understand that all behavior has a communicative function and should not be a "problem." Individuals who are deafblind should have the opportunity to express their needs and frustrations without being judged.
3. Each individual who is deafblind should be provided a communication facilitator (certified interpreter, trained intervener, teacher assistant, etc.).
4. Training should be provided to ensure that a variety of people are able to communicate with the child.
5. Children and adults who are deafblind should be given the right to communicate and be "listened to" with adequate time to respond.

6. Children and adults who are deafblind should be provided with the necessary tools to encourage acceptance into his or her preferred community (i.e., deaf community or other appropriate communities).
7. Individuals who are deafblind should be provided the opportunities to succeed, take risks and even fail.
8. American Sign Language should be offered as a foreign/second language in school and community settings.
9. Communities and businesses should provide access to communication (in a variety of modalities).
10. Professionals and paraprofessionals should be appropriately trained and required to maintain high standards of practice.

Important Practices in Instructional Strategies and Program Development

1. A range of housing, supported living, supported and independent work, community, recreation and social options should be available.
2. Expectations for the child should not be underestimated. Give the child opportunities to succeed, take risks and even fail in an environment of security, affection, and love. Focus instruction on the strengths of the individual with expectations for success.
3. Provide activities that are age appropriate and meet the child's needs.
4. Parents should be provided with training which enables them to be advocates for their child (i.e., teaching strategies, futures planning, legislation, how to understand the planning process, etc.).
5. Families and service providers need to be able to teach advocacy skills to the child. The process should continue over a lifetime.
6. It is important for the individual who is deafblind to have a place in his or her community with access to a full spectrum of life experiences.
7. There should be increased community awareness and choices for persons who are deafblind (i.e., social opportunities).
8. Provisions for a continuum of life-long services. Provide continued and non-interrupted services needed throughout the life of the deafblind individual.
9. It is important for local and state community services to be mandated and funded for deafblind youth and adults.
10. The deafblind individual must be a valued member of a community that affords him or her a full spectrum of accessible life experiences.

Important Practices In Positive Behavior Strategies

1. Behavior is a communicative function that must be understood and acknowledged as communication.

2. Individuals with deafblindness have unique needs that must be met. Their individual likes, dislikes and personality must be respected.
3. All service providers, including those in the mental health field, need comprehensive training about the uniqueness of deafblindness and its impact on behavior. A range of services must also be available.
4. All persons who interact with the deafblind individual must understand the impact of deafblindness on life.
5. All deafblind youth and young adults need to be prepared and trained in self-advocacy and leadership.
6. All parents of deafblind children need networking opportunities to share information on behavioral issues in order to learn new ideas and strategies.
7. Service providers and others should know appropriate, current, and positive behavior strategies and supports.
8. It is important to provide the individual who is deafblind with a sense of security, affection, love and patience.
9. Encourage self-advocacy from an early age, focusing on the person first, not the disability.
10. Members of a team and other service providers working with the individual who is deafblind must understand that medical issues/medication can impact behavior.

Student's Will to Survive with Visual Impairments Brightens School Halls

By Timothy Hatch, Student, Flour Bluff, Texas

Editor's Note: Toward the end of last school year, one of the Outreach staff shared this article with me written by Timothy Hatch. It was originally published in the school newspaper of Flour Bluff High School near Corpus Christi where Timothy, a student who has low vision, was a freshman.

The bell rings. You step outside the door and hear a rush of people come by. Nothing is recognizable. You can only see light and dark or your vision is so bad you don't recognize your friends across the hall at their lockers. This is what life is like for sophomores Shannon McGinnis and Marion Webb.

"I can only see five feet in front of me. My vision is 20/1600," Shannon said. That means that Shannon can see at 20 feet what a sighted person can at 1600 ft.

Getting around school can be very frightening when you first lose your vision, but after Orientation and Mobility training, it's not any harder than being sighted. Orientation and Mobility is learning to become familiar with your surroundings, and navigating through your world with a visual impairment.

"Teaching visually impaired kids is different because I have to put myself in their shoes," vision teacher Michelle Hartig said.

With the help of her friends and Orientation and Mobility training, Shannon can get around school with no

help. Unlike Shannon, Marion has to deal with getting around in a wheelchair, as well as a visual impairment.

“It’s sort of easy because people help me with my wheelchair and they like my monocular,” Marion said.

As for me (Timothy), I’m the one always wearing a hat or visor which helps me see. I have 20/80 vision, so it’s hard to see fifteen feet away. The hat helps me by eliminating glare.

It may be hard to tell if Shannon is visually impaired if you don’t watch closely. Blind people who are very outgoing adapt to their impairment faster. However there are times when people notice Shannon’s visual impairment.

“Some people think I have no feelings and that they are better than me,” Shannon said. Marion said that she rarely gets teased.

In a survey, 63% said they would be able to adapt to their visual impairment if they were blinded. The survey also showed that blind and visually impaired have the same capabilities as sighted people.

“Visually impaired students aren’t any different from sighted people. They can see, just not through their eyes,” said freshman Jonathan Valk.

Welcome to Our-Kids <<http://rdz.acor.org/lists/our-kids/>>

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Our-Kids is a "Family" of parents, caregivers and others who are working with children with physical and/or mental disabilities and delays. We call the list "Our-Kids". While it isn't exactly descriptive, it avoids the pitfalls of labeling our kids anything but what they most certainly are: The wonderful little people in our lives.

The Our-Kids list consists of over 800 people representing children of varying diagnoses; everything from indefinite developmental delays and sensory integration problems, to cerebral palsy, to rare genetic disorders. Over 35 countries are represented on the list now.

Here we can discuss our children's accomplishments and defeats, knowing that the audience includes others who know what we are going through. We can also get some idea of how others address specific problems/concerns with feeding, learning, schools, medical resources, techniques and equipment, as well as describing the problems to friends and family or just coping. A few professionals, organizations and therapists also monitor and contribute to the list. This list is not for the canvassing of any particular religious or political ideals nor is it a forum to debate for/against abortion or euthanasia. In fact, the list is not for debate whatsoever. The sole purpose of this list is for support and information for ourselves and our kids.

My name is Randy, and I represent my son Sean, who is 6 years old and has severe cerebral palsy, spastic-quad, as a result of severe muconium aspiration. Sean is non-verbal and non-ambulatory. He is very aware though, has a great laugh, and a horrible grump which he has artfully mastered to effectively manipulate his daddy. The originator of this list is Ashley, who formed this list in January 1993 on behalf of her son Austin, who has Angelman Syndrome, on the basis of chromosomal testing.

Some of the kids represented on this list have more severe problems than ours, while others do not. Some are further ahead in capability and age, while others are not. But all of us and our kids have all benefited in the areas of support and knowledge thanks to the wonderful participants of this list. Please join us.

About the Sibling Support Project

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The Sibling Support Project is a national program dedicated to the interests of brothers and sisters of people with special health and developmental needs. The Project's primary goal is to increase the availability of peer support and education programs for brothers and sisters of people with special health and developmental needs.

GOALS OF THE SIBLING SUPPORT PROJECT

To accomplish this goal, project staff:

- create awareness materials (e.g., curricula, children's books, websites, newsletters) for parents, service providers, and brothers and sisters;
- conduct workshops in each of the 50 states for parents and providers on the life-long issues facing brothers and sisters and how to start a Sibshop;
- provide technical assistance to those starting a local Sibshop;
- maintain a database of over 200 Sibshops and other sibling programs across the United States;
- conduct Sibshops for Seattle-area brothers and sisters of children with special health and developmental needs and
- evaluate the effects of programs for siblings.

MATERIALS

Materials created by Sibling Support Project staff include:

- *Sibshops: Workshops for brothers and sisters of children with special needs*, 1994, by Donald J. Meyer and Patricia F. Vadasy (Baltimore: Paul H. Brookes). To order call (800) 638-3775. Also available at Barnes and Noble Bookstores.
- *Living with a brother or sister with special needs: A book for sibs*, 1996, (2nd edition, revised and expanded) by Donald Meyer and Patricia Vadasy (Seattle: University of Washington Press). To order call 1-800-441-4115. Also available at Barnes and Noble Bookstores.
- *Uncommon Fathers: Reflections on raising a child with a disability*, 1995, Donald Meyer (ed.). (Bethesda, Maryland: Woodbine House). To order, call (800) 843-7323. Also available from Barnes and Noble bookstores.
- *Views from our Shoes: Growing up with a brother or sister with special needs*, 1997, by Donald Meyer (ed.) (Bethesda, Maryland: Woodbine House). To order, call (800) 843-7323. Also available from Barnes and Noble bookstores.
- *The National Association of Sibling Programs (NASP) Newsletter*. The Sibling Support Project, CL-09, Children's Hospital and Medical Center, 4800 Sand Point Way, NE Seattle, WA 98105.
- *Sibling Support Project Web Page*: <<http://www.chmc.org/departmt/sibsupp>>.
- *The SibNet and SibKids Listservs*, email-type bulletin boards for brothers and sisters of all ages and others interested in the well-being of siblings.

For a *free* subscription, visit the Sibling Support Project Web Page or contact the Sibling Support Project. The Sibling Support Project receives funding from the U.S. Department of Education, Office of Special Education,

Personnel Preparation Program. For more information about Sibshops and the Sibling Support Project, contact:

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 <<http://www.chmc.org/departmt/sibsupp/>>

PRESENTING *SIB TO SIB!*

Sib to Sib! is a newsletter for brothers and sisters. Should you wish, you can subscribe to *Sib to Sib!*. At the moment, the subscription to *Sib to Sib!* is free--and it doesn't get much better than that, eh? To subscribe, write: Andrew Lanier, *Sib to Sib!* Editor

c/o Rhoda Berlin
 Little Red School House
 P.O. Box 992
 Lynnwood, WA 9804

It is a pleasure to present a Web version of the *Sib to Sib!* newsletter! To get to the *Sib to Sib!* newsletter go to <<http://www.chmc.org/departmt/sibsupp/newsletters.htm>>. Written, edited, and published by our Sibshop friends in Lynnwood, Washington, *Sib to Sib!* features articles written for and by brothers and sisters of kids with special needs.

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about specific syndromes or conditions that occur with children who have visual impairments and/or deafblindness such as Usher Syndrome, retinoblastoma, cerebral palsy, ROP, etc. The News & Views section contains information on legislative issues, resources, workshops, agencies, etc. We will also continue to offer the newsletter in a range of formats: English and Spanish regular print, and English large print, braille, disk, and audio. We are also now making the full newsletter, in both English and Spanish, available on the TSBVI website at <www.tsbvi.edu>. You can also find many articles from past editions of both the English and Spanish version of SEE/HEAR archived there.

The other big change with SEE/HEAR involves the addition of several more staff members. Joining the SEE/HEAR publication committee are: Jean Robinson, Family Editor, Ann Rash, Programming Editor, Gigi Newton, Syndromes/Conditions Editor, and Jim Durkel, News & Views Editor. Returning to Deafblind Outreach this fall is one of my dear friends, Craig Axelrod; we are all so pleased to have him back with us. Craig will take over as Layout Editor. Of course, Berta Green, Production Editor and Edgenie Lindquist, TCB Editor continue to do the great work I've come to depend on in getting the newsletter out to you. I will serve as Editor-in-Chief. Once again Jim Allan, Webmaster from TSBVI, Recording for the Blind & Dyslexic, and Juanita Barker and Stephanie Campbell from TCB in Lubbock will lend their support to our efforts.

Please let us hear from you regarding the changes we have made. Our goal is to make the information in SEE/HEAR practical, timely, and enjoyable to read. Let us know if you think we are meeting our goal. You may contact me at TSBVI, Texas Deafblind Outreach, 1100 West 45th St., Austin, TX 78756, phone (512) 206-9224 or (800) 872-5273, or email to moss_k@tsb1.tsbvi.edu.

Let me also encourage you to visit the TSBVI web page. Our web address is <www.tsbvi.edu>. If you do not have a computer at home, go to your public library. Most libraries now have Internet access. You can find the web version of our newsletter, publications from our school, plus much more. Check us out!

Orientation and Mobility Training: The Way to Go

By Carolina Martinez, O & M Specialist, TSBVI

with help from Kate Moss, Family Support Specialist, TSBVI, Texas Deafblind Outreach

WHAT IS O & M?

Movement is a building block for learning. As a child explores his world and has physical contact with it, learning takes place. Children with visual impairments typically need encouragement to explore their surroundings. To them the world may be a startling and unpredictable place, or it may not be very motivating.

Orientation and mobility training (O & M) helps a blind or visually impaired child know where he is in space and where he wants to go (orientation). It also helps him be able to carry out a plan to get there (mobility). Orientation and mobility skills should begin to be developed in infancy starting with basic body awareness and movement, and continuing on into adulthood as the individual learns skills that allow him to navigate his world efficiently, effectively, and safely.

Orientation and mobility training actually began after World War II when techniques were developed to help veterans who had been blinded. In the 1960s universities started training programs for Orientation and Mobility Specialists who worked with adults and school-aged children. In the 1980s the O & M field recognized the benefit of providing services to preschool-aged children. Today, orientation and mobility specialists have developed strategies and approaches for serving increasingly younger populations so that O & M training may begin in infancy.

WHAT SKILLS ARE TAUGHT THROUGH O & M?

When planning an O & M program for children the focus of training may include such things as:

- sensory awareness: gaining information about the world through hearing, smell, touch and proprioception
- spatial concepts: realizing that objects exist even if not heard or felt, and understanding the relationships which exist between objects in the environment
- searching skills: locating items or places efficiently
- independent movement: which includes crawling, rolling, walking, etc.
- sighted guide: using another person to aid in travel
- protective techniques: specific skills which provide added protection in unfamiliar areas
- cane skills: use of various cane techniques to clear one's path or to locate objects along the way

Although Orientation & Mobility Specialists are primarily responsible for O & M training, their work may not always be done directly with the child. When the child is very young, for example, the O&M may provide consultation to the vision teacher, occupational therapist, physical therapist, early intervention specialist, and the family. It is important that an O & M Specialist be a part of the team because it is the O & M who must build upon these early concepts to meet long-range goals. In Texas, the vision teacher makes the referral to the O & M Specialist for an O & M assessment.

Even visually impaired children who have motor impairments need training in orientation and mobility. Though their O & M goal may not be independent travel, they may need O&M to participate more fully in events in their environment. For example, understanding that your wheelchair is in front of you can help you find it to assist with the transfer to the chair. Knowing that your switch is on the right side of your lap-tray may allow you to play your CD player whenever you choose, instead of having to wait for someone to come help you. Even if you are not yet walking, it would probably be good to know that you could listen for the sounds mom is making in the kitchen to help you find your way to her.

Children who are deafblind also need orientation and mobility training. Because their other distance sense (hearing) is affected, orienting to their environment and traveling safely becomes even more important. Orientation and mobility specialists have specific knowledge which is critical to the child with deafblindness.

Orientation and mobility is important for every visually impaired child. It does not matter how young or old he is, how physically active or inactive, how much vision he has, or how smart a child he is, there are probably skills that he needs to develop or refine in the area of orientation and mobility.

LOOKING AT O & M SKILLS

Sensory awareness

When a child can not access his world efficiently through his vision, he must learn to use his other senses more effectively. Systematic instruction is needed to develop the other senses for use in travel and finding things in the environment. He must understand that some of the sounds and smells and textures he experiences can be used as permanent markers (landmarks) to let him know where he is in the world. Other pieces of information may be there sometimes and not at other times (clues) such as the sound of the water fountain. Developing sensory awareness is critical for the child with visual impairments or blindness.

Sounds, when not paired with clear visual information, can be very confusing. Try sitting in a busy mall or park for a period of time with your eyes closed. You will probably hear sounds you can't identify and be tempted to open your eyes, to try to pair a sound to its source. You might assume that sounds which get louder and louder are coming towards you because of your visual knowledge of the world. A child with a visual impairment may not make the same assumption. The ringing noise he hears may not mean "telephone" or that the honking sound may not mean "car." He needs help in learning to use his hearing to interpret the world around him. If his hearing is impaired even to a small degree that task will become much more difficult. Close your eyes and plug your ears while you stand on a busy street corner. Can you tell which way the traffic is flowing or when it will be safe to cross the street? Are you startled or distracted by other noises you hear? Children need to learn to localize sounds and use sound clues for orientation, straight line travel, and safety.

Though we may not be aware of it, we know much of the world through touch. However, if the things you touch or that touch you feel funny, or hurt, you may become resistant to using touch to examine things in your environment. Touch alone may not be helpful in identifying an object if you can't touch the whole object at one time. Is the furry thing a cat or a rabbit? If you aren't touching the ears or the teeth or the tail you might not know. Developing the tactual sense will help the child in ways that range from finding a toy he dropped on the floor to feeling the difference between the curb and the street with his cane.

Normally I don't pay much attention to smells unless they are extremely pleasant or offensive, but I might use that kind of information to help me know exactly where I am in certain environments. Smells can also serve as landmarks and clues for environmental awareness. For example, the smells that can be found in my kitchen differ greatly from the smells in my bedroom. I can also smell food being cooked near mealtime in my kitchen, but after a meal I am more likely to smell the soap used in the dishwasher. If I am looking for a clue to my location, I need to know that both of those smells might mean I'm in the kitchen. The gym at school, unlike my kitchen at home, might always smell about the same. If I have no sight, this smell, especially combined with other clues and landmarks, might help me know that I am in the gym.

It is important for children with visual impairments to participate in activities that enable them to fully use their other senses. Learning to interpret the information they tune in to is equally important. Parents and educational staff, with support from the O & M, can do a lot to help children develop their other senses.

Spatial concepts

“Go down the street three blocks and turn right at the corner. I live in the upstairs apartment of the large, red brick building on the left.” Pretty clear directions right? What if you don’t know “blocks” and “corner” or “upstairs” and “left”? Doesn’t “down” mean under? How large is “large?” When vision is impaired these concepts are much more difficult to understand and need to be taught. How do you teach the concept of “corner” without vision? Do you touch corners or draw corners? If you can touch a corner or draw a corner, where do I find the corner to touch when I am walking along the street?

Orientation and mobility specialists work to develop distance, size and directional concepts in children with visual impairments. Mom and Dad, and Mrs. Henry the art teacher, may work on these concepts too, but having the support of an O & M would likely make their job much easier.

Our joints and muscles give us feedback about where our body parts are positioned. This is our proprioceptive sense. Proprioceptors located in the muscles and joints tell us if we are slumping or standing up straight, if our fingers are curled or extended, etc. Our vision system and our proprioceptive system work closely together. When vision is impacted, so is our proprioceptive sense. Children with visual impairments generally need help to learn where their bodies are in space, and in relation to things in the environment. The physical therapist and occupational therapist, along with the O & M, can work directly with the child. They may also be able to suggest specific activities for the family, to help their visually impaired child develop the proprioceptive sense.

Independent movement

Most children with visual impairments are capable of learning routes in familiar environments. They learn to use landmarks and clues to help them know where they are along a particular route. They learn specific adaptations to aid them in their movement. These might include understanding that tactual markers on doorways identify the gym or the restroom, using an adaptive mobility device or a cane to identify obstacles and drop-offs, or locating a street sign using a monocular. A primary goal of orientation and mobility training is to help each child with visual impairments achieve independent movement to as great a degree as possible.

Some children may be preparing to get a dog guide, or learning how to access public transportation to get across town to a job. For children with additional disabilities, independent movement might focus on traveling independently in a wheelchair, or learning how to help get yourself into a van using a lift. It might mean helping the child learn to control the speed of movement on his walker as he goes down a ramp.

Independent movement is tied to growth in other areas, such as communication and socialization. For example, though a child may not be able to tell you he’s hungry, if he can take you to the kitchen you will probably understand that he wants something to eat or drink. Peers are more likely to invite your daughter to go to the mall if she can keep up with the group by using sighted guide technique or traveling with a cane. Going where we want when we want gives us control and allows us to make choices.

ELECTRONIC AIDS FOR ORIENTATION AND MOBILITY

There are a variety of O&M devices that individuals with visual impairment use. Most are considered “low tech” because they are very simple devices, typically a cane or adaptive mobility device. These are the devices that most people with visual impairment will use for two good reasons: (1) they are relatively inexpensive to purchase and maintain, and (2) you typically must be able to use these basic devices (especially a cane) before you can learn to use other types of mobility devices or strategies such as ultrasonic technology or dog guides. Your O&M specialist can show you canes and adaptive mobility devices and will be able to dispense these

“low tech” devices to your child. There are also other O&M devices, more “high tech” and less well known, that we thought you might like to learn about. These devices can only be issued by an O & M Specialist with ETA certification. The ETA certified O & M Specialist must also provide training in the use of these devices. Non-ETA certified O & M Specialists may not dispense or train individuals using these devices.

The **Sonic Pathfinder** is a head mounted ultrasonic mobility device designed for outdoor use in conjunction with either a long cane, dog guide or residual vision. The Sonic Pathfinder gives the user advance warning of objects which lie within the travel path. The distance and position of a detected object is signaled via the ear pieces using the eight tones of the musical scale. Price: \$1695, plus \$20 shipping & handling.

The **Sensory 6** detects objects that are farther away than a long cane, and the user hears tones that indicate the distance to the objects. As objects are approached, the tones become higher pitched. The Sensory 6 is not intended to be the only travel aid. It should probably be used in conjunction with another aid, such as a cane. Price: \$975, plus \$15 shipping & handling.

The **MOWAT Sensor** is a small hand-held device that uses high frequency sound to detect objects within a narrow beam. The entire sensor vibrates if an object is present. To avoid confusion, the sensor responds only to the closest object within the beam and the vibration rate increases as the user approaches the object. Price: \$995, plus \$20 shipping & handling.

The **Polaron** is a compact aid that utilizes ultrasonic technology to detect objects within four, eight, or sixteen feet. The Polaron may be used as a secondary aid to a standard long cane, or with a guide dog. When an obstacle is within range, the Polaron either vibrates or emits a sound. The Polaron is designed specifically for the blind, visually impaired and deafblind wheelchair user. Price: approximately \$900.

The **Wheelchair Pathfinder** is a set of small rectangular boxes mounted to the front of the wheelchair. Lasers point downward while ultrasonic beams are transmitted in front and to the sides of the wheelchair. When the beam contacts an object, it bounces back to a receiver, triggering an audible warning signal or optional tactile signal. The Wheelchair Pathfinder has forward detection (an intermittent beeping sound), side detection (a continuous tone on the side where the object is) and step detection (a low pitch signal within 4 feet in front of a drop off). Price: approximately \$4,500.

The **Laser Cane** operates with three lasers that emit invisible beams of light from the cane. The beams detect drop offs and obstacles at different heights and distances. In this way, the cane provides the user with advance warning of obstacles in his/her path through an audible and tactual alarm system. There are three distinctly different audible tones: high, middle, and low pitched. The vibrating unit, known as the tactile stimulator, signals the index finger when there is an obstruction straight ahead. Price: approximately \$200.

For more information on these electronic devices contact: MSI Mobility Services Inc., 761 Peachtree St. Suite 3, Atlanta, GA 30308, phone (800) 876-2636. Similar devices may be available from other companies. TSBVI does not intend to recommend these products over any other.

CONCLUSION

Independent movement is critical for all children with visual impairments. Orientation and Mobility specialists are trained to provide instruction which will enable children with visual impairments to reach their highest level of independence. The services provided by an O & M may not always need to be delivered directly to be effective, but even infants or children with multiple disabilities need the special support of a trained Orientation & Mobility Specialist. Make sure your child’s O & M needs are being addressed as a part of his/her school programming. You may want to meet with your school’s Orientation and Mobility Specialist to discuss your concerns. If your school district does not have its own O & M, ask your child’s vision teacher to help you connect with the O & M at the Regional Education Service Center or Special Education Co-op in your area. Orientation and mobility training...it’s the way to go.

RESOURCES ON ORIENTATION & MOBILITY

Association for Education and Rehabilitation of the Blind and Visually Impaired (AER)
Division 9, Orientation and Mobility
4600 Duke Street, Suite 430
Alexandria, VA 22304
(703) 823-9690

Living Book Online - Orientation and Mobility Book
<<http://isd.saginaw.k12.mi.us/~mobility/index.htm>>

Reaching, Crawling, Walking . . . Orientation and Mobility for Preschool Children by Susan S. Simmons, Ph.D. and Sharon O'Mara Maida, M.Ed. available from the Blind Childrens Center, 4120 Marathon St., Los Angeles, CA 90029, phone (213) 664-2153 or (800) 222-3566, web page <<http://www3.primenet.com/bcc/about.htm>>.

O & M Around the World

By Rhonda Adams, COMS, Education Service Center Region 12

This summer I had the opportunity to attend the ninth International Mobility Conference in Atlanta, Georgia. This was truly one of the greatest experiences of my professional career! It was awesome and amazing to sit and talk with other O&M Specialists from all over the world, to see where their needs are, the research they are developing, and the difficulties they face.

During the pre-conference, at any point in time, I would find myself sitting next to O & M specialists from Uganda, Botswana, Denmark, Bahran, Saudi Arabia, Estonia, Australia, Israel, Poland, South Africa, Fiji, Mexico, Spain, Japan, China, Canada, and other places. It was nice to see that many of the problems I face in the USA are the same problems O & M Specialists face the world over. I found it very heart wrenching to listen to international O & M Specialists discuss their case loads. In Alberta, Canada there are three O & M Specialists, and each has a caseload of ninety. There is no O & M in the country of Botswana. That country is trying to start a training program for O & M, but is having difficulty finding a sponsor. In Uganda there are an estimated five-hundred-thousand individuals with visual impairments. Only fifty of these individuals have received O & M services, and that thanks to training sponsored by Norway.

I was also struck by the amounts of research other countries are doing. There was research presented by the USA, but not nearly as much as is being done in other countries. Germany is finishing up research on infant and toddler O & M training. They are also designing an assessment based on their findings. This research is not yet available in English.

I also had the opportunity to visit with vendors from all over the world. I saw the ultimate in travel canes. It is manufactured in Germany and costs approximately \$220 dollars (U.S.). It seems that the socialized medical system allows for higher prices. I also saw firsthand the advancements in cane tip manufacturing, new and more flexible canes (color coded), and the advancements in audible street signals.

I came away from this conference with a new and refreshed view of O &M and the impact our profession has on the consumers of our services. The next International Mobility Conference will be in the summer of 2000 in Warwick, England. It looks like it will be very affordable! Start making plans now to attend. I promise it's worth it!

Hand-Over-Hand Guidance: What Lesson Do We Teach?

By Andrea Story, Anchorage, Alaska

originally published in The National Newspatch, November 1997

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Independence is emphasized in much of the literature concerning young children who are blind. In the revised edition of *Can't Your Child See? A Guide for Parents of Visually Impaired Children* it states that, "The more they (parents) teach the child to function independently in the first three or four years, the less they will have to do later (Scott, Jan, Freeman, 1985)." But how do you "teach" independence to a one-, two-, or three-year-old child without sight? How do you bring the world to the child and how do you teach skills such as putting on a jacket without making the child dependent on constant prompts and cues? It has often been observed that many children with visual impairments, especially those with additional impairments, are much more passive than their sighted peers. They seem to think of themselves not as a doer but as one who must wait for assistance or a prompt.

Literature on young children with blindness often mentions the "fairy godmother" syndrome. The child has little information to make the connections of how and why things are appearing and disappearing within their world. There is also the concern of imitation: how do you show a child how to eat with a spoon if they can't see how others are doing it? The solution offered for these concerns has often been a hand-over-hand guide technique. The adult holds the back of the child's hand and the child is guided to the objects to be explored and guided through the motions of the activity to be learned.

Some have begun to question and reject this method. Dr. Lilli Nielsen of Denmark noticed that children often pulled away when an adult attempted to direct or guide the child's hands. Lilli writes, "I changed my approach so that guiding or leading the child's hand was used infrequently. This resulted in the children seldom withdrawing their hands. On the contrary they became more eager to initiate exploration and examine objects, thus improving their ability to grasp and to use their hands in various ways." (Nielsen, 1992)

Watching Nielsen play with a child, one can see how touching the inside of the child's hand with an object elicits a grasp quickly and much more independently on the child's part than forcibly placing the child's hand on the same objects. Once the child is motivated by the objects, a reach and grasp can be elicited by a sound or vibration nearby. The children she has worked with at her presentations often begin to imitate activities such as strumming a stringed instrument, blowing into a harmonica, or dropping balls into a container. The children's hands were never guided, and they stayed actively engaged for up to an hour. The children's parents, teachers, and therapists are often amazed at how much the child would do for Lilli. A bigger challenge may be the very passive child who moves very little. It will take these children longer to learn, and small steps should be appreciated when they do occur. As Lilli has said, these children do not have time to waste.

Enthused by Nielsen's results, many who attend her lectures focus on equipment such as the Little Room™, and yet continue to guide the child's hand. The child's reaction is most often to pull their hands away, or to passively allow their hands to be manipulated. It is an issue that I still struggle with, for although I have seen some wonderful results in using alternatives, I still have to sit on my own hands sometimes to stop myself from guiding a child's hand. Even if I do restrain my own hands, I still have to convince educators, therapists, and parents that there are alternatives. Fortunately, some of the parents I've worked with have had success with getting their children to hold their own bottle, finger feed, and eventually spoon feed without guiding/controlling their child's hands. These successes make me question the standard advice given parents and others about teaching a child without sight.

Hand-over-hand guidance is recommended in most of the literature (or at least there are photos or videos demonstrating it). For a sighted person, it seems an almost instinctual response to guide the child's hands. Some children protest the guidance but eventually come to accept it and wait for "their turn" to explore. How frustrating to have to wait to explore something yourself! One child that I worked with seemed to actually enjoy the hand-over-hand guidance for finger plays and songs but was still quick to push the adult's hands away if the activity or object was unfamiliar to her. Other children seem much more affected by the technique and become more passive, or more defensive, to touch. These children do not repeat the skill by themselves after being guided. It should be considered that this technique of guiding a child's hand has been used too often and too quickly. Often it seems that the sighted person forgets or is unaware of the unique perspective of those that are blind. Martha Pamperin wrote about this perspective on the AER listserv recently.

"As I, a blind adult, go about getting myself a cup of coffee, I may (1) search the shelf tactually to locate cup and coffee pot, before (2) pouring the coffee. This preliminary search is normal for me, especially if I am at the home of a friend. It does not, however, look normal to the watching friend. Often as not, the friend concludes that I am not able to pour coffee and does it for me or watches in amazement as I do it myself. Since a blind person, at the beginning of a task, uses a tactual search to substitute for the visual search made by a sighted person, blind people can "look" unable when they are actually very able indeed."

Martha compares the sighted method vs. the tactual method of putting a jacket on.

"While the sighted kindergartner (1) sees the arm hole where his arm needs to go, and (2) puts his arm right in, the blind child will probably (1) aim his arm in the general direction of the arm hole and touch the front or back of the jacket, feel around to find the arm hole, then (2) put his arm in it. It is hard to resist directing the arm into the arm hole or moving the jacket. . . . The tactual search and the pause for auditory searching may make us look blind, but, surprise, surprise, we are blind. Consider the beauty of gently searching hands and the wonderful awareness of the listening posture. Wait, let it be."

Another educator who is searching for alternatives to controlling hands is Barbara Miles, who presented a workshop entitled "Hands: Tools, Sense Organs, Voice" at the 1997 National Conference on Deafblindness. Barbara listed this topic, among others in her agenda; "skillful ways of touching and inviting touch, including alternatives to "hand-over-hand" techniques." Barbara showed a video in which she gained the trust of a child described as tactually defensive. Barbara used her hands to "invite" and "comment" on objects and activities rather than directing his activity. Her hands followed the child's very gently, and were slightly under the child's hands rather than over them, thus allowing the child to know that his tactile attention was shared. From this hand-under-hand position, the teacher could gently invite the child to touch an object or person without controlling. This freedom resulted in dramatically increased hand activity.

Consider the O&M technique of the sighted guide. We are taught that the sighted guide does not hold onto the blind person's arm and pull—that would take all control away from the one being guided. The guiding must be invited and even then it is understood that the one being guided will have a harder time repeating the route by themselves because the guide-ee is dependent on the guide-er.

Hand-over-hand guidance has been promoted as a catchall solution without much question as how it is done, when, and why. The challenge remains in our work with young children to explore this issue of teaching, yet still promote independence.

If you want more information about the National Newspatch please contact: Marilyn Gense, Oregon Department of Education, 255 Capitol St. NE, Salem, OR 97310-0203, phone (503) 378-3598, ext. 653, email: marilyn.gense@state.or.us.

Read Any Good Books Lately?

Compiled by Ann Rash, Teacher Trainer, TSBVI, VI Outreach

A vision loss impacts all areas of development. As vision teachers, we do not always have the expertise we need in motor and language development. We usually work closely with the speech therapists and occupational therapists but they do not always have the needed expertise on the impact of the vision loss. A possible solution would be to read and share these two new booklets from the TSBVI curriculum department, written by an OT for OTs and a speech therapist for speech therapists.

FOR OTS AND PTS

Excerpted from *Impact of Vision Loss on Motor Development: Information for Occupational and Physical Therapists Working with Students with Visual Impairments* by Chris Strickling, OTR (Pages 13-14).

Mouthing Persists

Mouthing gives information about temperature, composition, texture, shape, and weight. This information is sometimes unavailable through other means for the child with low vision or blindness, so mouthing will sometimes persist up to age 4 or 5 or beyond. Children with low vision also use their chins and mouths as stabilizers. They are reluctant to put the objects down because putting an object down often means losing it. Mouthing usually diminishes as pincer grasp is developed, which can be quite late for these children.

Possible Interventions:

Ask yourself these questions when considering whether or not to intervene in mouthing behaviors:

Is there functional use of objects, or just mouthing?

If the student already has some functional manipulation schemes with objects, redirect the mouthing behavior to more appropriate manipulation. If not, try to engage the child in a meaningful action on the object as a replacement. Teaching more meaningful interactions with objects will often result in a decrease in mouthing.

Is this the child's only way to explore the object?

If the child is not yet ready for manipulation schemes, then helping the child explore the object will expand the child's exploration. Using the object in a game, adding pressure to the object and contacting the body with it; and adding texture, vibration, or sound to the action of the object are all ways of increasing exploration. In some cases offering more and different objects to explore orally before attempting to move the child from mouthing to a more mature exploration may be helpful. Alternatives for appropriate oral stimulation should be considered if mouthing is being used to increase sensory awareness.

Is the mouthing for exploration or just a way to retain the object?

Teach the child how to keep an object within grasp by providing a container, placing it in a pocket, or establishing some other place for it. Mouthing is sometimes just a way to keep objects close at hand.

FOR SPEECH-LANGUAGE PATHOLOGISTS

Excerpted from *Language Assessment and Intervention with Children Who Have Visual Impairments: A Guide for Speech-Language Pathologists* by Maria L. Munoz, M.A., CCC-SLP (Page 22).

Effective Intervention Strategies

Visually impaired children who also have language impairments may have difficulty relating the language they hear to their sensory experiences, so these connections must be taught explicitly. Children need to relate sensory events to the language of an event. Developing these relationships helps children learn to organize and interpret information. One effective strategy is to modify what the child is already doing to make it more functional. Children who are echolalic or who use only question forms are trying to fulfill particular communicative functions, such as commenting, requesting, or maintaining an interaction. An SLP can model more appropriate language for the child to meet these functions.

When working with children with visual impairments, these additional guidelines will enhance the effectiveness of intervention strategies. Such strategies should:

- Be concrete and experientially based using multisensory approaches, including touch, taste, smell, hearing, and vision
- Be relevant to the child's daily experiences
- Facilitate the generalization of skills
- Expand the child's repertoire of meaningful topics by providing the language needed to talk about familiar events
- Be structured to make novel experiences more comprehensible AND
- Develop associations between concepts and the child's experiences.

(Both of these booklets are available from Texas School for the Blind and Visually Impaired for \$5 each.)

FOR VI TEACHERS SERVING CHILDREN WITH VISUAL AND MULTIPLE IMPAIRMENTS

Vision teachers are often asked to assist or adapt classrooms for students with visual and multiple impairments. Many VI teachers are comfortable adapting the classroom but become frustrated when asked to design the schedule and all of the activities for the student with the visual impairment. *Teaching Students with Visual and Multiple Impairments: A Resource Guide* by Millie Smith and Nancy Levack is a resource for classroom teachers and vision teachers. An excerpt (Pages 152-153) follows:

Establishing a Schedule of Meaningful Activities

Activities can be meaningful to students for a variety of reasons. They may value the activity because family, peers, and teachers value it. They may enjoy it because it relates to personal likes and interests. Or it may be significant only because it provides an opportunity to interact with people whose company they enjoy. Activities are usually more meaningful when they are a regular part of students' lives and when students understand the outcome of participating in an activity and value that outcome.

In the past, many self-contained special education classrooms were designed with a combined medical and developmental model. A student's schedule consisted of various therapies, positionings, diaper changes, medications, and meals. Toys, stacking rings, puzzles, and stuffed animals were provided regardless of age.

Today, we know that a better approach is to establish a daily schedule for a student which integrates special services into meaningful activities. However, special services can't be integrated until activities are established. Teams switching from a medical/developmental model can use inventories to generate ideas for activities. In inventories, typical environments are listed for a given student. These might include cafeteria, classroom, gym, bathroom, music room, and playground. Next, at least one meaningful activity for each environment is identified.

A sample inventory of environments and activities for a 10-year-old nonambulatory, nonspeaking student with low vision might look like this:

Sample Environment/Activity Inventory

ENVIRONMENT	ACTIVITY
cafeteria	Eat breakfast and lunch.
classroom	Clean chalkboard using a sponge mop. Play bingo with classmates. Play cassette tapes. Make snack.
gym	Race in wheelchair relays. Throw basketballs in a basket.
bathroom	Wash hands. Toilet.
music room (with regular ed class)	Play rhythm instrument while peers sing. Record and play back songs.
playground	Turn the rope for jump rope. Hit T-ball with bat and run bases with peer assistance.

The chalkboard-cleaning activity was chosen for this student because she likes water and enjoys squeezing the sponge mop out in a pan of water. Typical peers also have chores. Playing cassette tapes was chosen as a recreation/leisure activity in order to give her a chance to learn to play her favorite music independently using adaptive equipment. The direct implementors of instruction are the classroom teacher and the paraprofessional. The VI teacher assists by planning modifications and adaptations and by role releasing procedures for teaching specific sensory skills.

(This book is available from the Texas School for the Blind and Visually Impaired for \$40.)

If you are interested in other books and materials available through TSBVI, please contact our Curriculum Office by mail at 1100 West 45th St., Austin, TX 78756, phone (512) 206-9183, or visit the TSBVI website at <www.tsbvi.edu>.

Cerebral Palsy and Children with Vision and Hearing Loss

By Stacy Shafer, Early Childhood Specialist
& Kate Moss, Family Support Specialist, TSBVI, Outreach

WHAT IS CEREBRAL PALSY?

Cerebral Palsy or CP is a condition that is mainly characterized by an inability to fully control motor function. This may include muscle tightness or spasm, involuntary movement, and/or disturbance in gait and mobility. It is NOT a disease, is not communicable, and is not progressive. It is caused by damage to the brain, rather than muscles. This damage can occur before, during or shortly after birth. Lack of oxygen, illness, poisoning, and head injury are some factors that can cause cerebral palsy.

People who have CP may also experience a range of conditions in addition to impaired motor function. These may include:

- abnormal sensation and perception
- impairment of sight, hearing, or speech
- seizures
- mental retardation
- difficulties in feeding, bladder and bowel control, and breathing (because of postural difficulties)
- skin disorders (because of pressure sores)
- learning difficulties

CP can range from very mild to very severe. No two people are affected in exactly the same way. Some children with mild CP may not be diagnosed until after they are two years old.

There are three main types of CP:

- Spastic which produces stiff and difficult movement
- Athetoid which produces involuntary and uncontrolled movement
- Ataxic which produces a disturbed sense of balance, position in space and general uncoordinated movement

It is important to note that these three types of CP may also occur in various combinations.

Physical therapists who work with children who have CP will often describe the child as having low tone (hypotonia), high tone (hypertonia), or fluctuating tone. Other terms you may hear them use in discussing CP refer to the area of the body affected by the brain damage. Problems to one side of the body are referred to as hemiplegia. Quadriplegia occurs when the individual has upper and low body involvement. Diplegia describes lower body involvement and paraplegia describes upper body involvement. (Harris, 1987)

VISION ISSUES

“Over 40-75% of children with cerebral palsy have some form of a visual problem or impairment.” (Black, P.D., 1980) They may have an acuity loss, field loss, oculomotor problem and/or a processing problem. These conditions often result in visual concentration issues and/or problems with eye-hand coordination. It is very important that an eye care specialist be consulted regularly for possible treatment, including glasses, eye patching, surgery, etc.

Acuity loss

An acuity loss typically makes things appear blurry. Nearsightedness (myopia) and farsightedness (hyperopia) are types of acuity loss caused when the image does not hit the retina correctly (refractive errors). Glasses

are prescribed to help improve refractive errors. Those of us who have an acuity loss and wear glasses know how much information we miss from our environment when we don't have our glasses on. Glasses are very important for a child who has CP and acuity loss. Glasses can greatly improve incidental learning or learning that takes place by observation.

Field loss

The field of vision is everything you can see when you look straight ahead which is normally about 180 degrees in all directions. A field loss means that part(s) of the field is missing. Types of field losses include:

- hemianopsia: right or left, upper or lower half of the field is missing,
- central loss: like holding your fist up in front of your eyes,
- scotomas: isolated spots are missing from your vision,
- islands of vision: you can see only scattered spots, and
- peripheral loss: you can see straight ahead but misses information from the sides

Oculomotor problems

An individual with CP may also experience conditions with their eye that can affect depth perception and smooth movements of the eye. These are called oculomotor problems and include:

- eye turns in towards the nose (esotropia or esophoria),
- eye turns out towards the ears (exotropia or exophoria),
- eye turns up (hypertropia or hyperphoria),
- eye turns down (hypotropia or hypophoria),
- eye misalignment due to muscle imbalance (strabismus),
- lazy eye (amblyopia)

Processing problems

This means that the child has problems making sense of visual information. Cortical visual impairment or CVI causes processing problems. CVI can cause the vision to fluctuate from day to day and minute to minute. It can also impact depth perception and cause a field loss.

Visual concentration and eye-hand coordination

Children with CP may also have problems with visual concentration and/or eye-hand skills. Many of the children expend so much energy and concentration on keeping their body upright, controlling an accurate reach, etc. they have little left over to use for visual tasks. Asking some children with CP to hold their body in alignment, look at a toy and then reach for it, might be like asking you to read *War and Peace* and put a bicycle together while serving your mother-in-law high tea. We are asking the child to do too much at one time. If we can support and stabilize his body, he will be able to concentrate on looking and reaching. If trunk and head control is the skill you want to work on, you may not want to use a visual toy as a motivator. As a team you need to consider the types of demands you are placing on the child within any given activity.

HEARING LOSS AND LANGUAGE PROBLEMS

“Robinson (1983) noted that 20% of children with cerebral palsy display hearing or language problems.” (Anthony, T. 1993) Typically the hearing loss is sensorineural. Beyond that, not much research has been done to date on hearing loss and CP. It is important, however, that children with CP also have their hearing assessed, especially if they also have a visual impairment.

Children with CP often have speech problems. This happens because the muscles that are used in producing speech (in the tongue, throat, lungs, etc.) are impacted by the CP, a condition known as dysarthria. Their

speech may be slow and slurred. Their voices may have a very nasal quality (hypernasal) if too much air comes through the nose or sound like they have a bad cold if too little air comes through the nose (hyponasal). The child's facial features may also seem distorted when they are speaking. A speech therapist should be consulted to determine if a therapeutic approach might help the child with these problems.

Many people consider using voice output devices with individuals who have CP. Before making such a recommendation, it is important to thoroughly evaluate the child's hearing. His ability to use such a device will be impacted by how well he hears. He may also have problems hearing what the teacher says, participating in group discussions, or any other tasks that requires the use of hearing. If hearing and vision losses are both present, an educational approach for deafblindness should be used.

LEARNING PROBLEMS

Other problems that may impact learning for some children with CP include learning disabilities, mental retardation, and seizures. Good assessment should insure that these issues are appropriately addressed in developing the IEP and providing the necessary adaptations, modifications and related services the child needs to be successful.

BENEFITS OF A TEAM APPROACH

It is critical that everyone who works with the child share information and ask questions. The parent, teachers of the visually impaired and hearing impaired, occupational and physical therapists, assistive technology specialist, orientation and mobility specialist, ophthalmologist and audiologist, classroom teacher and others have vital information that is necessary to consider when building a successful program for the child. When the team is designing activities for the child to participate in at home or at school, here are some of questions you might want to ask each other:

- What does the child like to do?
- Are there activities that pose problems because the child doesn't seem to pay attention (i.e., shift gaze, focus on person or object, tracking, use good eye-hand coordination)? What are these activities?
- Which position(s) is best for visual activities? Auditory activities? Hand-eye activities?
- How do I get the child into each of these positions? What tips do you have for getting the child into these positions without hurting the child or the adult?
- What positions place high energy demands on the child?
- What positions make it difficult for the child to use her vision? Hearing? What other types of activities can she do in those positions?
- Will the child need any special equipment for positioning in various activities?
- Will the child's hearing aid be adequate for the activity or should other devices such as an FM system be considered? Are any low vision devices needed for the activity? What about augmentative communication devices?
- How will his hearing aid and/or low vision devices interface with adaptive equipment and augmentative communication devices?

RESOURCES ON CEREBRAL PALSY

Organizations

Look in your phone book for your local Cerebral Palsy Center or contact :

United Cerebral Palsy Associations
1660 L. St. NW, Suite 700
Washington, DC 20036-5602
(800) 872-5827 (voice) or (202) 776-0406 (voice)
(202) 776-0414 (fax)
(202) 973-7197 (TTY)
<www.ucpa.org>

American Academy for Cerebral Palsy and Developmental Medicine (AACPDM)
6300 North River Road, Suite 727
Rosemont, IL 60018-4226
(847) 698-1635 (voice)
(847) 823-0536 (fax)
Email: woppenhe@ucla.edu
Website: <<http://aacpdm.org/>>

This organization is a multidisciplinary scientific society devoted to the study of cerebral palsy and other childhood onset disabilities, promoting professional education for the treatment and management of these conditions, and improving the quality of life for people with these disabilities.

Internet Resources

<<http://hometown.aol.com/anee/index.html>>

This is a site whose webmaster has cerebral palsy. This site provides good basic information as well as links to other sites dealing with cerebral palsy. Keep scrolling down and you will find information about cerebral palsy and visual impairments.

CP Tutorial - The Children's Medical Center of the University of Virginia offers this wonderful tutorial for parents, kids, and others related to CP. Check it out at: <<http://hsc.virginia.edu/cmc/tutorials/cp/cp.htm>>.

Books, Papers, and Videos

Bobath, B., and Bobath, K. *Motor Development in the Different Types of Cerebral Palsy*, 1975, Publisher: Heineman, London.

Finnie, Nancy. *Handling Your Young Cerebral Palsied Child at Home*, ISBN 0-452-26658-0, Publisher: Penguin USA, Phone: (800) 253-6476, PB \$14.95.

Geralis, Elaine (Ed). *Children With Cerebral Palsy: A Parents' Guide*, 1991, ISBN 0-933149-15-8, Publisher: Woodbine House, Phone: (800) 843-7323, PB \$14.95.

Miller, Freeman and Steven Bachrach, et al. *Cerebral Palsy: A Complete Guide for Caregiving*, 1995, ISBN 0-8018-5091-6, Publisher: Johns Hopkins University Press. Phone: (800) 537-5487, HC \$35.95.

Schleichkorn, Jay. *Coping with Cerebral Palsy: Answers to Questions Parents Often Ask* 2nd ed., 1993, ISBN 0-890-795-762, Publisher: Pro-Ed, Phone: (512) 451-3246, PB \$26.00.

The Management of the Child with CP with Low Vision; an NDT Perspective (\$12), a monograph from North Rocks Press, Royal New South Wales Institute for Deaf and Blind Children, 361-365 North Rocks Road, North Rocks, NSW, 2151 Australia.

Handling and Positioning Young Children with Motor Impairments (30 minute video for \$198 each) from Learner Managed Designs, P.O. Box 747, Lawrence, KS 66044, (800) 467-1644.

Feeding Young Infants and Children with Special Needs (30 minute video for \$198 each) from Learner Managed Designs, P.O. Box 747, Lawrence, KS 66044, (800) 467-1644.

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Cortical Visual Impairment Pediatric Visual Diagnosis Fact Sheet™

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DEFINITION

Cortical Visual Impairment (CVI) is a temporary or permanent visual impairment caused by the disturbance of the posterior visual pathways and/or the occipital lobes of the brain. The degree of vision impairment can range from severe visual impairment to total blindness. The degree of neurological damage and visual impairment depends upon the time of onset, as well as the location and intensity of the insult. It is a condition that indicates that the visual systems of the brain do not consistently understand or interpret what the eyes see. The presence of CVI is not an indicator of the child's cognitive ability.

CAUSE

The major causes of CVI are asphyxia, perinatal hypoxia ischemia ("hypoxia": a lack of sufficient oxygen in the body cells or blood; "ischemia": not enough blood supply to the brain), developmental brain defects, head injury, hydrocephalus, and infections of the central nervous system, such as meningitis, and encephalitis.

CHARACTERISTICS

Initially, children with CVI appear blind. However, vision tends to improve. Therefore, Cortical Visual Impairment is a more appropriate term than Cortical Blindness. A great number of neurological disorders can cause CVI, and CVI often coexists with ocular visual loss, so the child should be seen by both a pediatric neurologist and a pediatric ophthalmologist.

The diagnosis of Cortical Visual Impairment is a difficult diagnosis to make. It is diagnosed when a child has poor or no visual response and yet has normal pupillary reactions and a normal eye examination. The

child's eye movements are most often normal. The visual functioning will be variable.

The result of an MRI (Magnetic Resonance Imaging) in combination with an evaluation of how the child is functioning visually, provide the basis for diagnosis.

BEHAVIORAL/VISUAL CHARACTERISTICS

Children with CVI have different abilities and needs. The presence of and type of additional handicaps vary. Some children have good language skills and others do not. Spatial confusion is common in children with CVI because of the closeness of the occipital and parietal lobes of the brain.

Habilitation should be carefully planned.

A full evaluation by a number of professionals is essential. The evaluation team could include: teachers (of the visually impaired or severely handicapped), physical therapists (PTs), occupational therapists (OTs), speech therapists, and orientation and mobility specialists.

Common characteristics of visual function demonstrated by children with CVI:

- Vision appears to be variable: sometimes on, sometimes off; changing minute by minute, day by day.
- Many children with CVI may be able to use their peripheral vision more effectively than their central vision.
- One third of children with CVI are photophobic, others are compulsive light gazers.
- Color vision is generally preserved in children with CVI (color perception is represented bilaterally in the brain, and is less susceptible to complete elimination).
- The vision of children with CVI has been described much like looking through a piece of Swiss Cheese.
- Children may exhibit poor depth perception, influencing their ability to reach for a target.
- Vision may be better when either the visual target or the child is moving.

The behaviors of children with CVI reflect their adaptive response to the characteristics of their condition:

- Children with CVI may experience a “crowding phenomenon” when looking at a picture: difficulty differentiating between background and foreground visual information.
- Close viewing is common, to magnify the object or to reduce crowding.
- Rapid horizontal head shaking or eye pressing is not common among children with CVI.
- Overstimulation can result in fading behavior by the child, or in short visual attention span.
- The ability of children with CVI to navigate through cluttered environments without bumping into anything could be attributed to “blindsight”, a brain stem visual system.
- Children are often able to see better when told what to look for ahead of time.
- Children with CVI may use their peripheral vision when presented with a visual stimulus, appearing as if they are looking away from the target.

- Some children look at an object momentarily and turn away as they reach for it.

MYTHS

The following statements are not true, according to current knowledge in the field:

- Children with CVI are visually inattentive and poorly motivated.
- All children with CVI will have cognitive deficits.
- CVI is not a true visual impairment.
- Children with CVI are totally blind.
- Children whose visual cortex is damaged are Cortically Blind.

TEACHING STRATEGIES

- A great deal of energy is needed to process information visually. The child might tire easily, when called upon to use his visual sense. Allow for intermittent “break” times.
- Positioning is important. Keep the child comfortable when vision use is the goal in order that “seeing” is the only task.
- Head support should be provided during play or work sessions, to avoid involuntary shifting of the visual field.
- Try many different positions to find the one in which the child feels most secure. Infants and toddlers will demonstrate when and where they see best by their adaptive behaviors.
- If the child needs to use a lot of energy for fine motor tasks, work on fine motor and vision separately, until integration of the modalities is possible.
- The simpler, more constant and more predictable the visual information, the better the child with CVI is likely to deal with it. Keep toys and environment simple and uncluttered. Use books with one clear picture on a contrasting simple background.
- Use familiar/real objects (bottle, bowl, plate, bath toy, diaper, cup, spoon, favorite toy) one at a time. Familiarity and simplicity are very important.
- Since the color system is often intact, use bright fluorescent colors like red, yellow, pink, and orange. Colored mylar tissue seems to evoke visual responses.
- Repetition is very helpful: use the same objects and same process each time to provide familiarity and security for the child. Familiarity breeds response.
- Look for toys and activities that motivate the child.
- Vision is often best stimulated when paired with another sensory system. For example, auditory cues from the handling of mylar may help attract the child’s attention.
- Introduce new and old objects via touch and verbal description.

- Try different lighting situations to assess optimal conditions for viewing. Try locating a light source behind, and/or to the side of the child.
- Try moving the target that you want the child to see: try different visual fields.
- Allow lots of time for the child to see and to respond to what is being seen.
- Learn to interpret each child's subtle response cues: such as changes in breathing patterns, shifts of gaze or body position, etc.

“When a child with CVI needs to control his head, use his vision, and perform fine motor tasks, the effort can be compared to a neurologically intact adult learning to knit while walking a tightrope.”

RESOURCES

1. “Observations on the Habilitation of Children with Cortical Visual Impairment” Groenveld, M.; Jan, J.E.; Leader, P., Journal of Visual Impairment and Blindness, January, 1990.
2. “Visual Behaviors and Adaptations Associated with Cortical and Ocular Impairment in Children,” Jan, J.E.; Groenveld, M; Journal of Visual Impairment and Blindness, April 1993, American Foundation for the Blind.
3. Video: “Issues in Pediatric Ophthalmology: Cortical Visual Impairment (1994),” Child Health and Developmental Media, Inc., 5632 Van Nuys Blvd., Suite 286, Van Nuys, CA 91401.
4. “Cortical Visual Impairment in Children,” Good, W.; Jan, J.E.; Luis, D. (1994) Surveys of Ophthalmology. 38:4: 351-364.

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NOTE: Blind Babies Foundation has developed 7 Pediatric Visual Diagnosis Fact Sheets™ on the following topics: Cortical Visual Impairment, Retinopathy of Prematurity, Optic Nerve Hypoplasia, Albinism, Optic Atrophy, Retinal Diseases, and Vision Assessment. One complete set costs \$10. Families can get one Fact Sheet free of charge upon request. The Blind Children's Center will soon have the Fact Sheets available on their website at <www.blindcntr.org/bbc>.

June Usher Retreat a Success

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

Parents from around the state met in Austin this past June to share their experiences and plan for continued support in helping their children who have Usher Syndrome. The group was small but the experience was powerful, as families shared their fears and their hopes for the future. The final day of the meeting these families worked to develop an action plan for activities they would like to help bring about for families of individuals with Usher Syndrome. The goals the families established for the upcoming year are listed below.

- Development of a newsletter to send out to all the families of children with Usher Syndrome. This may be a collection of family biographies and initially be featured in editions of SEE/HEAR. These biographies and the newsletter will be developed by the parents from the retreat and translated into Spanish.
- Have a Family Retreat for the parents, siblings, extended family members and children with Usher Syndrome.
- Offer a workshop on orientation and mobility for the parents and teachers working with students who have Usher Syndrome which includes: simulation activities, opportunities to learn about adaptive devices, and information about O&M instruction.
- Development of a videotape for families, including parents who have recently received the diagnosis and those who are further along in coming to terms with Usher Syndrome.

Families also suggested other activities that could help promote a better understanding of Usher Syndrome and help individuals with Usher Syndrome. These included: a chatroom or electronic bulletin board, support groups for individuals (21 and older) with Usher Syndrome, presentations on Usher Syndrome at the Statewide Deaf Conference, Texas Focus, and Regional Day School Programs for the Deaf, onsite consultations, targeted mailouts and a support group for families.

Cornelia de Lange Syndrome Conference

By Gwen Solis, Parent, San Antonio, Texas

Cornelia de Lange Syndrome (CdLS) is a genetic disorder that causes mental, physical, and developmental delays. Each year families and professionals come together from all over the world for a weekend full of informative workshops, sibling activities, parental bonding and lots of food and fun! This year is the 20th Annual International Conference for the families of children with Cornelia de Lange Syndrome. Our conference will be held at the beautiful Doubletree Hotel in Dallas, Texas from June 24-27, 1999.

Each year, no matter where the conference is held, Girl Scout Troop 905/959 from Bogata, New Jersey, raise their own funds to come to the conference and provide loving childcare for the CdLS children, so their families can attend the conference and receive invaluable information.

CdLS has its own Scientific Advisory Board. It consists of top medical professionals who specialize in CdLS and attend the conference each year. They range from geneticists, ophthalmologists, ENTs, gastroenterologists, psychologists, orthopedists, dentists, and more.

This is always a memorable and important event. If you or anyone you know want to learn more about CdLS or the upcoming conference, please call the CdLS Foundation at (800) 223-8355.

Leber's Congenital Amaurosis Newsletter Update

By Kit Looper, Grandmother, Canadian, Texas

I am a grandmother of two small granddaughters with Leber's Congenital Amaurosis (LCA) and have been working steadily to start an LCA newsletter. The Newsletter is still a work in progress, and unfortunately, had to be put on hold for awhile, but things are finally coming together. Even though I haven't been able to work on the newsletter during this 'off' time, I have 'met' some very interesting LCA parents, and found this 'network of families' expanding. They include among others, Janet Gresham, in Selma, Alabama, who has experience producing a newsletter on handicapped children, and offers her help in getting our 'show on the road' for LCA. Janet and I are fellow Alabamians and have established a great working internet friendship, sight unseen.

Also, Brenda Sutherland of Ontario (Canada) contacted me, and she is working with and through The Hospital for Sick Children (HSC) in Toronto, to set up a registry of LCA parents in Canada. They are eager to contact any LCA parents in the USA we might reach through a newsletter, to give them an opportunity to join their registry, too. Brenda is a funny lady, and introduced me to ICQ on the internet, so we sometimes have animated, two-way, 'visual conversations' on screen.

Last, but not least, it seems we are now in the fast track toward global possibilities--about half way around the world, to be specific. Cheryl Marley, a British citizen, lives in--are you ready--Saigon, Viet Nam, and has been spurred to begin her own website for Families of LCA Children. When Cheryl and I first 'met' on the internet through a list-serve, she was full of enthusiasm, energy, and frustration-- and had a lot of questions on what she could do to make a difference. Eventually she found the answer--her Leber's Links webpage. I had to leave town for about 10 days last summer, and when I got back, Cheryl Marley had hit the World Wide Web bigtime. She literally taught herself how to create a website in just a few days and went online! She has had over 1000 hits in about three months.

I include my latest email from Cheryl, and encourage you to support her efforts. And for the clockwatchers among you, Cheryl's time is exactly twelve hours (halfway around the clock,) from Texas (Central) time. Noon here, is Viet nam's midnight. I always email her late at night, my time, just as she is greeting the sun in Viet Nam. Works out very well, as I then have email from Cheryl waiting when I get up next morning. Here is a bit of her personal email to me about her "Leber's Links" project:

"I am continuously working on [the webpage] and have lots of plans for additions in the near future. Please publish the URL which is: <<http://www.freeyellow.com/members4/leberslinks/index.html>>. Also, my email address which is cheryl@hcm.vnn.vn. Here is what I usually tell people who ask about the page--Leber's Links: (Leber's Congenital Amaurosis, Blindness and Visual Impairment) - A new web site set up by the parent of a young child diagnosed with the genetic eye disorder, LCA. Fast becoming the central arena for LCA families and professionals to source and share information on the disorder, blindness and other associated issues. Updated regularly, lots of links to LCA articles and information, visual impairment and related web sites. Includes the international LCA register."

Cheryl has kindly asked me to be a contributor to her effort. If you have LCA in your family, and are reading of the Texas LCA Newsletter for the first time, please contact me so I can add your name to the mailing list. It will be available both on email and through the postal service. Research is proliferating on this rare genetic condition--LCA--and we hope to bring you the latest in the medical field, and put you in touch with other LCA families for support. Contact me, Kit Looper, at 810 Summit Avenue, Canadian, Texas 79014; email: kit@hhtx.com or kit@pan-tex.net; or call me at (806) 323-8500.

Coming Soon to a Neighborhood Near You . . .

By Glenda Embree, Supervisor of Program Specialists, Texas Commission for the Blind

The Texas Commission for the Blind is excited about innovative projects being pursued across the State. Our goal in making these grants and contracts available is to expand services to people with visual impairments of all ages through the creative efforts of nonprofit organizations.

Several of these projects especially benefit children. Here's a sneak preview of projects being explored:

Region XIII Education Service Center in Austin proposes a summer career exploration program for approximately 16 students, 12 to 14 years old. These students would be introduced to a variety of jobs to familiarize them to the connection between personal interests and skills, individual transition planning, and post-graduate work selection.

The Lighthouse of Houston is pursuing a summer transition program for approximately 16 students who are blind or visually impaired. The project will enable students to live in a supervised apartment setting, participate in recreational activities, and gain vocational skills that will assist them in the transition from school to work.

The River Performing and Visual Arts Center in Houston presents an after-school arts program for an estimated 500 students, including 75 with visual disabilities. A descriptive service for students who are visually impaired or blind will be provided in collaboration with Dr. Sidney Berger and the University of Houston Children's Theater Festival.

A proposal from Amarillo entitled "Lifetime Independence for Everyone" will create an Independent Living Center for 100 or more children and their families in the Panhandle and South Plains areas. Services will support children who have visual impairments and their families for the purpose of maximizing full inclusion for children with disabilities.

The Texas School for the Blind and Visually Impaired suggests a unique project entitled "What Families Need to Know." An estimated 660 family members of children who are blind or visually impaired will interact with each other and with blind adults in weekend (Saturday-Sunday) workshops to help them gain a new, more powerful vision of the options and potential for their children. Sessions for blind and visually impaired children and their siblings will be held separately from those held for parents.

Access Arts Austin proposes to increase the availability of audio description services in art, entertainment, employment, and education settings. The project will produce training materials for video descriptors. Training tapes would be duplicated and used throughout Texas.

The National Federation of the Blind of Texas (NFBT) requested funds to continue *Newsline* services to blind Texans and additional funds to expand into Lubbock and Tyler. With the support of the Texas Commission for the Blind, NFBT has been providing *Newsline* service to blind Texans for more than two years. The service started in Austin and Houston and then expanded to the Dallas/Fort Worth and San Antonio areas. The expansion into Lubbock and Tyler is estimated to add 750 new subscribers. It is projected that *Newsline* will be serving 1,900 people by the end of the first grant year and 2,700 people by the end of the second year of the two grants.

Commission staff are working through details on the projects. For more information on our progress, call Edgenie Lindquist at (512) 459-2579.

TCB's Corner

By Terrell I. Murphy, Executive Director, Texas Commission for the Blind

Happy New Year! It may not be January 1, but it's a new school year, a new fiscal year for the Texas Commission for the Blind, and a new year for the *See/Hear* newsletter. My thanks to the editors for not only this opportunity to visit with you about a few exciting things that are happening at the Commission, but also for their hard work in producing a newsletter that pulls us all together in creating a brighter future for children who are blind.

One of the most important terms buzzing around TCB these days is *Texas Confidence Builders* (or for you acronym lovers, TCB²) — our way of breathing renewed life into who we are. Our job is to provide Texans who are blind and visually impaired with the skills, training, knowledge, and equipment they need to be confident in their own abilities. Therefore, every service we deliver must promote a positive, can-do attitude. Every employee will be training hard in the coming months to make this a reality.

That same can-do attitude from TCB² will be flowing over into what has become known as *Opportunity 2000*, our plans for creating more comprehensive services for children with visual impairments and their families. In the spirit of one of my other favorite acronyms, we are using TEAM-work (Together, Each Accomplishes More) to help us design a blueprint for building an even better children's program. Our staff has been busy meeting with Texans who are blind, their families, education professionals, advocates, consumer groups and national organizations since August, and I'm looking forward to sharing the results in a future issue.

On the horizon are innovative projects coming into communities across the state as a result of grants and contracts approved by the Commission's Board in August. Our goal in making these funds available is to expand services to people with visual impairments through the creative efforts of nonprofit organizations. Glenda Embree shares information about some of these projects on page 30.

The "numbers" for the year that just ended are all in as I write this, and once again our dedicated staff set new records or stayed at previous year's record levels. With the help of our many partners such as yourselves, this new year will offer many new opportunities for children who are blind.

Superintendent's Corner

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

I'm pleased to begin the column in *See/Hear* for a couple of reasons. First, it will give me a chance to remind you every once in a while that the outstanding work of the Outreach Department at TSBVI is truly a part of the Texas School for the Blind and Visually Impaired. Since the children of many of you will not experience on-campus life at TSBVI, it must sometimes be difficult to imagine that Outreach services are really a part of the mission of this residential school. TSBVI is strongly committed to parents and children having many options for school placement. It is our firm belief that, for each child, there is a best placement at a particular time in the child's life. This school setting may change from year-to-year, and fortunate is the family that has options that meet the needs of children. It is also our belief that most blind and visually impaired students, including those with additional disabilities, should be educated in their local district if at all possible. So, you see, with the TSBVI philosophy, it's no wonder that our Outreach Department is highly valued by all of us here on the campus. Outreach is a part of our mission.

Another reason why this column pleases me is that it gives me a chance to share with you some of the new

and exciting programs and services we are developing. For example, this year we have three students on our campus who have already graduated from their local school district. They are taking courses and experiencing work in our career education program. It isn't always easy for a local district to provide a vocational education program that addresses the specific problems of work and the visually impaired person. TSBVI does this very well, and we're pleased to begin this program. Also, we are now offering certain academic courses to students from local districts who may benefit from taking Algebra, for example, on our campus from a teacher who knows both subject matter and is experienced teaching visually impaired students. Such classes may have an enrollment as low as four or five students, and this might also be an advantage to some students from local districts. Another new program called EXIT (EXperiences In Transition) is now available for certain students during their last two years of high school.

TSBVI is a school on the move. We continually explore ways in which we can supplement or complement the services available in local school districts, and we work hard to meet the educational needs of all blind and visually impaired students throughout Texas, either on-campus or where they live.

Americans with Disabilities Still Face Sharp Gaps in Securing Jobs, Education, Transportation, and in Many Areas of Daily Life

New Landmark Harris Survey Shows Little Improvement (Press Release)

Editor's Note: A recent Louis Harris poll of people with disabilities of all kinds found they continue to lag in employment, educational levels, and indicators of quality of life. Working age adults with disabilities are no more likely to be employed now than 10 years ago. Nationally, blind consumers are even less likely to be employed. In Texas, however, statistics from Texas Commission for the Blind indicate that legally blind working age adults have a far higher rate of employment than the national average.

WASHINGTON, D.C., July 23, 1998 - Americans with disabilities still face gaps in securing jobs, education, accessible public transportation and in many areas of daily life including recreation and worship. Those findings were presented in a new U.S. survey of 1,000 adults with disabilities announced today at a Washington, D.C. news conference by the National Organization on Disability (N.O.D.).

For disability advocates, these findings are disturbing yet motivating for public and private decision-makers. The findings, commissioned by N.O.D in cooperation with Louis Harris & Associates, define the current status of persons with disabilities in American life.

The highlights of the 1998 N.O.D./Harris Survey of Americans with Disabilities released today queried adults with disabilities, early this year (with a sampling error of plus or minus 4 percentage points). This survey is the first such national poll taken by Harris in cooperation with N.O.D. since 1994, and the third conducted by Harris since 1986.

Among the most startling findings about the workforce, the research exposed significant gaps between the employment rates of the working disabled versus the working non-disabled. Only 29% of disabled persons of working age (18-64) work full or part-time, compared to 79% of the non-disabled population, a gap of 50 percentage points. Of those with disabilities of working age who are not working, 72% say that they would prefer to work.

Fully a third (34%) of adults with disabilities live in households with total income of \$15,000 or less, compared to only 12% of those without disabilities.

Approximately one in five (20%) of adults with disabilities have not completed high school compared to 9% of adults with no disabilities.

Alan A. Reich, President of N.O.D. stated, “These gaps are unconscionable. America must do better!” He added, “At a time when the U.S. unemployment rate is at an historic low and there is a crying need for workers, it is astounding to learn that the employment gap remains so wide. As the survey shows, over 72% of people with disabilities out of the workforce want to work and contribute to the economy. America must remove attitudinal and physical barriers in the workplace and in all other areas of life.”

Humphrey Taylor, Chairman of Louis Harris & Associates, commented, “The purpose of this research is not just to measure the gaps in key life areas between people with and without disabilities, but to provide information to help close them. I anticipate that the results will be used by people both inside and outside the disability community, with the media, with corporate America, legislators and state and federal administrators.”

This survey is rich with information stemming from the answers to 145 questions on life activities considered most important to people with disabilities. Other findings include:

- Only one-third (33%) of adults with disabilities are very satisfied with life in general, compared to 61% of the non-disabled population.
- Only seven out of ten (69%) adults with disabilities socialize with close friends, relatives or neighbors at least once a week, compared to more than eight out of ten (84%) among the non-disabled, a gap of 15 percentage points.
- About a third (33%) of adults with disabilities go to a restaurant at least once a week, compared to six out of ten (60%) of those without disabilities, a gap of 27 percentage points.
- Inadequate transportation is identified as a problem by 30% of adults with disabilities. However, only 17% of non-disabled adults consider daily transportation a problem in any way, representing a gap of 13 percentage points.

What can Americans do to close these participation gaps? According to Reich, “A lot. Each of us can help eliminate the gaps in participation by finally focusing on the abilities not disabilities of every American.”

EMPLOYMENT

Employers - in business, government, public agencies, community institutions and groups - all can examine their practices and develop strategies for seeking out and hiring people with disabilities. Businesses must and can implement Americans with Disabilities Act requirements for accommodations in the workplace for people with disabilities, and at reasonable cost. Recent business studies show, it requires on average less than \$300 to accommodate a worker with a disability. Home based employment and other forms of workplace flexibility are beneficial to many workers, including the disabled. From working parents to people with disabilities, many people are taking advantage of technology advances that allow them to telecommute and still play an active role in filling the nation’s growing job vacancies. Disability awareness and accessibility is good business. Consumers prefer to deal with businesses that address their needs. The 54 million Americans with disabilities are a prime consumer market actively courted by companies who can meet their needs. Use an untapped pool of talent. People with disabilities can contribute innovative and resourceful thinking to the collective knowledge of their workplaces and communities, because they face unique external challenges as they negotiate the physical world around them, as well an internal challenges to their identity as individuals and as members of society.

COMMUNITIES

Community groups, religious organizations, professional and trade organizations, labor unions and service organizations can examine their practices and adopt plans for including disabled persons. Elected local leaders and officials can ensure that their communities are in full compliance with the law - the Americans with Disabilities Act, the Rehabilitation Act, the Motor Voter Law, and the Individuals with Disabilities Education Act. Recreational, cultural and sports groups and institutions should ensure full accessibility and encourage participation of disabled persons. The recent debate about Casey Martin's participation in the PGA tours highlights the bias people with disabilities face in America today. Recognize people with disabilities as positive contributors to community diversity. People with disabilities, the nation's largest minority, often are not included as a group in corporate and community planning, although they impact diversity at least as much as other minority groups. Moreover the disability population is highly diverse within itself, and, unlike other minority groups anyone can join in an instant.

INDIVIDUALS

Those of us with disabilities, family members and friends can take the lead by providing guidance to others in encouraging full participation of people with disabilities in community life. Active involvement by people with disabilities in educational and civic life on all levels expands our awareness of how those outside the mainstream live; this allows our communities to be more thoughtfully inclusive of all differences. Americans must extend themselves to their fellow citizens with disabilities, and overcome their fears of the unknown. We need to become more aware of what people with disabilities can contribute; we need to respect their abilities.

ACROSS THE NATION

The media can ensure that people with disabilities are portrayed fairly as individuals engaging in public and private life. Negative portrayals of people with disabilities in movies, such as the recent "There's Something About Mary", TV shows and so on, are inaccurate and should not be permitted.

As more people with disabilities participate in the various aspects of American life, the general population will become more informed, and they will abandon their stereotypes based on misconceptions. Attitudes will improve. The full participation of people with disabilities in an increasingly diverse American population overall will result. Just because we have enacted the ADA does not mean that we can rely on it to change attitudes and perceptions about America's disabled. By valuing each individual for his or her abilities allows our nation to benefit globally by demonstrating democracy at its best.

The National Organization on Disability promotes the full and equal participation of America's 54 million men, women and children with disabilities in all aspects of life. Founded in 1982, N.O.D. is the only national network organization concerned with all disabilities, all age groups and all disability issues. N.O.D. receives no government funds and is supported entirely by private donations from individuals, corporations and foundations. For more information, contact N.O.D. at (202) 293-5960, TDD (202) 293-5968.

WWW Resources on hearing loss

<http://www.earinfo.com>

Want to learn how to read an audiogram? Go to this web page to do this as well as get information about buying hearing aids.

<http://www.gwha.com/projects/hear/link/linkbody.html>

This web page provides links to a wide variety of sites dealing with hearing loss. Take a virtual tour of the ear, learn about cochlear implants, or get the latest on ASL. This large, comprehensive site can take you there!

TSBVI Invites You to the Family Discussion Room

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

For a long time now, families have contacted me about wanting to connect with other families. I've heard from many parents who want to talk with another parent whose child has a particular syndrome or condition. Perhaps their son or daughter wants to have a pen pal or they are grandparents wanting to meet other grandparents. Workshops and family retreats are great places for these connections to be made. I also know that some of the SEE/HEAR readers have connected through articles in the newsletter. The new TSBVI Family Discussion Room provides one more option for making connections.

More and more families are getting Internet access at home, at work, or at school. Some folks are even using their public libraries to "surf the net." Many students who are visually impaired or deafblind are learning the computer skills they need to access this new resource in school. So, we decided to add a new space on the TSBVI website for family members to connect with each other. This is an electronic bulletin board, not a chat room. That means that you can post messages for other people to read, and they can respond to you if they like. If you want to have a more direct conversation you can exchange your email address with them for private conversations at a later time. Eventually, if this service is popular, we may have additional boards for specific groups. Some that have been proposed by parents include a board for Usher Syndrome, Leber's Congenital Amaurosis, Siblings, and Teens with Visual Impairments or Deafblindness. We are open to your ideas and suggestions. Let us hear from you.

The Family Discussion Room should be up and running by December, 1998, just in time for the Christmas holidays. Please drop in for a visit and post a message. Simply go to the TSBVI website at <www.tsbvi.edu>, click on "Family Discussion Room", and follow the directions.

Mentor Training Update

By Ruth Ann Marsh, Mentor Coordinator, TSBVI, Outreach

The next two mentor training sessions will precede the professional conferences listed below. Now mentors won't have to choose between a conference and mentor training, or ask permission to take yet another trip away from students. Here are the dates:

Mentor training	Conference attached to	Location
January 13 - 14	"Helen" January 15 - 16	Austin, TX
April 22 - 24	TAER April 25 - 26	Austin, TX

The Mentor Program will pay for travel to and from the training site. Food and lodging for the mentor training days, including the night prior to the first day of training, will also be provided. Mentors wishing to attend a conference will be responsible for registration fees and other conference related expenses.

The first day of training, Dr. Leslie Huling, an expert in mentoring from Southwest Texas State University, will speak generally about being a mentor. On the second day, the trainees will be divided into two groups, VI mentors and O&M mentors. Each group will have a well-known expert facilitate discussion about the specifics of being a mentor for a new O&M or VI professional.

If you are an experienced O&M specialist or VI teacher in Texas, and are interested in becoming a mentor for an O&M specialist or VI teacher in training, please call Ruth Ann Marsh, Mentor Coordinator at (512) 206-9203 or send an email to marsh_ra@tsb1.tsbvi.edu.

Bits and Pieces from Here and There

AER

Congratulations to Billy Brookshire. A Senior Human Resource Development Specialist for the Texas Commission for the Blind, Billy has been named President-elect for AER. AER is a national organization for people involved in education and rehabilitation of people with visual impairments. Billy has been employed at TCB for over 20 years! (Funny, he doesn't act that old!)

Congratulations to Robbie Blaha with the Texas Deafblind Outreach at TSBVI. She was awarded an AER Division 3 (Multiple Disabilities and Deafblind) Outstanding Practice Award.

AVIT

AVIT, The Alliance of and for Visually Impaired Texans, is an interorganizational coalition committed to speak on behalf of Texas' children and adults with visual impairments. With regards to people with visual impairments, AVIT works for:

- The advancement and protection of human and civil rights,
- The improvement of social welfare and economic conditions,
- The education of the public with respect to special concerns, and
- The promotion of interorganizational cooperation and support on issues.

More information may be heard at a "listen only" line at (800) 394-0666. AVIT will hold its next meeting on November 18, 1998 at Criss Cole Rehabilitation Center in Austin. The purpose of this meeting will be to develop a legislative platform. Visit the AVIT website at <<http://www.christal-vision.com//AVIT/>>.

KORAN

The Arizona Instructional Resource Center at the Foundation for Blind Children in Phoenix announces the sale of a braille transcription of an English translation of The Holy Koran. The 7 volumes are available for purchase by calling (602) 331-1470.

Katlyn's Hope, Inc.

By Shari Willis

I am Shari Willis, president of Katlyn's Hope, Inc. Following the death of our deafblind daughter, my husband and I started this organization. We give scholarships to deafblind children. You may contact us at this toll free number: (877) 677-HOPE (for parents only please). The phone number for others to call is: (316) 326-6118. Our e-mail address is khope@idir.net and our snail-mail address is Katlyn's Hope, Inc., 303 South Elm, Wellington, KS 67152. We will be getting a Web site very soon, hopefully by November 1st.

On November 15, 1998, CBS is airing a program, "Monday after the Miracle" starring Roma Downey. It is the story of Anne Sullivan and Helen Keller in Helen's adult years. The movie was filmed in Lawrence, Kansas, and as a result, we had the great fortune of hooking up with the producer. She invited us and several deafblind teenagers to the set, and let them tour the place and enjoy some of the filming. As a result of our meetings with the producer, she has arranged for a Public Service Announcement to air following the program. It is only 10 seconds in length, but it will give all pertinent Katlyn's Hope information so that families can contact us. We are really excited! The premiere for the movie was wonderful, the scholarship recipients were incredible, and we gave a 13 year-old boy (and his family), whose dream is to see the Statue of Liberty before he loses his remaining vision, a surprise trip to New York City for Christmas. "Monday After the Miracle" will air November 15th. Be sure to tune in!

CLASSIFIED

Don't wait! Send your new classifieds to Jim Durkel now, so he can update the Statewide Staff Development Calendar posted on TSBVI's website at <www.tsbvi.edu>. Mail or email your ads to 1100 West 45th Street, Austin, TX 78756, or durkel_j@tsb1.tsbvi.edu.

Through Your Child's Eyes

Have you ever wondered how your child "sees" the world? Have you ever considered what a world with little or no sight might be like? If these questions seem important to you, then Through Your Child's Eyes was designed with you in mind. At this workshop you will have the opportunity to:

- meet other parents of children with visual impairments and deafblindness
- learn how the eye works and how your child's visual impairment impacts his vision
- participate in activities that simulate visual impairments
- learn about the resources available to you and your child
- learn about advocating for quality programming for your child
- meet adults who have visual impairments

Target audience: Parents of young or recently diagnosed children with visual impairments, including multiple impairments. This workshop has been scheduled in the following locations:

San Antonio, TX
November 6-8, 1998
Contact: Judy Wright at TCB
(210) 732-9751

Bryan/College Station, TX
February 20-21, 1999
Contact: Bettye Giordano or Alice Thomas
at TCB (409) 696-9610

This workshop is also planned for the Winter/Spring of 1999 in Victoria and Abilene, Texas.

Cornelia de Lange Syndrome 20th Annual Conference for Families

**June 24-27, 1999
Doubletree Hotel
Dallas, Texas**

For more information contact:
CdLS Foundation
(800) 223-8355

CHARGE into the New Millennium!

CHARGE Syndrome Conference

**July 23-25, 1999
Houston, TX**

Contact:
(800) 442-7604 (for families only)
(573) 499-4694 (for professionals)
or
mnorbury@mail.coin.missouri.edu

Helen Called Her “Teacher”

January 15-16, 1999

Texas School for the Blind
and Visually Impaired
Austin, TX

This workshop is for new and experienced VI teachers, O&M specialists, and paraprofessionals working with children who have visual impairments. Tentatively, we will focus on issues related to preparing our students for life after graduation.

Contact: Jim Durkel, TSBVI
(512) 206-9270 or
durkel_j@tsb1.tsbvi.edu

Statewide Conference on Community Services and Supports for All Texans

Sponsored by:
Texas Respite Resource Network
and the
Coalition of Texans with Disabilities /
Personal Assistance Services Task Force

December 13-16
Hyatt Regency on the Riverwalk
San Antonio, TX

This conference will provide up-to-date information about statewide issues in community supports and how you can impact legislative action, as well as provide an opportunity for networking. Family and consumer stipends may be available.

Contact: Texas Respite Resource Network
(210) 704-2794 or diana_cerna@srhcc.org

November 11

Beginning Abacus

Location: Region XII ESC, Waco, TX

Target audience: Teachers for students with visual impairments

Description: This workshop will focus on introducing teachers to using and teaching the abacus. This is a beginning level workshop.

Presenters: Debra Sewell

Contact: Tina Herzberg, Region XII ESC
(254) 666-0707, ext. 260

November 16-18

Every Move Counts

Location: Region XX ESC, San Antonio, TX

Target audience: Professionals working with students with profound disabilities

Description: This workshop covers assessment and intervention strategies for students with profound disabilities.

Presenters: Jane Korsten

Contact: Deborah Thompson, Region XX ESC
(210) 370-5433

November 18

Before the Technology Assessment

Location: Region X ESC, Richardson, TX

Target Audience: Teachers for the visual impaired serving students with either no other impairments, or with multiple impairments.

Description: This session will give teachers some resources to try before asking their technology teams to conduct a full assessment on a student.

Presenter: Sharon Nichols, TSBVI, Austin, TX

Contact: Kitra Gray, Reg. X ESC (972) 348-1580

November 19-20

Tactile Communication Systems for Students with Sensory Impairments

Location: Region IV ESC, Houston, TX

Presenters: Ann Rash and Craig Axelrod, TSBVI

Contact: Cecilia Robinson, Region IV ESC
(713) 744-6368

December 9

Tactile Graphics and TAAS

Location: Region IV ESC, Houston, TX

Presenters: Diane Spence, Irene Rojas,
Ana May Hernandez

Contact: Cecilia Robinson, Region IV ESC
(713) 744-6368

December 11

A New Era of Braille Instruction

Location: Region XI ESC, Ft. Worth, TX

Target audience: Teachers for the visually impaired

Description: This workshop will discuss relevant educational factors for selecting a primary learning media, braille readiness activities, and activities to minimize rubbing, scrubbing, and letter reversal.

Presenters: Sally Mangold, San Francisco, CA

Contact: Olga Uriegas, Region XI ESC
(817) 625-5311

Jan. 19, Feb. 16,

Mar. 16, April 20, May 11

VIISA: Vision Impaired In-Service in America

Location: Region XVIII ESC, Midland, TX

Target audience: Professionals working with students with visual impairments, birth to 3 years of age

Description: This workshop will help participants gain skills in understanding the unique needs of infants and toddlers who are visually impaired, and their families.

Contact: Miriam Powell, Region XVIII ESC
(915) 563-2380 or mpowell@esc18.net

January 26

Ecological Evaluations: Practical Solutions to Complex Concerns for Students with Visual Impairments

Location: Region X ESC, Richardson, TX

Presenter: Karen Wolffe, Austin, TX

Contact: Kitra Gray, Region X ESC (972) 348-1580

January 27

Career Education for Students with Visual Impairments

Location: Region X ESC, Richardson, TX

Presenter: Karen Wolffe, Austin, TX

Contact: Kitra Gray, Region X ESC (972) 348-1580

January 28-29, and February 25

Every Move Counts

Location: Region XII ESC, Waco, TX

Target audience: Professionals working with students with profound disabilities

Description: This workshop covers assessment and intervention strategies for students with profound disabilities.

Presenters: Jane Korsten

Contact: Tina Herzberg, Region XII ESC
(254) 666-0707, ext. 260

January 28-29 Part 1

February 25-26 Part 2

March 29-30 Part 3

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

Location: Region XI ESC, Ft. Worth, TX

Target Audience: School and ECI professionals working with families who have children, birth to 5 years, with multiple impairments, including an impairment in at least one of the sensory systems.

Description: This is a 6-day training divided into 3 parts. Attendance at all 6 days is required. Topics include information on vision loss, hearing loss, communication development, motor development, active learning, and working with families.

Contact: Olga Ureigas, Region XI ESC
(817) 625-5311

For a complete and up-to-date listing of workshops and conferences, visit the TSBVI website at <www.tsbvi.edu>.

Medicaid Expansion for Teens

As of July 1998, more Texas teenagers can qualify for Medicaid for their health care. Medicaid changed the family income limits for teens. Teenageers who are under 19 years old may now qualify for Medicaid even if they did not qualify before.

Last year, Congress passed legislation which helps states provide health care for children who are uninsured and whose families have low incomes. Each state develops its own children's health insurance plan. The first phase of the the Texas plan to cover more children who are uninsured is an expansion of Medicaid for older teens, 15-18 years old, whose family income is less than 100% of the federal poverty limits. Teens younger than 15 are currently eligible at this family income level. Families must still meet other Medicaid requirements, such as asset limits.

Please help teenagers take advantage of this opportunity to get health coverage (medical and dental check-ups, equipment and supplies, prescriptions, etc.). Contact your local Texas Department of Human Services (TDHS) office to learn more about the Medicaid Expansion for Teens.

SEE/HEAR

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Articles can be mailed or emailed to section editors at:

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December 2nd for the February edition
March 3rd for the May edition
June 3rd for the August edition
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SEE/HEAR is available in Spanish and English on TSBVI's website at <www.tsbvi.edu>.

If you no longer wish to receive this newsletter, please call (512) 206-9314.

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