

SEE/HEAR

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

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Kate's Corner

Outreach is pleased to welcome a new VI Outreach member, Eva Lavigne formerly from Lubbock. Eva has spent 10 years as a teacher of the visually impaired with the Lubbock Independent School District. Eva, we are extremely glad you decided to join us. Eva will be working in ESC Regions 5, 6, 9, 14, 16, and 17.

It's a brand new year for Outreach, and we are already as busy as we can be. Deaf-Blind Outreach hosts the Annual Intervener meeting here in Austin that will include a special presentation by Dr. Jan van Dijk of the Netherlands for interveners and their supervising teachers. Joining them for this event and some informal meeting time of their own will be the new Regional Deaf-Blind Specialists from the education service centers, and the new DBMAT Regional Coordinators. This meeting takes place November 7 - 9 following the ESC Region 11 van Dijk workshop on the 3rd and 4th.

One of our primary focuses for both Deaf-Blind and Visually Impaired Outreach is to help develop supports at a regional level. We are working in collaboration with The Three Low Incidence Disabilities Decentralized Project at

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Region 3 ESC to pilot a process in several regions that will develop stakeholder groups which examine and address the needs of individuals with deafblindness. We are also lending our support to the Deaf-Blind Multihandicapped Association of Texas (DBMAT) to train Regional Coordinators for that organization in all of the education service center areas. VI Outreach is working with NAPVI and other parent support groups on initiatives that include expanding the number of support groups for families regionally and developing a Spanish-speaking Family Network.

Of course, we see 1999 - 2000 as a time of continued training for parents and professionals. Texas Focus 2000, Helen Called Her Teacher, and the Second Annual Usher Syndrome Family Retreat are already being planned. Watch the Classified section or visit the TSBVI website to stay up-to-date on the plans for these and other events. We will also continue to offer workshops such as Through Your Child's Eyes, topical workshops (on braille instruction, communication, etc.), and activities such as the INSITE Curriculum Training and Quality Program for Visually Impaired (QPVI) in collaboration with the education service centers and Texas Commission for the Blind. Our Technology Specialist, Sharon Nichols has developed a packet of materials to assist local districts in completing technology assessments. In addition, she offers two days of onsite training to assist a teacher and student with the new device or software program borrowed from the TSBVI Technology Loan Program. Onsite consultations remain on the menu as another training option available to families and professionals.

Through the VIP program over 100 vision professionals have been trained in Texas over the past two years, and we continue to collaborate with Universities and ESCs to train more professionals in the area of vision and orientation and mobility through this program. Through the Mentor Program 139 O&M Specialist and VI teachers have been approved as mentors with 36 applicants waiting to be approved. Connecting with these mentors are 115 O&M specialists-in-training and VI teachers-in-training, and an additional 64 individuals waiting to receive a mentor. Of course, APH Quota materials and the TEA VI Registry are still being ably administered by Nick Necaize.

Please keep reading SEE/HEAR to stay informed about the many wonderful activities that are occurring in Texas. As a result of this excellent collaboration of parents and professional, 1999 - 2000 has the makings of a very good year.

“Tuff” Love or Raising Laurie

By Annie Wade, Parent, Tulia, Texas

Editor's note: Many of you will remember Annie from the video "Power of the Heart". This 1987 video is often shown to university classes to demonstrate effective ways for parents and service providers to work together. Recently, a professor from Ball State University in Indiana contacted me to ask, "What happened to Laurie and her family?" I connected her with Annie, who is now a TCB children's caseworker in Amarillo. Then it dawned on me that perhaps others would want to know what happened to Laurie; so I nagged Annie until she agreed to write an article. Annie is too modest to tell many people that she was the first editor of this newsletter when it was still called P.S. News!!!, and one of the first Outreach Family Support Specialists! Thanks, Annie (and husband, Garland) for taking the time and emotional energy to once again to share your life.

Laurie is flying home from Dallas for a long weekend. I arrive at the air terminal almost an hour early to wait for her plane. Mental pictures race through my mind, and I shed tears of joy at how far she has come since the day she was born almost 32 years ago, deafblind multihandicapped. I can visualize that sweet baby lying on the carpet, flicking at the sun's rays filtered through the living room window, a victim of an awful circumstance. It was so easy to love her in that contented "world of her own" knowing little, completely dependent, and caring less. We pondered. Is this all there is? Can there be more? If so, how much more?

I think of the surgeries when I watched, as my baby had to be restrained to prevent injuries to her eyes. Her dad and I rocked a million miles with her arms in restraints being held under our arms, because she could wiggle out of the restraints. Then, there was eating. It took years of consistently presenting foods and cleaning up messes, manipulating, self-feeding and chewing, frustration on the part of mom and Laurie, therapists and teachers. Eventually, Laurie learned to feed herself and eat a variety of healthy foods. Of course toilet training was really fun. There were two years of putting Laurie on the potty-chair every 30 minutes and charting every occurrence. The toilet chair went in the back seat of the car and even on the airplane to a conference (which we borrowed money to attend) so Laurie would have “her” chair. Consistency was the name of the game. Laurie really didn’t want to sit on the potty-chair. She tantrumed and beat her head. Her dad had to leave the house. It hurt to hear her screaming and to know what she was doing.

It hurt to teach Laurie, both physically and emotionally. She wore orthopedic shoes and kicked the shins of the person sitting across the table when learning table tasks. Laurie had no desire to learn. She preferred to be the victim, lie on the floor or the bed, and engage in self-stimulation behaviors. This was not acceptable to team members. A very wise physical therapist, one of the first professionals who worked with Laurie told me that Laurie would never learn until she exhibited resistance. This was in reference to physical development because Laurie just wouldn’t try to roll over, crawl, stand up...or anything – she would just go limp. However, I soon learned that exhibiting resistance was a prerequisite to all of her progress. At the same time, Laurie’s occupational therapist also provided very wise direction. She counseled us that Laurie’s family should be informed (learn as much as they could) and that it was imperative that we follow through at home with everything she was learning in therapy and at school. Then, there was the teacher who never gave up, and would never let us give up. Every member of the family was involved. This meant we couldn’t just sit around and enjoy our sweet deafblind daughter. If we wanted her to realize her fullest potential, we had to be willing to “sacrifice our time and energies” to encourage her to do things she didn’t want to do. She needed to wear her hearing aids. She needed to wear her glasses. She threw them off, but they were put right back on.

Some of the things Laurie most hated to do during school years have brought her the most fulfillment. The most important has been the development of communication which began with a sound motor base and evolved into the calendar system, incorporating experience stories into planned every day activities. This might include fun things, but also included work. Now, Laurie relies on her calendar to plan trips home, to visit her sister in Spicewood or her brother in Colorado, or attend Camp Summit. (She has been attending every year since it began and starts asking about it right after Christmas.) Although Laurie doesn’t require the calendar as much now because she understands more sign language, upcoming activities still go on the calendar so she won’t pester people so much. It may also be used to anticipate activities such as doctors visits. I must confess that I hated doing the calendar as much as Laurie did for a long time. It was disruptive to go to the calendar before we could do anything, but now I am glad we did.

Perhaps the “tuffest” thing we faced was helping Laurie grieve the loss of her dearest friend and sweetheart. Yes, a child with disabilities does go through a grieving process. Brad was a schoolmate with similar disabilities. She had been with Brad as his health declined and when he died, we had to be “tuff” to be sure Laurie understood and could deal with her sadness and go on with her life. This meant involving Laurie in the events that occurred. She was told immediately. We took her to buy flowers and to visit Brad as he lay in state. She patted him and signed his name over and over again. Laurie attended the funeral and quietly shed her tears in back of the seeing/hearing crowd. At her request she has continued to make trips to take flowers to Brad’s grave and “talk” to him in sign language. Although finding it difficult, we continued to maintain consistency in our expectations while giving Laurie the time to grieve. It was a precarious balancing act, but she needed to learn that life does go on.

The airline has just announced that Laurie’s plane is approaching the runway and will soon be at the gate. As I reflect how Laurie was able to arrive at this station in her life, I think of all of the people who gave so much of themselves in helping her reach this destination. Many of you would recognize the people if I had enough room to list them all. The list includes, professionals, friends, and of most importance - her family. Laurie was so fortunate to have the best. We all learned so much and without any one person in this network, Laurie would not be who she is. They

should all be very proud. Perhaps you would like to know why I speak with so much pride. Well, let me tell you. We always worked as a team. The team was made up of people who, I believe, genuinely loved Laurie and believed in her. As a result, there were realistic expectations placed on Laurie that were never compromised – discussed – yes, adjusted – yes, reviewed – yes, deleted – yes, discussed – yes, and the process repeated itself again and again. Through this process Laurie learned and progressed; found plateaus; failed and survived; then learned some more.

The plane has landed and is approaching the gate now. I think about last night when I called Betty (the supervisor of the deafblind group home at the Autistic Treatment Center in Dallas) to check to see if everything regarding this trip was on schedule. Betty told me how excited Laurie has been since we planned this visit home about three weeks ago. How wonderful it is that Laurie has become such an independent, confident woman who enjoys so many activities, so many things and her relationships with so many people. This is not to say that Laurie is “normal” - far from it! She still needs full time supervision at home and at work. ATC in Dallas has been Laurie’s home for 6 years - and I have to say, these six years have been great.

The door to the passenger tunnel is open and I see Laurie hurriedly dragging her wheeled luggage toward me. We meet, have a long hug...some patting and a few signs about spaghetti or pizza for lunch. Hand in hand we leave the gate with Laurie in the lead.

As I look back over the last 30 years, I realize that many things we did fit into the category of “tuff” love. There are those who would say we were cruel and that we shouldn’t have made Laurie sit on the potty chair, or forced her to eat things she didn’t want, or made her do therapy at home. There are those who will say that we shouldn’t have required so much of Laurie and her siblings. There are those who did not agree with the philosophy we followed in raising Laurie. In answer, permit me to relate something that was recently shared with me by those who know her so well now. I was told that Laurie is the gentlest and most compassionate person one could ever meet. Of all the things that could be said of her, this is the best. And, this can only be said of Laurie because of those who were willing to practice “tuff” love while helping us raise our Laurie.

Through the years I have worked with families of children with deafblindness, and families of children with visual impairments or other disabilities. My observations are that the most successful and happiest children are the ones that had realistic expectations placed on them by staff and family. They are the children whose families exhibited self-discipline, calmness of spirit, stubbornness, and consistency in working with their child while relying on an inner strength from the Heavens. The only word for this is “tuff” love.

Finally, consider this: Practicing “tuff” love is much tougher on the caregiver than the child. To provide consistency and expectations you must also endure consistency and expectations. You may have completed preparations to go to a friend’s party, when your child decides to “do his/her own thing”. If you stop to attend to your child’s needs, you will be delayed or even prevented from going out altogether. You can stay and properly attend to the situation, and help your child grow or you can give in to your natural desire and go to the party anyway. However, if the latter choice occurs too often, your child may never learn.

Furthermore, never ask or expect anything of a professional that you are not willing to do yourself. Sure, they get paid. However, they can only work very hard toward a goal and do all they can with your child during the session or school day. If you are not willing to observe and follow through at home with the goals you have set for your child, he/she will likely never accomplish them.

Although there were times when the sacrifice seemed to overwhelm me, I have never regretted doing therapy activities, eating programs, dressing programs, or other programs the team established. I have never regretted doing strange things in public places or staying home when the rest of the family went to play, in order to accomplish the goals we set for Laurie. It has not always been uphill. I have not always been as diligent as I should have been. Yet, the

anxiety lingers even though Laurie has been doing well for over six years. I am well aware that at any given moment I may receive that phone call - bringing me bad news - such as a reoccurrence of behavior problems, or some negative incident, etc.

In the meantime, we are truly enjoying Laurie because of the person she has become and above all, she enjoys herself...she is a product of "tuff" love.

Editor's note: If you want to learn more about Annie and Garland's early years with Laurie, check out "Power of the Heart", which can be ordered through the TSBVI Curriculum Department at (512) 206-9240 or the TSBVI website at <www.tsbvi.edu>.

Letter to Laurie

By Roxy Wade Sauer, Sister, Spicewood, Texas

This article appeared in the first edition of P.S. News!!!, September 1987

Laurie,

I'm not you -

You're not me

But, do you know that if it weren't for you

I wouldn't be me?

I've learned so much from you - my little sister

I'll never be able to explain it to you,

You'll never know - it hurts.

But then again maybe you do.

Sometimes you communicate better than most people I know.

You understand me on your level,

I understand you on mine.

Do you remember the time

You held my head in your lap as I wept?

I do - so very well.

I know you're frustrated, sister,

You have so much to tell and such limited means to do so.

I'm frustrated, too.

Sometimes you make others angry.

But has anyone ever thought,

About how many times they've made you angry?

You have the rights everybody else does.

You express yourself differently and that's okay.

You're okay.

I'm glad you're my sister and that

You are and will always be a part of me and my life.

With all my love,

Roxy (Laurie's Sister)

Communicating with Bruno

By Gretchen Hester

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My three-year-old son, Bruno loves to be active. I try to involve him in many activities with his cousins - swimming, carving pumpkins at Halloween, visiting the Discovery Museum, and the petting zoo. Swimming is a favorite activity for Bruno because he enjoys more freedom of movement in the water. He enjoys touching objects, toys, and pets. He loves his English bull dogs! We use books that have scents, shiny objects, and different textures to “read” to him. He will attend to a light box to play with his toys. He loves to be rocked back and forth, and to swing in his swing. For his birthday, I had pony rides and he enjoyed being on a pony although he was very medicated because of a big seizure the previous day.

When Bruno was born, the doctors told me that he would not live and I should just take him home from the hospital and let him die. He just celebrated his third birthday! Bruno has multiple disabilities which include severe epilepsy, developmental delays, cerebral palsy, a temperature regulation problem, and is cortically deaf and blind because of global brain malformations. He has agenesis (absence) of the corpus callosum (band of white matter that connects both hemispheres of the brain). He also has optic nerve hypoplasia in both eyes (it is much more severe in the right eye as compared to the left) and suffers from nystagmus as well. Bruno’s medical needs have always been extensive so he has nursing care. He has been on many drugs to control his seizures, but they haven’t worked. Last year, he started the ketogenic diet and that worked for a few months. Last October, he had a vagal nerve implant and that had helped him healthwise - but he still has seizures. Recently, he was in a study with Dr. Bill Good at the University of California, San Francisco. Dr. Good found that Bruno’s myoclonic seizures affected his vision for several minutes after the seizure.

I’ve learned how to interpret Bruno’s communication by watching him carefully. When I was working at the University of California, San Francisco, I noticed that when we went outside, he would stop breathing, throw his arms back, and turn blue. I didn’t know if this was a seizure. This happened several times and then after a hospitalization (attempting to determine the cause of the episodes) I figured out that wind was frightening him so much that he would stop breathing. There was a sort of a “wind tunnel” as we went out of the hospital building. Bruno is still afraid of the wind but is able to continue to breath. When we last went ice-skating, he was terribly scared when the wind hit his face while he was in his wheelchair on the ice. He much preferred attempting to skate with me holding him. This way, we were going at a slower speed and there was no wind, as well as he was more involved and could tell what was going on with sensory input of the ice skates on the ice. He is scared when he is not sure what is going on since he can’t see or hear things that approach him, even wind.

Often people who don’t know him have a difficult time understanding him. They are not sure why he does not look at or listen to them. It is difficult for them to comprehend the idea of him as a deaf-blind child. Sometimes people will touch him on his face. He doesn’t like this, and I believe it is because of all the tubes he had as a baby in the hospital. California Deaf-Blind Services and Jeri Hart from the Blind Babies Foundation have helped me learn how to communicate with Bruno. I use specific touch cues in particular situations. When he is in the hospital, I tap his toes before an injection or blood test. This warns him that something unpleasant is about to happen. At the swimming pool, I touch his lips to signal that he is going underwater. Before eating, I tap his hand that is holding the spoon.

When he was a baby, I started with scents during everyday activities to help him understand what was coming up. I put rosemary in his bath to signal bath time, lavender on his pillow so that he would know it was time to sleep, and he felt and smelled bananas and pears at meals when he was going to eat them. Once he got the idea that certain scents

were tied to these particular activities, I paired them with objects (a rubber ducky was used with the rosemary scent before going into the bath). I used other object cues like a leash to mean that we are going to walk his dogs. Because of his cerebral palsy it is difficult for Bruno to make signs but I have added a few signs to his object cues. I speak to him at the same time that I make a sign on his hand or help him make a sign. I'm learning signs and how to adapt them for him. By his behavior, I know that he understands the signs for STAND, SIT, WALK, EAT, DRINK, and MORE.

I use "identification cues" to help Bruno identify familiar people. He touches their ring, watch, or they touch him in a special way. For example, his grandmother kisses him on both cheeks to greet him. His aunt sings to him by placing her lips on his face. Because he can't see or hear me, he likes being physically close; so if he is alone, he yells to get my attention. Bruno has a little piano that he likes to play; he'll push on the same button over and over again to get me to come over to him and reset it.

I was told that he would never drink or hold a bottle by himself, but now he does. I was told that he would never eat by himself. He doesn't as yet, but he holds his spoon and he loves eating, so eventually he will.

Editor's note: I was fortunate to see Gretchen speak about Bruno through a wonderful distance education program from the California Deaf-Blind Project. She presented with Dr. Deborah Chen as part of a workshop on developing communication in children with deafblindness. I want to thank California Deaf-Blind Services and Dr. Chen for allowing us to reprint Gretchen's article and an additional article, "Learning to Communicate: Strategies for Developing Communication with Infants Whose Multiple Disabilities Include Visual Impairment and Hearing Loss" which appears on pages 17-24 of this edition of SEE/HEAR.

Family Finds Answers at CHARGE Conference

By Bobbi Easler, mother of Katy Easler,
a deafblind student at Pershing Park Elementary Killeen, Texas

The 4th International CHARGE Syndrome Conference held in Houston, July 23 - 25, 1999, proved to be an eye-opening event. Questions that my husband and I began asking more than a decade ago about our daughter Katy's deformities were answered at that seminar. CHARGE is an acronym, with each letter representing the six malformations noted nearly 20 years ago by researchers who were studying the commonalties of specific abnormalities in their patients.

Those common problems being:

- Coloboma (holes) of the eye (in the lens, retina or both)
- Heart defects
- Atresia of the choanae (basically a lack of nasal passages)
- Retardation of growth and/or development
- Genitourinary abnormalities (small sex organs in both males and females)
- Ear anomalies and/or deafness.

The person does not have to have all six or, as was thought prior to 1981, four of the six common problems for a diagnosis of CHARGE to be made. Rather, a combination of major and minor criteria can indicate the patient has CHARGE. This important point was emphasized during more than one session at the conference, because many health care agencies are still going by the old standards and the syndrome goes undiagnosed. Without a proper diagnosis, certain facts, such as a need to test for growth and sex hormones levels, can go unnoticed and untreated until the youngsters are heading into their teens. A revision of the diagnostic criteria for the syndrome now takes into account that there are several features that are extremely common in CHARGE but very rare in other conditions.

The four major features that cause a red flag are: Coloboma, Choanae Atresia, Ear Anomalies (“characteristic CHARGE ears”) and Cranial Nerve Dysfunction (a factor not listed in the initial study of CHARGE). The cranial nerve dysfunction includes: a lack of smell; facial palsy; sensorineural hearing loss or vestibular problems; and swallowing dysfunction. In Katy’s case she does not have choanae atresia, but has the other three hallmarks of the syndrome. She was also born with several other problems that appear on the “minor diagnostic criteria” list for CHARGE, features that may occur, but are not consistent enough to be considered major criteria.

Katy was born in March of 1988. Within the first 18 months of her birth, I suspected she might have CHARGE or something closely related to it, after reading about the syndrome in a book titled, “Handicapping Conditions in Children” by Bill Gillham. However, the genetics department of our area hospital, apparently still using the pre-1981 guidelines in 1988, “poo-pooed” my suggestion, pointing out Katy did not have all, nor even four, of the six abnormalities. Instead, they decided she had Treacher Collins Syndrome. After finding a support group for Treacher Collins, I began corresponding and exchanging photographs with other families. It quickly became apparent, to me and my pen pals, that Katy had been misdiagnosed.

During that same time frame, we decided to get a second opinion on the treatment plan our area hospital had drawn up to correct Katy’s facial deformities. We had heard a lot of good things about the plastic surgery done at the Children’s Hospital in Houston, so we went there for a second opinion. While we were there I quizzed the doctors about Treacher Collins Syndrome. The doctors there confirmed what I and the other “lay people/parents” had suspected - Katy did not have Treacher Collins Syndrome. Unfortunately, we had not scheduled an appointment to see a geneticist during that trip, and the doctors we were consulting with were not able to suggest what syndrome she might have. We went home knowing we had been sent down the wrong path by our area hospital.

With no new leads, we were back to square one. We had planned to seek out another geneticist closer to home for more tests, when Katy faced yet another round of hospital stays for pneumonia and other problems. Getting Katy healthy and keeping her that way was the main focus of our concern. After weathering that crisis, we were in no rush to visit new doctors and have more expensive tests run, knowing that we might walk away with no new information. Without a syndrome to pin Katy’s deformities to, we had nothing to guide us on what the future might hold. I resigned myself to being in limbo about my daughter’s future. That is, until a little over a year ago when I spoke with Robbie Blaha, who is with Texas Deaf-Blind Outreach in Austin. Robbie had attended a conference that featured information on CHARGE syndrome. After hearing about the various characteristics of these children she was convinced Katy needed a follow-up exam to determine if she had CHARGE.

Wanting to learn more, but doubtful that our area hospital would be of any help, I began researching the Internet for information and tried to remain patient until the next CHARGE conference which, happily, was planned for Houston. On July 24, one of the guest speakers, Dr. John Graham, M.D., Sc.D., the director of Clinical Genetics and Professor of Pediatrics at the UCLA School of Medicine, met with us and diagnosed Katy as having CHARGE Syndrome.

With his diagnosis and a two-inch binder full of information in hand, I am confident I can have Treacher Collins Syndrome removed from Katy’s health records and replaced with the proper information. There is still no answer to the nagging question: Why was she born this way? But studies are being done. In fact, Katy and I had blood drawn at the conference for a CHARGE study being done by the Baylor College of Medicine in Houston. They also provided us with a kit to take home so my husband, John, who did not attend the conference, can also supply his blood for the study.

Having been in the dark about Katy’s condition means we had to face a lot of uncertainty alone - no support groups or case studies describing what we might expect. During the conference I learned that many of the problems we faced with Katy, like the seemingly endless rounds of sickness, are common for children with CHARGE during

their first two to three years of life. Also prevalent is an inability to walk until age 3, and the need for g-buttons and trachs because of throat problems that cause trouble with eating and breathing. I learned that children, like Katy, who survive the first three rocky years, tend to “turn the corner.” Their health and many other aspects of their lives improve dramatically. This point is helping to ease our concerns about what might lie ahead health-wise, thus allowing us to focus on her educational needs and growth as a person. The list of “If we had only known” is quite lengthy, but rather than mourn the past we can now look towards the future with a better idea of what to expect and how to be better prepared to help Katy to flourish into a healthy, productive person. My thanks go out to Katy’s fantastic case manager, Molly O’Leary and the Texas Commission for the Blind for sponsoring our trip. Thanks also to Robbie Blaha and Texas Deaf-Blind Outreach for alerting us about the conference, supplying us with all the forms and registration fee to attend.

If you have any questions about the CHARGE conference or about Katy I will do my best to answer your queries. My e-mail address is bobbike@vvm.com (please indicate CHARGE or something similar in the subject line so I don’t delete your note as unknown/spam mail). Our address is 301 Myra Lou Ave., Copperas Cove, TX 76522-2028.

Editor’s note: You may also wish to contact the CHARGE Syndrome Foundation, Inc., 2004 Parkade Boulevard, Columbia, MO 65202-3121. Phone: (800) 442-7604 or (573) 499-4694. Contact Marion Norbury (Executive Director) at marion@chargesyndrome.org, or Meg Hefner (Genetic Counselor) at meg@chargesyndrome.org. The 2001 Conference will be in Indianapolis, Indiana on July 20 - July 22, 2001. For more information please contact Marilyn Ogan (2001 - Conference Chair): marilyn@chargesyndrome.org.

Dear God, Please Take Away My Energy - It’s Too Hard to Handle

By Edgenie Lindquist, Jonathan’s Mom, Austin, Texas

Editor’s note: Children with visual impairments or deafblindness are not immune from having other disabilities to deal with in their lives. Recently I have had a number of families of children with visual impairment or deafblindness contact me about Attention Deficit Hyperactivity Disorder (ADHD) or Attention Deficit Disorder (ADD). The next two articles helped me understand some of the issues children with this type of disorder face and also what their families face.

These words from one of my son’s nighttime visits with God early this year will stay with me forever. They continue to fill me with mixed emotions - mixed in the sense that I’m grateful that at the age of seven Jonathan is very much aware that his energy sometimes needs “handling”, but also saddened that this particular day had been very hard for him. Being a typical mom, days that overwhelm Jonathan are usually the pits for me, too. After all, moms are supposed to be able to kiss bad days away, aren’t we?

This particular night I hugged Jonathan and we talked about how he was feeling. We were able to explore what his energy meant to him. We came to the place where we agreed that he indeed has a lot of energy but that energy is also a good thing. We talked about how energy can be channeled to help him with his innate gifts of creativity and compassion. Hard work would be required - more than most people - but he had it in him to do it. After all, I told him, he comes from a family of hard workers.

Jonathan and I have had other such conversations, but this one felt different - perhaps because he was at a different developmental stage where we could talk about his feelings more in depth, but more than likely it was because I now fully believe what we were talking about - with all my heart and mind. I saw my child differently that night. I saw a child with gifts that with some focus and hard work will lead him to a successful life. My shattered dream child had finally been put back together into a “real dream” - complete, whole and positive.

I couldn't have had this conversation with my son as little as three years ago. As the old commercial says, I've come a long way.... When I first learned that Jonathan had ADHD, he was about to turn four and I was recently divorced. Needless to say, our lives were a tad bit tumultuous. The diagnosis was not easy because Jonathan was so young and because there were so many factors intermingled (the effects of a divorce, Jonathan having an auditory processing problem, etc.). I was determined to prevent a misdiagnosis. However, Jonathan's ADHD was severe enough that ultimately it became clear that although there were other issues, he needed immediate help. Because a support system for families dealing with ADHD wasn't readily available, I tapped into the system I knew best - the field (rehabilitation and visual impairments) I had been working in for over ten years. When I talked with people about our experiences with the multiple assessments, therapies, and entering into special education for speech services, most of the people were quick to make statements like: "You are so fortunate that you have your professional background to guide you through this process."

Although their statement had some truth to it, my professional background was really a double-edged sword at the onset of my journey as a parent of a child with ADHD. Yes, I had some knowledge of how to make the system work, but this time it was my child - it was often tremendously difficult to put head knowledge to work about the person I cared most about in this world. I found that while professionals openly accepted me as a member of my son's team, they often would forget to explain basic information that I was unable to remember because of my new role as a parent participant. I was overly hard on myself for making mistakes and feeling the full impact of the grief. After all, I went in knowing what it was all about!

As a mother, I spent my share of time wishing my son could be spared the challenges he faces. I spent so much time looking at the early challenges that I was in danger of overlooking his splendid gifts and talents. Jonathan and I had to break out of that mold. This was a wonderful kid with oodles of potential - I knew it and it was time to get him around other people that knew it. We both needed the boost. We both needed a circle of positive support. It took hearing from another parent in my profession to ease up on myself. She wisely said that just because I was "in the business" didn't mean that I didn't get the privilege of going through everything that parents go through when they learn their child has a disability. That was my first "ah-ha experience" of making a connection between what I knew in my head (my background) and what I needed to feel in my heart (I am first and foremost Jonathan's mom!).

When Jonathan's ADHD was diagnosed it was hard not to fall into step with the world's faulty message that people who have disabilities are somehow "broken". Trust me, the world is full of role models out there if you want to concentrate on the negative. I've always been an advocate of strength-based services but was finding it very hard to infuse this principle into services for my son. It seemed that at every turn a professional would give me information that highlighted another deficit, another negative. I found it very hard to operate with all this information and to deal with society's negative (and often incorrect) view of children who have ADHD. I wanted to concentrate on Jonathan's strengths!

When Jonathan and I were leaving a speech therapy session one day, the therapist, whom I had grown to trust immensely, told me that we needed to have Jonathan evaluated by an OT because she saw several problems related to motor planning and sensory integration. The now familiar "kick in the stomach" feeling hit me so hard that I had to lean against a wall for support. Although I knew she was right (I was observing the same things), it was a major blow because I viewed his athletic ability as one of his strengths. Slowly but surely I began to realize that Jonathan can have a strength and a challenge in the same area. I began to learn how much strength-based services helped me not give in to the urge to give up but instead to accept the emotions I was feeling as healthy and to move on. I began to realize that how I reacted to what was happening with my child had a big influence on how others perceived him. It was then that I began to talk openly about Jonathan having ADHD as well as the other "dance partners" associated with the condition.

I found that talking frankly about the challenges, and acknowledging what those challenges present to the people around him, put people in a better frame of mind. Yes, my child does have considerable "high energy". If the

environment is full of stimuli, he can become a living ping pong ball. Bringing this out and talking about it helped everyone realize that they were supported and that we were not making excuses for Jonathan’s behavior. With that foundation in place, seeing his strengths seemed to come almost naturally. It was easier to build a support system for Jonathan that would help him develop skills needed to channel his challenges into strengths.

Building a support system of family, friends, doctors, teachers, childcare providers, therapist, and church community that has a positive attitude toward Jonathan has been an imperfect process. In our search we still keep coming across people who operate by focusing on what is wrong or broken or unsuccessful. Every time we get into this situation, it has disastrous results.

Sometimes I’ve been quick to see a potential disaster, like the time I told a doctor to never tell any mother - including me - that she was “in denial” simply because she was asking what options her child has. We didn’t go back.

Sometimes I’ve been too slow in responding and Jonathan has paid dearly for it - like the time that I learned that a childcare facility was locking him in what they called the “bad boy” room when he was having difficulty with his emotions. I found out about the room one day when Jonathan said that he was a bad boy and no one should ever love him. He was just three years old! We left the facility that day.

Our greatest successes have been with those wonderful people who are gifted in focusing on the positive. Most of these people unknowingly served as my mentors during our years of breaking out of the mold. For example, the speech therapist from Jonathan’s school for the past two years shared with us such jewels as “Our kids just need more time on this earth to get it all right.” This helped everyone keep the perspective that Jonathan may be developmentally behind in an area but he will catch up with the right support and in his own time. To help Jonathan begin the process of learning that taking medication is only one of the tools he needs to have self-control, she said, “The control is also within you, not just in the pill.”

We’ve been blessed with the world’s best teachers, therapists, family, and friends. Each one has done a beautiful job of helping Jonathan shape a positive self-image and learn strategies for dealing with his ADHD. They have all held up high expectations for him and cheered him on as he met them with glee. (Don’t doubt for a minute that he didn’t work hard for his successes - he has given it his all to achieve goals.) They’ve held mirrors up to both of us so that we could see his gifts: his artistic talent, wonderful sense of humor, and compassionate heart. I wish I could find the words to express how much their statements of his strengths helped me move beyond focusing on what wasn’t right and to transition into a frame of mind where I’m confident that he will be all right.

James Ochoa summarizes it perfectly in his article when he says, “Although parenting ADHD children is a complicated process, the rewards are numerous.” Jonathan and I have many years ahead of us as we grow through this process. Through it all, I’m sure that he will continue teaching me how to live life to its fullest. We will cherish our strong circle of support as helps keep us focused on our goals, reminds us to take care of ourselves, and celebrates the beauty of life’s many special moments when Jonathan shines.

Editor’s note: I asked Edgenie for a list of books that other parents might like to know about. Here are her favorite and most recommended titles:

BOOKS FOR PARENTS

Driven to Distraction by Edward M. Hallowell, M.D. and John J. Retey, M.D.; Simon and Schuster.

Answers to Distraction by Edward M. Hallowell, M.D. and John J. Retey, M.D.; Bantam Books.

Attention Deficit Disorder: a different perception by Thom Hartmann; Underwood Books (the "hunter in a farmer's world" book).

Taking Charge of ADHD by Russell A. Barkey, Ph D.; Guilford Press.

Survival Strategies for Parenting Your ADD Child: dealing with obsessions, compulsions, depression, explosive behavior, and rage by George T. Lynn, M.A., C.M.H.C.; Underwood Books, Inc.

GREAT CHILDREN'S BOOKS

Shelley the Hyperactive Turtle by Debra Moss; Woodbine House Press (ages 3-7).

Sometimes I Drive My Mom Crazy but I Know She's Crazy About Me by Lawrence R. Shapiro, Ph. D.; CTAPS (ages 6-12).

Editor's note: Parents and professionals may also want to contact CHADD (Children and Adults with Attention Deficit/Hyperactivity Disorder), 8181 Professional Place, Suite 201, Landover, MD 20785; Phone (800) 233-4050, or (301) 306-7070; Fax (301) 306-7090. CHADD held it's Eleventh Annual Conference on Attention Deficit/Hyperactivity Disorder in Washington, D.C., October 7 - 9, 1999. To find out about future conferences and other information, contact them or visit their website at <www.chadd.org>.

Parenting the Child with ADHD: Lessons in Humility & Courage

By James Ochoa, M.Ed., LPC, LCDC, Austin, Texas

Editor's note: Sometimes we assume that, if a child is visually impaired, this is his greatest challenge. Unfortunately, that may not be the case, especially if the child also has ADHD. Parents may think that the problems their child is having is related to his vision loss when in fact it may be related, at least in part, to the ADHD. I would like to thank James Ochoa for writing this article for SEE/HEAR. Hopefully it will help parents develop a better understanding about the importance of addressing the ADHD in their child with visual impairments. Mr. Ochoa is a psychotherapist in Austin, Texas. He has developed programs for ADHD children, adolescents and adults since 1979. He is married to his wife, Edie, whom he regards as his best friend. He has two sons, ages 4 and 8, and a beautiful Shetland sheep dog who constantly provide opportunities for his personal growth. James can be reached at (512) 918-ADHD (2343), or e-mail him at adhd@tcms.com.

Parenting children with ADHD is one of the greatest challenges in a lifetime. Doing a good job of it could produce some of the most creative adults in the world.

ADHD (Attention Deficit Hyperactivity Disorder) is a condition in which children, adolescents and adults have difficulty maintaining attention, concentration, and following through on tasks. They can be hyperactive and impulsive. Research indicates that conservatively 3 - 5% of the population is affected by this genetic condition. The severity level of ADHD varies with each individual. Generally the condition is diagnosed when the effects of the symptoms significantly impair the major life areas of school, social interactions, work and home. An individual can be diagnosed as:

- ADHD/Predominately Hyperactive, where hyperactivity and impulsivity are the major problem areas,
- ADHD/Inattentive Type, where difficulty maintaining attention and concentration is the primary problem, or
- ADHD/Combined Type, where an individual has significant problems in all areas.

ADHD has only recently been recognized as a condition that continues into adulthood. Research now indicates that 50% of children and adolescents will continue to have clinically significant impairment that is diagnosable as adult ADHD. The parenting process then becomes complicated by the fact that many parents have the very condition they are parenting in their children. It is essential these parents learn skills for parenting ADHD children or they will find themselves unable to intervene effectively due to their own issues with ADHD.

Parents first need new information about ADHD research and skills for parenting to approach this monumental task. Then, by understanding the strengths of the ADHD child and incorporating them into the parenting process, parents will be able to face the challenge with an open mind and a positive outlook for success.

INTERACTING WITH THE ADHD CHILD

First, parents must develop a new mind-set about ADHD. Then, they must help their ADHD children develop a healthy mind-set as well. So how do you tell a child that he has ADHD? If you tell him that he has a “deficit” or a “disorder” it may leave him with the impression that he is broken. He probably already senses that he’s different because of the comments and feedback he has received from peers, teachers, the media, and other uninformed adults. The last thing a parent wants to do is to make his child feel dysfunctional.

Children rely on their parents to provide them with accurate information about themselves and the ways of the world. They are very perceptive and may be sensitive to the fact that there is a problem. So if parents decide not to say anything to their child about his ADHD, they are making a big mistake. Parents may buy into the fallacy that if they just pretend that nothing is wrong with their child he will never know there is a problem. However, he gets a different message from those around him. This creates confusion and sets him up for more dysfunctional feelings. By not saying anything, well-meaning parents add to the problem they were trying to avoid in the first place.

How much do you tell a child about ADHD? Six-year-olds perceive information very differently than ten-year-olds. It is important to consider the child’s developmental stage. There are many books available to educate children about ADHD. By using these storybooks parents can put knowledge about attentional problems into language that their child can understand.

Timing is also very important. Parents may want to take advantage of situations when their child is at ease (during play, car trips, or participating in an interesting activity) to discuss attentional problems. Using concrete examples from the child’s own experiences may help him better understand his differences.

The relationship between the parents and child plays a vital role in the development process of a child who has ADHD. It often determines whether or not the child will understand and trust what his parents tell him. Parents must address the child’s ADHD. They can’t assume that he doesn’t notice his differences or, worse yet, they must not try to act like the ADHD is not really a big deal. It is! ADHD is a huge deal to the child. It will have lifelong implications for the parents, the child, and their relationship.

Parents will be challenged at every level in their relationship with their ADHD child. These challenges often force (or create an opportunity for) the parents to take a closer look at themselves. The relationship is often a difficult one, and parents tend to become overwhelmed with their parental role. They feel like failures. Parents may look into every new fad, try every possible intervention and support group, and still feel as if their child is an unbelievable challenge. It’s at times like these when the relationship becomes most strained.

It is important that parents monitor the relationship between themselves and their ADHD child. Parents must learn to recognize the point at which they step out of the parental role and become overly emotional. Beware! An overly emotional adult pitted against an overly emotional child usually results in a power struggle that spins out of control.

Parents find themselves doing and/or saying things that they never would have thought possible. As parents develop a greater understanding about parenting an ADHD child, they become better able to recognize the patterns of conflict in their relationship. This is the first step in unwinding the cycle of conflict.

Once parents recognize their own overly emotional behavior, they must learn exactly what triggers their distress. ADHD children are very perceptive and are quick to pick up on their parents' weaknesses. Parents must reach deep within themselves to remain calm and rational. Parents may need to examine their own childhood. If parents have unresolved childhood relationships with their own parents, it may be particularly difficult for them to handle similar situations with their child. They may experience greater emotional stress and overreact when their child goes through a developmental stage that caused them distress as a child. They may be emotionally blinded to see the situation for what it is.

When parents become overly emotional they lose the perspective that allows them to be effective as parents. Sadly, if this powerful struggle goes unrecognized, it often leads to an abusive situation for both the parents and the child. This is why it is so important for the parent to become aware of his or her own emotional history as a child. Once parents recognize what triggers their distress, they can develop coping skills that will help them maintain control. For example, they may elect to take a break to cool down. A more composed parent can start anew in a more functional frame of mind. They also model an effective way for the child to monitor his own behavior by taking a break just as his parents do.

UNDERSTANDING ADHD

Parents can benefit from creating a more functional frame of reference for ADHD. Many professionals approach this with a neurodevelopmental perspective. They believe that each child has a unique neurological development. While there are clear developmental norms where all children are similar, genetics, personality, and environmental aspects vary extensively. For this reason each child has a unique rate of neurological development. A child's rate of development may be accelerated in some areas and delayed in others.

Dr. Mel Levine, of the University of North Carolina, takes the neurodevelopmental perspective even further. He formed the All Kinds of Minds Institute, which trains professionals to understand a child's behavior from a neurodevelopmental point of view. The adults learn about the neurodevelopmental process by interacting with children and helping them. Both adults and children learn that all children develop independently, at their own unique rate. Adults are taught to intervene effectively by highlighting a child's strengths and helping him accommodate for his weaknesses. According to Dr. Levine, there are no disorders, just differences in development. He teaches children to recognize their developmental strengths and weaknesses and to understand their individual differences.

Attention is a neurological process. Research has shown that the attention centers in the brain are located in the frontal lobe. This area of the brain has been found to be less active in individuals with ADHD than in individuals who do not have ADHD. Research in this area has focused primarily on the neurochemical processes in the frontal lobe, particularly on the neurotransmitters like Serotonin, Norepinephrine and Dopamine. We have learned that Serotonin is responsible for regulating the mood. Norepinephrine is responsible for evaluating the relationship of cause and effect which contributes to impulsive acts. Dopamine is the brain's focusing agent. It helps bring information from deep within the brain to the surface and helps the brain hold on to external stimuli.

All of these neurotransmitters contribute to an individual's ADHD, but Dopamine appears to contribute the most. Medications are used to control or lessen ADHD symptoms. It is imperative to share this information with children in a way that they can understand.

The School Home Improvement Programming Strategies (SHIPS) Project, founded by Byron Kocen, M.D.,

takes a more functional approach to ADHD. Research has shown that when there is a difficulty maintaining attention, a true neurological problem exists. SHIPS has taken this link one step further, maintaining that individuals with ADHD are highly creative and often very passionate about something in their lives. They are often talented and their level of interest in their creative areas surpasses that of their peers. They also have a different way of looking at life and a different way of doing things. Because children with ADHD go about life a little differently, their ideas and behaviors are frequently misunderstood. Thus, SHIPS created a different way to describe them, as individuals with “Attention Creative Difference”.

Attentional differences do become a “deficit” and a “disorder” for ADHD children when they are asked to complete tasks which seem boring, routine or monotonous. This is especially true when tasks require excessive attention to detail with little room for flexibility. The SHIPS Project works to reframe the “deficit” and “disorder” by building on the child’s individual creative strengths and talents. It teaches parents to work with their ADHD child to develop systems and routines to help monitor the details in all areas of their lives. This results in a much more successful parenting relationship and a happier, emotionally healthy child.

PARENTAL INTERVENTION

The behavior of an ADHD child is one area that requires considerable energy and involvement on the part of the parent. Children with ADHD respond to the world, and to their parents, differently. They are often able to see through the situation and manipulate the outcome because they are very smart, creative, and quick to perceive parental weaknesses. Disciplining the ADHD child requires quick thinking, creative parents. Parents are encouraged to learn as much as they can about ADHD so they can monitor their child’s behavior and creatively intervene when there are differences.

PROBLEM SOLVING TECHNIQUES

All children need to feel as if they have some control over their lives. This is especially true of children with ADHD because they often feel as if they have no control over their internal environment. Involving an ADHD child in the discipline process gives him a sense of control. Involving the child in the problem solving process makes him feel as if he has a stake in the outcome. It often encourages him to access his creativity to find solutions to the problem.

When problems arise, as they so often do with attentional children, parents must intervene to redirect inappropriate behaviors. The best strategy is to help the child monitor his own behavior to prevent a problem before it occurs. If that fails, the parents must creatively work with the child to solve the problem. This requires the parent to remain calm in a time of frustration. It’s important to remember that the attentional child looks at the world from a different point of view and may not see his behavior as a problem.

IDENTIFY THE PROBLEM

Frequently the parent’s first task is to help the child identify the problem with his behavior. Let him retell the event in his own words. Be careful not to subject him to your feelings or opinions; this can make him feel powerless. Ask him to state the problem in his own words. Listen to him intently, being careful not to interrupt, and encourage him to find a way to communicate clearly. After the child finishes explaining the problem, you can help by clarifying misperceptions.

BRAINSTORM POSSIBLE SOLUTIONS

After identifying the problem, the next step is to begin finding a solution. Brainstorming possible solutions with your child is the ideal place to begin. In this step it is important to identify as many solutions as possible, even some that may appear quite outlandish. Later in the process you will evaluate them, but for now just throw out ideas. Write them down. Try not to discourage his participation by being critical of his ideas either verbally or through body language.

EVALUATE THE SOLUTIONS

After brainstorming, ask your child to help evaluate all of the solutions. Assist the child to see the whole picture and how each solution will affect it. Be careful not to make light of any solution offered by your child and be as flexible as possible. You do not want to discourage his participation in the future. Work together to eliminate suggested solutions that won't work. Your child may feel discouraged if you cross off more of his ideas than yours. So, when you are generating possible solutions, you may want to put some silly solutions into the mix so some of your solutions can be crossed through as well.

Since your child will be held accountable for whatever solution is decided upon, it will help if he feels as if he has some say in the process. Even if your child arrives at a solution that is different from yours, if it will work without damaging property or endangering anyone, give it serious consideration. After coming to agreement on the solution, write it down. Praise your child for helping you solve the problem and ask him to commit to the solution.

BEHAVIOR MANAGEMENT SYSTEMS

The use of positive reinforcement with ADHD children can be the most effective part of any program. Children with ADHD receive so much negative feedback that positive feedback is always needed - the more the better. One treatment center required that a positive statement be given every 15 seconds in a group of eight to ten ADHD children. An ADHD psychologist used to say that if you don't go to bed tired of giving your child positive statements, then you have not given him enough. It is more likely you are tired from criticizing and redirecting behaviors. Positive reinforcement should be the essential part of every system for an ADHD child.

Children with ADHD often respond well to a reward system, especially when they are involved in the process. These systems can be very simple or very complex. Generally speaking, the severity of behaviors you want to extinguish will determine the degree of complexity needed in the reward system.

The most important rule is to involve the child. Focus on and explain the behaviors you want to see. Do not put emphasis on the behaviors you do not want to see. Use a positive tone of voice when you identify behaviors that you would like to see. It is best not to address more than three behaviors at a time.

There are three key factors in successful parental intervention to keep in mind when designing a behavior management system:

1. First and foremost, keep it simple. If your child appears to be frustrated or becomes oppositional, it may mean that your behavior management system is too complicated.
2. Tell your child exactly what is expected of him, using words or pictures to provide an example of the outcome you would like to see.
3. If you are attempting to create a certain behavior, let him help decide what the behavior should be. For example, if you are targeting the behavior of keeping his room clean, it might help to give him some control over where the trophies, toys, and so forth should be kept.

Behavior management systems usually work well with ADHD children if the reward motivates him. Find out such things as what he would like to spend his money on or whom he would like to spend time with. This will give you clues about possible rewards.

When your child achieves the targeted behavior it is tallied. Younger children under 7 years old usually respond better to getting a chip or sticker. Children older than 7 years tend to respond better to a point system. When they have acquired a specific number of chips or points, they will receive the reward. The reward system will probably need to be used for six or seven weeks, until the desired behavior has been established. Taper the system down slowly after

it is no longer needed. Keep in mind, however, that you may need to pull it out again two or three times a year, depending on the needs of the family.

Although parenting ADHD children is a complicated process, the rewards are numerous. The joy of seeing an ADHD child develop to his full capacity and grow into a successful adult is every parent's wish.

The vigor with which many individuals with ADHD live their life is phenomenal. They grasp life by the horns and ride it, never letting a moment pass that they can fully experience. The shutting down effect that the media, uneducated adults and peers has on individuals with ADHD is heartbreaking. I urge you to join in the effort to create a new understanding of these individuals so they can live happy, full, creative, and successful lives.

Learning to Communicate: Strategies for Developing Communication with Infants Whose Multiple Disabilities Include Visual Impairment and Hearing Loss

By Deborah Chen, Ph.D. Professor, California State University, Northridge

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All infants communicate through crying, fussing, smiling, body movements, and other nonverbal behaviors. With repeated interactions, their parents, families, and other significant caregivers interpret the meaning of these signals and respond accordingly. Through these early exchanges, infants discover that their behaviors have a powerful effect on their caregivers and develop more efficient ways to communicate - through gestures and words. However, when infants have a visual impairment and hearing loss in addition to other disabilities, the communication process does not develop naturally. Their early communicative behaviors may be subtle or unusual and therefore difficult to identify and interpret. For example, an infant (who is totally blind and hard of hearing) may become quiet when her mother speaks to her. This passivity may be misinterpreted as disinterest rather than attentiveness. Another infant (who has cerebral palsy and is deaf) may grimace his body when his father picks him up. These behaviors may be misinterpreted as rejection rather than excitement.

At the same time, our usual responses, i.e., by talking to hearing infants or by signing to deaf infants, may not be understood or even perceived by infants with sensory impairments and multiple disabilities. Communication with these infants requires careful planning, consistent attention, and specific procedures. The purpose of this article is to discuss selected strategies that families and service providers can use for communicating with infants (birth to 36 months) who are not yet using words and who have significant and multiple disabilities.

GETTING STARTED

Because the meaning of an infant's early communication behaviors is tied to context, we must first identify how and why an infant communicates during familiar activities. These observations provide information on an infant's current level of communication and ways to support interactions.

Make careful observations to interpret infant behaviors

1. Observe the infant in an everyday caregiving activity (e.g., diaper change, dressing, feeding, or bathtime) and a familiar social activity (e.g., being tickled, action songs, being rocked, or other early games).
2. Identify how the infant shows interest, dislike, fatigue, or boredom through his or her behavior.

3. Identify whether the infant communicates for (a) behavior regulation (e.g., to get someone to stop or start doing something by protesting, refusing, or rejecting; requesting objects; or requesting actions); or for (b) social interaction (e.g., to get someone's attention by greeting, seeking attention; requesting social routines; or requesting comfort).

Next, we should find out about the family's typical activities and communication practices. This way, strategies will be tailored to fit the family's lifestyle and will be more useful to the family.

Family information

1. What is a typical day like for your infant?
2. What are your infant's favorite objects, activities, and people?
3. What are your infant's most disliked objects, activities, and people?
4. How does your infant communicate with you? What is he or she usually trying to tell you?
5. When is your infant the most communicative?
6. Have you found any special ways that help you to communicate with your infant?
7. What activities do you enjoy doing with your infant?
8. What songs or baby games do you play in your family?
9. What words do you use frequently in everyday activities with your baby?
10. What do you say when your baby does something that you like or makes you feel proud?
11. When is a good time or what is a good activity for playing with your baby?

Taking time to discuss these questions is important for all families and absolutely essential when service providers and families have different cultural and linguistic backgrounds. Otherwise, a service provider's suggestions for supporting the infant's communication may conflict with family practices. For example, an infant may be confused if an English-speaking service provider says "good boy" to praise him while his Spanish-speaking mother says "bravo." Explanations of sign hand shapes based on English letters, e.g., "S hands" for the sign SHOE, will not make sense to non-English speaking families who do not know the manual alphabet and is not immediately useful if the infant does not wear shoes. Only through careful observations of the infant and thoughtful discussions with families, can service providers suggest communication strategies that are most appropriate for a particular infant and respectful of the family's culture.

SELECTED STRATEGIES

We must differentiate between the methods for communicating with an infant (input) and the ways in which an infant is most likely to communicate (output). Input and output communication methods must be tailored to meet the individual learning needs of each infant. For example, a mother may ask an infant "want to swing?" by using an object cue (a blanket) for input, while this infant indicates "yes" by wiggling her body (output).

COMMUNICATION INPUT MUST BE ACCESSIBLE TO THE INFANT

Make use of the infant's available senses

Infants with multiple disabilities must receive comprehensive audiological and ophthalmological evaluations since they are more likely to have vision and hearing problems than infants without disabilities. An infant's visual impairment

is usually identified before a hearing problem because it is more obvious. If an infant is identified as having a visual impairment and hearing loss, then every effort must be made to determine whether the infant would benefit from corrective lenses and hearing aids.

Communication tips

- Speak naturally and close to an infant’s ear. This is a natural way to help the infant discriminate speech from the environmental sounds, particularly if the infant has a slight hearing loss, middle ear infection, or other hearing problem, and does not wear a hearing aid.
- Reduce unnecessary noise. Turn off the television or radio and reduce other background sounds if you want the infant to pay attention to what is being said or other spoken information. The signal (speech) must be at least 30-40 dB louder than the background for a hearing infant to be able to attend to it; so background sounds will interfere with the ability to understand what is said.
- Hold the infant on your chest and dance or sway in time to vocalizations to help the infant make a connection between sound and movement.
- Imitate the infant’s own vocalizations or actions. Infants will imitate behaviors that are within their own repertoire before they imitate new behaviors. These imitation exchanges can become enjoyable turntaking games.
- Develop other infant games, for example, by playing “peek-a-boo” and removing the scarf from the infant’s face after saying ‘peek-a-boo” or bouncing the baby in time to vocalizations.

Match the infant’s developmental level. Our communication should fit the infant’s cognitive ability and be tied to ongoing actions and objects that the infant can perceive. Many infants whose multiple disabilities include visual impairment and hearing loss benefit from the use of caregiverese, anticipatory cues and key word signs.

CAREGIVERESE

How we interact with infants is very different from the ways in which we interact with children who have language. Hearing parents speak to infants using higher pitch and exaggerated intonation. Deaf parents sign to infants by making the movements bigger, making the signs on the infant’s body, or making the sign on the object to which it refers. In these interactions, both hearing parents and Deaf parents use animated facial expressions, gestures, short simple phrases about what the infant is seeing or doing, and repeat words, touch the infant, wait for the infant’s response, interpret the infant’s behaviors as communication, and imitate and expand on the infant’s utterances. These characteristics of so-called “motherese” or “fatherese” help infants to participate in early conversations.

Communication tips

- Use short phrases with repetitive words to allow the infant time to process and understand what is said/signed, for example, “take a drink”, “you’re thirsty”, “drink some juice”, ‘thirsty baby.’
- Add words to the infant’s action to assist the infant’s understanding of words and their meanings, for example, “up, up, up” when picking the infant up.
- Use facial animated expression to engage the infant’s visual attention, if appropriate, and to support what is said, and to communicate in a natural way.
- Use natural gestures visually or tactually to engage the infant’s attention, to communicate the meaning of words, and to model the use of gestures in communication, e.g., wave bye-bye when saying “bye-bye”, gesture when saying “down.”

ANTICIPATORY CUES

Anticipatory cues are specific sensory prompts to help prepare the infant for an upcoming activity. They include: tactile cues (e.g., “let’s put your sock on” may be communicated by touching the infant’s foot which is a touch cue) or by having the infant touch the sock (object cue); auditory cues (e.g., tapping the spoon against the bowl to indicate “let’s eat”); kinesthetic cues (e.g., rocking the infant in your arms before placing her in the hammock); olfactory cues (e.g., having the baby take a whiff of the soap before bathing him); or visual cues (e.g., wiggling your fingers in the infant’s visual field before picking him up). Do not use cues that elicit a negative reaction or are difficult for the infant to perceive. For example, for infants who have had many pricks on their feet from blood tests, touching the foot would be an aversive tactile cue for “let’s put your socks on.” Other infants may be very sensitive to certain scents and react negatively to olfactory cues. Cues should be selected carefully for each infant, made in a consistent and precise manner, and have a clear connection with what they represent. This way the infant can develop an understanding of their meaning. For example, an infant will be confused if different tactile cues are used for the same message (e.g., touching the lips, or the chin, or the cheek to indicate “let’s eat”) or if different tactile cues on the face have different messages (e.g., touching the lips means “let’s eat”, touching the chin means “open up for your toothbrush.”).

FREQUENTLY ASKED QUESTIONS ABOUT CUES

Is there a certain sequence for using cues with infants?

There is no research on the use of cues with infants to guide how they should be introduced. Cues should be individualized for each infant and dependent on the specific activity. However, a helpful principle is to begin with a cue that will be easily understood by the infant, that is clearly related to the activity, and that is presented immediately before the activity begins. For example, initially, it is probably easier for an infant to understand “get ready for your bath” through a tactile cue (putting his hand in the water just before being put in the tub) than being given a whiff of bathsoap (olfactory cue). Begin with just a few cues that are very different from each other, and that represent different activities, and are therefore easy for the infant to discriminate and to discover what they mean. For example, use a tactile cue for bathtime (putting the infant’s hand in the water), a touch cue for diaper change (tug on the infant’s diaper), and an object cue for playtime (quilt for the blanket swing).

What is the difference between a sign and a cue?

A manual sign is a symbol, a word, or a unit of language that represents something. For example, the sign MAMA represents mother no matter the situation. A cue is a prompt that is individualized for each child, is dependent on the specific activity or context, and is used to encourage a specific behavior. For example, tapping a child on the chin may be a prompt for “open up” if the caregiver wants to brush the child’s teeth; or for “take a bite” during meals; or “close your mouth” to prevent drooling.

KEY WORD SIGNS

Many infants with multiple disabilities benefit from *key word signs* which are selected signs adapted for the infant’s learning needs. Using key word signs is not the same as using the simultaneous method (spoken English together with a sign system based on English) or using American Sign Language (ASL) which has its own grammar and visual-spatial rules and is a different language than English. Initially, a key word sign is really a prompt or cue to engage the infant’s attention and to build an understanding of the meaning of a word and what it represents. For example, the sign EAT made either by the adult touching the infant’s lips with a flat O handshape or by assisting the infant to touch his own lips is really a *touch cue* or *gesture* rather than a sign. When key word signs are used with infants who have low vision, the infant’s visual needs must be considered. Signs should be made so the infant can see them, that is, within the infant’s visual field and at an optimal viewing distance; the rate of sign production and size of hand movements should be modified to enable the infant to see the sign; and the signer’s hands should be clearly visible in contrast to his or her clothing.

SELECTING KEY WORD SIGNS FOR COMMUNICATION INPUT

1. Ask the family to make a list of words that are most important for communicating with their baby.
2. Develop a list of vocabulary with family members and service providers, decide on the signs to be used for these words, identify any adaptations that are needed, and use selected signs consistently across activities.

SELECTED ADAPTATIONS FOR KEY WORD SIGNS

- Make signs on the infant's body.
- Physically guide the infant to produce signs (coactive signing).
- Make signs smaller and close to the infant's face.
- Orient the infant's attention to a signer by touching the infant's face or body.
- Use tactile modeling by placing the baby's hands on yours to feel the sign movements (interactive signing).
- Match the number of movements of the sign with the number of syllables in the word when providing communication input, e.g., MAMA is two movements.

Build on the infant's interests and strengths. Infants are likely to attend to objects, activities, and people they like and are more likely to request these favorite things. For example, an infant who loves movement will be motivated to ask for "more" of a bouncing game. This favorite activity may be used in an interrupted routine strategy to elicit communication output, as shown below. Selected methods for encouraging the infant's expressive communication should be based on the infant's abilities. For example, infants who can control their hand movements are more likely to use some signs expressively than infants who have motor problems. An infant is more likely to make a choice between a favorite object and a disliked object than between two objects of equal appeal.

INTERRUPTED ROUTINE STRATEGY

1. Select a movement activity that the infant enjoys and do about three movements.
2. Create a need for the infant to communicate by stopping the movement.
3. Wait quietly (count silently to 10 or 15 depending on the infant's response time) and observe what the infant does.
4. If the infant responds, interpret the infant's behavior as communicative. Add words to the infant's behaviors. Respond to the infant's communication by continuing the activity.
5. If the infant does not demonstrate an observable response, prompt the desired response (e.g., wiggle the infant's arms or legs), and immediately continue the activity.

Repeat this prompting procedure two more times so that the infant has three direct instruction experiences. Then repeat from Step 3: interrupt the activity and wait quietly for the infant's response.

CRITERIA FOR SELECTING FIRST SIGNS FOR PROMOTING COMMUNICATION OUTPUT

1. Identify the infant's favorite activities, objects, and people based on observations and the family interview described previously.
2. To represent these preferences, select signs that are easy to produce, touch the body (e.g., EAT, MAMA), have symmetrical movements (e.g., MORE), and look like or feel like what they represent (e.g., EAT, WASH, DOWN).

3. Provide frequent opportunities for the infant to use these signs.

CONSIDERATIONS FOR SELECTING KEY WORD SIGNS AS COMMUNICATION OUTPUT FOR INFANTS WITH MOTOR PROBLEMS

- Identify key words that have been selected by the infant's family and service providers and determine their usefulness for the infant's expressive communication.
- Determine whether a manual sign is the most effective way for this infant to express a desire or need. What type of physical assistance does the infant need to produce the selected sign? Is there an easier way for the infant to communicate (e.g., using an object, picture, or other signal system)?

Provide time and repetition. Very young children without disabilities need to hear a word used in context about 200 times before they use it. Infants with multiple disabilities will need even more repeated experiences to understand the meaning of a cue or word used in everyday activities. This significant need for consistency and repetition highlights the importance of making communication an essential part of every learning activity and daily routine. Not only the infants, but everyone involved with them - family members and service providers - should all be learning how to communicate.

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Ultraviolet A, Blue Light and Children

By Elaine Kitchel, Low Vision Research Associate,
American Printing House for the Blind

For years now, professionals in the fields of light energy and vision have known about the hazards of ultraviolet (UV) light. Even experts differ as to the exact wavelength of UV light waves. Generally speaking, however, UV light is defined as the part of the spectrum which is divided into UV-A (380-315 nm), UV-B (314-280 nm), and UV-C (279-200 nm).

UV-C and UV-B, though harmful will not be discussed here since they are virtually absent from indoor light. However, a recent boom in the number of practitioners using blacklight activities has brought about high levels of exposure to UV-A and blue light for a significant number of children. Why is that a problem? Recent research in cellular biology has shown that exposure to the UV-A and blue light waves emitted by blacklight tubes can have long term negative effects for persons exposed to it, especially children.

Blue light, that part of the visible spectrum which ranges for 500 to 381 nm, makes up half of the light emitted from black light range. However, until recently, little had been offered in the way of information about how blue light, and UV-A affect the eye structures of children.

Bear in mind that as the lens of the eye ages, it begins to yellow. This yellowing gives adults some, but not adequate, protection against UV-A and blue light. However, children have not lived long enough to have this yellowing. Therefore UV or blue light which enters the eye will strike the retina at full-strength exposing not only the retina, but the lens to damage. Dr. W.T. Ham, who has conducted research on the effects of UV and blue light has written,

Most authorities do not believe that the near UV radiation absorbed throughout life by the lens is a contributing factor to aging and senile cataract. Thus by protecting the retina from near UV radiation, the lens may become cataractous. My own personal opinion is that both the retina and the lens should be protected throughout life from both blue light and near UV radiation. (Ham, 1983, p. 101)

If Dr. Ham is concerned about exposure to UV and blue light from the exposures of daily living, one has to wonder what he would say about young children who are being exposed several times a week to UV and blue light from

blacklight activities. Many of these children receive no protection for their eyes, and for those that do, most of it is woefully inadequate.

What is it about UV-A and blue light which make them hazardous? Tests done by Drs. Ham and Chen show that when UV-A and blue light strike the retina the light waves inhibit the formation of a chemical called cytochrome oxidase. This chemical is an important part of retinal cells because it transports oxygen to photoreceptor and other retinal cells. Without cytochrome oxidase, the cells become deprived of oxygen and eventually die. When enough cells die, retinal degeneration occurs.

Many people have said that UV-A and blue light will not harm children if the length of time of exposure is limited, or if frequency of exposure is limited. In Sweden, Dr. E. Chen exposed the retinas of mice to moderate levels of blue light. Two days later, lesions showed up on the rodent's retinas after only 2 minutes of exposure. Similar research was conducted by Drs. Gorels and van Noren. They concluded that the retinal damage done was a feature of the wavelength, not duration or frequency of exposure. This means, that even a short exposure to blue light, without adequate protection, can cause retinal damage.

The experiments of Drs. Chen, Gorels, and van Noren were later done on primates with similar results. The eyes of rhesus monkeys are very similar to our own. Drs. Sperling, Johnson and Hawerth exposed the retinas of rhesus monkeys to blue light and found,

...extensive damage in the retinal pigmented epithelium from absorption of energy by the melanin granules. It should be pointed out that the damage seen, including the macrophagic activity, disrupted cells and plaque formation, is characteristic of that seen by Ham et al. (1978), and others in what he calls the photochemical lesion.

Often the lesions from UV-A and blue light are scattered on the retina. It is only when enough of them appear and coalesce that one begins to notice a vision loss. This is why vision loss is not immediate, but often takes many years to manifest. This is the reason why children, especially ones who already are suffering from a vision loss, must be adequately protected.

Protection against blue light damage is simple. However, most practitioners who use blacklight tubes do not use adequate protection. Most who bother to use any protection at all, use clear polycarbonate lenses for the child and none for themselves. It cannot be emphasized strongly enough *both practitioner and child who are exposed to the light emitted from blacklight tubes must be protected*. Yellow polycarbonate lenses offer complete protection, in most cases, against blue light hazard. Various goggles and lenses are available from such vendors as NoIR Medical Technologies and Solar Shield. Objects will still appear to fluoresce if viewed through a yellow polycarbonate filter.

With adequate protection being inexpensive and available, practitioners should be vigilant in their efforts to protect the eyes of themselves and of the children who are exposed to the damaging effects of UV-A and blue light.

You may read more about blue light hazard by requesting a copy of "The Effects of Blue Light" from Elaine Kitchel at APH, 1839 Frankfort Avenue, Louisville, KY 40206-0085.

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Visually Impaired Go to Camp - Students Learn About the Sea and a Lot About Independence

By Mel Huff, The Brownsville Herald, Brownsville, Texas

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A young girl with shoulder-length brown hair held a starfish upside down in her cupped hand and touched the mouth at its center. "Look at that!" Brittany Madsen exclaimed as the thing curled a leg.

Madsen, a white cane tucked under her arm, crowded around a table with other students who were examining seaweed, urchins and other creatures in one of several large plastic trays. At the head of the table, Scarlet Colley held a large hermit crab close to a group of students.

"This is a red hermit crab," she said. "He's got green, green eyes!"

"Awesome!" another girl breathed.

The students were taking a hands-on tour of marine life with environmental educators George and Scarlet Colley on South Padre Island. The students could have been any children at camp, but these children are visually impaired.

For seven years now the Region I Education Service Center has held camps for blind students. For the last three years, children from Region II in Corpus Christi and Region III in Victoria have joined them. The camp was designed with parents as well as children in mind, said Peter Graves, who wrote the original grant proposal with Linda Chromaster. Both are Region One education specialists and certified vision instructors. Graves noted that it's hard for lots of parents to let a child with a disability go away and develop independence. "Our goal is to help parents learn to relax,"

he said. At the same time, children with disabilities can have a hard time developing independent living skills.

Graves said he expects that many campers will go to camps sponsored by the Texas School for the Blind and Visually Impaired in Austin in the future. Our camp is a “first camp experience” close to home. If they have never been away from home before, the transition is much more difficult. “This helps prepare them and their families,” Graves said.

This is the second year Jessica Blake, 8, has been to the camp. Her mother, Cheryl Blake, said going to camp again was all Jessica could talk about since January. “They learn they can do things by themselves. It really builds their confidence,” she said. Blake, a nurse at Valley Baptist Medical Center, volunteered to help with her daughter’s camp this year. “Homesick youngsters can call home at no charge at night, and parents can call or visit camp to see how their children are doing,” Blake said.

The children were at Jeremiah’s Water Park on Wednesday. The park has a trail with railings on both sides, Graves noted, so “once kids get the feel of it, they’re on their own, (although) we’re always there watching.”

Since Monday, the 32 campers, ages 7-18 have gone fishing on the Island Princess, played at Jeremiah’s, driven at Ben’s Go-Karts and ordered dinners at Blackbeard’s.

“Most haven’t had these kinds of experiences,” Graves said. “We have children who have never been to the beach, who have never been to a buffet or ordered a meal in a restaurant.” One camper last year had never seen a dishwasher.

Camp refines the children’s skills for daily living, said Christie Waida, a teacher from Region III in Victoria. The campers make their breakfasts and lunches, pick up their clothes, and make their beds. “Some have never made their sandwich or put a toaster pop in the toaster,” Waida said. Graves gives the campers money to buy their own dinners, and they have to figure out how much they can spend for a meal, adding in their drink and tip. They order from menus Graves types in Braille.

In addition to providing campers the experience of responsibility, camp gives children the experience of freedom. Wednesday evening many campers who will never drive a car controlled the speed and steered go-karts, with a teacher telling them when to turn right or left. “At first I said, ‘Oh, no! Am I going to drive?’” said Hilda Niño, a 16-year-old student from Rivera High School. “Then I said, ‘This is really cool!’”

“I don’t like to go out at night,” remarked Yesenia Burgos, also 16 and a student at Lopez. (Burgos has limited night vision.) “We crashed a couple of times, but it was really fun!” she added. Burgos said the camp offers visually impaired students an opportunity to meet others who are like them.

“They don’t treat us differently,” Niño said. “At school, they are afraid of talking to you or even touching you. Here they aren’t.” This is Niño’s second year at camp and Burgos’ third. Some children have come back for four or five years. Many teachers and lifeguards also come back year after year.

Waida talks about witnessing “the wonder of discovery” when she watches campers touch a fish for the first time or hold a fiddler crab and see how soft its claws are or experience what a wave is. “This is the greatest refresher and learning experience I have all year,” she said. “It reminds me why I decided to dedicate my life to teaching.”

Fabian Lara has been a lifeguard at the camp for three years. After the first year, he changed his major to education for the hearing and vision impaired. “Some of these kids had never been near the water,” he said. “Just to see their expression change” when they get in is what draws him back every year.

TSBVI Short Courses: A New Service Delivery Model

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

The Texas School for the Blind and Visually Impaired is developing new ways to serve students in Texas with visual impairments. TSBVI will be offering intensive *short courses* in special areas related to vision impairment (e.g., technology, independent living skills, O&M). The focus will be on courses that may be difficult to teach with enough intensity in some public school settings. The programs could vary in time from a long weekend to a week, two weeks, a month or a semester, depending on the subject(s) being taught. Similar intensive, short-term programs are being developed throughout the country for children who are generally successful in their local districts but could benefit from a special boost in certain disability-related areas of instruction.

In Spring 2000, TSBVI will pilot two new programs. In addition, I will be talking with schools and parents across Texas to learn more about other programs they would like to see for their children. These programs are offered at no cost to local districts and parents (other than a small family fee for community outings when applicable). At the present time, this offer includes transportation costs. The spring programs will be small so that TSBVI staff can work out problems before expanding. They will be:

- A one-week, intensive technology class during the month of March
- A three-weekends camp for specific Independent Living Skills (January, February, March)

In Summer 2000, TSBVI will offer additional short instructional courses. These courses will occur simultaneously with the enrichment programs the school has traditionally provided in the summer. Then beginning Fall 2000, short courses will gradually increase during the regular school year.

Short-term programs will become better defined as they are implemented and evaluated by schools and parents. *Students eligible for programs at this time are those who are on grade level, or no more than two years below grade level.* These are the students who are most likely to benefit from brief instruction, then continue to progress in their regular classrooms.

All programs will contain supplementary instruction in the areas of Independent Living and Social Skills. Transition services for a student's transfer to TSBVI and then back to the local school will be an important part of every program. Our goal is that transition services will be jointly implemented by local district staff, parents and TSBVI. A short intervention is likely to have little lasting effect without this help for the student when he or she returns to the district.

The content of future classes is being considered at this time but remains open to input from statewide consumers. Some possibilities are:

- Adapted Mathematics (e.g., Nemeth code, abacus, tactile graphs and graphics)
- Adapted Science (emphasis on labs and tactile representation of concepts)
- Elementary School programming focused on literacy, math, O&M and technology
- Adapted Technology
- Orientation and Mobility
- Literacy
- Independent Living Skills
- Social and Self-advocacy Skills

TSBVI will continue to publish updated information in SEE/HEAR and on the TSBVI website as the short courses are better developed. Please direct your questions and comments to:

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Life's Continuing Education Courses

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

Both of my kids are in college now and soon their mother and I will be in the empty nest stage of our lives. As we continue the process of nudging them out of the nest, I keep reminding my son and daughter that their education doesn't stop when they get out of school. This first year as executive director of the Commission has certainly been one uninterrupted continuing education course for me! I learn something valuable every day.

Two of the most interesting "electives" I recently signed up for were a week-long orientation and mobility class here in Austin and a three-day trip to The Seeing Eye in New Jersey as an invited guest. Learning some of the basic skills of traveling with a cane and dog guide were great opportunities to experience confidence building in action. During each session I was under blindfold and under the wings of a competent instructor's watchful eyes. I was nudged along with encouragement, and with every step I took my self-confidence grew.

There's been some speculation about whether simulated experiences such as these are realistic enough to give a person a smattering of what it's like to be blind. That's a debate that will live on way past me. I know I could have taken my blindfold off, but I didn't. I actually learned to cross a busy street with a cane and got better at sensing the directional changes in the harness of a meticulously trained dog as he guided me around shin-threatening fence posts. The result? I not only learned more about the methods used to teach travel skills but also learned more about myself. I found that the head knowledge I'd gained after 27 years in the field of rehabilitation matched my personal experiences. If I were to lose my sight tomorrow or ten years from now, I know a lot of hard work would be ahead, but I'm confident that with some good instruction I can still learn. Blindness is life-altering and sometimes a detour, but it isn't the end of productivity.

We've been talking a lot about confidence at the Commission this past year, and I mentioned our Texas Confidence Builders initiative in another issue of SEE/HEAR. Blindfold training is only one aspect of our initiative. Looking back, we have gained a lot of ground in making sure our services concentrate on building self-confidence rather than dependence on government and others. Although the Commission certainly isn't in the parenting business, we feel a sense of pride when the individuals we work with gain the confidence to leave the nest of rehabilitation services because they have learned the skills to be confident travelers, workers, and participating community members either for the first time or once again. It's equally rewarding to watch children who have visual impairments grow more self-confident because of the specialized services available today. Along with their parents, we celebrate their day-to-day progress toward being all they can be.

As this issue is being written, our new fiscal year planning initiatives are underway and another school year has just begun. I hope your learning experiences have been and continue to be as exciting as mine!

New Guidelines Will Assist States

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

For the past two years, a group of writers has been working hard drafting a new publication called "Blind and Visually Impaired Students: Educational Service Guidelines". The National Association of State Directors of Special Education (NASDSE) is in charge of this project, which has been funded by the Hilton/Perkins Foundation. Dr. Gaylen Pugh was selected as Project Director, and has been very effective in keeping the writing of this document on track. I was privileged to be one of the writers.

I want to emphasize the potential impact of this publication. NASDSE membership is comprised of the special education leaders in each state. They have a tremendous influence on policy and practice regarding educational services for students in their respective states. More specifically, members of NASDSE have the capability of determining educational services for blind and visually impaired students. I also emphasize that we educators for blind and visually impaired students did not go to NASDSE to promote the writing of this publication. They came to us. I have to believe that the members of NASDSE recognize the need for new guidelines that will enable them to serve blind and visually impaired students more effectively.

What follows is a NASDSE news release announcing the new publication. It provides some detail about the content of "Blind and Visually Impaired Students: Educational Service Guidelines". If you do not receive a copy, please order one - you'll be glad you did.

It's Ready, It's Out There!

NASDE and Hilton/Perkins Publish the Blind Initiative Guidelines

In September, NASDSE and the Hilton/Perkins Program of the Perkins School for the Blind disseminated their educational service guidelines for students who are blind or visually impaired. The intention of this guidelines document is to provide assistance to state and local education agencies, service providers, and parents. The document describes essential program elements and features which must be considered when designing appropriate services for students who are blind or visually impaired, including those students with multiple disabilities. A full continuum of options is included.

The process for developing this guidelines document, as well as its format and design, was patterned after NASDSE's Deaf Initiative guidelines published in 1994. The Blind Initiative document is the collaborative effort of 13 national organizations that have special interest in the provision of services to visually impaired persons and their families. Representatives from the major national consumer, advocacy, and educational organizations comprised the writing team. A larger panel of content experts provided review and comment on draft chapters.

The document is organized into five chapters, a glossary, and extensive appendices. Chapter One presents the theoretical constructs on which the other chapters are based. It discusses what educators need to know about the unique educational needs of students with visual impairments. It outlines public policy and legislation that affect these students and their rights to full participant in the general school curriculum. In Chapter One and subsequent chapters, the role of parents as equal partners in the educational process is discussed.

Chapter Two presents the framework for services. It outlines the responsibilities of the state education agency to maintain a unit to ensure the policies, procedures, and personnel are in place to meet the unique educational requirements of students with visual impairment. The role of the state agency in providing adequate and timely resources and appropriate reading materials, along with a full array of placement options, is discussed.

Chapter Three describes the process of identifying and assessing individual needs. It addresses the issues of personnel administering assessments, the need for on-going assessment of student progress, the interaction of functional vision and additional disabilities, and appropriate learning and literacy media. This chapter reinforces the need for parent involvement and the responsibility of the educational system to include parents in meaningful ways throughout the process and decision making.

Chapter Four identifies concepts that must be addressed following assessment in reviewing program options and placement. Educators working collaboratively with parents and students develop programs in educational setting which meet the unique individual needs of each student who is blind or visually impaired. These options allow the students an expanded core curriculum and appropriate opportunities to participate with peers and mentors who are visually impaired, as well as with those who are sighted.

Chapter Five describes characteristics of personnel who will work with students who are blind or visually impaired, including those with multiple disabilities, in appropriate placements once they have been identified. This chapter discusses the specialized knowledge, skills, and attributes needed to provide educational and orientation and mobility services to students who are visually impaired. Proficiency of educational personnel in literacy and communication modes (including Braille reading and writing and use of optical devices) and specialized training of service providers in orientation and mobility, assistive devices and technology including Braille, speech, and low vision technology are also discussed.

The Glossary provides an in-depth look at some of the terminology used throughout the document. A user-friendly table of contents assists the reader in locating specific information as some issues overlap and are repeated in different contexts. The Appendices section will provide the reader with valuable resources and more extensive explanation of chapter content.

The document has been distributed to state directors of special education, organizations, and parent and consumer groups by the Hilton/Perkins Foundation. Individuals seeking additional copies should contact the Hilton/Perkins Foundation, Perkins School for the Blind, Watertown, MA. For further information on the project, contact Dr. Gaylen Pugh, Project Director, National Association of State Directors of Special Education, (256) 772-4350 or via e-mail at hlpughjr@aol.com.

Editor's note: There are several new books out that parents and even professionals may want to purchase related to IEPs and IDEA. These books were review in the 1999 Library Summer Selection (a special supplement to Exceptional Parent magazine). We thought you might enjoy learning about these publications.

The Prospector and Goal Mine

Written by Don & Maureen Cahill

Reviewed by Tricia and Calvin Luker

Reprinted with the expressed consent and approval of Exceptional Parent, a monthly magazine for parents and families of children with disabilities and special health care needs. Subscription cost is \$36 per year for 12 issues; Call 1-877-372-7368. Offices at 555 Kinderkamack Rd. Oradell, N.J. 07649.

We parents of children with special needs must learn to navigate through many different service systems while raising our children. For most parents, the school system provides the greatest challenge and requires the most effort. Federal and state laws protect the educational rights of children with special needs. However, these laws are enforced through a procedural maze most parents find to be complex and unfriendly.

The Prospector and Goal Mine, by Don and Maureen Cahill, gently but effectively guides parents through the special education maze, empowering them to be strong advocates for their children's needs. Although the authors assume readers are generally familiar with an Individualized Educational Plan (IEP), they breathe life and understanding into the core element - goals and objectives - of all IEPs.

The Prospector and Goal Mine come in a single, spiral bound volume written in parent-friendly language. Sample goals and objectives are divided into practical subject areas to make it easy for readers to find suggestions specific to their particular need.

The Prospector concisely describes educational "goals" and "objectives", and clarifies the distinctions between them. The authors walk the reader through how goals and objectives are developed and how they should be used to plan and measure a child's educational course.

In *Goal Mine*, the authors apply *The Prospector's* lessons in 26 educational needs areas. Over 5,000 examples show what good goals and objectives look like and give readers specific goals and objectives to use on their child's IEP. Suppose a child diagnosed with Attention Deficit Disorder has difficulty attending school. *Goal Mine* offers 51 specific goals/objectives which promote the targeted need of improved attendance.

While the special education system can overwhelm many families, *The Prospector and Goal Mine's* wealth of accessible information helps ease the confusion. They are a "must carry" item in every parent's or advocate's educational arsenal. We highly recommend this volume.

Free and Appropriate Public Education (5th Edition)

By Rud and Ann Turnbull, Love Publishing

Reprinted with the expressed consent and approval of Exceptional Parent, a monthly magazine for parents and families of children with disabilities and special health care needs. Subscription cost is \$36 per year for 12 issues; Call 1-877-372-7368. Offices at 555 Kinderkamack Rd. Oradell, N.J. 07649.

Our first book review presented what we believe is a "must carry" resource in every advocate's briefcase - *The Prospector and Goal Mine*, by Don and Maureen Cahill. We are now pleased to present the second book that is a "must" for the effective advocate - *Free and Appropriate Public Education (5th Edition)*, by Rud and Ann Turnbull. It is the defining legal resource for all special education advocates.

The Turnbull's, who co-founded and co-directed the Beach Center on Families with Disability at the University of Kansas, take the cumbersome legal process that is special education and turn it into a powerful, reader-friendly guide to understanding special education advocacy. The book has three parts which include: an introduction to the Individuals with Disabilities Education Act (IDEA); the six principles of the law; and the enforcement of the law. This edition is updated to include the 1997 IDEA amendments.

The first part of the book places the special education struggle in historical context, preparing the reader for the principles at the heart of IDEA. The Turnbolls tell the reader where the law comes from, and why it is needed. This explains its power in the special education process. The reader learns how to make this law work for individual students. A reader who understands why IDEA was needed in the first place will be well armed to advocate for a free, appropriate public education for all students. This historical framework alone makes the book invaluable.

The second part of *Free and Appropriate Public Education* focuses on the six principles of IDEA: zero reject (including discipline); nondiscriminatory evaluation; appropriate education (including positive behavior support); least

restrictive environment (access to general education); due process (including mediation); and parent participation. The Turnbolls leave no stone unturned in detailing what families of children with disabilities have a right to expect from school administrators and teachers. The first-time reader is thoroughly educated about the law and how it relates to children with disabilities. The return reader and practicing advocate is given sophisticated information directly applicable to specific issues. The Turnbolls put each principle into historical perspective as well as the script of practical day-to-day reality.

The book's final section tells parents how to use the law to obtain a truly free appropriate education for children with special needs. They give the reader a straightforward discussion of how IDEA is enforced. The authors give equal emphasis to hardball legal mechanisms and emerging alternative dispute resolution practices. A parent or advocate who understands how the law really works is better able to weigh specific choices for their child.

Free and Appropriate Public Education also includes comprehensive resources. This 400-page hard cover book contains the 1997 IDEA amendments; a glossary; a table of important cases; and extensive excerpts from the three landmark educational rights cases.

This book is ideal for the parent who cannot take advantage of opportunities to attend or participate in special education training or conferences. In addition, it serves as an invaluable resource to those parents and advocates who provide training opportunities or direct advocacy for other parents and families. The book is easy to use to refresh one's understanding of specific concepts or procedures. Finally, *Free and Appropriate Public Education* constantly reminds readers that IDEA belongs to the families and not to the schools. It is not unreasonable for families to ask that IDEA be followed. The Turnbolls have given families a brief case resource which lets them put reason into practice. We heartily recommend this book and award it the Exceptional Parent Symbol of Excellence.

Free and Appropriate Education, item code LV129ED, can be ordered through the Exceptional Parent Library, telephone (800) 535-1910.

Secrets

By Nancy Adrian, Volunteer Coordinator
North Texas Taping and Radio for the Blind, Dallas, Texas

There are some well-kept secrets in Dallas, Texas - approximately 2,400 of them - and they are multiplying rapidly. "THEY" are the 2,400 titles of recorded books waiting for listeners in the library of North Texas Taping and Radio for the Blind. Never waiting to gather dust, these books are educating, instructing and entertaining thousands of children and adults across the state - people with vision impairments, learning disabilities and those with the inability to pick up or hold their books and magazines.

Of course, there are other sources for recorded books. The National Library Service, city and county libraries, American Foundation for the Blind, American Printing House, local commercial firms which rent and sell books on tape - all with their benefits, all with some drawbacks. So, how is NTTRB better (or worse) than these?

At NTTRB, we read on request books sent to us by our clients. Once completed, and if deemed to have a wide appeal, the books go into our standing library for distribution to everyone. Herein also lies our one drawback - speed of completion. Because we utilize strictly volunteer readers, the time it takes us to produce can create an embarrassment for us and an aggravation for our clients. Most, however, have learned that our readers are wonderful, and with our other benefits, the wait is worth it.

At NTTRB, we utilize standard two-track cassettes. This makes the bundle which arrives at your door a little larger, but this enables you to play these recordings in the car, on a “Walkman”, or on any regular tape player.

At NTTRB, we believe you probably like some books so much that you’d like to keep them around for a second or third listening. We also know that moving tapes back and forth sometimes gets to be inconvenient. Thus, the recordings become your property. We don’t want them back. Besides, if you leave them in the car on a 100+ degree-day, or spill the morning coffee on them, we’d rather this be your problem. We will, rest assured, replace the damage at no cost. If, however, you receive a book and don’t like it at all, do send it back. Somewhere out there someone is aching to hear it.

At NTTRB, all we ask to get the process started is a phone call to our 800 number - no application or enrollment forms required.

At NTTRB, the cost to you is NOTHING. As long as you live within the state, we send your recorded books through the mail as “FREE MATTER FOR THE BLIND”, at no charge to you, our listeners.

So you see, there are some differences! Hopefully enough to make you curious enough to give us a try. With as much talent as exists within our agency, and with the amazing time and devotion our volunteers give to the production of the recordings, we want their voices to fulfill the mission which brings them in to read in the first place. Catalogs of our recorded books are available for a phone call. Sorry, no copies in Braille or on cassette - they change daily, and would require an inordinate amount of time to keep updated.

Well, the secrets are out! Please, give us a call at (800) 871-7668 or (214) 871- 7668. Our fax number is (214) 871-7669. Direct your inquiries to Sharon Komorn or Nancy Adrian and they will make certain you find many books worth listening to.

Funding Assistive Technology

From the UCP website

<www.ucpa.org>

United Cerebral Palsy (UCP) is pleased to offer you a series of booklets developed by Neighborhood Legal Services National Assistive Technology Project and UCP. These booklets contain the most up-to-date information on funding assistive technology through the health, education and Vocational Rehab systems.

Funding of Assistive Technology - The Public School’s Special Education System as a Funding Source

The Individuals with Disabilities Education Act of 1997 (IDEA) offers many exciting opportunities to support students with disabilities, family members and school personnel through the use of assistive technology. UCP is pleased to provide with you a comprehensive document that gives you with the most current information on the state of the law and AT funding. This document should provide you with a working knowledge of the relevant laws, regulations and interpretations of them as they relate to a school district’s obligations under the law. We hope you find this publication useful and find it useful in helping families and students with disabilities gain access to technology.

Funding Augmentative and Alternative Communication Devices Through Medicare - The Decision Making and Appeals Process for Non-HMO Participants

As the number of adults with disabilities eligible for Medicare increases, the use of this untapped resource for

funding creates new funding options for individuals seeking augmentative communication devices. We hope you find this publication useful in your continuing efforts to fund technology for those who need it.

Funding of Assistive Technology:

State Vocational Rehabilitation Agencies and Their Obligation to Maximize Employment

This publication covers important topics of critical importance to individuals with disabilities who are entering the workforce including students transitioning from school, assistive technology for the college student, and the availability of assistive technology.

If you would like a paper copy of any of these booklets, contact United Cerebral Palsy, 1660 L Street, NW, Suite 700, Washington, DC 20036-5602. Phone: (800) USA-5-UCP or (202) 776-0406; TTY: (202) 973-7197; Fax: (202) 776-0414; E-mail: ucpnatl@ucpa.org; or visit the website at www.ucpa.org.

The SURE Project

By Jean Robinson, Family Support Specialist, TSBVI, VI Outreach

I recently received some information from Partners Resource Network outlining a new project that has just been funded and is called The SURE Project. The mission of the SURE (Seeking Unlimited Recreational Experiences) Project is to improve the quality of life for children and adults with disabilities through recreation and social activities. The project's goals include:

1. Build Partners Ranch, a 26 acre camp/retreat center near Evadale, TX. The camp will be 100 % accessible to people with disabilities.
2. Integration of people with disabilities into current programs through community education and awareness.
3. Create recreation and social activities for children and adults with disabilities.
4. Become financially stable through community support and fundraising.
5. Have some fun and games.

The SURE project will be sponsoring events and activities year round. One of the main areas of focus is outdoor activities, e.g., nature hikes, ball games, camp-outs, and picnics. The project will enlist the help of various service organizations as well as individuals who would like to volunteer their time. Events and activities take place primarily in Angelina, Chambers, Hardin, Jasper, Jefferson, Liberty, Montgomery, Nacogdoches, Newton, Orange, Polk, Sabine, San Augustine, San Jacinto, Tyler, and Walker Counties.

Contact SURE Project at (409) 898-4684 for an up-to-date schedule of new activities. This project is funded by a federal grant through the US Department of Education.

For more information contact: Partners Resource Network, Inc. - The SURE Project, 1090 Longfellow, Suite B, Beaumont, TX 77706-4819; phone (409) 898-4684 or (800) 866-4726; or visit their website at <http://www.partnerstx.org>.

www.puzzlemaker.com

Teachers and parents, welcome to Puzzlemaker! On this website you can create puzzles and games for your newsletters, flyers, handouts, or classroom assignments.

CLASSIFIED

Mail or e-mail your new classifieds to Jim Durkel at:
TSBVI Outreach, 1100 West 45th St., Austin, TX 78756, or durkel_j@tsb1.tsbvi.edu.
An up-to-date Statewide Staff Development Calendar is posted on TSBVI's website at www.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:

Corpus Christi: January 8 - 9, 2000

Contact: Joyce West at ESC 2
(361) 561-8524

Waco: February 25 - 27, 2000

Contact: Tina Herzberg at ESC 12
(254) 666-0707

or

Mollie O'Leary at TCB
(254) 753-1552

Ft. Worth: April 28 - 30, 2000

Contact: Judy Hamilton at TCB
(817) 926-4646

International Parent to Parent Conference 2000: "Pioneering Spirit - Blazing New Trails"

May 5 - 7, 2000

Reno Hilton Casino and Resort
in Reno, Nevada

Nevada will be the host for the 10th biennial International Parent-to-Parent Conference, one of the largest conferences of parents and families in the world. It will bring parents/families and professionals from around the world together to share and learn from each other about how best to support families and develop best practices for people with disabilities as we transition into the 21st Century.

Topic areas include:

- Family - professional relationships & partnerships
- Innovative programs and strategies
- Community resources and collaboration
- Leadership building for family members
- Strategies for addressing challenges of diversity and culture
- Legal rights and the system
- Fathers
- Technology
- Medicine
- Education

For more information contact:
Cheryl Dinnell, (702) 784-4921, ext. 2352
or cdinnell@scs.unr.edu

**INSITE:
A HOME-BASED MODEL FOR
INFANTS, TODDLERS, & PRESCHOOLERS
WHO ARE SENSORY IMPAIRED
WITH OTHER DISABILITIES**

The training is for professionals who work
with families and their children
who are sensory impaired

Six-day training to be held in El Paso

NOVEMBER 18 & 19, 1999
DECEMBER 9 & 10, 1999
JANUARY 20 & 21, 2000

Six-day training to be held in Austin

MAY 1- 6, 2000

Contact Gigi Newton, Texas Deaf-Blind Outreach
Texas School for the Blind and Visually Impaired
1100 West 45th
Austin, TX 79756
(512) 206-9272
newton_g@tsb1.tsbvi.edu

**Parents as Case Managers Seminar
February 26 - 27, 2000
Galveston, Texas**

This seminar is full of information for individuals with disabilities, their families, educators, caregivers and professionals. Some information is also applicable to the needs of the elderly infirmed.

For registration information, contact Norma Archer at (281) 807-4663 or (281) 315-8811. The seminar includes a 400-page resource manual provided by a grant from the Texas Planning Council on Developmental Disabilities.

Topics include: special needs trust, qualifying for Social Security Disability Income and SSI, guardianship, Social Security Work Incentives, and more.

The **TSBVI Website** at <www.tsbvi.edu> is constantly being updated. Check it out today for new information about teaching children with visual and multiple impairments.

REGIONAL WORKSHOPS

**Region 1 Education Service Center
12/10/99 - Braille Strategies & Techniques**

Location: McAllen - Doubletree Hotel

Registration Deadline: 11/29/99

Presenter: Debra Sewell, TSBVI Outreach

Audience: VI Teachers

ESC Contact: Peter Graves at (956) 383-5611

Braille strategies and techniques will be explored and the new braille curriculum from Texas School for the Blind and Visually Impaired will be introduced.

1/28/00 - Advanced MegaDots

Location: Region 1 ESC - AT Lab

Registration Deadline: 1/14/00

Presenters: Linda Chromaster & Peter Graves

Audience: VI Teachers

ESC Contact: Linda Chromaster at (956) 383-5611

Participants must be experienced with MegaDots software. Training will cover import/export of documents, style sheets, find & replace, spell check, textbook formatting, rules files, tabs & tables, use of clipboard, and foreign languages.

2/15/00 - Advanced Abacus

Location: Region 1 ESC

Registration Deadline: 2/01/00

Presenter: Debra Sewell, TSBVI Outreach

Audience: VI Teachers

ESC Contact: Peter Graves at (956) 383-5611

Advanced strategies and techniques will be introduced for the instruction of abacus skills to VI students.

2/22 - 24/00 - Integrating the TEKS

Location: Region 1 ESC - Starr Room

Presenters: Region 1 ESC Staff

Audience: Elementary Teachers

ESC Contact: Harold Mosher at (956) 383-5611

Two-day workshop, with a third day follow up inservice to assist teachers in developing interdisciplinary, thematic lessons to meet TEKS Student Expectations.

2/29 - 3/2/00 - Integrating the TEKS

Location: Weslaco - Victoria Palms Convention Center

Presenters: Region 1 ESC Staff

Audience: Elementary Teachers

ESC Contact: Harold Mosher at (956) 383-5611

Two-day workshop, with a third day follow up inservice to assist teachers in developing interdisciplinary, thematic lessons to meet TEKS Student Expectations.

Region 2 Education Service Center**1/17/00 - LIFE - The Syracuse Curriculum for Students with Moderate/Severe Disabilities**

Location: Region 2 ESC

Presenters: Debbie Bravenec and Susan Matthews

Audience: Teachers of students with moderate or severe disabilities

ESC Contact: Debbie Bravenec at (361) 561-8525

Participants will learn strategies for evaluating & revising IEPs; practice writing functional, measurable IEP goals; become familiar with the basics of effective room arrangement; learn strategies for planning and implementing activity-based lessons; review skill sequences for teaching functional academics; and explore possible assistive technology solutions.

Region 3 Education Service Center**11/12/99 - Toilet Training for Students with Autism and other Disabilities**

Location: Region 3 ESC

Presenter: Maria Bird Wheeler

Audience: Educators and Parents

ESC Contact: Mary Scott at (361) 573-0731

Maria brings us an excellent guide through the special difficulties encountered when toilet training an individual with autism. Her book brings over 200 toilet training tips, 50 case examples from which you can learn, and 40 "cautions".

Registration Fee: \$20 (covers the price of the book)

11/19/99 - Itinerant Vision Teacher Meeting

Location: Region 3 ESC

Presenter: Brian Jones

Audience: Vision Teachers

ESC 3 Contact: Brian Jones at (361) 573-0731

In this meeting vision teachers will have an opportunity to share ideas about working with students who have visual impairments. The discussion will include issues related to ECI and deafblindness.

11/17/99 - The Nuts & Bolts of Transition Planning

Location: Region 3 ESC

Presenter: Nancy Hunter, Transition Spec., ESC 20

Audience: VACs, Transition Specialists and Secondary Diagnosticians for students grades 7 - 12

ESC Contact: Sandi Baecker at (361) 573-0731

A discussion of important issues in transition planning for VAC's and Transition Specialists. Topics will focus on the development of the ITP, federal legal issues involving transition, transition indicators on the DEC, courses credits, and TEKS.

Region 4 Education Service Center**12/2 - 3/99 - "Where Do I Begin?": A Problem-Solving Approach to Address the Needs of Children with Autism Spectrum Disorder (ASD)**

Location: Region 4 ESC

Presenter: Denise Sawan Caruso, CCC-SLP

Audience: SLPs, Educational Diagnosticians, School Psychologists and Teachers of all levels

ESC Contact: Elaine Bergman at (713) 744-6597

Are you constantly seeking problem-solving strategies for children with autism spectrum disorders? This two-day workshop will discuss the ASD/PDD spectrum and the variability of needs for this population of children.

Registration Fee: \$50, Non-Region 4 Fee: \$75

12/7/99 - Administrative Issues: Supports & Services for Students with Complex Health Care Needs

Location: Region 4 ESC

Presenter: Janet Little Horton

Audience: Campus and District Administrators, Supervisors and Coordinators, K - 12 Educators and School Nurses

ESC Contact: Susan Parker at (713) 744-6398

Registration Fee: \$20, Non-Region 4 Fee: \$30

12/8 - 9/99 - Consider The Possibilities: Every Move Counts

Location: Region 4 ESC

Presenter: Jane Korsten, CCC-SLP,

Independent Consultant, Overland Park, KS

Audience: Staff working with students using assistive technology, SLPs, Educational Diagnosticians and related service staff

ESC Contact: Angela Standridge at (713) 744-6831

Registration Fee: \$50, Non-Region 4 Fee: \$75

Region 7 Education Service Center

12/10/99 - Adaptive Technology Made Simple

Location: Region 7 ESC - Building 1, Preview Center

Presenter: Don Patterson, Lufkin ISD

Audience: VI & Classroom Teachers, Paraprofessionals and Parents

ESC Contact: Susan Bassham at (903) 984-3071

This workshop will include a discussion on Adaptive Technology for VI students and how it can be made simple. Participants will install software and receive hands-on instruction on basic keystrokes needed for accessing the adaptive technology.

Region 20 Education Service Center

1/20 - 21/00 - Assessment & Treatment of Feeding Disorders Workshop

Location: Region 20 ESC - Conference Center

Presenter: Sandy Mader, M.A., CCC-SLP

Audience: Speech Pathologists, Teachers, Teacher Assistants, Parents and related services personnel

ESC Contact: Britt Green at (210) 370-5431

Neuro-developmental treatment focuses on inhibiting abnormal movement patterns while facilitating normal movements. This program focuses on diagnosis and treatment of oral motor problems and swallowing disorders associated with cerebral palsy. Participants learn to facilitate more normal spoon feeding, cup drinking, biting and chewing, and selection of appropriate foods, utensils and positioning. Children will be present to demonstrate appropriate techniques.

Registration Fee: \$25

1/25/00 - Assessment for Transition Planning

Location: Region 20 ESC - Conference Center

Presenter: James Patton, Ph.D., UT Adjunct Professor, Director of Development at Pro-Ed Corporation

Audience: Educational Diagnosticians and licensed specialists in school psychology

ESC Contact: Dee Dee Lewis at (210) 370-5478

This workshop will present a thorough review of the theory and practice of transition planning for individual students. By using the Transition Planning Inventory (TPI) it is possible to identify areas of transition strengths and needs in a manner which is comprehensive and guides further assessment, planning, and/or linkage to services. The process uses formal and informal methods and includes as part of the assessment team the student, the family, and school/community professionals. Knowledge, skills, and behaviors are

evaluated in each of the eight planning areas including: employment, further education/training, daily living, leisure activities, community participation, health, self-determination, communication, and interpersonal relationships. Each participant will receive a copy of *Transition Planning Inventory: Assessing Transition Needs*, authored by the presenter.

Registration Fee: \$25

1/31 - 2/1/00 - Seating & Access II - Those Students Who Grow Up!

Location: Region 20 ESC - Conference Center

Presenter: Karen Kangas, OTR

Audience: Teachers, Occupational and Physical Therapists and Speech Pathologists

ESC Contact: Britt Green at (210) 370-5431

With students who are non-speaking, have physical disabilities, require alternative access for augmentative communication, power mobility, and other assistive technology there are finally systems at work. With appropriate systems students grow and change. Should the system of seating, access, and technology be replicated or changed? How can we make this complicated transition work? This workshop will explore supporting the continued growth and changes of these students and facing the complicated issues involved. Students will be used as part of the assessment process. Please call Britt Green if you have a student who would benefit.

Workshop Fee: \$25

Job Announcement

**Spring Branch Independent School District
is looking for a Vision Teacher**

SBISD is looking for a Vision Specialist who has at least a Bachelor's degree in a related field, previous teaching experience, a valid Texas teaching certificate, the ability to work effectively with both adults and children, and the physical capacity to assist students with physical disabilities.

Inquiries should be made to:

Personnel Department

Spring Branch ISD

955 Campbell Road

Houston, Texas 77024

Phone: (713) 464-1511; Fax: (713) 365-4879

SEE/HEAR

published quarterly: February, May, August, and November

Contributions to the newsletter are always welcome.
Articles can be mailed or e-mailed to section editors at:

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

FAMILY - Jean Robinson (512) 206-9418; robinson_j@tsb1.tsbvi.edu
PROGRAMMING - Ann Rash (512) 206-9269; rash_a@tsb1.tsbvi.edu
and Gigi Newton (512) 206-9272; newton_g@tsb1.tsbvi.edu
SYNDROMES/CONDITIONS - Kate Moss (512) 206-92224; moss_k@tsb1.tsbvi.edu
NEWS & VIEWS - Jim Durkel (512) 206-9270; durkel_j@tsb1.tsbvi.edu

Deadlines for articles are:
December 1st for the Winter edition
March 1st for the Spring edition
June 1st for the Summer edition
September 1st for the Fall edition

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

SEE/HEAR is available in Spanish and English on TSBVI's website at <www.tsbvi.edu>.

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