# 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 Department of Assistive and Rehabilitative Services, Division for Blind Services

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#### My First Job

By Mary Sefzik, Student, Garland, Texas

Abstract: A young lady who is blind shares her experiences with her first job in the mountains of Glorieta, New Mexico.

Key Words: Family, blind, deafblind, summer work, independent living skills

Editor's Note: Mary is a twenty-one-year-old college student from Garland, Texas. She has been totally blind since birth due to retinopathy of prematurity. She attended public school from kindergarten through 12th grade and completed two years at Eastfield Community College in Mesquite. Mary was honored to receive a scholarship from TAER this past spring and was Student of the Year in 2002. This fall she will be attending Texas A&M University in Commerce where she hopes to major in speech communication with a minor in music.

I arrived in Glorieta with many unanswered questions... would I be able to do the tasks that were expected of me? Would the other workers accept me and treat me as an equal? How would I get from place to place on the big confusing campus?

I spent six weeks of my summer working on the college summer staff at Lifeway Conference Center in Glorieta, New Mexico. My specific assignment was singing and reading stories to children in preschool (birth to age 5) and day camp (grades 1-6). I also went on hikes and helped out where I could. I decided to include a question and answer time about Braille and blindness for the school-age children. This was my first daily job and it taught me so many things! It is amazing and wonderful how all the pieces of the puzzle came into place to make for a wonderful summer experience! I had many new experiences on and off the job and each one taught me a little something more about myself and my capabilities.

My first experience living in an apartment with a roommate taught me that I could manage things on my own. I couldn't have asked for a better first roommate! She accepted my blindness right away, and we shared many good laughs and late night talks.

Thanks to my roommate, I also had my first experience behind the wheel of a car! We were driving home from church one Sunday, and I made the off-handed remark that if I could see, one thing I would love to do was drive a car. Several minutes later she surprised me by saying, "Get out of the car. We're in the dining hall parking lot, and you're going to drive!" She explained to me how the pedals worked, and I took my shoes off so that I could get a better feel for things. My roommate helped me steer, of course, but I got to get a good feel for how everything works. Even though blind people aren't able to drive, I think they should still have an opportunity to sit in the driver's seat and experience it firsthand.

My first whitewater rafting trip showed me the fun and rewards of trying something new and a little challenging. My experience on the 40-foot-high ropes course taught me to trust my coworkers and served as a great icebreaker! It showed my coworkers that even though I couldn't see, I was still willing to try new things.

I was nervous about working with the children at first, but quickly learned that they loved what I had to share and genuinely wanted to learn from me. I especially appreciated the hugs at the end of the week and one day camp group's insistence upon giving me a bowl of homemade vanilla ice cream ... even though it was half melted! After a long work week, my first paycheck allowed me to reap the rewards of a job well done!

I'm not the only one who learned from this experience, though. My fellow day camp and pre-school workers probably learned more than they ever wanted to know about a blind person, thanks to the many questions that the kids asked! Sometimes after answering a question, I'd hear a response from one of the workers like "Wow! I'd never thought of that before!" I think I had an impact on the kids, too. Some of them asked very well thought-out questions and others brought their parents over to meet me. My boss, who was very apprehensive at first, told me that she had received nothing but good reports about me.

On the days when I was weary after answering the same question for the hundredth time or when I felt that there was nothing that I could do to help, I thought of the many good things that I had been blessed with... wonderful coworkers who accepted me for who I was, and a beautiful cool place to work away from the Texas heat! I was reminded that even though I couldn't see it at the time, I was truly making a difference and that is the best thing that any of us could hope to do!

#### **How I Spent My Summer Vacation**

By Jeanette McClennan, Parent, Baytown, Texas

Abstract: A parent describes her experience at the DeMorsier Syndrome/Optic Nerve Hypoplasia/Septo Optic Dysplasia Conference.

Keywords: Family, blind, deafblind, national conference, DeMorsier syndrome, Optic Nerve Hypoplasia/ONH, Septo Optic Dysplasia/SOD

My name is Jeanette, and we have a son who will be nine years old in October 2004. James has DeMorsier Syndrome/ONH/SOD. DeMorsier is the name of the physician who first diagnosed children with ONH (Optic Nerve Hypoplasia) and SOD (Septo-optic Dysplasia). ONH/SOD have similar traits (and I am not here to argue the difference), but they include underdeveloped optic nerves, midline abnormalities and underdeveloped pituitary glands.

I recently went to a Family Focus conference in Kansas City, Missouri. Yes, it's a little further from home than I usually travel, but it was well worth the trip. This is a national conference focused on providing information about ONH/SOD and other related conditions. I wanted to let everyone know what a wonderful conference this was.

Dr. Mark Borchert who spoke on ONH was very informative, and I felt that I got a lot of information from him. He went into some detail on what studies have shown to cause this disorder. He also spoke of the different medical traits that can occur with children having ONH/SOD. Dr. Jill Jacobson spoke on SOD. She was a good speaker with quite a bit of information, but I must say, I didn't agree with everything that she had to say.

Friday evening we took a charter bus to a local church where we had a barbecue dinner and were privileged to hear Kodi Lee sing. Kodi Lee is an amazing young man who not only has ONH but is autistic as well. He does not communicate well verbally, but he can sing and play piano. It was quite amazing to see and hear him. Kodi listens to the song or music and in a very short time can play and sing the song back. He really got the crowd rocking with "Great Balls of Fire" and other songs.

On Saturday morning a behavior analyst, Dr. Campbell Thompson, discussed behavioral traits and medical problems some of these children can have. He was a very entertaining speaker. Last, but certainly not least, was Craig Reeves, an attorney in both Kansas and Missouri, who spoke about special needs trusts. Mr. Reeves discussed different options for providing for our children that would not cause them to lose the benefits they may be receiving now or in the future. I learned so much from all of the speakers. Each provided me with information that previously I had not considered relevant to my child.

The Family Focus families are a wonderful bunch of people who were so friendly. They had a silent auction to raise money to help defer the cost of the conference to keep the cost down for the families wishing to get a better understanding of ONH/SOD. We had a good time outbidding each other. The only thing that I wish could have been different was to have brought my child with me. Family Focus provided childcare, keeping the children well entertained. My son stayed with his grandparents and had a wonderful time being "spoilt" but he would have had such a good time with the other children and swimming in the indoor pool.

Next year's conference has not been finalized but it is to be held in New Mexico. Further information on ONH/SOD is available by going to <www.focusfamilies.org>.

#### Riding by Feel

By Dana Joseph

Reprinted with permission from Cowboys & Indians magazine, June 2004. <cowboysindians.com>

Abstract: For a young rider in Weatherford, Texas, a horse is more than a way to get around life's barrels.

Key Words: Family, blind, deafbind, horseback riding, recreation and leisure

Lots of folks come to trainer Jyme Beth Cochrane's Lightning C Arena in McAlester, Oklahoma, with special horse needs. One client from Weatherford, Texas, is especially particular. Her horse has to be gentle and calm and willing to let her halter and groom him and load him in a trailer. Her horse has to be knowing and willing to take care of her no matter what. He has to automatically sense her every nuance. And he has to run barrels like nobody's business.

This rider isn't overly picky. This buckle-winning barrel racer is blind.

Not that you'd know it when you meet 14-year-old Brittney Holland, who rode first as a baby in the saddle in front of her mom and started riding alone at age 4. If her story sounds vaguely familiar, you might have seen her featured on an episode of *Miracle Pets* three years ago. Though Brittney was born with no macula - she is totally blind in her right eye and can make out only movement and blurred images in her 20/400 left eye - she zips around house, school, barn, and barrels like a sighted kid. She lives and rides almost exclusively by feel - and heart.

Blindness hasn't stopped her from becoming a real contender in barrel racing either. In fact, it just might have propelled her. "I like competing against others," she says. "I just want to try to get as good as I can. A fast time or slow time doesn't matter. Just riding horses is fun." Still, she has set her sights on riding in the National Finals Rodeo and meeting her idol and role model, Charmane James.

If Britt's accomplishments in school are any indication, she'll get it done. Until a high-tech device called

a Flipper Port recently came on the sight-impaired scene - allowing her to read two fuzzy letters at a time by aiming and rolling a powerful magnifier - Britt used to read in two-letter increments holding a little telescope. Determination and perseverance have made her a straight-A student.

She goes at barrel racing with the same can-do-it-darn-it attitude. She's been bucked off several times, and almost been stepped on. But she takes it in stride and gets back on the horse. "I believe God made me the way I am, and He has a plan for me," she says. "If I weren't like this, I wouldn't be able to do the things He has planned for me."

It's a faith the whole family has relied on. "When the doctor looked in her eyes and said they hadn't developed, it was one of the darkest days of our lives," her mother says. "It took a year - and the confirming diagnosis of five doctors - to accept it." But they had a deep faith that "with God's guidance, Brittney was still going to do great things."

One of those great things turned out to be barrel racing, a talent she in part comes by naturally. Britney's mother, Susie Holland, barrel raced competitively. She intimately knows both the exhilaration of barrel racing - the skill, precision, and courage it takes - and the challenges her daughter faces in life and the saddle. "The first time I had to tell Brittney she wouldn't be able to see was when we were on a horse together riding next to her sister, Hayley. I said, 'Look at Hayley, Brittney; and of course she couldn't. She said, 'Mom, will I ever be able to see Hayley?"

Though she couldn't see Hayley, she could compete like her. "Britt knew that her sister was competing, and she wanted to do it, too." So Susie got Brittney her first horse, Doc, a sedate old soul who knew his way around the barrels. Though he was the perfect starter horse for Brittney, she outgrew him, and Susie started going to her old friend Jyme Beth for horses. With Jyme Beth's help, Britt moved on to Mr. Ed, who would lope, trot, and mind her. On Mr. Ed, Susie says, Brittney became a real contender.

But however gentle and intuitive her horses were, Brittney still had to develop very special methods for barrel racing blind. "When I was little," Brittney says, "we had walkie-talkies with an earpiece. My mom would talk me through the race and tell me where to turn." As her confidence and skills grew, Brittney started riding Red. Her latest - and fastest - horse is Two Dollar Colonel (Dollar for short), a 6-year-old registered quarter horse, who stands 15.3 hands and runs like the wind. As she has gotten older and the horses have gotten faster, Brittney has come to rely more and more on a system: Trust the horse.

"When I'm riding, I can't see where the barrels are," Brittney says. "I trust that my horse knows which barrel to go to." Like an athlete who walks the course before the race, she tries to "sight" the barrel placement before the rodeo starts. "I usually stand in the middle of the alleyway next to my horse and look through my telescope. I find the barrels and a color on them and look to a wall so I can sort of place the barrel relative to the wall. When I'm racing and I see that color, I know where I am." And she knows when Dollar goes to turn, she has to help him around the barrel, pulling him around it. Hearing her mom or Jyme Beth *yell* from the stands helps, too.

Though the horse-rider connection was immediate with Dollar, it will take time for the team to develop the speed and skill they'll need to make it to the NFR. Jyme Beth should know: She picked the horse for Brittney with that in mind, and she herself has been in the top 15 of the NFR. "Dollar was young and not seasoned, but I had a feeling about him for Brittney," Jyme Beth says. Even though he was young, Dollar was calm and easy down the alley, not jumpy at all or ready to run. "I said, 'Just take him and ride him and see." Which Brittney

did - and she knew she'd found her horse. They've been getting faster together ever since. "Dollar has really picked up on Britt," Jyme Beth says. "You know how some animals just know? It seems like he just knows."

And if the horse knows, and the trainer knows, mother Susie has the fix on Brittney, too. "When she's riding, she has control of a 1,500-pound animal," Susie says. "That helps her spirit. We believe she sees with her heart."

For Brittney, though, it's all in a day's work as a teenager. In her "Texas Couture" T-shirt and leather-embellished studded jeans, she is in many ways like any other eighth-grade girl. She likes math and Garth Brooks and wants to be a veterinary assistant or a politician. She's constantly on the phone with friends. She dances with a competitive clogging troupe. She plays snare and bass drum in the school band. Her Uncle Roger is teaching her to rope. When she goes to high school, she'll join the rodeo team. She grooms and rides Dollar every day to keep him legged up. She does chores, feeding her horse every morning and night and cleaning out his stall. And she treasures a very special gift her Aunt Becky brought back from the NFR: an autographed poster of Charmane James that hangs above her bed.

Today Britt's going to help Jason the horseshoer while he fits Dollar with new rims and slicks. Later, she's babysitting for special-needs kids during the Bible study at church. And somewhere in there, she'll find the key to the shed where one of her cats got locked in accidentally. It's a busy life, but she's still got time to be thoughtful about what a relationship with a horse can mean.

"A horse is my best friend," Brittney says. "It's like a person I see and take care of every day. I get freedom and a friend in return." She loves it that horses try to be funny. "Like Dollar," she says, "when I give him a drink of water out of his bucket after a ride, he throws it on me - hay, too. He comes to his name. Horses like to be loved, and they try to give love back to you."

And horses give her something that the rest of her life can't. "It's the one thing I don't have to ask for help on," Britt says. "When I'm riding I feel free."

On that note, she's off to the barn, jumping a puddle of water that she feels more than sees.

#### Cornelia de Lange Gene Identified

By Mel Dugosh, Parent, Hondo, Texas

Abstract: A parent describes a medical breakthrough announced at the  $22^{nd}$  National Conference of the Cornelia de Lange Syndrome Foundation held in Chicago this summer.

Keywords: Family, blind, deafblind, national conference, Cornelia de Lange Syndrome Foundation, medical breakthrough

Attendees at the 22<sup>nd</sup> National Conference of the Cornelia de Lange Syndrome Foundation held in Chicago in late June 2004 were astonished when Dr. Ian Krantz of the Children's Hospital of Philadelphia announced the identification of the gene on chromosome 5 that is the cause of Cornelia de Lange Syndrome(CdLS). His official findings in close collaboration with colleague Dr. Laird Jackson are that the "Cornelia de Lange Syndrome is caused by mutations in NIPBL, the human homolog of the Drosphila Nipped-B gene."

In the past the diagnosis of CdLS derived from assessing the number of tangible manifestations which

might include, but were not limited to deaf/blindness, mental retardation, facial features, limb differences, small stature, and gastroentrological distress.

Christopher Dugosh, my son and a student at TSBVI, and our family provided one set of the original 150 blood samples available to Dr.Krantz for testing. It took more than a decade to obtain enough viable samples and raise the funds for the tidious research to begin the testing. At present NIPBL mutations have been found in about half of all the sampled children with CdLS. This research also discovered that the change of the NIPBL arose as the result of a new mutation in the single egg or sperm that went on to form those children. This knowledge is important to the vast majority of families with a child with CdLS because they will not have an increased risk for having future affected children.

The newly identified NIPBL marker has resulted in a genetic test that is now available to confirm the diagnosis of CdLS. Unfortunately is believed that over 10,000 individuals in the United States have CdLS but have been living without a diagnosis. Subsequently the CdLS Foundation located in Avon, Connecticut has launched an all out "Find One Child" campaign to assist in the finding these undiagnosed individuals who may be without benefits of appropriate services.

This huge discovery for CdLS combined with many more years of diligent research might someday lead to implications for treatments of individuals currently living with CdLS. The current crucial need for the advancement of stem cell research could eventually provide the means potentially for the gene to be altered close to conception, prior to birth.

More information about CdLS can be accessed at <www.CdLSusa.org>. More specifics on the critical "Find One Child" campaign can be obtained by emailing <awareness@cdlsusa.org> or calling (800)753-2357.

#### **Legally Blind Musher Withdraws from 2004 Race**

By Jon Little Reprinted with permission from Cabella's website <www.cabelasiditarod>

Abstract: A story about a legally blind woman's attempts to qualify for the Iditarod.

Keywords: Family, blind, deafbind, achromatopsia, Iditarod, blind athletes, accommodations

The Iditarod's record wave of rookies converged on Anchorage Dec. 6 and 7 from Alaska, Canada, the Lower 48 and Europe for a mandatory two-day race orientation, but there was a significant no show.

Rachael Scdoris, a legally blind musher from Bend, Oregon, did not attend the meeting, a move that makes her ineligible to run the 2004 race. The withdrawal is the second from a record field of 109 mushers, 51 of which are rookies. Melanie Shirilla, wife of four-time champion Doug Swingley, would have been a rookie this year but withdrew her entry before the rookie meeting. About 10 to 20 percent of the entrants are historically winnowed out by the March 6 race start.

Rachael Scdoris' father, Jerry, said his daughter's decision to stay home was based chiefly on money, but said it also gives her another year of training and running qualifying races.

Scdoris, 19, originally hoped to have a visual assistant ride along on a snowmobile and alert her via

handheld radio when she was about to run into something tricky like an overhanging branch, steep turn or open water. The Iditarod Trail Committee initially rejected that plan, but later offered a compromise: The visual interpreter could be another qualified Iditarod musher traveling by dog team. The pair can use radios.

The need to pay for a second dog team was a budget breaker, at least for 2004, Jerry Scdoris said. "It doubled her budget, and we just don't have the money, but we will next year. And also, she's just going to spend the winter getting qualified. She's got 1,000 miles on her dogs right now and they're looking great. But the proof's in the pudding." She aims to run The Atta Boy 300, a premier stage race managed by Jerry Scdoris, the Seeley Lake 200 in Montana and Montana's Race to the Sky, a 350 miler.

The Scdoris family had planned on Iditarod 2004 costing between \$40,000 and \$50,000. That was without having to pay for a second team. They assume costs will double with the other dog team.

Scdoris acknowledged that the dollar figures are fairly high. Many mushers can field a team for a fraction of that, especially mushers living within Alaska. But travel and shipping costs spike up for those outside the state, and there are some unique expenses created by Rachael Scdoris' disability, her father said.

For instance, he said, five-time Iditarod finisher Dan MacEachen would be the likely visual interpreter. He's done it before in other races, by snowmobile. But MacEachen runs a profitable sled dog tour business in Aspen, Colo., and Scdoris said he would pay MacEachen's expenses for the time he was away.

Scdoris has congenital achromatopsia, which leaves her with 20/200 vision. She is both near- and far-sighted and color blind. Her vision has been described as like looking through a pair of glasses smeared with grease. Questions have been raised about her ability to care not just for herself on the grueling and challenging Iditarod trail, but also for her dogs during the two-week endurance event.

The Scdorises wanted to get an assistance compromise worked out with the Iditarod beforehand, Jerry Scdoris said, because it was important to know what would be an acceptable qualifier and what wouldn't. The 1,100-mile Iditarod requires mushers to have completed 500 miles of racing within two years of the race start.

Even though Rachael Scdoris is officially withdrawn from the 2004 race, she is just as optimistic as she was before, her father said. "She's got to qualify just like every other person running the race. If she doesn't qualify, it's real simple. She won't run."

Editor's note: Rachael has qualified for the race in March 2005!

#### **NOAH Conference 2004: A Life Changing Event**

By Erika Martinez, Parent, Lozano, Texas

Abstract: A parent describes her family's experience attending the National Organization for Albinism and Hypopigmentation conference.

Keywords: Family, blind, Albinism, Hypopigmentation, NOAH

My husband Jorge, our two daughters Scarlett and Hailey, and I returned home this summer from the most amazing trip of our lives. We drove to Atlanta, Georgia, to attend the 10<sup>th</sup> annual NOAH conference. The

conference is sponsored by the National Organization for Albinism and Hypopigmentation (NOAH) for people with albinism and their families.



Erika, Hailey, Jorge, and Scarlett Martinez

Our youngest daughter, Hailey, who is 2 ½ years old, has oculocutaneous albinism. This means she lacks pigment in her hair, skin, and eyes. This was the first time we have attended a NOAH conference, which are held every two years. It was a 3 ½ day event, with each day's schedule comprised of different sessions with different speakers, events for children, teenagers, and parents, and optional tours and trips of the city of Atlanta. There were different sessions that pertained to the interests of every age group and sessions for parents of children with albinism, or adults or teens with albinism.

The sessions that we attended were very diverse, so educational, and informative. Topics ranged from the latest genetic research concerning albinism presented by geneticists from all over the country; to vision and education with Dr. Ann Corn from Vanderbilt University (a leading expert on low vision and education); to the latest research and information on ophthalmology from expert ophthalmologists in the field of low vision; to support groups for parents of children with albinism. These were just a few of the sessions that were offered. There were many others that appealed to different ages and people.

One of the things that was so amazing about the



The Martinez family discover a life changing event in the 10th Annual NOAH Conference.

conference was how friendly, kind, and polite everyone we met was. We have never been anywhere where we have experienced so much warmth and friendship coming from such a large and diverse group of people. There were over 600 attendees from all over the U.S.A., Canada, and other countries. It is so amazing that everyone is so kind, and all because of the very special bond we share of albinism.

Thanks to partial funding from TSBVI Outreach, our family was able to attend this life-changing event! We appreciate your generosity so very much. Your support made our dream of attending the NOAH conference a reality. We are so thankful for the kindness and support you gave us. This conference was truly magical! We are very grateful that our daughter, Hailey, has these conferences to look forward to throughout her life. The support and love you feel from the albinism community is like no other!

#### **HAPVI** is Back in Houston!

By Laura Bostick Adair, HAPVI President, Houston

Abstract: Read about the parent support group that is active in the Houston area.

Keywords: Family, blind, deafblind, support group, Houston

The Houston Association for Parents of Children with Visual Impairments (HAPVI) is a network of parents of children with visual impairments, with or without other disabilities, in the greater Houston area. Our goal is to provide support, resources, educational opportunities, and fellowship to families dealing with blindness issues. HAPVI is an affiliate of the National Association for Parents of Children with Visual Impairments (NAPVI) <a href="https://www.spedex.com/napvi">www.spedex.com/napvi</a> and of TAPVI – the Texas statewide NAPVI affiliate <a href="https://www.tapvi.org">www.tapvi.org</a>.

HAPVI started out as the Texas Commission for the Blind (TCB) Parent Network in 1995, and later became an active chapter of NAPVI. HAPVI offered monthly educational and social opportunities for members. After several years, some board members moved away, and the group stopped meeting. Then in 2004, a few new families interested in starting a parent support group contacted Alison Rickerl, former HAPVI cofounder and now NAPVI Region 5 Representative, and HAPVI was reborn!

Our first HAPVI event was a social gathering on April 24, 2004. "Picnic in the Park" was held in the Challenger Seven Memorial Park, and it was a great success. There were eleven adults (including two grand-parents and a TCB/DARS caseworker!), six blind or visually impaired children, and one sibling in attendance.

Our first HAPVI general educational meeting was on August 26, 2004, at the Clear Lake United Methodist Church. Colleen Davis, a La Porte ISD teacher of students with visual impairments (TVI), spoke on the topic "How Will My Child Learn to Read?" She talked about the roles of classroom teachers and TVIs in teaching children to read, the reading process, and special considerations in learning to read Braille. Jean Robinson traveled all the way from the Austin area to tell us about TSBVI (Texas School for the Blind and Visually Impaired) services. In addition to Colleen and Jean, ten parents, two Lighthouse of Houston employees, two children with visual impairments, and four siblings attended. Childcare and refreshments were provided. Colleen and Jean answered questions and handed out materials, and Colleen was very generous in giving away a lot of the Braille books she brought with her in a drawing!

Our next HAPVI event is on September 29, 2004, from 5:30 p.m. to 7:30 p.m. at the Region IV Education

Center. The topic is "How Assistive Technology Can Impact Braille Literacy." Mr. Jim Sullivan of Optelec (USA) will be on hand to discuss the importance of Braille Literacy and to give those in attendance a first hand look at the Mountbatten Braille Writer and the Jot a Dot. This will be a very informal open house atmosphere where parents and children can get hands on experience with the equipment.

If you live in the Houston area, and you are interested in joining HAPVI, please contact one of the board members:

Laura Bostick Adair, President, (281) 648-6459, <ladair@houston.rr.com>
Alison Rickerl, Vice President, (281) 286-9820, <arickerl@hotmail.com>
Rick Taylor, Secretary, (281) 218-9196, <Rick.Taylor@Honeywell.com>

If you would like to join a Texas parent support group, but you do not live in the Houston area, please contact the Texas Association for Parents of Children with Visual Impairments (TAPVI):

TAPVI www.tapvi.org 12801 Midway RD Suite 212 PMB 231 Dallas, TX 75244 Toll free: 866-99-TAPVI (82784)

No one understands the needs and concerns of a parent of a child with a visual impairment like another parent does. I urge you to join a parent support group. There are plenty of parents willing to help you, and many others who may need your help. Together we are stronger.

# Supporting High Quality Interactions with Students Who are Deafblind Part One: A Summary of Current Research

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

Abstract: Educators can have more positive, responsive and reciprocal interactions with their students who are deafblind by learning how to modify their own interactive behaviors and adapt the interactive context. High quality interactions contribute to improved educational outcomes for students with deafblindness.

Key Words: programming, blind, deafblind, Jan van Dijk, research-based, interaction, behavior, communication, educator-oriented intervention, instructional strategies, video analysis

"Interaction is defined here as the process by which two individuals mutually influence each other's behavior." (Janssen, Riksen-Walraven & van Dijk, 2003b, p.198).

During a visit to Texas School for the Blind and Visually Impaired (TSBVI), Dr. Jan van Dijk suggested that a team from the school review recent research about interactions with students who are deafblind, then develop a process for sharing the information with other educators and helping them put its principles into practice. Part One of this two-part article summarizes research-based conclusions about interactions with students who are deafblind. Part Two, which will appear in the Winter 2005 edition of *SEE/HEAR*, describes the educator-oriented interaction training that was developed at TSBVI and incorporates these findings.

#### INTERACTION PROBLEMS AND POSSIBILITIES

Many in the field of deafblindness intuitively value and try to maintain high quality interactions with students who are deafblind. As research continues to validate the role of interaction in attachment, security, relationships, learning and communication, the need for educators of students with deafblindness to develop their interaction skills becomes more apparent. Appreciating the importance of positive interactions is a step in the process. Improving the quality of one's own interactions with students who are deafblind is a bigger challenge.

#### **Typical development**

"It is a universal trait of our species that mothers have the innate skill of mothering. They are able (and it seems that this is similar in all cultures) to provide the newborn child with warmth and security. Mothers feel that the newborn child needs a safe harbor for exploration." (van Dijk, 1999, p.1). "Children who are securely attached to their caregivers have a secure base from which to explore the environment....Children see individuals to whom they are securely attached as available and responsive....Secure attachments are built when caregivers are sensitive and responsive to the infant's communications....Positive interactions occur as the caregiver and the infant respond to each other...The infant sends cues, the caregiver responds, and the infant responds in turn. Each partner learns the rules of turn-taking from the feedback of the dydactic partner." (van Dijk and Nelson, 2001, p. 18). "Given that interaction is the 'vehicle of communication,' it is obvious that harmonious (smooth, balanced and finely attuned) interactions are indispensable to develop high-quality communication." (Janssen, et al., 2003b, p. 198).

"Harmonious interactions and their importance have been characterized in various terms. Attachment theorists emphasize the importance of sensitive responsiveness: A sensitive caregiver is keenly aware of a child's signals, interprets them accurately, and reacts promptly and appropriately so that the child feels understood. During such harmonious interactions, the child learns to trust the caregiver's availability as a source of emotional comfort and support." (Janssen, et al., 2003b, p.198). Dr. van Dijk has referred to this quality of sensitive responsiveness as "IT." This is how he once described IT. "I have been looking all over the place to find a CD-rom fragment of Suzanne with her mother interacting. Mother wants her to clap her hands, but S. wants her to touch her lips. Mother adjusts her intention to S.'s request. This is IT." (personal communication, October 18, 2002).

"Harmonious caregiver-child interactions have been found to relate to later socioemotional development in various empirical studies....a secure infant-parent attachment relationship – which clearly relates to sensitive parenting – predicts various developmental outcomes for children up to late adolescence....early harmonious interactions influence the development of brain structures and brain functions that mediate the future regulation of emotions, adaptation to changing circumstances, and ability to cope with stress....Particularly, the sharing of high levels of positive affect during interactions appears to have beneficial effects on early brain development." (Janssen, et al., 2003b, pp. 199-200).

#### The impact of deafblindness

"Children who are deafblind often require considerable time as they establish relationships with others and become comfortable in new environments....The ability of children with severe multiple disabilities to develop secure attachment and turn-taking social interactions may be threatened by multiple factors including:

(a) time spent in intensive care units separated from their parents, (b) severe health problems which may have limited physical contact with caregivers, (c) low levels of arousal and an alert state that is not long enough for attachment to occur, (d) extremely elevated levels of arousal that lead to over-stimulation, (e) communicative

cues that are atypical and difficult to read, and (f) limited ability to read caregiver cues (e.g., if vision is limited, the young child may not be able to imitate the social cues of his caregiver such as a smile and he may not know when he should take his turn in a social interaction)." (van Dijk and Nelson, 2001, pp. 4, 18-19).

#### **Interactive challenges**

"Various studies have indeed shown both deafblind children and their parents to encounter serious difficulties with their interactions. The visual impairments of the children greatly affect quality of the children's interactions with their parents. Eye contact, reading facial expressions, or mutually gazing at the same object are virtually impossible. Lack of responsiveness or over-sensitive reactions such as 'slipping away' in the children may cause feelings of disappointment or frustration in the parents....Auditory stimuli are not wellperceived or processed by deafblind children due to sensory-neural impairment. They may respond very little, not at all, or even negatively to voices and other sounds. Caregivers are therefore dependent on touch and proprioceptive stimulation to keep the interaction going...Rowland (1984) showed the mothers of multiple handicapped visually impaired children to encounter difficulties with the regulation of turn-taking and to inconsistently respond to the vocalizations of the child....Preisler (1996) found deafblind children to elicit contact with their parents by means of body movements, facial expressions, and vocalizations. The children can also take part in joyful interactions, mostly in the form of body games. It is nevertheless difficult to read signals of deafblind children. Their movements and expressions are often very subtle or vague and unfold at a much slower pace when compared to those of sighted and hearing children. Use of idiosyncratic signals and forms of communication by the deafblind can easily lead to misunderstandings." (Janssen, Riksen-Walraven & van Dijk, 2002, pp. 88-89). "The attachment process described by Bowlby (1969), through which the child develops a secure bonding with his primary caregiver allowing him/her to explore and access new opportunities for experience and learning, is endangered in children with multiple disabilities due to the described difficulties in establishing readable signaling systems." (Amaral, 2003, p. 4).

"For educators, the first hampering factor in building harmonious interactions is the lack of natural skills to participate in the deaf-blind world of touch and proximity....In her study of the communicative interactions between children with multiple disabilities and their teachers, Amaral (2002) concluded that teachers do not spontaneously develop the interaction and communication skills that are necessary for responding to the needs of such children....The educators of deaf-blind children are often not fully aware of the importance of developing harmonious interactions before they focus on understanding the children's message or on further developing communication and language." (Janssen, et al., 2003b, pp. 198, 201). "When the educator of deafblind individuals lacks the insight and skills to understand the world of the deafblind child, one can observe how the individual retreats into himself, avoids touching objects, and attempts to cope with his 'unbalanced organism' by exhibiting stereotypic behaviours." (van Dijk, J., 1999, p. 2). "Professional educators, such as teachers, classroom-assistants, and the residential staff face the same interaction problems as the parents and sometimes even more serious problems. The educators typically start interacting with the deafblind children at a later age than the parents, which means that many of the children have already developed a number of idiosyncratic and 'difficult' behaviors that can hamper further interaction." (Janssen et al., 2002, p. 89). "The final factor that is known to hamper harmonious interactions with deaf-blind children holds particularly in institutional settings (schools and residential facilities) and concerns continuous changes. While professional educators regularly rotate from one class, home setting, or group in a residential facility to the next and thus from one deaf-blind child to another, the risk of disharmonious interactions increases with each switch, particularly when the professionals have not been sufficiently introduced in the new work setting and too many staff changes occur at the same time." (Janssen, et al., 2003b, p. 202). "It is obvious that when a child, whose emotional balance is easily disturbed, is provided with many different caregivers, it is hard, if not impossible, for the foundation of security to be laid." (van Dijk, J., 1999, p. 3). "Given that the principles of individuals' communication and interaction are often not well recorded, the risk of disharmonious interactions following such staff switches increases." (Janssen, et al., 2003b, p. 202).

#### **Adult-dominated interactions**

Rick van Dijk and his colleagues noted, "In normal language development, one would expect a parent or a professional teacher to leave the initiative in communication to the child and to respond in a contingent way whenever the parent or teacher feels the child has the possibility to take the initiative. Only in this manner does the child have the opportunity to explore his communicative possibilities...Communication will only lead to language development if the child is enabled to actively take part in communication....we know that parents often have a tendency to control the interaction with a deaf child because they cannot fully understand the utterances of the child. Although understandable, this control is, in itself, detrimental to language development. The more parents try to control the responses of a child, the turn taking interaction, and especially the topic of conversation, the slower language development will proceed. There is solid empirical evidence that a less controlling interaction style by parents not only facilitates the quality of interaction between parents and deaf children, but also the process of language development....there is no reason to think that this is not also the case in children who are deafblind." They suggested that "...if one studies interaction and communication, and most certainly if one studies these processes in relation to the facilitation of language development, one would...want to study aspects such as initiation of interaction, contingent and noncontingent reactions of communication partners, and the functions of interactive turns." (van Dijk, R., Vervloed, Knoors & van Dijk, J, 2002, pp. 5, 16-17).

A study was designed to analyze the interactions between a teacher and his 3-year-old student with congenital deafblindness. The primary research question asked, "...to what extent it would be possible for the teacher to attend to the deafblind child's initiatives and responses and respond appropriately, thereby resulting in contingent interaction patterns...Three target activities that offered many opportunities for close interaction were chosen for study....These events were selected because they recur daily and fit in the schedule of daily routines for this boy. It is widely accepted that such daily routines foster effective interactions and enhance memory processes." Videotaping the observations was considered necessary "...because online [during the interaction], it is extremely difficult to notice all the potential communicative signals exhibited by the deafblind child." (van Dijk, et al., 2002, pp. 6, 7).

"Over a period of 4 months, 16 hours of recording were made during bathing, dressing, and playing....specific events were chosen for video recording in order to capture the most favorable conditions for the elicitation of social interaction and communication....The following criteria were used to include scenes into the study: 1. Both the teacher and the child should be within reach of the camera. 2. The recordings should be of good quality...3. There should be a prolonged period of communicative activity of at least several seconds." Of the original recordings, "...less than 2% of the recording time contained prolonged interactions between teacher and child...most of the failures were due to the teacher being too far away from the child to be able to communicate properly or due to the total absence of prolonged communication periods between the two." (van Dijk, et al., 2002, pp. 8, 11). Video fragments that met the criteria were reviewed, and each of the teacher's and student's interactive behaviors were assigned to one of "six observational categories:

- A. Child acts in order to influence adult's behavior
- B. Child reacts
- C. Child acts, no attempt to influence adult's behavior

- D. Teacher acts, initiates interaction
- E. Teacher reacts
- F. Teacher takes action, no intent to influence child's behavior." (van Dijk, et al., 2002, pp. 23-24).

The authors then counted the frequency of these interactive behaviors and analyzed the transitions between them. They concluded, "The amount of interaction is...representative of normal daily interactions between this teacher and deafblind boy....only a limited portion of the time when the teacher and deafblind child were together was devoted to communication and interaction....There exists a true interaction between teacher and child, although both miss the initiatives of each other frequently....Both teacher and child did not respond significantly to each other's responses....the number of the teacher's initiatives exceeds the number of responses considerably." They also speculated "...that interaction between the partners stops after one response." From this study, the authors determined that "...it is possible to quantify interaction between teachers and deafblind children and this can be accomplished in a way that gives insight into the elements of the interaction and communication process that are important for the development of language." (van Dijk, et al., 2002, pp. 14, 15).

#### **Consequences of disharmonious interactions**

"It is likely that the emotional and behavioral problems of deafblind children are at least partially due to the difficulties they experience, from birth on, in their everyday interactions with caregivers. High quality interactions with primary caregivers who sensitively respond to normal children's signals and needs have been found to foster a sense of security and competence in the children and to positively affect both their social and personality development in later years. In contrast, children with insecure attachment relationships reflecting a history of disharmonious interactions with their primary caregivers have been found to be at risk for development of disorders such as problems in self-regulation, depression, and conduct disorders....Given that the interactive signals of deafblind children are often subtle and difficult to interpret, they are frequently missed or misunderstood by caregivers. As a result, children tend to intensify their signals, express frustration via self-abuse or aggressive behaviors or both, and withdraw into stereotypic behaviors or passivity. Such 'inappropriate' behaviors can then elicit inadequate responses from the caregivers, with the risk of both the caregiver and child getting caught in a downward spiral." (Janssen et al., 2002, pp. 88, 90).

#### **Educator-oriented intervention**

Dr. Marleen Janssen and her co-authors designed an educator-oriented intervention program to improve the quality of interactions between deafblind children and their professional educators. To determine the program's effectiveness, their research questions were, "(1) Does the intervention produce an increase of appropriate [educator] responses and a decrease of inappropriate [educator] responses to the interactive behaviors of the children? (2) Does the intervention result in an increase of appropriate interactive behaviors and a decrease of inappropriate interactive behaviors on the part of the children? (3) Is the intervention effective with different educators and in different situations?" (Janssen et al., 2002, p. 90).

After identifying appropriate and inappropriate child behaviors, and appropriate and inappropriate educator responses, "First, the educators were trained to respond more appropriately to the children's interactive behaviors. Second, the educators were trained to adapt the interactive context to facilitate the occurrence of appropriate interactive child behaviors. Such adaptations were as follows: (1) offering communicative aids [in an] orderly [way], (2) offering choices, (3) removal of distracting stimuli, (4) removal of stimuli not wanted by the child, (5) attuning activities to child's abilities (sensory or motor), and (6) demonstration of appropriate interactive behaviors to the child." (Janssen et al., 2002, p. 94).

The study concluded that "...it is possible to improve the interactive competence of deafblind children by teaching their educators to respond more appropriately to [the children's] interactive behaviors. In three of the four target children, both an increase in appropriate interactive behaviors and a decrease in inappropriate interactive behaviors were observed. The intervention also proved to be effective for different educators across various situations." (Janssen et al., 2002, p. 104).

#### Development of an intervention model

As a continuation of their earlier work, Dr. Janssen and her colleagues developed "...a diagnostic intervention model as a guide for designing and conducting interventions to foster harmonious interactions between deaf-blind children and their educators in various settings...The intervention is educator oriented and thus aimed at achieving the goals of intervention for the children who are deaf-blind by changing the behaviors of their educators." (Janssen, et al., 2003b, pp. 197, 208).

In this model, the behaviors of both the child and educator are assigned to one of eight core categories of interactive behavior. "The definitions of the categories are adapted for the purposes of an intervention and are translated into concrete behaviors per individual case." (Janssen et al., 2003b, p. 207). The eight core categories of behavior "...are as follows:

- 1. Initiatives: starting an interaction or raising something new as part of a reaction
- 2. Confirmation: clear acknowledgement that an initiative has been noticed and recognized
- 3. Answers: positive (approving) or negative (disapproving) reaction to an utterance of the partner
- 4. Turns: turn taking, or becoming the actor, and turn giving, or allowing the other to become the actor
- 5. Attention: focus on the interaction partner, the content of the interaction, and the people and/or objects within the interaction context
- 6. Regulation of intensity of the interaction. For the educator: waiting while the deaf-blind child regulates the intensity of the interaction. For the child: appropriate regulation of intensity by, for example, withdrawing (turning his or her head away) or some other individual signal (such as laying his or her hand on the partner's hand) and apparent processing of information, and inappropriate regulation of intensity by, for example, self-abusive or aggressive behaviors
- 7. Affective involvement: mutual sharing of emotions
- 8. Independent acting. For the educator: acting with no focus on the child. For the child: executing actions independently (e.g., putting a garment or part of a garment on alone)." (Janssen et al., 2003b, p. 207).

"On the basis of video analyses, the educators learn to recognize a deaf-blind child's signals, to attune their own interactive behaviors to those of the child, and to adapt the interactive context to promote the occurrence of certain target behaviors....The intervention is evaluated in terms of the intervention aims and the occurrence of particular behaviors before and after intervention." (Janssen, et al., 2003b, p. 208).

A companion study summarizes the successful implementation of the intervention model described above, with six congenitally deafblind children and adolescents, and their teachers, caregivers and parents, in different settings and interactional situations. (Janssen, Riksen-Walraven & van Dijk, 2003a).

#### TO BE CONTINUED

Part One of this article summarizes recent research about the importance of high quality interactions with students who are deafblind, including information about characteristics of deafblindness that can result in interaction problems, and the description of an educator-oriented approach that helps clarify and address those problems. In the next issue of SEE/HEAR, Part Two will describe the interaction training process developed at TSBVI that incorporates this information. Case studies will be presented of four training participants and their students with deafblindness. There will be a session about TSBVI's interaction training process at the 2005 Texas Symposium on Deafblindness which takes place February 25-26, 2005 in Austin.

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#### Where Is There Joy in This IEP? or, What Did I Bring Away from The Deafblind International Conference?

by David Wiley, Transition Specialist, with help from Kate Moss, Education Specialist Texas Deafblind Outreach

Abstract: This article discusses the importance of building highly motivating instructional elements into daily programming in order to improve the students openness to instruction.

Key Words: programming, blind, deafblind, appetite/aversion, motivation, assessment

Several years ago I received a call from a teacher wanting some help in addressing a behavior problem for one of her students. I receive such calls from time to time in my role at Texas Deafblind Outreach, and always explain that it would be very difficult to offer advice without observing and knowing all the facts in the

situation. She wanted to give it a try over the phone, however. I don't remember all the details, but the conversation included an unusual problem.

She explained that the problem was that most days the student was refusing to even come to school. When at school, there was seldom a problem, but often she would refuse to get on the school bus, or cooperate with her parents in getting her to school. The student would only willingly come to school on days when she was going to do something fun.

"What do you mean?" I asked.

"Well, she understands her schedule well, and only comes to school on days when something fun is planned, like a party, pep rally, or special event. Otherwise, she will tantrum and refuse to leave her house."

I must admit, that I hadn't encountered this specific issue before. Though it is hard to fully understand a situation without being there, one solution seemed obvious. My suggestion: why not plan to do something fun every day?

She reacted as if I was crazy. To paraphrase, the teacher's response was something like, "We can't do something fun every day. This is school. There is work to be done." This ended the conversation. I suppose she considered me thoroughly unhelpful, and I never heard how the situation turned out.

This story was brought back to my mind last summer as I was attending my first Deafblind International (DBI) conference in Toronto. DBI is a worldwide organization of people concerned with deafblindness, and participants from the conference last year came from 48 countries. I had a number of "aha" moments during the event, but my first came during the first plenary panel on the first morning of the conference. One of the panelists talked about the need for joy in communication instruction. She showed video clips of students learning language at her school. The students had differing abilities and communication styles, but they were all engaged in exchanges about subjects they found highly motivating, things they were passionate about, things that brought them joy. The speaker was from India, and I reflected that I seldom hear communication presentations around here in which the key theme is joy.

The next morning Dr. Jude Nicholas of Norway provided some neuropsychological background in a talk about his paper, "Communicating Research to Practice and Practice to Research: From Theoretical Contributions to Therapeutic Interventions." In describing new research and views of how the brain works, he writes, "emotions are the mechanisms that set the brain's highest-level goals. Perhaps, then, in the field of deafblind education, communicative exchanges in interpersonal processes should pay more attention to the emotional aspects of the communication process." (Nicholas, 2003) So maybe we should pay more attention to the child's emotions when planning instructional goals.

What if the child described in the phone call above experienced joy every day in her learning activities? Would she be more willing to go to school? Would she look forward to learning? Unfortunately, I think too often we fail to consider the student's preferences, passions, and joys when developing classroom activities and routines.

So how do we create joy in the classroom. These simple solutions will make the students look forward to coming to class, create positive emotions, and maybe improve their learning.

#### FIND OUT WHAT IS MOTIVATING TO STUDENTS

In order to find out what is motivating to a student it is important to be a good observer. Take some time to simply watch the child during a variety of activities and settings. When does the child smile or laugh? When does the child become fussy or go to sleep? If there are four objects nearby, which, if any, will the child try to get?

It is important to consider the child's self-stimulations as well. Does the child use his hand to flick in front of his face? Does he make interesting noises? Does he find things in his environment that vibrate? Does she constantly bounce or spin? Chances are, whatever the child does as self-stimulation is somehow pleasing or interesting to him or her.

Talking to the child's parents is also an important step to take in finding out what is motivating or just as importantly <u>not</u> motivating. Ask them how they calm their child when the child becomes upset. What are the child's favorite play things? What are the child's favorite activities with mom, dad, and siblings?

Once you begin to collect this information it is a good idea to organize it. A simple form that we have used for a number of years is the Appetite/Aversion Form shown below.

## Appetite/Aversion Form Adapted from personal notes from a seminar by van Dijk, J. 1985

Fill one sheet out for each child. Over a period of time through listening to stories from others and through observation of the child, simply list things the child likes and things he doesn't like. We all enjoy things that we are good at and that we understand. The child's "Likes" will be his areas of strength and using sensory channels that are working. His "Dislikes" will be areas of weakness and sensory channels that may not be working efficiently. The information gathered on this form will give you underlying themes that you can use for modifications, teaching strategies, topics for communication, ideas, and activities.

Child's Name	Date
APPETITE(LIKES)	AVERSION(DISLIKES)

#### **Summary Information:**

What sensory channels is the child using the most?

What are possible topics for communication?

What are some new activities that the child might enjoy?

What other modifications or strategies are suggested by the above information?

#### ASSESS TO SEE IF STUDENT IS ENJOYING THE DAY AT SCHOOL

Take time to observe the student's day at school and identify the times when the child is experiencing some joy in the activity. How much of the day is fun for the student? When does the student become bored, fussy, or disruptive? Is most of the day unpleasant? Are there times when including a fun activity would help the student regain his or her composure and willingness to participate? Are there activities that need to be scraped or greatly modified to include more motivating components or materials?

#### PLAN ACTIVITIES THAT INCORPORATE MOTIVATING ELEMENTS FOR THE STUDENT

Once you know what the child finds motivating, think about how some of these elements can be incorporated in the routines you are currently doing daily with the child such as dressing, eating, bathing, and so forth. For example, if the student really likes the color red you can have red items of clothing, include red plates or cups, select foods that might incorporate red in each meal (ketchup, apple, strawberries), use a red wash cloth and towel or red bubble bath.

You can also brainstorm new activities that might include a particular element or several elements. For example, the student likes playing in water. Can we build an activity where the child waters plants, washes the dishes, bathes a doll, or paints the sidewalk with clear water? Think of as many potential activities as you can, then decide which one has the most potential for including opportunities to work on goals and objectives and allow for as many motivating factors to be included in it as possible. For example, the child might like vibration, food that is blended, and banging with a spoon. You could create a blender activity to make a smoothie or pudding that you have to rake out of the blender with a long wooden spoon.

#### ALTERNATE LESS MOTIVATING ACTIVITIES WITH ONES THAT CREATE JOY

Sometimes there are activities that cannot be made terribly motivating to the child, but that still need to be done. First of all, try to eliminate as many of the negatives as possible in the activity. If cold lotion makes her cry when you are changing diapers, place the lotion in a cup of hot water to warm it slightly BEFORE you start changing the diaper.

Once you have eliminated as many aversive aspects of the activity as possible, try to place a highly motivating activity immediately following the negative one. The child may not like to do the job of loading the washer, but will suffer through it in order to do the next activity, which is buying a coke from the vending machine or going for a walk outside.

#### TEACH LANGUAGE USING HIGHLY MOTIVATING TOPICS

Think about the last great conversation you had with someone. Wasn't part of the pleasure related to having a topic to discuss that you found interesting? If we looking for highly motivating topics to focus language instruction around, the chances are much better that the student will be motivated to learn. If lights are motivating to the student, think of all the great activities that can include lights. You can talk about the color of lights, the number of lights, the size of lights, the temperature of lights, the purpose of lights, how lights can be turned off and on, who uses lights, where lights are typically found, and so forth.

#### TEACH LITERACY USING HIGHLY MOTIVATING TOPICS

Literacy is a natural expansion of language instruction, and so making the topics you use to teach literacy highly motivating makes sense as well. When the student has a great experience, create memory books or experience stories about the experience. Have the student share information about the object or experience

and write that information in the book. For some students this might be in Braille and for other students it might be in print. Always include objects that are motivating to the child as well when selecting objects or pictures to include in the book. For example, if the student is delighted with the ice cream at the Dairy Queen, but only lukewarm about the french fries, choose the ice cream cup as the object for the experience book or story. Pick the favorite activity of the day for the topic of your story rather than an activity that the child finds minimally interesting.

It really is a myth that school can't be fun. Learning should be fun. Learning should bring you great joy. It doesn't take much most times to turn a school day around for a student if we look for ways to bring the fun back into the classroom. The additional payoff is that the teacher will usually find more joy in the day as well.

#### Job One for Educators: Becoming a Good Playmate

By Stacy Shafer and Kate Moss, Educational Specialists, TSBVI Outreach

Abstract: If children learn through, then we must become better playmates in order to facilitate better learning for the child.

Key Words: programming, blind, deafblind, assessment, appetite/aversion, Active Learning, van Dijk, communication, instruction, routines, model, turn-taking

All human beings are motivated to learn when they find the learning activity interesting, useful or fun. Learning takes place best for us when we are in a calm and alert state. This means that we need to be physically comfortable, feel emotionally or physically safe, and have the physical vigor to be able to interact with people or objects in the environment. Children with visual impairments, deafblindness and other physical and cognitive disabilities are no different from other learners in these requirements. Unfortunately, many of these children may not have the language or physical ability to easily tell us their needs and preferences so we can make learning fun and motivating for them. Often times we feel at a loss for how to begin.

There are some strategies that we know work for these children. One strategy, often discussed by Dr. Jan van Dijk and Dr. Lilli Nielsen, is to follow the child's lead. Another is to build predictable interactions with people and environments through the use of routines or highly structured activities. Barbara Miles reminds us that, children who are deafblind (and to some degree, children who are visually and multiply disabled) use their hands as tools, eyes, ears, voice and also to relieve stress. We also know we need to recognize and respond to any attempt a child makes to communicate if we want to foster the child's communication skills development. Underlying all of these strategies is the notion of making the experience inviting and fun for the child. In short we have to become good playmates for the child.

#### **FIRST ASSESS**

So how can we do this? First we have to get a clear picture of where the child is by thoroughly assessing the child's skills in the areas of vision, hearing, communication, fine and gross motor, emotional development, and cognitive development. We also want to get an idea of the level of play and interaction skills the child uses with people and objects. A list of some resources educators might use to do this assessment is included at the end of this article.

We also need to take a thorough inventory of what the child likes and dislikes, what is often referred to as

an Appetite/Aversion assessment. This includes types of sensory input, objects, people, activities or actions, and environments that are preferred or not well tolerated.

#### GAIN THE CHILD'S TRUST

Once you know where the child is and what is interesting to the child you begin by gaining the child's trust. This means sometimes, simply sitting in the same room as the child and not making any demands upon him. You also show an interest in what the child finds motivating whether that is moving his body a particular way or interacting with particular types of objects. As the child becomes more comfortable with you, you can increase the level and amount of contact with the child until he readily accepts your close proximity and begins to seek you out.

#### DISPLAY THE CHARACTERISTICS OF A GOOD PLAYMATE

When the child trusts you, you are ready to become more of an active playmate. Think about the type of playmates you experienced as a child. Remember when you were required to play with a child at some event you attended with your parents? Did you ever get stuck with the child who was bossy, always controlled the objects or activity, didn't play any of the games you knew and liked or only played games that you were bad at, and who hoarded all the good toys? Did you enjoy that interaction? No! You probably tried to get away from that child as soon as possible. Most of us were happier if we had an opportunity to find a generous playmate, someone willing to share all his toys with us. We wanted someone who was interested in the things that interested us. A good playmate was someone who took turns, and offered new ideas and experiences without demanding that we go along with his suggestion.

As an educator (or parent) working with a child who is deafblind or visually impaired with additional disabilities you must become the good playmate to the child. So how do you do this?

#### Slow your pace

First of all, consider the pace of your interactions with the child. How fast can this child take in information? How long does it take for the child to physically be able to respond to sensory input? Is the child unsure of what you might do with him and a little fearful of the speed at which you move? A much slower pace than you would typically utilize may be needed. Unless we discipline ourselves to be aware of how fast we are moving around the child, we are likely to frighten him or simply overwhelm him. Step one, slow down.

#### Be generous

Be generous with the toys you have. Offer the whole toy box and see what the child picks. In order to learn about objects and their properties children have to have a wide variety of objects so they can compare the objects to each other. Typical two-year-olds don't play with one object. They play with many objects in a sequence, often returning to familiar objects to compare with a new object.

Be generous with yourself in your interactions with the child. If the child is interested in continuing the interaction, give him extra turns. Make your hands available for the child to use to as he chooses allowing him to guide you in the interaction. Wait and give him time to consider how he wants you to respond. Let him know you understand or value what he is trying to tell you by mirroring back what he shows you. This type of generosity is the beginning of many good conversational interactions.

#### Don't be bossy or controlling

Don't be bossy. Let the child control the activity. Be quiet and don't make demands of the child. For

example when you are sharing a ball don't say, "Throw me the ball. Let's put it in the basket." Instead make a variety of balls available to the child and imitate what he does with the ball.

Don't try to control the action or the object. Offer to be a part of the exploration, but respect the child if he refuses your involvement. Don't correct him or tell him he is handling the object incorrectly or not completing the correct action. He will be much more inclined to include you in his game if you aren't trying to take over.

#### Don't make him share until he is ready

Having duplicates or a sufficient quantity of toys is also an important. This allows you to model things to do with an object without making the child share his toy with you. Remember, at first the child with not be open to sharing his toys with you. He may show you his toy and you can comment on how lovely it is, but don't make the mistake of taking it from him until he insists you have it. It takes longer for some of us to learn to share, so don't rush it.

#### Be an interesting model

As the child experiences success in the way he is acting on the object you can offer an idea of something new to do by modeling an action. Try to determine what is interesting to the child about that object based on how he is playing with it. Is he fascinated with the shape of the object? Show him how the object's shape will fit with another shape, for example putting the ball into a tube or a container. Is he interested in the texture of the object? Show him a different object with the same texture or offer a very different texture in a similar object for him to compare. Is the child interested in the way the object bounces or sounds when you throw it? Show him how many different objects bounce or sound. Remember, if the child decides he is not interested in what you are showing him you should return to his game. A little later you can try modeling the new action again.

#### Let the child feel success as well as challenges

Make sure that what you model is only slightly higher developmentally than the child is currently demonstrating. For example, if the child is taking things out of a container you might show him how to put things in a container. It is important to have a clear notion of the "next step" when you sit down to play with a child so that you don't target skills that are too high.

Educators have a natural tendency to constantly be working on the child's IEP goals, which typically are written just above where the child is able to function. However, to be a good playmate, you need to strike a balance between letting the child feel success by practicing learned skills and challenging him to develop new slightly higher level skills. Let the child be competent in play.

#### Go from imitation to turn-taking to participating in routines

As the child becomes more inclined to engage with you, slowly work from imitating him to having him imitate you, to setting up turn-taking interactions. Taking a turn is a first step in participating with someone in an activity. Learning a series of steps is what we do when we teach a child a routine. Being able to carry out a routine means that the child has a memory of a series of events that can be expanded on by adding new information.

By being a good playmate we can entice the child to join in with us as we explore the world around us. As good playmates we can share information about actions and interactions that are possible. When we are good playmates, we are also being good educators. When we are good playmate we generally enjoy teaching more.

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Make It Routine. <a href="http://www.tsbvi.edu/Outreach/seehear/archive/routine.html">http://www.tsbvi.edu/Outreach/seehear/archive/routine.html</a>

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#### Communication and Concept Development:

Non-Verbal Communication: Cues, Signals, and Symbols <a href="http://www.tsbvi.edu/Education/vmi/nonverbal.htm">http://www.tsbvi.edu/Education/vmi/nonverbal.htm</a>

What a Concept! <a href="http://www.tsbvi.edu/Outreach/seehear/spring00/concept.htm">http://www.tsbvi.edu/Outreach/seehear/spring00/concept.htm</a>.

Information from Students with Profound Impairments: Gathering Information and Planning Instruction: (This will available on the TSBVI website, <www.tsbvi.edu> soon.)

- Appetite/Aversion Form and Appetite Summary Form
- Types of Responses from "Non-Responsive" Children
- Thoughts on the Assessment of the Student with the Most Profound Disabilities

#### **Books About Active Learning:**

Dr. Nielsen's Books are available from Vision Associates <a href="http://www.visionkits.com/kits/lilli.html">http://www.visionkits.com/kits/lilli.html</a>

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#### **Santa Claus Is Coming to Town**

By Kate Moss, Education Specialist, Texas Deafblind Outreach

Abstract: Thoughts about selecting appropriate gifts for children who are visually impaired or deafblind.

Key Words: Programming, blind, deafblind, toys, play

This time of year parents become painfully aware that Santa Claus is coming to town, sooner not later. Moms, dads, grandparents, aunts and uncles all start searching for the perfect Christmas present for the children in the family. Sometimes when the child is visually impaired or deafblind finding the perfect present becomes much more difficult.

Part of the problem is that many toys are so visual there is not much pay off for the child who doesn't see or who sees very little. Most of the toys nowadays are made from plastic, so there is not much to offer that is tactually interesting. Other toys focus on sounds or require good hearing to be able to utilize them. For many children, the developmental level, in terms of cognitive and motor skills, is too advanced for the child or if the toy is at their level it may appear to be inappropriate for their chronological age. What's Santa to do?

#### THINK ABOUT THE THINGS THAT ARE VERY INTERESTING TO YOUR CHILD

It's always a good idea to think about the things that interest your child. What things or activities really bring pleasure or interest? Is your child most happy when he is outside? Does your daughter like playing in the water? Is music the thing that always brings a smile? Start by making a list of these things then think about the aspects of these pleasurable things seem to be the most motivating. Is it feeling the water flowing from the faucet or is it pouring water from different containers? Is it the loud bass sound, the slow calming refrain or the singer that makes the music work? Once you have a clear idea about what your child really finds enjoyable it is easier to get creative about finding new things and activities that share similar characteristics.

#### ARE THERE BIG-TICKET ITEMS TO CONSIDER?

Sometimes holiday gifts are more costly such as bicycles, television sets, computers and so forth. Consider asking relatives who want to give gifts to contribute to the purchase of more expensive items. For example, if your child is using some of the Active Learning equipment at school and you think he might also enjoy playing with these things at home, could duplicate materials be purchased if everyone pitched in to pay for it? Maybe the child could ride a bicycle if it were a tandem bike. If family members typically want to buy gifts, suggest that they may want to make a contribution toward a bigger ticket item instead of buying individual inexpensive gifts.

#### THINK ABOUT A COUPON FOR A SPECIAL ACTIVITY

Instead of a toy that may not appeal to the child, family members might consider giving a coupon for a special outing or event. For example, one trip to the ice cream store with Aunt Susie, a fishing trip with Grampa, a ticket to a skating rink with dad, or a day at the beauty shop with mom might make lovely gifts. The coupon can be attached to something the child would like such as a candy bar or small stuffed animal if you want to make sure he has something to open. Planning for the outing and sharing the experience with others later gets a lot of mileage out of the event.

#### THINK ABOUT TRADITIONAL AND NONTRADITIONAL "TOYS"

There are many wonderful manufactured toys and games, but sometimes the thing the child might like most isn't a toy at all. Is the child interested in keys? How about getting him a collection of different kinds of keys? Maybe you could throw in a few locks as well. Does the child like lights? What about getting an aquarium with very colorful fish inside and interesting plants? The child could have the enjoyment of watching the fish in the aquarium and maybe learn to feed the fish as well. Let yourself think outside the box when purchasing gifts.

If you do buy traditional toys, consider these guidelines mentioned in the article, *Helping Your Customers Choose Toys for Children Who Are Blind or Visually Impaired*, from the American Toy Institute and American Foundation for the Blind:

• Consider toys that talk or produce sounds. Children with visual impairments will benefit from the influx of technology in today's toys. Toys that talk or imitate real life noises attract children's attention to the world of sounds, help them understand cause and effect, and teach them to use auditory senses effectively as they grow. (Make sure the child's hearing is good enough to be able to access the noise each toy produces.)

- Have bright colors, high contrast and emit light. Toys with simple contrasting patterns of lines and shapes that are brightly colored or light up during play stimulate children to use their vision to its best potential.
- Feature a variety of interesting surfaces and textures. Toys that have dials, switches, buttons and other surfaces that are fun to touch and operate encourage children to use their fingers and hands to explore. Textures introduce children to the way everyday objects feel. Interesting, flexible or rubbery surfaces make dolls, rattles and balls easy to play with and appealing.
- Stimulate thinking and creativity. Puzzles, building toys and railroads help children discover how parts make up the whole, and stimulate their imagination to plan and build. Toy letters and numbers marked in Braille and phonics toys introduce children to the wonders of learning through reading. Craft kits and art supplies help enhance creativity.
- Encourage movement and exploration. Climbing and riding toys, athletic equipment and other action toys engage children in movement and exploration. Physical activity promotes the growth of strong muscles for walking, running and sports; toy rattles, hand puppets and musical toys enhance the development of fine motor and hand skills, and facilitate graceful and easy movement.
- Promote cooperation, sharing and social growth. Games and role-playing activities engage children in play with their friends, family and teachers. Games that encourage cooperation and sharing build the foundation of friendship and relationships with others.
- Develop awareness of people, places and things. Dolls, stuffed animals, puppets, vehicles and play towns introduce the sights and sounds of daily living, acquaint children with the jobs that people do at home and at work, and stimulate creative role-play.

Here's wishing you a merry holiday shopping season. Have fun!

#### We're Not an Island

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

Abstract: Dr. Phil Hatlen discusses the issues facing our state and the nation related to individuals with visual impairments and the importance of keeping existing VI systems intact.

Key Words: News & Views, blind, deafblind, education, rehabilitation, systems, visually impaired professionals

We should be forever thankful that blindness and low vision are low prevalence disabilities. However, when a child becomes blind or low vision, we must be prepared to offer the family and the child the very best developmental and educational services possible. A lesson we at TSBVI continue to learn is that what we do has potential to impact children throughout the U.S. And what a teacher in Montana, for example, does, may well effect how we teach children at TSBVI. We are a small profession serving a small number of children and families.

When it comes to serving blind and visually impaired students, there should be no city, region, or state boundaries. I care very deeply about the education being offered to children in Oklahoma, in Maine, in Oregon. We mutually benefit from one another if are always open to sharing and communicating. We also often face the same issues.

Challenges in the education of blind and visually impaired students exist everywhere, and I want to share some of these with you—we are not an island, but a part of a state and national system of education.

At the national level, our country continues to suffer from a chronic shortage of teachers and orientation and mobility specialists. This is not a mild shortage—it is massive, and those charged with attempting to minimize the shortage have not yet found a solution. Imagine if you were a parent of a blind child and were told by your local district that no teacher was available for your child! This happens in some form countless times in this country where we place such a high value on equal opportunity for all of our citizens.

Nationally, there are issues regarding who is blind and who is low vision, issues around appropriate placement, issues related to delivery of the expanded core curriculum, issues about vocational preparation, issues about quality services to blind and visually impaired infants and preschool children. I'm sure some of you could name many more vexing issues, but the situation is clear—we still do not have all the answers we need in order to provide the services we should to blind and visually impaired students. The National Agenda is an excellent, positive step forward, and all of us need to be active in its progress.

At the state level, issues of children living in rural areas continue to defy solutions. While we have made significant progress toward minimizing the teacher shortage, thanks to the collaborative efforts of Texas Tech University, Stephen F. Austin University, and TSBVI, we have not closed the gap enough, and there is soon to be a mass exodus of a very large graying population of teachers and O&M specialists.

One of the critical keys to the success of a continuum of service model in Texas is the Education Service Centers (ESC). The presence of expertise in both education and O&M in these regional offices makes a tremendous difference in the quality of services in local school districts. Since I've been in Texas, there has been a precarious feeling about the continuation of this expertise at the ESC level. Also, Texas is very fortunate to be one of the only remaining states that has a consultant at the state level who is an expert in visual impairment. However, it seems that every year this person is given more responsibilities that have nothing to do with her expertise.

Both national and statewide issues involving the education of blind and visually impaired students impact TSBVI every day. We are part of a national and a statewide system, and we do our job well in large part because the rest of the system works well. If one part of the system were to disappear or be severely damaged, it will affect the entire system, including TSBVI. This why we must be vigilant and persistent in communicating to policy-makers and legislators about how vital it is that at the national, state, and ESC level, there be expertise in education and O&M for blind and visually impaired students.

#### Some Things Haven't Changed!

By Barbara J. Madrigal, Assistant Commissioner, Division of Blind Services E-mail: barbara.j.madrigal@dars.state.tx.us

Abstract: In Assistant Commissioner Madrigal's debut article in See/Hear, she reviews the recent changes in state government and discusses the things that have not changed in the Division of Blind Services, such as the service delivery systems, the quality of programs and staff, and the gratitude to those who support staff and programs.

Key Words: News & Views, blind, deafblind, Division for Blind Services, DBS, DARS, consolidation,

Blind Children's Vocational Discovery and Development Program, Transition Program, succession planning, consumer mentoring program.

This is my first article for *See/Hear* as Assistant Commissioner of the Division for Blind Services (DBS). I am honored to serve in this capacity, and I appreciate the Department of Assistive and Rehabilitative Services (DARS) Commissioner Terry Murphy's confidence in me.

This is an interesting time to work in state government—particularly in the health and human services arena where so much is changing so rapidly. It can be quite a challenge to maintain high quality services to Texans who are blind while managing the demands of changing roles, responsibilities, organizational structures and other things associated with building a new, consolidated agency. Nonetheless, let me assure you that DBS staff is meeting the challenge!

I have never been more proud to work with this fine group of professionals than I am now. They are dedicated to our mission. They are working hard to stay focused on what's most important—the consumers and families who rely on our expertise and support.

Much of the news we hear about DARS and HHSC is what has changed or is about to change. I think it's important to remember a few things that haven't changed at DBS. Our staff's commitment to providing quality services certainly tops the list.

Our service delivery programs have not changed. We are still the vocational rehabilitation agency for persons who are blind. We have the same regional structure, same number of counselors, teachers, independent living specialists and support staff members as there were before DARS came into existence. Our Blind Children's Vocational Discovery and Development Program, Transition and Independent Living programs are thriving. We have more and better workshops and activities for children and their families than ever. A recent example is the First Confidence Builder's Conference - Foundation for Life - held in Corpus Christi at the end of July with 30 families and over 140 individuals attending the three day conference. Consumers, parents and siblings had an opportunity to interact, learn and increase their confidence! The Criss Cole Rehabilitation Center (CCRC) continues to do an outstanding job of teaching independence, confidence and how to LIVE with blindness. And our programs to assist employers provide assistive technology and offer employment opportunities through Business Enterprises of Texas (BET) are as strong as ever.

Something else that will not change is our gratitude to friends and colleagues for their ongoing support of our programs. We know the changes we experience often have an impact on others—directly or indirectly. We appreciate everyone's patience and guidance as we work our way through these changing times. And we look forward to working together now and in the future to promote the independence and productivity of Texans who are blind.

Speaking of the future, we have a full agenda in the immediate months ahead. As you may know, we have just started a new state fiscal year—SFY 2005. Like the other DARS divisions, we are likely to face more changes and refinements to strengthen the consolidated agency in the coming year; but it appears most of the major structural changes are behind us.

That's a good thing because it's time to devote attention to the upcoming legislative session and our Legislative Appropriations Request (LAR). For the latter, we have already started meeting with the Legislative Budget Board (LBB) staff to negotiate performance measures, among other things. I will provide more

detail about the LAR and other legislative issues as we get beyond this preliminary work.

In the meantime, I'm proud to report that we ended SFY 2004 in good shape in terms of our service numbers. We are still tallying the results, but it appears that we maintained our previous level of service in all programs, and gained ground in a couple. Considering the climate of change and uncertainty our staff was working in, we can be proud that it did not have a negative impact in terms of the number of people we served.

That gives us something to build on as we start this New Year in this new environment. We're steadfast in our determination to continue to strengthen our programs and services to the benefit of Texans who are blind. As an example, we have already started work on a couple of exciting initiatives that may be of interest to you:

- Succession planning is a way to assure that there are highly qualified people in all positions in an organization—today and in the years to come. With everything going on in the health and human services world today, it's especially important that we have a plan to guarantee that Texans who are blind will be served by qualified and experienced staff for years to come; so, we are initiating succession planning for DBS. We're working with the Region VI Rehabilitation Continuing Education Program (RCEP) and researching what other states are doing in this area.
- *Consumer mentoring programs* already exist in some DBS regions. They are yielding such positive results that we are working to establish a consumer mentoring program in each region.

In future columns, I'll keep you posted on our progress on these and other initiatives aimed at continuing to provide the best possible services to Texans who are blind. In the meantime, I hope you will feel free to contact me if you have questions or concerns about DBS activities. As always, thank you for your interest in our programs and services.

#### So, What Do You Want to Be When You Grow Up?

By Karen Wolffe, Ph.D., Austin, TX

Abstract: AFB has a new feature on its website, CareerConnect, that helps individuals learn about career opporutnities for individuals with visual impairments.

Key Words: News & Views, blind, deafblind, careers, job exploration, mentor

Such a simple question, "So, what do you want to be when you grow up?" and such a difficult one for many children and young adults with visual impairments to answer. Unfortunately, the expectations of many in the larger society are that young people with disabilities are not likely to go to work when they grow up. Hence, they frequently don't even bother to ask children with disabilities the "What do you want to be when you grow up?" question. If they do, it is usually with a preconceived idea of what they think the child can do. So if the child should be so bold as to say doctor, policeman, fireman, or some other job that the average person cannot fathom a person with a visual impairment doing; the response from the adult may well be, "Oh, honey, I don't think that's possible, but have you thought about working with computers or answering the phone – I know that someone without sight can do those jobs." It's rare that someone will actually encourage the child to dream or consider related jobs – and that's what children with visual impairments need from adults – the prerogative to dream and the support to investigate broadly in the career fields that appeal to them.

The "So, what do you want to be when you grow up?" question begs an answer, and the reality is that blind

and visually impaired children can look forward to doing almost anything when they grow up – just like their peers with good eyesight. Technology has opened many career doors that were once closed and adults with visual impairments can be found who are working in many, many different kinds of jobs, from physicist to florist. How though can students with visual impairments, their parents or caregivers, and teachers find successfully employed adults and learn about the jobs that they are doing as well as find information about related careers? The answer is to access the American Foundation for the Blind's latest career exploration and job seeking skills tool, AFB CareerConnect<sup>TM</sup>. CareerConnect is a free, fully accessible and interactive web site <www.afb.org/careerconnect> that hosts a mentor database of blind and visually impaired adults who are successfully employed and willing to share their experiences about how they got their jobs and how they do their jobs.

#### AFB CAREERCONNECT<sup>TM</sup>

When you first visit the CareerConnect site, you will see a logo, which looks like a window with four panes – one with a globe and the other three with the letter W in them. This is the logo for a new feature on the CareerConnect site, Window on the Working World. Window on the Working World presents first-hand accounts of jobs being performed by individuals who are blind or have low vision. The feature is changed every other month and articles that come down are archived under the mentor option on the web site. Also on the home page, you will find an option to register. Please do register – it's free and only by registering can you experience the full power of the web site. By registering, you are able to make contact with mentors and access the interactive components of the site. When you first visit CareerConnect, I suggest that you take advantage of the overview of the site – it will help you understand fully what's available on the site and how best to use the site's features to accomplish your goals. For visitors who are visually impaired, the home page also offers an opportunity to become a CareerConnect mentor. There's always room for more successfully employed blind and visually impaired adults – if you know someone or if you are visually impaired and working, please consider becoming a mentor or encouraging the person you know to do so.

On the CareerConnect web site, there is also general information about careers (under the Careers tab) that has been imported from the federal government's career databases and reformatted for ease of navigation with speech or braille output devices. The general career information includes the job category that an occupation resides in and a general description of the most common tasks a worker in that occupation performs. There is also information about other typical job titles in that particular job category and a list of related job categories. In addition, there is a link following the job tasks list to any mentors that are available within the CareerConnect database. There are also links to any of the related job categories listed that the site user would like to investigate further.

Following the general career information section, is an option to connect with mentors (under the Mentors tab). This is where you can contact a mentor directly or search for a mentor by city, state or province, key word (law, nursing, computer programming, and so forth), vision status (no useful vision, some useful vision), or member identification number (more about that later!), and you have a choice as to whether you want to include mentors whose former jobs match the job in which you are currently interested. Before you contact a mentor, however, I encourage you to read Tips on Contacting a Mentor. This tip sheet gives you examples of some of the questions that you may want to pose to a prospective mentor.

In addition to the information about careers and mentors, the CareerConnect web site offers tips for job seekers (under the Tips tab). The tips are divided into three broad categories: finding a job, getting hired, and keeping a job once you've been hired. Under each category, there are short articles or tip sheets on subjects ranging from organizing your workspace to deciding when to disclose that you have a disability in the job

search process. These tip sheets can be downloaded and printed or brailled out for students' or adults' future reference.

The site also includes an interactive component, My CareerConnect, which enables a registered user to develop a personal data sheet (to assist with completing applications) or a resume. These documents can be saved on the site or printed for immediate use. Under the My CareerConnect tab, there is an electronic calendar option for keeping track of appointments or interviews and a electronic message board. The message board provides young people with an option for sending and receiving messages with mentors that allows for confidentiality. They can send their messages from the CareerConnect web site, using the CareerConnect Internet address and receive messages in response at the same address. Although mentors all are required to sign a "Terms of Service" agreement that specifies that they "can do no harm" this added measure of security is a built-in protection for young people who may not be mature enough to screen e-mail messages from strangers.

Another wonderfully informative option on the CareerConnect web site is the technology section. Technology has truly made many jobs viable that were once off-limits to people with severe visual impairments and this site shares important information about the many assistive technology devices that are available to use in the work place. Under the Technology tab, there is information about screen magnification systems, braille technology, synthetic speech systems, optical character recognition equipment, video magnifiers, and more. There is both descriptive information and details about where such equipment is available, at what cost, and a listing of vendors from whom equipment can be purchased. Finally, my favorite place to visit in the technology section: a link to AccessWorld. AccessWorld is AFB's premier publication about technology and people with visual impairments, now available on-line without a paid subscription. AccessWorld describes technology (mainstream and assistive technology) and presents articles about how people are using technology to do their jobs.

The final section on CareerConnect is the Resource section. In the resource section, a visitor will find links to job listings, disability-related employment resources, a listing of local resources for job seeking assistance (by state or province), recommended readings, and a bibliography of biographies and autobiographies of blind and visually impaired people. Also included under the resources section are a series of guides that have been developed for teachers, parents, students, rehabilitation practitioners, and adult job seekers that describe how to use the CareerConnect materials and offer additional career exploration and job seeking tools and techniques. In addition, there is a link to a web cast of a demonstration of the CareerConnect site.

If you don't have easy access to the Internet, you can still access many of the features described in this article by requesting a CareerConnect CD-ROM. To request the CD, call 888.824.2184 (toll-free) or send a request via e-mail <careerconnect@afb.net>. The CareerConnect CD contains a listing of the jobs represented in the CareerConnect mentor database and general information about the mentors. Although private, identifying information about the people in the database has been omitted for purposes of confidentiality; each prospective mentor has been assigned an identification number, which you can use to refer to a particular individual. You may contact CareerConnect members via e-mail, telephone, or through written correspondence. To find out how to reach the mentors, call the toll-free telephone number for CareerConnect (888.824.2184) and speak with a CareerConnect staff member.

The CD also contains the guides described earlier, the tips, the information about technology, and the resources. What it doesn't contain is the interactive component, My CareerConnect, the general career information database, and the Window on the Working World feature. Obviously, the Internet option, AFB

CareerConnect<sup>TM</sup>, is richer and lends itself to a more dynamic environment; therefore, when possible that is the preferred avenue for accessing information about careers and doing job searches. However, when Internet access is not available, the CD is an excellent second choice for gathering relevant career information. Finally, it is important to note that parents, teachers, and students are encouraged to seek out information from the people behind these resources: the staff at CareerConnect, including the author of this article. To reach the staff, you can call the toll-free number (888.824.2184), write via e-mail <careerconnect@afb.net>, or correspond by post (AFB TECH, Suite 200, 949 3<sup>rd</sup> Avenue, Huntington, WV 25701).

Happy career exploring...may the children and students you know and orient to these resources delight in answering, "So, what do you want to be when you grow up?"

#### Listen Up – Blind Birders Tune in to Nature's Call

By Eric Garza, staff writer for The Monitor in McAllen, Texas (Reprinted by permission of the author. This article may not be reprinted in other publications or websites without consent from Eric Garza. You may contact him at egarza@themonitor.com)

Abstract: the author reports on the Outta-Sight Song Birder Tournament, a bird watching group composed of contestants who are blind and visually impaired.

Key Words: News & Views, blind, bird watching, recreation

MISSION – A smile crept across Valerie Mercurio's face early Sunday morning at Bentson State Park in Mission when she heard the birdsong.

Her ears perked up as she strained to identify the small gray bird she could not see.

"Oh, I think that's a beardless-tyrannulet," she said, waiting for confirmation from the five other members of the group.

The others listened intently before nodding in agreement. Her husband, Tom, then pulled out a black felt tip pen and quickly added it to a list of birds they had identified earlier that morning.

The group of six were among the three teams competing in the Outta-Sight Song Birder Tournament, part of this year's Great Texas Birding Classic. But the contestants in the event were unlike any other ever seen in the Rio Grande Valley. Mercurio, along with three other members in the group, is blind.

Even the tour guides participating in the tournament did not have the benefit of their eyesight as they were blindfolded throughout the event.

"It was a little rough at the beginning, "said Roy Rodriguez, one of three tour guides for the participants. "I've been to the park a million times, so I figured I wouldn't have any problem, but the minute we stopped and turned in one direction and turned around again, I had no idea where we were."

The idea of bird watching as a hobby for the Valley's blind population was sparked by Raul Reyes. Reyes, who has been blind since 1989, said he often goes to local adult day care centers to find things to occupy his time.

During one of his visits late last year, one of the caregivers offered Reyes the opportunity to tag along on a birding trip with some of the other people at the center.

"I took the opportunity because I really had nothing else to do," Reyes said. "I'm always looking for something to do for the blind because there's nothing here in the Valley as far as activities go. The blind in the Valley are a large number but there's nothing for us."

He said he enjoyed the trip so much that he quickly contacted other blind people in the area and proposed an informal club for blind bird watchers.

Rodriguez said he was approached by several of Sunday's contestants about six months ago who asked for his help in organizing the event.

"They don't have very many activities...so they wanted something to motivate them and stimulate them mentally," Rodriguez said. "We introduced them to bird watching and told them that 80 percent of bird watching is by ear anyway."

Armed with compact discs, the blind birders started learning the songs of many indigenous birds. Their practice was often no more than wandering into their backyard to try to identify as many bird calls as they could. Their studies were apparent Sunday as most of the group was quick to identify at least a couple of the birds fluttering around them.

"At first I thought I hadn't studied the songs enough," Mercurio said. "I guess I did."

Jesse Garza said he's always enjoyed being outdoors. He said he was pleasantly surprised when he learned of plans to start a blind birders group. "It's something new. I never thought that it could be done," Garza said. "Even in my backyard in my home I can hear the Inca Dove or the woodpeckers." He said he expects that in the near future the hobby will grow by leaps and bounds. He said he hopes the hobby will spread quickly and that future tournaments will feature teams from across the state. "Right now this is something new, but I think the more people read about it...the more people will join," Garza said.

Gladie Cruz, another participant in Sunday's Outta-Sight tournament, said some of the blind birders could eventually become tour guides for other blind people interested in bird listening. "The beginners will eventually get better and be able to train other people," Cruz said. "It'll be the blind leading the blind."

#### The Power of Play

Press release from Hadley School for the Blind

Abstract" An announcement from Hadley School for the Blind describing their new course, "Learning Through Play."

Key Words: News & Views, blind, deafblind, Hadley School for the Blind, child development, play

Did you know that play is not only entertaining but also essential to a child's growth and development? The Hadley School for the Blind's new course, "Learning Through Play," explains how play teaches children who are visually impaired about themselves and the world around them. This tuition-free course suggests

various ways that parents and classroom personnel can use play to help children acquire self-confidence and independence.

In seven lessons, this course explores how play is vital to a child's growth and development. It begins by examining the importance of play. Then, it discusses the special considerations related to vision impairment that can affect a child's play. Also examined is the connection between a child's development and the development of play at different ages (i.e., newborn to six months, six to 18 months, and 18 months to five years). The course suggests ways to create a nurturing play environment. It even describes how to select toys and activities that suit the child. Also included is an appendix with additional play ideas and a Resource List with reading suggestions, contact information for vendors, and related Web sites.

"Play is a child's natural method for learning," says instructor Pam Winters. "After all, learning should be fun-not only for the child, but also for you. This course's suggestions can help you and the child enjoy learning through play." This course is open to students in the Family Education and Professional Education Programs. (Teachers of early-childhood-education vision classes may find the content of this course a review, however.) So, why not enroll in this course so you can play and learn with the child in your life? To do so, just call Student Services at (800) 526-9909.

Founded in 1920, The Hadley School for the Blind is one of the largest worldwide educators of people who are blind or visually impaired. Hadley offers more than 90 tuition-free courses to eligible students. The school serves 8,600 students annually, from all corners of the United States and 90 foreign countries. Courses are also available to blind individuals 14 years of age and older. Visit us on the Web at <a href="http://www.hadley-school.org/Web\_Site/Hadley-School.asp">http://www.hadley-school.org/Web\_Site/Hadley-School.asp</a>.

#### Perkins Panda Early Literacy Program

Abstract: Perkins School for the Blind announces the launch of the Perkins Panda Early Literacy Program.

Key Words: News & Views, blind, deafblind, Perkins School for the Blind, literacy, Braille, Odds Bodkin

After several years in development and nationwide testing, Perkins School for the Blind is proud to announce the launch of the *Perkins Panda Early Literacy Program* – a collection of materials designed both to teach fundamental literacy skills to children with visual impairments and to help parents and other caregivers support children's literacy development.

The kit consists of three interrelated storybooks, activity guides and cassettes; a resource guide; a story box; a Gund plush panda with a backpack that can hold a dual-speed tape player; and carry bags. All the storybooks have visually appealing high-contrast illustration, large print and uncontracted Braille. Odds Bodkin, a well-established storyteller and songwriter, worked with Perkins to write the books and the stories and songs on the cassettes.

The primary audience is families of children with visual impairments, ages birth to 8. In addition, the materials are valuable in program settings, to families with older children with multiple impairments and to parents and grandparents with visual impairments for use with sighted (grand)children.

All components are available as a kit or separately. For more information, call 800-972-7671 or 001-617-972-7667, e-mail <Perkins.Panda@Perkins.org>, or visit <www.Perkins.org>.

# Survey on the Assessment of Communication and Cognitive Skills in 2-8 Year Old Children who are Deafblind

By Charity Rowland, Ph.D., Oregon Health and Sciences University Email: rowlandc@ohsu.edu, Phone: 503-238-4030 ext. 115

Abstract: Request for participants to complete a survey on assessment of communication and cognitive skills as a part of a grant from the U.S. Department of Education.

Key Words: News & Views, blind, deafblind, survey, asssessment, communication, cognitive skills

Oregon Health & Science University, under the direction of Dr. Charity Rowland, has received a grant from the U.S. Department of Education to study and validate methods for assessing the communication and cognitive skills of 2-8 year old children who are deafblind. This is a collaborative effort with Dr. Deborah Chen (California State University, Northridge), Dr. Harvey Mar (St. Lukes/Roosevelt Hospital and Columbia University, New York), Dr. Robert Stillman (University of Texas at Dallas) and the National Family Association for Deaf-Blind.

We are currently distributing surveys to parents and professionals **who have recent experience in the assessment of 2-8 year old children who are deafblind**. We are seeking a nationwide sample of parents and professionals to provide information about the assessment process in general and about specific assessments that they recommend. The surveys are estimated to take about 35 minutes to complete. The survey information is collected without identifying information. A \$20.00 gift certificate is provided to those who (separately) provide a mailing address.

If you would like to suggest individuals to participate in the survey or would like to participate yourself, please contact me. I can either mail surveys directly to names/addresses that you provide or I can mail them to you for you to distribute. In either case, the surveys are returned to us without any identifying information, so we do not know who completed them. Thank you for considering this request.

#### TSBVI Short-Term Programs 2004-2005

#### Fall Semester 2004 **Spring Semester 2005** Oct ober 17- 22 Elementary IEP #1 January 9-14 Middle School IEP #1 November 7-12 High School IEP #1 **January 23-28** Technology Week #2 (secondary) Nov. 28 - Dec. 3 Math (secondary) February 10-13 Elem. Independence Weekend December 9-12 Middle School Independence **February 17-20** Low Vision Weekend (secondary) Weekend Feb. 27-Mar. 4 High School IEP #2 March 20-24 Capitol Experience (secondary) Contact: Lauren Newton, Ph.D. Principal of Special Programs Mar. 31- Apr. 3 High Sch. Independence Weekend Texas School for the Blind & Visually Impaired **April 10-15** Middle School IEP #2 (512) 206-9119 email: laurennewton@tsbvi.edu May 1-6 Elementary IEP #2

### **CLASSIFIED**

Mail or e-mail your new classified to Carolyn Perkins: TSBVI Outreach, 1100 West 45th St., Austin, TX 78756, or <arolynperkins@tsbvi.edu>. An up-to-date Statewide Staff Development Calendar is posted on TSBVI's website at <www.tsbvi.edu>

#### 2005 Texas Symposium on Deafblindness Feb. 25-26, 2005 **Hyatt Regency Hotel - Austin, TX**

Texas Deafblind Outreach is proud to host this event for family members, professionals and paraprofessionals involved inthe lives of children with deafblindness who are between the ages of birth and 22. This year's Symposium will include both general and breakout sessions featuring a variety of speakers from Texas and other parts of the United States.

General sessions include a keynote on concept development presented by Robbie Blaha from Texas Deafblind Outreach as well as presentations by Rosie Yanez and Leigh Ann Bryan, adults with deafblindness, on what it means to be a person with deafblindness. Also presenting is the Knapp family from Houston who will talk about their lives with Christian, a young adult with deafblindness and multiple disabilities.

Our national speakers include such individuals as Barbara Miles, co-author of Remarkable Converesations and consultant for Hilton-Perkins International, Cathy Nelson, co-author with Jan van Dijk of Child-Guided Strategies for Assessing Children who are Deafblind or Have Multiple Disabilities and Clinical Assistant Professor of Special Education University of Utah, Tim Hartshorn, parent of a child with CHARGE syndrome and professor of psychology at Central Michigan University, Dr. Sandra Davenport, Pediatric Geneticist, who is an internationally recognized expert on Usher Syndrome and CHARGE syndrome, Maurice Belote and David Brown from California Deafblind Services, and Tanni Anthony, COMS and Project Director for Colorado Services for Children with Combined Vision and Hearing Loss (Deafblindness) Project.

Texas presenters include: Tish Smith and Kim Conlan, Speech Language Pathologists at TSBVI and along with Craig Axelrod from Texas Deafblind Outreach. They will present information about a special project they are collaborating on, with support from Dr. Jan van Dijk, about supporting high quality interactions with students who are deafblind. Kate Moss from Outreach will present on Person-Centered Planning.

There will be opportunities to network and share ideas with committed people who are interested in educational and life issues for children and youth who are deafblind and their families. A social for parents on Friday will be cohosted by the Deaf-Blind Multihandicapped Association of Texas.

Registration by Jan. 10th: **Late Registration:** \$175 \$225 (after January 10th) **Family Members and Professionals:** free \$50 (after January 10th)

**Out-of-State Participants:** \$300 \$350 (after January 10th)

**Paraprofessionals:** 

For more information contact: Beth Bible at 512-206-9103 or <br/>bethbible@tsbvi.edu> or visit the TSBVI website at< www.tsbvi.edu>

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#### **INSITE Trainings for 2004-05**

#### ESC Region 7 Kilgore, TX

November 10 & 11, 2004 December 8 & 9, 2004 Liz Adams (Region 7) and Alicia Favila (Region10) will work together to support this INSITE training. 903-988-6899;

#### ESC Region 1 Edinburg, TX

October 21 & 22, 2004 (Thurs. & Fri.)
December 14 & 15, 2004 (Tues. & Wed.)
January 6 & 7, 2005 (Thurs. & Fri.)
Contact: Peter Graves, ESC 1
956/984-6165, Ext. 6165

#### ESC Region 14 Abilene, TX

February 14 & 15, 2005 March 28 & 29, 2005 April 18 & 19, 2005 Contact: Linda Laughlin 325-675-8632; llaughlin@esc14.net

# ESC Region 18 Midland, Texas

March 22 & 23, 2005 April 26 & 27, 2005 May 17 & 18, 2005 Contact: Fred Martinez, ESC 18 432/567-3254

#### **Understanding Usher's Syndrome** January 25, 2005

Region IV ESC, 7145 Tidwell, Houston TX 77092
Presenter: Jenny Lace, Outreach-TSBVI
Fee:\$30
Contact: Karen Crone, 713/744-6324
kcrone@esc4.net, or
Cecilia Robinson, 713/744-6379
crobinson@esc4.net

# **2004-2005 Intervener Training Opportunities**

A series of training opportunities are available for individuals currently working as interveners, their educational teams and others who are interested in learning more about the role of the intervener in working with students with deafblindness. Interveners wishing to attend the Symposium may receive free registration if they register before January 10th. A complete listing of the training opportunities for intervers and their teams are listed below:

#### TETN on November 3<sup>rd</sup> from 2:00-3:30

Topic: The Ins and Outs of the Intervener Model

#### The 2005 Symposium on Deafblindness February 25<sup>th</sup> & 26<sup>th</sup>

This event held in Austin will include opportunities for interveners to gather, network and learn.

# **Tentatively scheduled for June Introduction to the Intervener Model**

Introductory statewide training for interveners and a team member who have not attended previously.

If you are interested in learning more about the use of the Intervener Model with students who are deafblind, please contact Texas Deafblind Outreach (512-206-9103).

# An Introduction to Seating and Positioning for Accesss to Assistive Technology

December 2, 2004 Region XI ESC, Fort Worth TX Contact: <www.esc11.net>

## Orientation and Mobility for Individuals with Low Vision

February 28, 2005
Region 10 ESC - Richardson, TX
Presenter: Richard Ludt,
Orientation and Mobility Intern Coordinator
Western Blind Rehabilitation Center,
Palo Alto CA

Contact: Kitra Gray, GRAYK@esc10.ednet10.net

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#### From Region 4 ESC in Houston

#### Working Together: Teachers of the Deaf and Teachers of the Visually Impaired

December 1, 2004

Presenter: Kate Moss, Texas Deafblind Outreach, Austin TX

#### In Focus with Low Vision: Septo-Optic Dysplasia

December 10, 2004

Fee: \$20

Presenter: Dr. Randy Jose, University of Houston, College of Optometry

# **Exploring Technology for Elementary Students** with Visual Impairments

January 25, 2005 Fee:\$50

#### Cortical Visual Impairment: Identificiation, Assessment and Intervention

February 2-3, 2005 Fee: \$60

Presenter: Dr. Christine Roman, Marshall University, Huntington, West Virginia

#### In Focus with Low Vision: Congential Glaucoma

Fee: \$20

Presenter: Dr. Randy Jose, University of Houston, College of Optometry

Contact for information about these events: Karen Crone, 713/744-6324, kcrone@esc4.net Cecilia Robinson, 713/744-6379, crobinson@esc4.net

#### The North American Active Learning Convention, Lighting the Fire: Igniting the North American Active Learning Agenda

February 7-9, 2005

Oakland Marriott City Center, Oakland CA
Presenters: Dr. Lilli Nielsen and leading North
American Active Learning experts

Hosted by: LilliWorks Active Learning Foundation For more information: <www.lilliworks.com> 512/814 - 9111

#### **Technology Training at TSBVI**

These workshops will be offered on the campus of the Texas School for the Blind and Visually Impaired in Austin. Enrollment is limited to allow for hands-on participation. Registration information is available at <www.tsbvi.edu>.

November 13 - Technology for Students with Multiple Impairments: Using a Team Approach to Assess Needs and Implement Use

December 11 - What's New in Technology for Students with Visual Impairments: An Overview of the Latest Technology

**January 21 & 22 -** Using Duxbury to Prepare Materials in Braille

**February 12 -** Everything You Want to Know About Using Screen Readers with Email

#### **Distance Broadcasts on TETN**

Contact your regional ESC consultant to see if they will be connecting to these broadcasts. Broadcasts are from 1:30-3:30 P.M.Central Time. Sorry, these broadcasts are not available outside of Texas.

October 20 - Issues in deafblindness:
Involving deaf education in programming
for deafblind students

**November 17 -** Motor issues for older students with visual impairments

**January 19 -** A review of the Accessible Graphing calculator with Susan Osterhaus

**February 16 -** Conducting a Functional Behavior Analysis on students with visual impairments

**April 20 -** Transition issues for students with visual impairments

#### Josephine L. Taylor Leadership Institute March 11-13, 2005

Location: Boston MA, Marriott Long Wharf Hotel Registration Information: <www.afb.org/jltli.asp

#### SEE/HEAR

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> TSBVI Outreach 1100 West 45th Street Austin, Texas 78756

If you no longer wish to receive this newsletter, please call Beth Bible at (512) 206-9103 or email <br/> bethbible@tsbvi.edu>.

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