

# SEE/HEAR

A QUARTERLY NEWSLETTER ABOUT VISUAL IMPAIRMENTS  
AND DEAFBLINDNESS FOR FAMILIES AND PROFESSIONALS

**A collaborative effort of  
The Texas School for the Blind and Visually Impaired and  
Texas Commission for the Blind**

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**The Three Amigos**

By Alaine Hinds, Jennifer Vincent and Annette Oseguera,  
Texas Association for Parents of Children with Visual Impairments  
(TAPVI) Members, Houston Area  
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Summer 2004

*Abstract: Three parents share their thoughts on their friendship, the bond between their children, and supporting each other through their personal journeys of having children who are visually impaired.*

*Keywords: family, blind, deafblind, friendship, support*

*Editor’s Note: the following article appeared in the first newsletter produced by TAPVI. Alaine Hinds, TAPVI Co-Chair, shared in her introduction that she turned to her best friends, known to many as The Three Amigos, to help her write an article about their friendship and the bond between their children. While her intention was to combine all of their*

*thoughts to make a story, her friends' thoughts were as unique and individual as the three of them.*

*To learn more about TAPVI, please visit their website at <[www.tapvi.org](http://www.tapvi.org)>. To become a member, leave a telephone message stating that you would like a brochure. Their toll-free telephone number is 1-866-99TAPVI (1-866-998-2784). Please note that TAPVI has recently experienced difficulties with their telephone and mailing address so if you have tried to contact them in the past six months and not received a response, please contact them again. Written correspondence can be sent to 12801 Midway Rd., Suite 212, PO Box 231, Dallas, TX 75244. You may also communicate with them via email at <[info@tapvi.org](mailto:info@tapvi.org)>.*

## **THE UNSPOKEN WORDS OF FRIENDSHIP BY JENNIFER VINCENT**

My daughter, Alexandra has two incredible friends, Rebecca and Annette. The girls and moms have bonded over the past three years of their life because of their disabilities. Their “disabilities” have provided a great opportunity and “ability” to form friendships at such a young stage of their lives. The girls attend numerous events together including birthday parties, conferences, and social activities. The three girls share a love for music and attend music class once a week. Rebecca and Alexandra share the same classroom at school while our dear friend, Annette, receives services at home. The girls enjoy story-time at the public library, Mardi Gras for special people in Galveston, and the Strawberry Festival in Pasadena. I think our girls have a better social life than most adults do, and how blessed they are for that. We call them “the three amigos.” All three girls

would be considered nonverbal at this point but they know, recognize and love each other.

I would like to encourage all families with children who may have a disability to promote socialization as early as possible. All children need friendship and, more importantly, deserve friendship. Friendship is natural, but with our children it helps if we provide them with the opportunity to form the friendship. We all want our children to be as independent and self-sufficient as possible, but please remember, we don't want them to grow up lonely. As a parent and as an adult, I survive life by my friendships. Friends get us through tough times and help us enjoy the best of times.

### **MAKING FRIENDS BY ANNETTE OSEGUERA**

In 2002, several months after my little Annette had been trached, she was doing good health wise. I figured it was time to go out and meet other parents and make connections. The first parent group I went to was in Pasadena. It was at this meeting that I met Alaine Hinds and her daughter, Rebecca. Yes, I remember hearing that distinctive voice across the room. Alaine was talking about the problems she was having with ECI. I tuned into that. I was in the same boat as she was. Before the meeting, I had bought a new 2003 calendar appointment book, which I was using to write down notes from everything I heard. After the meeting, I went outside and started talking to Alaine. I asked her about the resources and services Rebecca received. She said, "Here, let me give you my number." She proceeded to write her phone number in my spanking new appointment book. Not only that, but she wrote it in pen, thus sealing our friendship, making it permanent.

It was at ECI's Christmas party that I saw Alaine again. We talked for a while and she told me about her friend, Jennifer Vincent. She thought I should really meet her. Well, it was days, maybe even weeks before I called Alaine again. We were going to meet at Hope's Mardi Gras Ball in Galveston. Jennifer would be there. By the time I found Alaine, my son Amadeus and little Annette were ready to go. I briefly talked with Jennifer, but I did meet beautiful Alexandra and her siblings Destiny and Bryant.

Little did I know that chance meeting with Alaine and that brief encounter with Jennifer would blossom into strong allies and friends in the special needs roller coaster ride, which I find myself on. Now, I have someone who knows how I feel, can listen without making judgments, shows no pity only empathy at my daughter's situation, and is genuinely happy at the little accomplishments my children achieve. I can unload and reload with both of my friends. The most wonderful facet of our alliance is the friendship our children have made with each other. When all of our children get together Alexandra, Amadeus, Annette, Bryant, Destiny, Luke, Rebecca and Sarah always have someone to play with. They share the same characteristics among each other as Jennifer, Alaine and myself. Annette, Alexandra and Rebecca's friendship mirrors our own. They know when the other is around and have come to know each other very well. Annette knows Alexandra the "hair puller" and Rebecca "the kicker." Her eyes will pop open when she hears their yells or laughs and she will frantically turn her head trying to find them. Because of their joyful clamor, Annette has begun voicing. Because of their movement, Annette has begun moving also. First her eyes, then her head, and now her body. Annette has become

more attentive and observant from being around such a big group. Like her mama, my little angel knows when her friends are around. You can just feel the warmth and know that you are not alone.

## **SILVER AND GOLD BY ALAINE HINDS**

When I first learned that my daughter was multiply-disabled, I grieved for all that she would not have. Friendship was one of the things that I feared was out of her reach. I was wrong. My three-year-old daughter has several friends; two are her best friends. Alexandra and Annette are special not only because they share in their disabilities, but also because they truly enjoy each other's company. My daughter has spent much time in music classes, play groups, and Lighthouse activities with these two girls. In fact, when you see one of them, you usually see the other two close behind. The bond between my daughter, Rebecca, and her friends is evident to all who see them. Most people now refer to them as the "three amigos."

My daughter has taught me a lot about friendship. She is the reason I have met my best friends. She has also shown me that friends don't have to talk to communicate. They don't have to walk to spend time together. They don't really have to do anything to be aware of the other person's companionship. Friendship is not really all that complicated. Rebecca, Alexandra and Annette have formed a truly unique bond over the last couple of years. They are blessed to have each other and they seem to know it.

I have become very close to the mothers of these wonderful girls. We have become best friends, also. We depend on

each other for support, companionship, and...well, I depend on them for everything. There is not anything I would not do for these two moms, and I feel confident the feeling is mutual. The girl's siblings have also connected and attend events like "Sibshop" together. We celebrate birthdays and milestones together as families. All of this because our girls share disabilities. There is a Girl Scout song that I learned when I was young that talks about friendship as silver and gold. My daughter and myself have found our silver and gold.

### **Ms. Vic's Volleys**

By Victoria Juskie, IPVI Treasurer

Reprinted with permission from IPVI Outlook

Illinois Association for Parents of Children with Visual Impairments

<[www.geocities.com/ipvi2002/](http://www.geocities.com/ipvi2002/)>

*Abstract: A parent shares her personal journey in understanding her son's visual impairment and being reminded of children's wonderful ability to be resilient and independent.*

*Keywords: Family, blind, deafblind, personal story*

*Author's note: Each child's vision, physical and mental issues vary so this is solely from my perspective as a mother of an 8-year-old with aniridia, nystagmus, and foveal hypoplasia. In layman's terms this means he sees at 10 feet what someone with 20/20 vision would see at 200 feet; he has a perpetual eye motion; and he's extremely light sensitive. He has poor depth perception but other than this is not physically or mentally challenged. He is currently learning Braille but can see print which is 14 pitch or higher by reading the print about two inches from his face.*

For a long time after our child was born we felt we were living under a dark cloud because of the many unknowns yet to come. For example, will he develop tumors in his kidneys, too? Does over use and strain deteriorate what vision he has? Will he lose his vision altogether? Besides direct pain while in bright sunlight, must he avoid going outside because it could have adverse effects on his vision? Will dark glasses and caps sufficiently protect the eyesight he has remaining? All these things still aren't answered, but we do the best we can.

As you know, for the first three years or so of a child's life, they really don't grasp what is being asked of them regarding the professional-posed vision questions. Articulating medical information about the concept of vision is hard enough for me to understand let alone a toddler. All a child knows is you're upset and worried. It's something about his eyes. Until he talks and conceptualizes vision to tell you, you just do your best at guessing for him. When I responded to the ophthalmologist's questions, my answers were based on my observations on how he reacted in every day life to objects and/or things in print. So you patiently wait for your child to talk to you and convey how things are. Then you find out that eyes usually continue developing until a child is seven or so, sometimes you really won't have a definite long-term prognosis until then, during which time your over-protectiveness may kick in.

For me, during the first three years of his life, I kept all twenty-three windows in our home covered with dark curtains and blinds. I only opened them for cleaning. Since my son is very light sensitive, I tried to protect him as much as possible.

He wore lightly darkened glasses indoors and the darkest glasses we could find outside since he was six months old.

He went through 0-3 intervention commencing at six months old and entered preschool at 36 months with itinerant vision services on a weekly basis. We learned all we could about his issues and struggled through it all. Our goal was to keep whatever vision he had.

But one day I found out I was going overboard. He came home from a regular preschool day and I was cleaning windows. He said, "You should keep the blinds open. I like the sunlight coming through the windows." At that moment, the cloud lifted. I no longer felt I had to physically live in darkness for my son. He was three and he told me that sunshine was good. From that moment I began to heal from the inside out emotionally. My son was going to go to a regular school on the bus with the other neighborhood kids, and he liked sunshine. Yes, he's going to have some rough time, but he was enjoying his life to the fullest.

## **Seven Habits of Highly Effective IEP Teams**

By Eileen Hammar & Anne Malatchi

(with acknowledgment and thanks to Stephen R. Covey)

Reprinted from The Parent Advocate Quarterly,

Published by Partners Resource Network, Inc., Beaumont, TX.

*Abstract: Using Stephen R. Covey's Habits, the authors share their recommendations on building highly effective IEP teams.*

*Keywords: Family, blind, deafblind, self-determination, IEP team strategies*

*Editor's Note: Fifteen years ago, Stephen R. Covey published the classic *The Seven Habits of Highly Effective People*. In an interview with Julie Chen, *Early Show* co-anchor, on November 12, 2004, Covey described *The Seven Habits Of Highly Effective People* as guiding principles that "...encouraged people to take a mindful approach to life --- not letting trivial urgencies of day-to-day life get in the way of the most important things." As you read the following article published in *The Parent Advocate*, I encourage you to expand the principles of *Seven Habits of Highly Successful IEP (Individual Education Program) Teams* to include the 8th Habit. What better way to develop an IEP that leads your child to find his own voice and do what he loves to do throughout his life!*

## **SEVEN HABITS OF HIGHLY EFFECTIVE IEP TEAMS**

### **1. BE PROACTIVE: TAKING INITIATIVE DOES NOT MEAN BEING PUSHY, OBNOXIOUS, OR AGGRESSIVE**

It does mean recognizing our responsibility, to make things happen. Fundamental in our efforts to become proactive members of the IEP/ARD teams is adopting an attitude that is collaborative and responsible. To be proactive requires a shift in our thinking from a deficit-based model of education to a capacity model. Often, goals for IEPs are developed as a result of a label or something that appears to be wrong --- i.e., reacting to a behavior that others do not think is acceptable. Proactive goals and objectives are based on the idea that the entire team is responsible for making things happen. John will use a transition object such as a computer disc when it is time to go to computer class. The

team realizes if John knows in advance it will soon be computer time, and can carry something with him where he is going, he will be less likely to exhibit challenging behaviors when asked to go to computer class.

## 2. BEGIN WITH THE END IN MIND

(This habit)...is based on imagination -- the ability to envision, to see the potential, to create with our minds what we cannot at present see with our eyes. Before developing an IEP, learn about the student. Be able to envision the future, the possibilities. What are his or her dreams? Nightmares? What are the learner's strengths and needs? Where does he or she want to live after school? What kind of job would he or she be filling? It has been too easy in the past to look at the small picture instead of determining what the end of the journey will look like. Once that picture is clear, it makes sense to decide what he or she must be taught in order to get there.

## 3. PUT FIRST THINGS FIRST

Create a clear, mutual understanding of what needs to be accomplished, focusing on what, not how; results, not methods. Spend time. Be patient. Visualize the desired result. Prioritize! It is impossible for anyone, in one year's time, to work on everything they would like to learn. Having nine or ten or more goals and dozens of objectives on an IEP is setting yourself up for failure. What is urgent or most important in the coming year that needs to be addressed on the IEP? It is better to come back and revise the IEP to add new goals and objectives. It shows progress and achievement.

#### 4. THINK WIN-WIN

*Win-win* means that agreements or solutions are mutually beneficial and satisfying. Consensus building is a key element of effective, collaborative IEP meetings. Reaching consensus indicates that power and control has been shared.

#### 5. SEEK FIRST TO UNDERSTAND, THEN TO BE UNDERSTOOD

*Seek first to understand* involves a very deep shift in thinking. We typically want to be understood. Most people do not listen with the intent to understand; they listen with the intent to reply. In truly collaborative IEP processes educators will listen to and understand parents; parents will listen to and understand educators.

#### 6. SYNERGIZE

It is teamwork, team building, the development of unity, and creativity with other human beings. Effective IEPs are those that have been developed collaboratively by a transdisciplinary team.

#### 7. SHARPENING THE SAW

It is the habit of continuous improvement that lifts you to new levels of understanding and to living each of the habits.

*Editor's Note: In November, Covey's sequel, The 8th Habit: From Effectiveness to Greatness, hit the bookstores. He describes The 8th Habit as adding another dimension to the first seven habits; a new mind set that is essential to surviving in today's world.*

*According to Covey, “The crucial challenge of our world today is this: to find our voice and inspire others to find theirs. “ This is what he calls the 8th Habit. “Finding your voice”, he says, “means finding what you love doing, that you feel passionate about, that serves a real need, and that your conscience tells you to do.”*

*Covey’s 8th Habit goes hand in hand with self-determination, which is often described as having knowledge, competency and opportunities to exercise freedom and choice in ways that are personally valuable.*

### **Uniting the Village**

By Juanita Barker, Regional Supervisor and  
Al’An Kessler, Children’s Specialist, Abilene, DARS –DBS,  
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Sharon Trusty, Education Specialist, Education Service Center  
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*Abstract: This article describes the unique collaboration between a number of the education service centers and the Department of Assistive and Rehabilitative Services - Division of Blind Services in providing training activities for parents and students with visual impairments in the Panhandle and West Texas regions of the state.*

*Key Words: Family, blind, deafblind, workshops, camps, collaboration.*

The year 2005 marks the eighth anniversary that a sprawling 91-county village consisting of counties in the Panhandle and West Texas decided to come together to better meet the needs of the children we all had a mission to serve.

*The Cluster*, as we named ourselves, was formed out of the simple recognition that what was undoable alone was achievable together. Results from this collaboration are a series of annual events offered to the children and families we serve. The powerful and effective nature of these collaborative events is best illustrated by the following quotes from families who have benefited from these services.

## **COMMENTS FROM THE FAMILIES**

*“This conference had information on (a) therapy method by Lilli Nielsen that will be very useful to help improve the quality of my child’s life. Networking with other families about doctors and therapists and equipment not available in my town. In addition to this – This conference gives families coping with children’s disabilities the opportunity to walk into a room full of people and not feel outcast. We experience compassion and understanding at this event that nothing else we take part in provides, not even church or family. We are empowered to prevail by each other’s struggle and success. This is so important for new, young parents and old war horses (like me). We draw strength from each other. Can anyone not living this life understand how closed out we feel sometimes?”*

## **PROGRAMMING**

*To see the families mingle on Saturday night is a pure joy. The children and adults dance, hop, follow, lead and visit like nothing else I have ever witnessed; there is a peace and an almost abandon about it. The joy of acceptance, I guess.*

*Two other points I want to make are these: Many of the families are probably unable to articulate their feelings on this, and more important it is often days or weeks after the conference (before) we can wrap our brains around all we learned this weekend. I thank you from the bottom of my heart for your financial assistance for this event. It is a ray of light in a dark, lonely world.”*

*“Good networking opportunity finding other families in my area.”*

*“Allow(s) me to be a better advocate for my child. Useful info on transition and preparing for ARD process. Wonderful help in networking with other families.”*

*“We have received valuable information to help us understand the ARD process and how to help the committee understand our child’s needs. We also gained knowledge on how to get our daughter to explore her environment and items around her. We are from a rural area and do not always get to meet families with needs and disabilities like ours. The information and relationships formed at this conference have been the most valuable.”*

*“I was really excited to learn specific techniques on how to teach my VI child how to communicate with me and my husband and especially others.”*

*“Things I can do with my child at home. First time here and enjoyed talking to other parents. Would like to come back next year and meet some more parents, and bring my baby back because she’ll be older and she’ll be able to enjoy it.”*

*“Learned new ways to let my child explore her world and interact with others. How to use play for teaching which has been a real problem with her multiple impairments. I also learned about new tools that are available or that we can make ourselves. Networking and talking with other families who are in similar circumstances or have dealt with similar problems already is very useful and provides needed emotional support.”*

*“Will help us to make decisions that are best for our children.”*

*“Because of this conference I have gained info on how to begin preparing for my child’s future. I have also met people who have the same needs as my family. I hope we have this conference each year, because I know I will need answers to more questions as (my child) grows up.”*

*“There were several good presenters that gave us good information that I will put to use with my VI/Multi-handicapped child in school through IEP’s and ARD meetings. Keep the conferences coming! The conference allows for families to meet and greet and continue networking and helping each other throughout the year. We look forward to coming from year to year.”*

*“I have learned how to better plan for my child’s future and what steps to take in getting started.”*

*“Gained lots of informative information concerning school and home activities to better serve my child in learning to deal with his disabilities.”*

## **UNITING THE VILLAGE**

This article is in response to the multiple requests we have had from others wanting to “unite their villages.” The process we recommend involves three steps and a number of key components.

### **FIRST, IDENTIFY WHO IS IN “YOUR CLUSTER.”**

The Cluster is comprised of families and service providers in a 91-county area of North and West Texas that includes the cities and areas surrounding Abilene, Amarillo, Lubbock, Midland/Odessa, and Wichita Falls. The service providers include the Division for Blind Services (formerly Texas Commission for the Blind), Education Service Centers in Region 9, 14, 16, 17, and 18, the Outreach Department of Texas School for the Blind and Visually Impaired, and Texas Tech University.

### **SECOND, MEET AND ESTABLISH YOUR COMMON GOALS AND OBJECTIVES.**

Each partner in the village brings a different set of resources, experience, and expertise to the table, but it is the combining of these differences that allows the creation of a group that derives its strength from its diversity.

### **THIRD, DETERMINE THE ACTIVITIES THAT WILL MOST EFFECTIVELY MEET YOUR NEEDS.**

*The Cluster* currently offers a wide range of confidence-building, group skills-training opportunities that include annual activities (Family Conference, Camp VILLA, Camp Experience, Project SWEEP), and one-day events.

## **SPECIFIC EVENTS SPONSORED BY THE CLUSTER**

### **FAMILY CONFERENCE**

A weekend-long conference that offers training to parents, caregivers, children with special needs, siblings, professionals and paraprofessionals. The training topics are determined by input received from families. Our next conference, "Discover the Magic Within," will be held on April 1-3, 2005 in Lubbock. This year's sessions will target the areas of deafblindness, multiple impairments, transition, infancy, preschool, resources and independent living.

### **CAMP VILLA**

VILLA: Vocational, Independent Living, Leisure/ Recreation Activities. This marks the 20<sup>th</sup> anniversary of our week-long camp held at Ceta Glen near Happy, Texas. The 9 to 15 year old campers participate in rigorous confidence and skill-building activities such as primitive tent camping on the prairie, mountain climbing in Palo Duro Canyon, and orienteering in the rugged outdoors. Camp VILLA is June 6-10, 2005.

### **CAMP EXPERIENCE**

Camp Experience was designed to introduce the camping experience to families with younger children as well as children whose needs might limit them in other camps. This camp is open to children who are not attendees of

Camp VILLA or Project SWEEP. It was designed to be a family camp where all members of the families benefit from a variety of confidence, skill-building activities. These include swimming, a ropes course, wall climbing, as well as nature hikes, crafts, and an evening by a campfire. Specialists are on hand to provide assistance with education, therapy, networking, and skills training. This year's camp will be August 1-4, 2005 at Camp Butman, near Merkel, Texas.

## PROJECT SWEEP

Job training and independent living skills are the focus of this five-week program for students who are 14-21 years of age and enrolled in public school. The Project is held in Lubbock. The students reside on the Texas Tech University campus and acquire summer jobs at various sites in the city. They have the opportunity to work with job coaches and develop job skills, travel on public transportation, using both local and long distance buses, develop and perform independent living skills such as laundry cooking shopping. One of the most valuable benefits is the opportunity to have ongoing social interactions with peers and community members. Project SWEEP will run June 20 to July 22, 2005.

## ONE-DAY TOPICAL WORKSHOPS

Various training opportunities for families and professionals on a variety of topics are offered each year.

## **KEY COMPONENTS OF THE COLLABORATION**

Key components to develop a powerful and strong group that is able to deliver world-class services to children who are blind and visually impaired and their families are:

1) EACH PARTNER WILL HAVE DIFFERING RESOURCES AT DIFFERENT TIMES.

Don't allow your cluster members to get bogged down by "Each partner's contribution has got to be equal for each event." Value each member's contribution. Recognize that each member's resources will vary from event to event and from year to year.

2) MAKE SURE THAT WHAT YOUR GROUP OFFERS TO CHILDREN AND FAMILIES IS DRIVEN BY ASSESSMENT, FEEDBACK AND EVALUATIONS OF THOSE YOU SERVE.

It HAS to be about these expressed needs, not what you "think they need". Planning for each event should be driven by the regional needs assessments that have been done and feedback received through evaluations and input from the families and students throughout the year.

3) LEAVE YOUR INDIVIDUAL IDENTITIES (AGENDAS, TERRITORIAL CONCERNS, CONFLICTS, TURF ISSUES, POLITICS, ETC.) AT HOME.

Come together as a group with the intent and purpose of creating something new. Each partner must have an equal, valued, and valid voice. Disagreement is part of the creative process. It must be done in an accepting atmosphere through a proactive, open process. Ultimately, all must come to consensus; discard individual differences and support fully the group decisions.

#### 4) ALLOW THE TIME TO MEET AND WORK AS A GROUP.

It is an evolutionary process. Like with any village, you must get to know one another, identify individual strengths, develop trust, and each of you must be committed 100% to give “birth” and “raise” the results of your village’s efforts. Having regular times to meet and discuss goals and issues without distractions is critical to this type of collaboration.

Do not veer in your commitment. You can unite your village. The rewards will far exceed the effort.

### **Hearing Aids**

Jim Durkel, CCC SLP/A

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*Abstract: This article provides basic information about hearing aids, assistive listening devices and cochlear implants and how they are fitted for children with deafblindness and additional disabilities.*

*Key Words: Programming, deafblind, hearing aids, assistive listening devices, cochlear implants*

A hearing aid is a device that helps a person with a hearing loss get better access to sound. Some of the earliest devices looked like huge horns or trumpets with the listener holding the small end to his or her ear and pointing the larger end towards the speaker. The good news is that hearing aids have become more sophisticated and useful to more people since that time. The bad news is that hearing aids have

become more expensive and rely on fine electronics that often need repair, especially when worn by a young child!

Today's hearing aids use batteries for power, have microphones to take in sounds, have circuits that make the sounds louder and have some way to get the changed sound to the listener's ear.

## **SIZE AND HOW THE HEARING AID IS WORN**

The first way that we categorize hearing aids is by the size and how the hearing aid is worn.

The largest hearing aid is called a body aid. A body aid is about the size of a pack of cigarettes. It is usually held to the listener's chest with a special harness or is carried in a shirt pocket. Body aids used to be necessary for listener's who needed power but as technology has improved they are no longer used very often. Body aids need to be connected to the users ear with ear molds. A wire runs from the hearing aid and connects to the ear mold by way of snap ring.

Behind-the-Ear (BTE) hearing aids are the most common type of hearing aid worn by children. The hearing fits behind the child's ear and is connected to the ear by the use of an ear mold. BTE hearing aids have the advantage of being small but still able to deliver power when needed.

A BTE aid will have a compartment to hold a battery, an on/off switch, and a volume control. Sometimes the on/off switch will have a setting marked T as well. We will talk about the T setting later.

The BTE has a curved hard plastic piece coming out of hearing aid and connecting to the tubing on the ear mold. This part is called the tone hook. Some times changing a tone hook's size and shape can help a BTE aid fit better.

It is easy to lose a BTE aid because they are small. Another problem is that even though BTE aids are small, they can be large compared to a young child's head. Sometimes there just isn't enough ear to hold the BTE against the child's head. Fortunately there are some things that can be done to solve the problem. Adjustments to the tone hook or ear mold often can help hold the hearing aid more tightly to the child's ear. There is also a piece of tubing, called a "Huggy", which connects to the hearing aid and helps hold it against the head.

The other types of hearing aids are In-the-Ear (ITE), In-the-Canal (ITC), and Completely-in-the-Canal (CIC). These smaller aids don't have as much power as BTE aids and are not typically recommended for children. These hearing aids are small and not very noticeable when worn. However, the hearing aid is built into the ear mold. Whenever there is a need for a new ear mold, the hearing aid user is without the hearing aid. Also because of the small size of the hearing aid, very good fine motor control is needed to operate the switches and replace batteries.

## **CIRCUITS**

Until recently, all hearing aids used analog circuits. What is important to know about these hearing aids is that while powerful, this type of hearing was not as adjustable as the newer (and more expensive) digital hearing aids.

Fitting a hearing aid is the process of making sure that the hearing aid is right for the listener's hearing loss. The first part of fitting an aid is to get a good behavioral audiogram. We want to know at what intensity level (decibels or dB) the listener can just detect whether or not a sound is present. This is called the threshold. We need thresholds across the frequency range of speech, from 250 Hertz (low pitch sounds) to 8000 Hertz (high pitch sounds). Hertz is a measure of frequency and is abbreviated as Hz. We look at the threshold the listener has without hearing aids, then look at what we would like the threshold to be. The difference is how much "gain" we need at that frequency. We pick and adjust hearing aids to provide just the right amount of gain for each frequency we test. This is why it is important to have an unaided behavioral audiogram and then redo the testing with the hearing aid; this lets us measure the actual gain the listener is getting.

If the listener can repeat words, it is best to do word discrimination testing with and without the hearing aid. During word discrimination testing, the listener repeats list of words and the percent of words repeated correctly is the word discrimination score. If the word discrimination score doesn't improve significantly, the hearing aid is not a good fit for the listener. Unfortunately children, especially those who are young or who have multiple impairments, can't do word discrimination testing. Therefore aided and unaided behavioral audiograms are even more important in hearing aid fitting for these children.

While both analog and digital aids may be able to be programmed, analog aids do not allow for as precise setting

of gain as digital aids. Digital aids have some additional “bells and whistles” that analog aids can’t offer. For example, digital aids do a better job at detecting noise and filtering it out. Digital aids also may have a feature that helps prevent feedback (whistle) that can happen when ear molds don’t fit tightly.

Many hearing aids have a feature known as compression. Compression means the hearing aid will amplify quiet sounds more than loud sounds. Without compression, hearing aids will make already loud sounds louder. This can be painful and irritating to a hearing aid user.

Some hearing aids may have multiple programs. That is, the listener can select a setting for listening in quiet and a different setting for listening in noise.

Generally, the hearing aid will be set so that the listener uses it with the volume control set about half way. This gives the least amount of distortion. If a listener is constantly changing the volume control, this may be a sign that the hearing aid was not correctly fit to the listener.

## **MICROPHONES**

All hearing aids use microphones to take in sounds from the environment. In typical auditory systems, we take have two ears that take in sound. It is usually best if a hearing user has two microphones at ear level. Having a microphone on each side of the head helps with an important auditory skill, localization. Localization is the ability to know from where in space a sound is coming. This skill is used during orientation and mobility training.

In a body aid, those microphones are on the hearing aid and so are at the level of the listener's chest. This kind of arrangement does not allow for good localization.

BTE hearing aids can have directional or omnidirectional microphones. Omni directional microphones pick up sounds more or less equally in 360 degrees. Directional microphones pick up sounds in coming into the front of the hearing aid more than sounds coming in from other directions. Directional microphones may improve listening in noise but may make localization for travel harder.

## **HEARING AIDS AND ASSISTIVE LISTENING DEVICES**

Even with the most sophisticated hearing aids, listening in noise is always hard. Localization may be affected. Following conversations in a large group is a very difficult listening situation. An assistive listening device (ALD) might be needed in conjunction with the hearing aid to help with some of these problems. See <<http://www.tsbvi.edu/Outreach/seehear/winter03/ald.htm>> for more information about ALDs.

Remember the T setting on the switch controls? T stands for telecoil. This is an alternate way for sound to get into the hearing aid. Inside the hearing aid is a coil that can receive electromagnetic energy. Old telephones used to leak this energy and hearing aid manufacturers took advantage of this fact to help hearing aid users use the telephone more efficiently. These days, you have to special order telephones that leak this energy. Children use the T setting most often to connect the hearing aid to an assistive listening device.

There are other ways to connect a hearing aid to an assistive listening device, such as the use of a “boot.” This is a connection on the hearing aid that allows the hearing aid to be directly connected to an ALD. There are some hearing aids that are built to receive information from a remote microphone; the ALD is built in. It is usually preferable to use a personal hearing aid in conjunction with an ALD rather than using the ALD as a personal hearing aid. This is because hearing aids can usually be better individualized than an ALD.

## **BATTERIES**

Depending on the type of hearing aid and how long each day the listener wears the hearing aid, a typical battery life is 5 to 7 days. Batteries can go any time so it is a good idea to always have spares handy. Hearing aid batteries can look like candy to young children, so care must be taken to dispose of used batteries. Sometimes the most economical thing to do is to join a hearing aid battery club where one can get batteries at a discount as well as getting free packs for every so many packs purchased.

## **EAR MOLDS**

All BTE and body hearing aids need a separate ear mold. The ear mold fits tightly in the ear. Ear molds need to be custom-made for the hearing aid user. They come in a variety of materials and colors. It is not uncommon for children to need a new ear mold every 6 months or so because as the child grows, the ear mold doesn't fit tightly any longer.

If a child is having middle ear infections, there may be feedback with the hearing aid even if the ear mold has a tight

fit. If a child has an infection of the ear canal, it can be painful to wear the ear mold. Sometimes hearing aid users have allergic reactions to one ear mold material and have to have the ear mold remade in another material.

Various modifications can be made to the ear mold to make it lighter, more comfortable, and more appropriate for a particular child's hearing loss. Talk with your audiologist or hearing aid dealer if it appears the ear mold is causing discomfort for the child. Sometimes the ear mold just needs a little bit of buffing to remove a small, but irritating, rough spot.

Ear molds need to be cleaned on a regular basis. It is common for earwax to accumulate in and block the ear mold. A mild dish soap and warm water can be used to clean the ear mold. Be sure to let the ear mold dry thoroughly before using it.

Ear molds can be "lubricated" to help get them into a child's ear. Just don't use any petroleum-based product, like Vaseline, to do this as these can cause some ear mold materials to disintegrate.

## **LEARNING TO USE A HEARING AID**

Hearing aids do not restore hearing or make hearing "normal." They help make some sounds more available to the listener. It is not reasonable to think that it is okay to just put a hearing aid on a child and that will take care of the child's hearing loss.

It may take some time for the child to become used to wearing the hearing aid. Ear molds can be uncomfortable to wear, but over time the hearing aid user learns to ignore

them. Hearing aids are giving the child auditory information the child never had before. At first, this information may be overwhelming and frightening to the child. Children may need some specific training to learn to use the new auditory information the hearing aid brings.

Auditory training is an important part of learning to use his or her hearing aid. This includes not only learning to use the auditory information coming in through the hearing aid but also learning how to care for the hearing aid itself.

## **BUYING AND MAINTAINING A HEARING AID**

The life of a hearing aid, even when well maintained, is five to seven years. Hearing aids wear out and when worn by children can be subjected to quite a bit of abuse! It is always a good idea to buy hearing aid insurance when buying a hearing aid. This way costs for repair and/or replacement for lost aids is covered.

Hearing aids can cost anywhere from several hundred dollars to several thousands of dollars. Sometimes private insurance will cover the cost of the hearing aids. For families who meet Medicaid eligibility, Texas has a program known as PACT (Program for Amplification for Children of Texas) administered through the Department of Health. For more information on PACT, see <<http://www.tdh.state.tx.us/audio/pact.htm>>. For families who don't meet Medicaid eligibility and do not have private insurance may have to explore community resources such as Lions or Soroptomist clubs. For children who are deafblind, the Texas Commission for the Blind may be able to help a family find resources to help cover the cost of hearing aids. Of course, the local

teacher for students with hearing impairments may be able to help find local resources, too.

Children with hearing aids should have their hearing with and without the aids tested at least every year. We want to be sure that the child's hearing hasn't changed and that the hearing aid is still a good fit for the child.

A hearing aid can only be of benefit if it is appropriately fitted, worn consistently and constantly, and is working at peak condition. This means that the functioning of the hearing aid should be checked daily. See <<http://www.tsbvi.edu/Outreach/seehear/spring00/hearingaids.htm>> for more information about checking hearing aids.

## **COCHLEAR IMPLANTS**

Sometimes a hearing loss can be so great that conventional hearing aids may not provide enough benefit. If aided thresholds aren't at least 30 decibels or more at least through 2000 Hertz, it might be time to consider the use of a cochlear implant. This is not a decision to be made lightly and requires consideration of several factors beyond just aided and unaided thresholds.

## **CHILDREN WITH MULTIPLE IMPAIRMENTS**

Children with multiple impairments, including deaf-blindness do have some different considerations with regards to hearing aids than children with hearing loss alone.

Obtaining good behavioral audiograms (unaided and aided) may require more time and effort. Teaming will be important to help make this happen.

Teaming will also be important when considering the impact of hearing aid use on orientation and mobility training or the use of assistive technology.

Teaming is necessary to discuss the impact of wearing a hearing aid when there are physical disabilities. For example, wearing a BTE hearing aid while in a wheelchair with head support may result in lots of feedback. In this situation a body aid might be a better fit. Some children have no ear in which to put an ear mold and may need use a bone conduction hearing aid.

Finally, teaming is important to insure that all adults in contact with the child who is using a hearing aid understand the importance of consistent use of the aid, understand what auditory skills to expect from the child, and how to deal with any problems related to hearing aid use.

It is important to keep in mind that if a child needs a hearing aid, that child should have an educational label of auditorially impaired (AI) and should have a teacher for students with hearing impairments. This teacher would be able to serve as an information resource as well as serving as a coordinator around audiological testing and hearing aid issues.

Hearing aids, when fitted and used properly, can open up a whole new world to our children with hearing loss!

# **Supporting High Quality Interactions with Students Who Are Deafblind Part Two: Research to Practice**

By Craig Axelrod, Teacher Trainer, TSBVI,  
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*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, deafblindness, Jan van Dijk, research-based, interaction, behavior, communication, educator-oriented intervention, instructional strategies, video analysis*

Based on current research sent by Dr. Jan van Dijk about interactions with students who are deafblind, and other resources, Kim Conlin, Tish Smith (communication specialists at TSBVI) and I designed a two-day training for TSBVI educational staff. To date, we have facilitated four trainings, with four participants (1:1 with students who are deafblind) in each training. In Part Two of a two-part article, this educator-oriented interaction training process is described. Part One, which appeared in the Fall 2004 edition of SEE/HEAR, summarizes research-based conclusions about the importance of supporting high quality interactions with students who are deafblind.

## **THE INTERACTION TRAINING PROCESS AT TSBVI**

When determining who will be invited to participate in interaction training, we consider interested staff who are

teaching students with deafblindness and understand the basics of good programming, such as how to structure a routine and use a calendar system. They have interaction challenges with their students that we want to address. Staff may also be teaching newer students we want to better understand. The students represent a variety of abilities and needs.

THE GENERAL LEARNING GOALS OF INTERACTION TRAINING ARE TO:

- Understand the unique characteristics of the child with deafblindness
- Understand the importance of student-initiated interaction
- Learn how to provide opportunities for the student to initiate interactions
- Learn how to recognize and interpret the student's interactive initiations and responses
- Learn how to respond to the student's initiations and responses in ways that support high quality interactions, positive relationships, exploration, learning and communication

Several weeks before interaction training, participants are asked to notice and think about the interactions they have with their students, then bring observations and questions to the first day of training. They are also asked to identify the "positive" interactive student behaviors they would like increased, and the "negative" interactive behaviors they would like decreased. As the training progresses, and more is understood about the unique characteristics of deafblind

children, interactions with deafblind children in general, and with their students in particular, questions, concerns and possible strategies for improving the quality of those interactions become more refined and specific.

On the first morning of training, after introductions and clarification of the general learning goals, information is presented about the interaction problems and possibilities of students who are deafblind (described in Part One). To help exemplify these ideas, participants view and discuss the videotaped interactions between a student and three adults. The three interactions are clearly very different, and the student's abilities also seem to differ. An Interaction Data form is introduced as a tool to help graphically represent those differences.

#### INTERACTION DATA

The Interaction Data Form codes these components of an interaction:

- Description of Turns: Each interactive turn is briefly described
- Interactive Turn categories (Each turn is assigned a letter, A-F, based on Rick van Dijk, et al.'s Observational Categories):
  - A. Student Initiates
  - B. Student Responds
  - C. Student Acts Independently or No Response
  - D. Adult Initiates
  - E. Adult Responds

## F. Adult Acts Independently or No Response

- Interactive Behavior categories (Each turn, the student's or adult's, is assigned a number, 1-8, based on Marleen Janssen, et al.'s Eight Core Categories of Interactive Behavior):
  1. Initiatives
  2. Confirmation
  3. Answers
  4. Turn Taking
  5. Turn Giving
  6. Attention
  7. Regulation of Intensity of the Interaction  
(additional behaviors of the adult for regulating the intensity of a student's behaviors include proximity [e.g., nearer or further away], pacing [e.g., faster or slower], animation [e.g., facial expression, size of movement], voice [e.g., inflection, volume] and touch [e.g., frequency, degree of forcefulness])
  8. Affective Involvement

(Note: Independent Acting is documented as Interactive Turn C or F)

- Connecting consecutive turns: Arrows are drawn between "related" consecutive turns, reflecting the duration of an interaction on a particular topic

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## Interaction Data Form

**Student:**

**Date:**

**Partner's Name:**

**Topic:**

**Interactive Turns:**

A - Student Initiates; B - Student Responds; C - Student Acts Independently / NR; D - Adult Initiates; E - Adult Responds; F- Adult Acts Independently / NR

**Interactive Behaviors:**

1 - Initiatives; 2 - Confirmation; 3 - Answers; 4 - Turn Taking; 5 - Turn Giving; 6 - Attention; 7 - Regulating Intensity; 8 - Affective Involvement

**Connect "related" consecutive turns with an arrow.**

<b>Description Of Turns</b>							
<b>Interactive Turns</b>							
<b>Adult's Interactive Behaviors</b>							
<b>Student's Interactive Behaviors</b>							

Coded video fragments from the three interactions are analyzed, to identify and compare components of the interactions that reflect their different characteristics and result in the student's varying degrees of interactive competence. Through this activity, participants also become familiar with the Interaction Data Form. Later in the training, they will use the form to code and analyze video fragments of their own interactions.

B is 19 years old and has microcephaly secondary to an encephalocele (a congenital protrusion of the brain through a cranial fissure). He's legally blind with a cortical visual impairment, is suspected of having a hearing loss, and has multiple disabilities that include mental retardation and cerebral palsy.

**Student:** B

**Date:** 5/02

**Partner's Name:** Teacher

**Topic:** Physical Therapy  
- Therapy Ball

**Interactive Turns:**

A - Student Initiates; B - Student Responds; C - Student Acts Independently / NR; D - Adult Initiates; E - Adult Responds; F - Adult Acts Independently / NR

**Interactive Behaviors:**

1 - Initiatives; 2 - Confirmation; 3 - Answers; 4 - Turn Taking; 5 - Turn Giving; 6 - Attention; 7 - Regulating Intensity; 8 - Affective Involvement

**Connect “related” consecutive turns with an arrow.**

<b>Description of Turns</b>	Teacher unbuckles seatbelt	Teacher takes towel	Teacher says, “Let’s get out of the chair,” etc.	Teacher stretches B’s arm	Teacher says, “There you go.”	Teacher stretches B’s fingers	Teacher picks up B to reposition
<b>Interactive Turns</b>	F	F	D	F	D	F	F
<b>Adult’s interactive Behaviors</b>	-----	-----	1	-----	2	-----	-----
<b>Student’s interactive Behaviors</b>							

B and the teacher—stretching on the therapy ball: The teacher talks to B twice in this fragment, but acts independently during the other turns. He prepares to move B, positions him on the therapy ball and stretches parts of his body with no interactive behaviors, no expectation for B to take a turn and no connected turns.

**Student:** B

**Date:** 5/02

**Partner's Name:** Aide

**Topic:** Eating

**Interactive Turns:**

A - Student Initiates; B - Student Responds; C - Student Acts Independently / NR; D - Adult Initiates; E - Adult Responds; F- Adult Acts Independently / NR

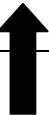
**Interactive Behaviors:**

1 - Initiatives; 2 - Confirmation; 3 - Answers; 4 - Turn Taking; 5 - Turn Giving; 6 - Attention; 7 - Regulating Intensity; 8 - Affective Involvement

**(See chart on page 40)**

B and the teacher aide – eating lunch: The aide is attentive to B, and waits until he's ready before offering a bite of food. B responds once by accepting the spoon (answering "Yes") and once by rejecting it (answering "No"). When he refuses the food, she offers a drink instead. Turns in both of these sequences are connected. She acts independently by wiping his mouth. There is no visible shared enjoyment (affective involvement) during the interaction.

**Connect “related” consecutive turns with an arrow.**

Description of Turns	Aide waits, then offers spoon	B takes a bite	Aide wipes B’s mouth	B chews and swallows	Aide offers spoon	B refuses bite	Aide offers drink
<b>Interactive Turns</b>	D	B	F	C	D	B	D
<b>Adult’s Interactive Behaviors</b>	1, 4, 6, 7		-----		1, 4, 6, 7		1, 4, 6
<b>Student’s Interactive Behaviors</b>		3, 4, 6		- - - - -		3, 4, 6	

**Student:** B

**Date:** 5/02

**Partner's Name:** Visitor

**Topic:** Conversation

**Interactive Turns:**

A - Student Initiates; B - Student Responds; C - Student Acts Independently / NR; D - Adult Initiates; E - Adult Responds; F- Adult Acts Independently / NR

**Interactive Behaviors:**

1 - Initiatives; 2 - Confirmation; 3 - Answers; 4 - Turn Taking; 5 - Turn Giving; 6 - Attention; 7 - Regulating Intensity; 8 - Affective Involvement

**(See chart on page 42)**

B and Visitor – having a conversation: B initiates the interaction, maybe unintentionally, by vocalizing. The visitor responds by asking “What,” which confirms B’s initiative and gives him a turn. B takes a turn, and initiates a new initiative, by extending the index finger of a hand in his lap (preparing to touch it to his nose). The visitor responds, takes a turn, and confirms B’s initiative saying, “There goes that finger to the nose.” He shows affective involvement with facial expressions and tone of voice. B does not initiate or respond. The visitor responds again to B’s previous initiative, and regulates the intensity of the interaction, by extending his own index finger, positioning it under B’s other hand, raising B’s hand and saying “hey” each time his own nose is touched. His affective involvement continues. B responds by lifting his finger, touching it to his nose, and smiling. The visitor responds, takes a turn, and

**Connect “related” consecutive turns with an arrow.**

<b>Description of Turns</b>	B vocalizes	Visitor says, “What?”	B extends finger in lap	Visitor says, “There goes that finger...”	Visitor lifts finger to nose, says, “Hey...”	B. lifts finger to nose	Visitor lifts finger to nose, says, “Hey....”
<b>Interactive Turns</b>	A	E	A	E	E	B	E
<b>Adult’s Interactive Behaviors</b>		2,5,6		2,4,6,8	2,4,6,8		2,4,6,8
<b>Student’s Interactive Behaviors</b>	1,4,6		1,4,6			4,6,8	



confirms B's actions by laughing, saying "hey" and touching his own nose again. B and the visitor are attentive to each other throughout the interaction. All turns are connected.

## DEVELOP GENERAL PROFILES

Prior to training, participants develop General Profiles of their students, by compiling information about them that impacts the quality of their interactions. This includes five general components:

1. Medical/Sensory Information: etiology, medications, vision (near and distant acuities, fields, and other visual considerations), hearing (functional implications of hearing loss with and without amplification, and recommendations), touch (hand guiding, tactile instruction, mutual tactile attention, tactile signing, etc.), as well as primary and secondary sensory learning channels
2. "Communication Assessment [based on the communication model developed at TSBVI for nonsymbolic and early symbolic students with visual and multiple impairments, including deafblindness]:
  - Form: the vehicle for conveying meaning; non-symbolic to symbolic
  - Social Aspects: these include the social skills and communicative functions which impact the quality of the student's interaction with other people

Social Interaction Skills: maintaining joint attention, bonding with primary caregivers, initiating an interaction, turn taking, etc.

Functions: requesting, rejecting, commenting, labeling, reporting on past events, etc.

- Communicative Content: what the student has to talk about

Topics: the specific subjects of interaction or conversation which emerge from the student's experiences with varied objects, people and events; swimming, snack, bathing, skating, etc.

Meaning Categories: the broad divisions for organizing topical knowledge. They provide a framework for teaching concepts and vocabulary; objects, actions, people, locations, attributes, etc.

Context: the situation in which communication occurs; here and now, past or future events, unfamiliar situations, etc." (Hagood, 1997, pp. 6-7).

The Communication Assessment often includes a description of the student's calendar system which, among its many benefits, plays "an important role in supporting and expanding students' communication." (Blaha, 2001, p. 10).

3. Present Levels of Educational Performance, especially in the areas of:
  - Language Arts
  - Social Communicative Interactions
  - Emotional Development
  - Organization - Senses and Motor Skills

- Basic Concepts
  - Representation/Cognition
  - Other (such as behavior)
4. Instructional Modifications: Examples include fine task analysis of activities, highly structured routines and learning environment, special materials to structure activities, extended time for processing, increased response time, concrete symbols, tactile symbols and special communication systems.
  5. Appetites/Aversions (Likes/Dislikes): “One sheet is completed for each student. Over a period of time, through observation and listening to stories from others, a list is developed of things the student likes and doesn’t like. We all enjoy things that we are good at and that we understand. A student’s ‘Likes’ will be areas of strength and indicate sensory channels that are working. ‘Dislikes’ will be areas of weakness and indicate sensory channels that may not be working efficiently. The information gathered on this form will suggest underlying themes that can be used for modifications, teaching strategies, topics of communication, and activities. (van Dijk, 1985).” (Blaha, 1996, p. 20).

After the video fragments of B’s interactions with the three adults are analyzed, participants review their students’ General Profiles and summarize them to the group.

## VIDEO ANALYSIS

Within a few weeks of training, a baseline videotape is made of each participant/student pair interacting during an

activity. When determining what to videotape, participants are asked to consider these criteria:

- They are 1:1 with their student
- Interaction (rather than independence) is a component of the activity
- The activity is, or has the potential to be, mutually enjoyable and/or satisfying
- The activity is familiar and occurs at least a few times every week
- The activity can be repeated during the training

After the General Profile summaries are shared, each baseline video is reviewed in its entirety, to provide an overall sense of the activity and to identify general participant and student interactive strengths and challenges. A few brief video fragments that highlight these qualities are selected for coding and analysis. The fragments are coded on the Interaction Data form, then analyzed to identify aspects of the interactions that are successful and possible causes of interactive challenges. Participants discuss ways the interactions might be improved, by changing their own interactive turns, interactive behaviors, and/or the interactive context. Student interactive turns and behaviors that might indicate progress toward improved interactions are also identified. For example:

- If coding indicates that most interactive turns progress from adult initiations to student responses (D to strategies that might encourage more student

initiations followed by adult responses (A to E) are identified.

- If an adult's interactive behaviors are predominantly initiatives (1) and turn taking (4), attention (6) to a student's actions, confirmation (2) of those actions, turn giving (5), regulating the intensity of the interaction (7), by slowing the pace or pausing, and affective involvement (8) may encourage the student to make more initiatives (1). Additional student interactive behaviors that would reflect a more preferred interaction include attention (6) and affective involvement (8).
- If few interactive turns are connected by arrows, indicating only brief interactions around topics, increased adult responsiveness to the student's interests could result in more turns on those topics.

On the second day of training, participants are videotaped as they incorporate new strategies into the same activities with their students that were taped for the baseline. Videos of the interactions are then reviewed, representative fragments are coded and analyzed, and strategies are further refined for future implementation.

At the end of the second day, to conclude interaction training, participants discuss what they've learned. They also describe how they will apply the principles of interaction training, in other situations with the same students and with their other students.

## CASE STUDIES

### *Matt and J*

J is 13 years old and deafblind due to prematurity. He is totally blind and has a severe to profound hearing loss, bilaterally (moderate when amplified).

J expresses interest and affection for his primary caregivers by smiling, laughing or hugging. He initiates familiar interaction routines when an adult is nearby. He maintains preferred, turn taking interactions for a long time. In stressful situations, these people can calm him with deep pressure hugs, redirection to a preferred activity, or by reviewing his schedule and giving him more time to process information.

J knows 125 receptive signs, and uses more than 60 expressive signs to request activities, interactions, assistance, and information about the day. These signs are often inexact, but recognized by familiar people. He'll place his hands in the adult's hands, sign "now" to ask about what's happening next, and sign "then" to ask about the day's sequence of activities. He is beginning to comment about past and future events. J recognizes at least 50 tactile symbols that represent activities on his calendar, identify possessions and activity areas, etc. He also uses them to choose between people, food and leisure activities.

J has a daily calendar, with an expansion strip that gives additional information about the "who," "what" and "where" of each activity, and a weekly calendar with a highlighted activity scheduled on each day. It's important to review J's daily

schedule with him throughout the day, especially in the morning. J anticipates and completes “next steps” in familiar routines.

J’s favorite topics are movement, food, sounds or music, and activities that incorporate these interests. He enjoys knowing what his peers are doing, attends to their actions if they’re close and, with support, will pass them materials in structured routines.

J may express frustration about changes in the schedule by refusing conversation, banging his head or crying. He often calms after multiple reviews of the new schedule, along with additional support and reduced demands.

Matt wanted J to communicate more spontaneously during his daily calendar discussions. The baseline videotape showed many interactive turns where Matt initiated and J responded (D to B). Matt decided to be more responsive to J’s initiations (A to E), and support his increased initiations on a topic (initiatives). It was thought that J might initiate more if he was encouraged to get his tactile symbols from their storage bag in the order they interested him, rather than prompted to get them in the order they occurred. After a conversation about each activity, he’d put its symbol on a slantboard (adapting the interactive context). When all of the activities had been discussed, the symbols would be brought from the slantboard and scheduled left to right on J’s daily calendar.

The strategies Matt introduced in the second taping included:

- Responding to J's initiation of touching a tactile symbol by touching it with him (confirmation, attention) then identifying/labeling and commenting (answers) about the activity represented by that symbol
- Signing "now" (turn giving) to establish a clear juncture between his response and an expectation for J to initiate something new about that activity or get another symbol (initiative)
- Using a third person to help model initiations for J from behind him

The change in expectations seemed to confuse J a little, but he did initiate more (sometimes with Matt's hands!) and had more initiatives on a topic. Matt was also more responsive (confirmation, turn giving) to J's initiatives. We learned that J initiates more when Matt pauses/waits (turn giving).

J was confused about putting calendar symbols onto a slantboard before scheduling them. This strategy needed to be further modified. The slant board was changed to a carpeted tray that sits on Matt's lap, between him and J (adapting the interactive context). This adaptation results in even more initiations from J. He now dumps all of his symbols for the day onto the tray, and initiates by handing to Matt a symbol he wants information about (initiative, turn giving). Matt responds (turn taking) by identifying/labeling and commenting (confirmation, answers) about the activity, then pauses and uses an open hand "What?" gesture (turn giving). This encourages J to initiate something new (initiative). After an activity has been discussed to J's satisfaction, Matt puts the

symbol where it belongs on J's daily calendar. When all of the symbols have been discussed and scheduled, Matt and J preview the entire calendar sequence.

Using a third person to model initiations with J was awkward, and was discontinued.

### *Laura and L*

L is 21 years old and has CHARGE Syndrome. He recently lost all of his vision, and has a profound bilateral hearing loss. L also has a history of perseverative, aggressive, destructive and mildly self-injurious behaviors, which are being treated with medication.

L enjoys interactions, forms bonds with adults and peers, and asks about them when they're not present. He expresses affection toward preferred people and encourages them to communicate with him. Before becoming totally blind, L initiated interactions by sight. He's now learning to get people's attention by tapping their arms or raising his hand, but interactions are most often initiated by others.

L has many topics of conversation, and an expressive vocabulary of approximately 200 signs, which he typically combines in 2-3 word phrases. He initiates conversation, in structured and unstructured situations, to request objects, activities, assistance and people, and to make comments. L also requests information about things that have happened in the past and will (or might) occur in the future.

L participates well in structured routines, has preferences and makes clear choices. L has a daily calendar with the

sequence of his daily activities and a monthly calendar for scheduling important events, such as which weekends he's going home or staying on the dorm, when he's going grocery shopping or to a restaurant, etc. Before losing his vision, L used standardized pictures, drawings, photos and some sight words with his calendar, for cooking recipes and other sequences, to label storage areas, etc. Calendar activities are now represented by object symbols and some alternate objects. Tactile symbols are gradually being introduced at the calendar and in a few other situations.

L is able to move about in his classroom without assistance, and has learned to travel many familiar routes independently. He's learning an organizational system for his calendar symbols and other symbols.

Laura wanted to have a more "connected" interaction with L during his footbath routine, which she knew he enjoyed. In the past, L had often introduced conversational topics unrelated to the activity at hand. After losing his vision he was constantly asking questions about current and former classmates (what they would be doing in 100 days, whether they were flying home that weekend or riding the bus, etc.). This also occurred during his footbath.

The baseline videotape reflected a chaotic conversation, with Laura and L initiating on different topics. (Laura communicated about the footbath while L asked about other students.) Only two or three turns were taken on the same topic. One person would initiate, the other would respond then initiate about something else (D to B to A to E to D to B to A to E, etc.).

Laura's goal was to increase the number of L's initiations around mutually interesting and less repetitive topics. She also wanted them both to have more turns (initiatives, turn taking, turn giving) around these topics. This would be reflected in the coding by more arrows connecting turns, indicating that Laura and L were taking multiple turns on the same topic.

Laura's strategies were:

- To make the footbath more mutually interesting (attention, affective involvement) by introducing novelty, such as wearing a toe ring
- To label the environment, reducing the need for "procedural communication" such as giving directions
- To share the activity more wholly with L by having her own footbath next to him. This would give her an additional role, besides helping L, answering his questions and following his commands, and create opportunities for them to help each other and comment on their mutual experience
- To encourage L to have more contact with the objects used in his footbath routine. This would enable him and Laura to increase their interactions around them

L smiled and enjoyed himself (affective involvement) during the second videotaped interaction. He and Laura took several turns around the same topic (more arrows!), and she responded more (confirmation) to his initiations.

We learned that introducing novelty to a topic helps L pay attention to it. Setting up the environment to give tactile procedural information, such as storing materials in consistent places and labeling storage areas (adapting the interactive context), reduces the need to tell him what to do, where to go, etc. He and Laura can then put more emphasis (attention) on mutual enjoyment (affective involvement) of the interaction. Laura will also begin using objects and parts of objects to support L's expanded conversation about other interesting topics, such as parties, changes in the schedule, etc., introduce more tactile symbols in the environment, and add tactile symbols of people to his daily calendar.

### *Hank and S*

S was born prematurely and is 9 years old. He has light perception in one eye and a moderate to severe hearing loss. He drinks Pediasure from a bottle and does not eat solid foods.

S will initiate interactions when a partner is near, but most interactions are initiated by others. He recognizes familiar people and initiates interaction games specific to each of them. He encourages (requests) interactions with others by smiling, laughing, signaling, repeating their words, taking and giving turns, saying "Thank you," and giving hugs. He can maintain interactions for up to 10 minutes on topics that incorporate music or movement, and will interact around topics with other sensory aspects (such as inflating and deflating balloons to feel the air, and imitating the sounds they make) for shorter periods of time. Some topics (for example, food and oral stimulation) appear to trigger strong negative reactions that disrupt interaction. He

discourages (rejects) these interactions by gently pushing away people or objects.

When S does not feel in control, he tries to end an interaction by saying “Finished,” or turning away from the activity. He is often less focused and more nervous in new environments or with novel materials. Information is taught within routines, which increases S’s sense of security and ability to focus. Novelty is infused into familiar routines to broaden his understanding of concepts and vocabulary. A divided choice board is used to present options within routines.

S understands numerous phrases spoken consistently in his routines and a few signs produced without speech. He can process signs and speech simultaneously. S expressively signals with his body and voice, hand guides adults, gives them objects, and is beginning to request leisure activities with tactile symbols during structured choice times. These symbols are stored in an accessible place so he’ll be able to initiate requests. He uses mitigated echolalia (repeating phrases previously heard in appropriate contexts for communicative purpose), and often repeats an adult’s spoken words immediately after hearing them.

S’s morning or afternoon activities are represented by tactile symbols in a 5-compartment calendar box. Expansion strips are used to pair two tactile symbols in each compartment, introducing the concept that familiar words can be combined in novel ways. Touch prompts remind him to scan left to right. Materials in S’s routines

are also sequenced in a calendar box, to provide additional structure and give him practice scanning left to right.

Hank was comfortable following S's lead during preferred interactions, such as playing with a balloon. He chose to analyze S's grooming routine because he wanted experience implementing interaction strategies during more outcome oriented routines. Hank's general goals were to feel calm during his interactions with S, be less directive and follow S's lead more often.

After reviewing the baseline videotape, he chose two specific interactive goals:

- The first was to help S stay engaged (attention) without becoming overstimulated (regulation of intensity of the interaction), by slowing the pace, using a quieter voice, focusing on feeling calm, and applying deep pressure to S's arms with lotion.
- He also wanted to make the routine more conversational, by pausing (turn giving) and allowing S to initiate (initiatives, turn taking), observing (attention) and discriminating between the behaviors S used to initiate, and appropriately responding (confirmation, answers) to those initiations.

During the second interaction, Hank was able to implement the strategies he'd identified. He felt calm, the pace was slower and the interaction more conversational. He paused more (turn giving), S initiated more (initiatives, turn taking), and he responded to those initiations (A to E). They both enjoyed the interaction (affective involvement).

S was drawn to the sensory experience of touching Hank's hair with his palms and face. When those behaviors lasted more than 5 seconds they seemed to cause sensory overload, which resulted in S hitting Hank and biting himself on the arm. During tooth brushing, Hank successfully redirected S's hand from his hair to his face before S escalated to the point of hitting or biting (regulation of intensity of the interaction). Simple, familiar labels spoken in a rhythmic manner, such as "jaw, jaw, jaw, chin, chin, chin, lip, lip, lip," helped S focus on (attention) and accept Hank's actions as his teeth were brushed. Simple, rhythmic vocal games (turn taking, turn giving) also seemed to organize, calm, and focus S (attention, regulation of intensity of the interaction). He knew where he would be touched and when. Hank's sound effects and funny voices also kept S engaged (attention, affective involvement).

While deep pressure to S's arms helped calm and organize him, he still showed signs of being overwhelmed by the lotion. S initiated more during interactions when Hank commented and paused (turn giving) instead of asking questions. By watching S's hands (attention), Hank got a lot of information about how S was feeling and what he was thinking. This helped him fine tune his responses to S's turns. We learned to keep interactive turns short in situations where S might become overstimulated, and to be sensitive about what his hands are "saying" during interactions (attention, regulation of intensity of the interaction).

Hank will continue to introduce rhythmic vocal play/turn taking games, that may incorporate sound

effects or funny voices, to help engage, focus, organize and calm S (attention, regulation of intensity of the interaction, affective involvement). He will offer deep pressure, but discontinue the lotion, and ask the OT for additional calming and focusing strategies. Hank will also encourage S to initiate interactive and conversational turns (initiatives, turn taking) by commenting then pausing (turn giving).

### *Sara and N*

N is 9 years old. She had a corpus callosotomy (surgical severing of the corpus callosum, the large fiber bundle that connects the two sides of the brain) at 4 years of age, to control seizure activity which began at 4 months. She has a cortical visual impairment and a suspected mild to moderate hearing loss. Without amplification (which she does not tolerate wearing), “She will at least be able to detect speech at a normal conversational level.”

N bonds quickly with her primary caregivers. These relationships are reinforced through resonance-level turn taking interaction routines, in which frequent pauses allow her to signal for continuation of the interaction. N is affectionate with familiar people, seeks them out and allows them to calm her when she becomes upset. Vibration, deep pressure touch and vestibular stimulation help calm N and enable her to attend. N will explore unfamiliar experiences with the people she trusts. Unexpected touching and guiding through movement may overstimulate her.

N receptively understands some object symbols, natural gestures and points. She will move toward, touch, or

physically guide people to desired objects, actions and locations. An object symbol placed in a single compartment calendar basket helps N anticipate the “next” activity in her day. She demonstrates recognition of these symbols by performing appropriate actions on the objects or moving toward the correct activity areas. The symbol is placed in a “finished” basket to conclude the activity. N shows a general awareness of the time of day by, for example, going to the breakfast table after arriving at school in the morning, and getting her jacket in the afternoon as she anticipates going home. She recognizes her classroom, calendar area, seat at the table and possessions.

A 3-step sequence box is used in some routines, such as breakfast, to help N anticipate the sequences of steps and to establish clear beginnings and endings. With other routines (for example, hygiene) she chooses the order of steps in the sequence. In general, N is more willing to participate in activities that have become familiar, when high demand activities are followed by those with low demand, and if she is allowed to observe and join in without being forced, then retreat and process the input. She is less distracted in learning environments where visual and auditory clutter is reduced.

Sara selected a hygiene routine to analyze, because she wanted to increase the length and improve the quality of her interactions with N during functional routines. After studying the baseline video, she decided to:

- Put more emphasis on creating and maintaining a positive social atmosphere and less on getting the job

done (regulating the intensity of the interaction, affective involvement)

- Increase the number of turns on N's topics (A to E)

During the second interaction, Sara responded more to N's topics (confirmation, positive answers, turn taking, turn giving, attention, affective involvement), and either decreased her focus on the routine (turn giving) or was willing to take breaks from it (regulating the intensity of the interaction). When N needed to stop and process information, Sara let her take breaks. By waiting during the pauses, and providing calming proprioceptive and vestibular input, Sara helped N manage her own biobehavioral state (regulating the intensity of the interaction). N was calmer after Sara provided this sensory input (attention) and seemed to benefit from it. The interaction lasted longer and N stayed in the activity area. There were more arrows between turns, indicating longer periods of connectedness within the activity, and the turns were on N's topics (C to E to A to E to A to E, etc.). When N signaled to make requests (initiatives, turn taking), Sara responded (turn taking, positive answers). During tooth brushing, N let Sara touch the toothbrush (turn giving), which she usually doesn't allow, and was attentive (attention) to Sara's imitation (confirmation, positive answers) of her actions. N and Sara both enjoyed this interaction (affective involvement).

We learned that the most effective way to support an interaction on N's topic is to pause (turn giving), notice her initiative (attention), and imitate that action (confirmation, positive answers). This verifies to N that her initiative has been acknowledged and approved.

Since the training, N has begun initiating interactions (initiatives, turn taking) from further away (indicating that she seems to be moving into a coactive phase of interaction), and attends (attention) for longer periods of time, sometimes for as many as 10 turns. The hygiene routine now goes on for quite a while, and sometimes must end before N's ready so she can participate in other scheduled activities. When N is allowed to initiate interactions on topics of her choice, even within functional routines, and those initiatives are positively responded to by the adult, she more willingly responds to the adult's initiatives at other times.

## ENDURING EFFECTS

In a recently published study, Dr. Marleen Janssen and her colleagues found "...that it is possible to improve the interactive competence of deafblind children by teaching their educators to respond more adequately to the children's signals and to adapt the interactional context." (Janssen, Riksen-Walraven & van Dijk, 2004, p. 88). They also concluded that "...the positive effects of the intervention were retained for two children and diminished but nevertheless remained well above the baseline level for two other children." (Janssen, et al., 2004, p. 89). In addition, these positive effects endured even after staff changes were made following the intervention. This was attributed to training provided by previous staff to new staff, and consisted of "...two components: a) the new staff member observes an educator working with a child and is given information by the educator; b) the new staff member is later coached by the educator while working with a child. While not instructed to do so, the current staff apparently transferred the principles of the intervention to the new staff members via either explicit

teaching or having the new staff observe their improved interactions with the deafblind children.” (Janssen, et al., 2004, p. 89-90).

At TSBVI, continuity in the implementation of student-specific interaction strategies is maintained with videotapes and written summaries from interaction training, ARD documentation that incorporates information learned during the training (communication assessment recommendations, IEP objectives, instructional modifications, etc.), end-of-the-year videotapes, instructional support staff who provide services to the same students for multiple years (especially communication and behavior specialists), and previous classroom staff, who may be teaching other students on campus but are available to assist new team members. Continuity is also provided by past interaction training participants, who have generalized their understanding and application of interaction principles and strategies.

## PARTICIPANT FEEDBACK

“These intensive trainings are extremely useful. Observing and analyzing oneself on video is so important. It always amazes me to see things that I’m not even aware of doing, or not doing. It is also useful to get feedback from a variety of people. Everyone has an opinion about how to make an activity better.”

“I was shown how to effectively communicate with my student, as well as how to increase his participation during activities. I liked being able to discuss my student with the other participants, share instructional challenges and frustrations, and brainstorm together. Through our discussions, and the

information that was provided, new solutions and strategies were discovered.”

“I’ll carry away valuable information that will help enhance the quality of my interactions with my students. Being aware of your own interactions, consciously thinking about them, can help improve them.”

“I will be more aware of possible initiations by my students, and remember the importance of having both physical and emotional presence during activities. The coding helped me break down interactions, and showed how even a student’s most seemingly insignificant gesture may be an attempt at communication.”

“I received a lot of helpful information about what a good interaction should look like and feel like; giving and taking turns, etc. I will introduce more novel routines, and label the environment so I can be there to comment, instead of always being the one to provide information. The before and after videos with my student showed me that positive interaction is possible, and that we can both enjoy the activity.”

“I will be more aware of my interactions with my students, and mindful about allowing maximum opportunities for student initiation. I really appreciated and valued the opportunity to evaluate my performance, to set goals and to see them being achieved. It helped re-spark my enthusiasm to try new ideas and see how they benefit my students. It also encouraged me to focus on the positive aspects of my teaching. Sometimes it’s easy to see only the negative.”

## **FURTHER INFORMATION**

This two-part article describes a training process at TSBVI based on current research about interactions with students who are deafblind. A written format, however, has its limitations. As Dr. van Dijk suggested, “Let the videoclips do the talking.” With his suggestion in mind, an introductory videotape about the importance of high quality interactions between students with deafblindness and those who interact with them is being developed, and will be available through TSBVI’s Curriculum/Publications Department. The video will show examples of the interactive turns and interactive behaviors of several students with deafblindness, and the adults who teach them. Case studies of adults and students participating in the training process will also be included. The students will represent a variety of ages, etiologies, degrees of vision and hearing loss, and educational strengths and needs.

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## **There Are Saints All Around Us**

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

*Abstract: Dr. Hatlen talks about people involved in the lives of children with visual impairment.*

*Key Words: News & Views, blind, deafblind, professionals, family*

As I write these words, it's still two weeks before our Winter Holiday at TSBVI. And, although you'll be reading this after the holidays, I wanted to share some thoughts with you.

Santa Claus is everywhere right now. And I think about this image and what he means, especially to children. That leads me to remember his original name—Saint Nicholas. I wonder why Nicholas is a saint. I wonder how “Saint” became “Santa.” Then, my constantly wandering mind began to think about the “Saints” in my life. With apologies to those of you who believe that sainthood is reserved strictly to people whom organized religions give this honor, I'd like to share with you my saints (I'll make the distinction by not capitalizing the word).

My friend Tom is a saint. He began teaching visually impaired students in Berkeley, California, in 1959. He retired

around 1992. Tom is one of the most creative and dedicated professionals I have ever known. His skills in working with blind and visually impaired children are legendary, and he was often urged to return to school, get a doctoral degree and become a university professor. Even I, one of his close friends, pleaded with him to move into other endeavors in his professional life. But Tom would just smile and say, “No, I’m where I want to be, helping young blind children learn and grow.” And so this very talented man stayed in the classroom, enriching the lives of many, many students, and, in turn, being enriched by them. I have so many memories of Tom with his students, and my life, too, has been deeply enriched by him. Tom is a saint.

Betty Brudno was a Braille transcriber when I first met her in 1957. I never knew what brought her to Braille, but she was a saint. She was among the leaders who founded the California Transcribers and Educators of the Visually Handicapped (CTEVH). She served as its first president from 1957 until 1959. Transcribers of Braille, large print, and audio recordings became an essential part of the success of early inclusion in California. They agreed to almost impossible tasks with very unreasonable deadlines and always came through. In my memory, Betty was “CTEVH.” She was the heart and soul of Braille and large print transcribing. Betty was a saint.

Bob Dasteel was a saint. He owned a company called The American Thermoform Corporation. They built huge, industrial-sized vacuum-form machines, and they were highly successful. At one time in history, my teacher colleagues and I were trying desperately to develop a product that would

produce short-run Braille. We needed two or three copies of a book, not 100 or 1,000. The American Printing House for the Blind couldn't do short-run books. I remember putting three pages of lightweight paper in a Perkins Braille in order to produce three copies of the same material. If you've ever transcribed, you can imagine the results. Then saint Dasteel came along with the idea of making a small vacuum-form machine that would reproduce plastic copies of paper Braille. Most of you know the rest of the story—The Thermoform Machine revolutionized the production of Braille and tactile graphics. Well, Bob Dasteel didn't stop with the invention. He exhibited at every conference I attended for many years. Bob was always there in person, and gave freely of his time to anyone working with blind students. Bob was a saint.

Margaret was a saint. She was the parent of a child blinded by “retrolental fibroplasia” (now known as ROP). As soon as her son was diagnosed, she began reading anything she could find on blindness. She sought out experts in child development and education and asked the right questions. She refused to even entertain the thought that her son would be very different from any other child. She convinced her local district to begin an inclusive education program, and soon there were 16 blind students attending an elementary school, among them her son. Saint Margaret knew what she wanted, knew what her son needed, and in a quiet, persuasive, and informed manner, managed to convince others of her son's educational strengths and needs. Margaret was a saint.

I have many, many more saints. I am surrounded by them at work. I am in the presence of one whenever I meet a parent.

So, you see, Saint Nicholas, you have a lot of company in my life.

Who are your saints? Have you told them so?

### **Collaboration: A Timely Topic**

By Barbara J. Madrigal, Assistant Commissioner,  
Division of Blind Services

*Abstract: Assistant Commissioner Madrigal discusses the importance of collaboration and reviews the various collaborations DARS has cultivated in order to establish and maintain effective services.*

*Key Words: News & Views, DARS, Division for Blind Services, TSBVI, collaboration, health and human service, agency.*

I was glad to learn that many of the articles in this issue of *See/Hear* focus, in one way or another, on the topic of “collaboration.” That’s one of my favorite words—maybe because I’ve seen a lot of good things come from effective collaboration over the years.

The thesaurus offers a number of synonyms for the “C” word: “teamwork, partnership, group effort, association, alliance, relationship, and cooperation.” I like these words, too. To me, they suggest community, common goals and shared visions.

This is a good time to be talking about collaboration. We are confronted with so many issues that beg for thoughtful collaboration.

For instance, the creation of DARS—by merging several distinct agencies and their respective missions and organizational cultures—has required months of collaboration at all levels of all of the affected agencies. For the most part, things have gone smoothly; but there is still a lot of work ahead of us—and a lot more opportunities for collaboration.

The same is true for DARS' relationship with other health and human services agencies that are dealing with their own consolidation issues. Many of our consumers rely heavily on these agencies for services and support beyond rehabilitation. Only with meaningful collaboration can agencies with distinct responsibilities assure that consumers will get the services they need without artificial barriers or bureaucratic red tape.

Then there's the upcoming session of the Texas Legislature—which, unbelievably, begins in January (weren't they just here??). Legislators are expected to pick up where they left off last session on government reorganization. And, the demand for services is growing right along with the population. Unfortunately, funding for services isn't keeping pace—and competition for the dollars that are available is fierce. If there was ever a time for collaboration, this is it. We can only hope that—even in these politically charged times—all of the stakeholders can put aside their special interests to work together to create solutions that will benefit all Texans.

All of these opportunities for collaboration and I haven't even mentioned what's going on at the federal level. You probably know that a Congressional conference committee has already passed new amendments to the Individuals with Disabilities Education Act (IDEA). At the last minute, they dropped language pertaining to the VR program's role in Transition. Generally, conferees could not come to terms on process and funding concerns.

The issue will come up again—along with several other VR-defining issues—as Congress begins work on reauthorization of the Workforce Investment Act and appropriations for a number of federal programs, including VR. What does that mean for the future of the program? To me, it depends on—you guessed it—the amount of time and energy we devote to collaborative efforts to create positive solutions to the programmatic and funding problems Congress is grappling with.

If only it were as simple as it sounds. Effective collaboration requires having the right “players” at the table. It's not enough for people in one agency to work with one another. The work has to take place between agencies and consumers and advocates and lawmakers and the public.

Effective collaboration requires honest, straightforward communication and tolerance for different viewpoints. It requires compromise, a willingness to let go of certain self-interests—and the strength to stand up for principles that shouldn't be compromised.

I think we can all probably come up with some examples of good collaboration that has taken place over the past year. But there's always room for more (and better).

An excellent example of collaboration is the upcoming "Take Charge of Your Future" training seminar developed by TSBVI Outreach Department with the organizational support of DARS Division for Blind Services. This conference will provide training for thirty 6<sup>th</sup> – 8<sup>th</sup> grade students with visual impairments and their families and will focus on the enhancement of skills essential in the development of independent and successful adults.

The approaching new year seems like a good time to renew our commitment to good collaboration—so I'm putting it on the top of my New Year Resolutions. How about you?

Speaking of the holidays, they are upon us! I would like to take this opportunity, on behalf of all the DBS staff, to wish you and yours the very best of the holidays and a Happy New Year!

## **TSBVI Summer Programs 2005: Rumor and Fact**

By Lauren Newton, Director of Special Programs, TSBVI

*Abstract: This article includes information on 2005 summer programs at TSBVI.*

*Key Words: News & Views, TSBVI, summer school, summer programs, blindness, visually impaired, deafblindness*

**RUMOR: THERE ARE NO MORE TSBVI SUMMER PROGRAMS.**

**FACT: SUMMER PROGRAMS WILL BE OFFERED AS USUAL IN 2005.**

TSBVI has submitted its request for funding to the legislature for the next biennium, 2005-2007. We were required to reduce our budget by 5%. This means that, beginning in 2006, we will not be able to offer summer programs. Another part of the information that was submitted to the legislature provided TSBVI with an opportunity to ask for funds beyond our "baseline" budget. Our first, and most important request, is for the legislature to restore the 5% reduction in our budget so that we can continue to provide exciting, educational summer programs for 250 or more students from throughout Texas.

For further information on this topic, please contact Phil Hatlen at (512) 206-9133, or email him at <philhatlen@tsbvi.edu>.

### **TSBVI SUMMER PROGRAMS FOR 2005**

It's time to apply for summer programs at the Texas School for the Blind and Visually Impaired. The program descriptions will be posted on our website during the winter break. Read carefully so that you select the right program for your child. If you have questions, please call the program's contact person. Deadlines are firm.

To get to the website, first go to <www.tsbvi.edu>. Under Instructional Programs/Special Programs, you will find

Summer Programs. Click on that and everything should appear.

*Classes being offered this summer are:*

- Secondary Academic: Fine Arts      1 week      June
- Secondary Academic: Projects      2 weeks      June
- Secondary Academic:  
Camp Challenge      1 week      June
- Secondary Functional: Projects      2 weeks      June
- Elementary Enrichment:  
One-Week      1 week      July
- Elementary Enrichment:  
Two-Weeks      2 weeks      June-  
July
- Life Skills Camps:  
Four different sessions      1 week      Various  
times
- WALIC  
(Functional Vocational Program)      4 weeks      June-  
July
- SWEAT  
(Academic Vocational Program)      5 weeks      June-  
July

## **Mosquito Netting or Pay Check – Which Will You Choose?**

By Ron Lucey, Medical Services Specialist

*Abstract: This article, updated and reprinted from Winter 2002 edition of See/Hear, discusses types of summer camp experiences and provides suggestions for selecting a camp for your child.*

*Key Words: News & Views, blind, visually impaired, camps, day camps, recreation, socialization, work experience, work program*

Each January I try to motivate families to start planning for their child's summer activities even though the Central Texas winter seems endless and summer still seems a distant notion. Recently I was inspired by my colleagues to broaden the annual summer camp article to include other suggestions for making the most of your child's summer break to better prepare them for their future.

### **WILL YOUR CHOICE BE MOSQUITO NETTING?**

There are a lot of benefits to be gained from attending camp, including telling war stories on the size of the mosquitoes swarming the campsite. Younger children may benefit from attending shorter camp sessions or day camp programs recommended for campers who may not be emotionally prepared to spend a week or more away from home. Often city parks and recreation departments sponsor day camps that seek to include youth with disabilities in city sponsored recreational and learning activities. Be sure to meet early with the recreation or day camp coordinator to

insure that your child's needs for meaningful participation are accommodated.

For many older children, residential summer camp programs offer a good opportunity to practice and learn new skills, develop a greater sense of confidence and independence, meet peers with similar interests, make new friends and, most importantly, have fun. An updated list of popular residential summer camp programs and other summer programs targeting youth who are blind or visually impaired may be found on the TSBVI web site at <[www.tsbvi.edu](http://www.tsbvi.edu)>. Type in the word "camps" in the search box and view the 2004 Summer Camp directory as well as articles related to summer camp selection.

### **SUGGESTIONS FOR SELECTING A CAMP:**

1. Be aware of camp deadlines. The more popular camp sessions fill up fast, leaving your family with fewer choices for camps and desired sessions if you fail to beat the rush. By Spring Break make sure you have made a final camp selection.
2. Call early (January or February) to request a camp application form. Some forms take longer to complete and may require a medical release signed by your child's doctor.
3. Talk to other parents, VI teachers, DBS children's caseworkers or Transition counselors about the camp you are considering for your child. Visit the camp's web site or, if possible, consider a visit to the camp in the off-season.

## **WILL YOUR CHOICE INCLUDE EARNING A PAYCHECK (OR VALUABLE WORK EXPERIENCE)?**

At an early age most of us can remember having a work experience, even if it was a volunteer job at our local church or hospital. Work experience is crucial for the vocational development of children who are blind or visually impaired. This summer, instead of considering the same camp options, why don't you consider involving your child in a summer work experience – either informal or formal?

Younger children benefit from having responsibility for jobs around the house and the reward of earning a little extra spending money. Focus on the jobs or portion of jobs your child is able to perform and work to teach them to develop alternative techniques for accomplishing other more challenging household chores. Suggested chores for younger kids include feeding and caring for the family pet, helping with laundry, washing and putting away dishes and, yes, even yard work. In addition to promoting jobs around the home, consider volunteer experiences with local organizations and/or businesses. Some experiences to consider are helping out in a friend's hair salon folding towels and sweeping, being a junior camp counselor at a local day camp, or volunteering at museums. To explore these options, contact your TCB Children's Program caseworker.

Older youth may wish to explore paid work outside the home through a summer job with a local employer. Local workforce centers offer a good resource for finding paid jobs in the community. The Texas Workforce Commission (TWC) website has a list of all local workforce centers as well as online job banks for performing a job search. The TWC web

site is located at <[www.twc.state.tx.us](http://www.twc.state.tx.us)>. Many City-County health and human service departments also sponsor summer youth employment programs with work opportunities in city departments throughout the community. The camp directory includes programs that provide the opportunity for summer work experience and skills for independent living. Recruitment for these programs may begin as early as January with mandatory pre-work training and orientation classes held in the spring. For more information on paid summer work programs, contact your local DBS Transition counselor, local education service center, or the Texas School for the Blind and Visually Impaired.

Regardless of whether your family chooses mosquito netting or a paycheck, the most important part of the experience is to enjoy the summer and all of the recreational, learning, and work opportunities it has to offer!

### **Announcing the Birth of *Blindosity* Newsletter**

By Judy Moore, Division of Blind Services  
Children's Specialist, Tyler, TX

*Abstract: an announcement of a quarterly newsletter staffed by teenagers who are blind or visually impaired.*

*Key Words: News & Views, newsletter, blind, visual impairment, deafblind*

In announcing the birth of this new quarterly newsletter, the first issue states, "This is not any ordinary newspaper; this newspaper is for people with visual impairments.

*Blindosity* will give us a variety of things that we would like, such as: travel, sports, and upcoming events. In the future we will have contests and opportunities for entries so you, the readers, can interact.”

***The staff members of this newsletter are:***

Krystle Hill, editor, an 18-year-old freshman at Stephen F. Austin University majoring in Political Science and Spanish who likes to swim, write, talk on the phone, and sleep.

Stacy Glover, assistant editor and advice columnist, a 17-year-old senior at Livingston High School who plays the trumpet in the band. In her free time she likes to play soccer, bowl, skate, surf the net, and baby-sit for five kids.

Fallon Garrett, travel columnist, a 17-year-old junior at Lufkin High School. She is in the choir, and in her spare time she likes to listen to music, talk on the phone, watch TV, and play with her 2-year-old sister, Kiley. Fallon will be also be in charge of contests.

Jimmy Hill, sports and general columnist, a 20-year-old junior at Texas A&M University Commerce who is minoring in music and majoring in psychology. A member of Kappa Sigma Fraternity at A&M, he plays the drums and likes to listen to music, watch TV, and ride four wheelers in his spare time.

Melissa Bobo, columnist, a 17-year-old junior at New Diana High School who likes to talk on the phone, play on the computer, watch TV, listen to music, and play the piano. She will also assist Fallon with *Blindosity* contests.

Two editions have been published and have included a rich variety of articles and personal interest stories. In an article entitled "Project Dot Power," Jimmy Hill writes about his experience mentoring two young children to reinforce their skills in Braille and abacus as well as encourage their social and academic development. Fallon Garret writes about her trip to Washington, D.C. and her relatives' experience traveling on Amtrak. Krystle Hill interviews a 17-year-old student and relates his story about driving with bioptics. And Dawn Adams writes about her journey to become a Consultant for the Visually Impaired.

If you would like to receive this newsletter, you may request it by email at <blindosity@hotmail.com>. It is definitely inspiring reading.

## **Described and Captioned Media Program**

*Abstract: announcement of the Captioned Media Program*

*Key Words: News & Views, deaf, deafblind, videos, captioned media*

The Described and Captioned Media Program (DCMP) provides free-loan open-captioned videos and other captioned media to teachers, families, and deaf and hard of hearing individuals across the United States. The DCMP is funded by the U. S. Department of Education and is administered by the National Association of the Deaf. Over 4,000 titles (some

Spanish) include material related to most school subjects and grade levels.

Over 800 titles are also delivered through Internet streaming. There is no charge to use the program, and DCMP even pays postage (both ways) for media mailed to you. Visit the DCMP web site at <[www.dcmp.org](http://www.dcmp.org)> to register for DCMP media loan service, search the on-line catalog, or reserve media for your use. In addition, DCMP provides a nation-wide captioning information and training center for use by schools, agencies, caption service providers, corporations, and businesses. Visit the web site, or contact the DCMP through email at <[info@dcmp.org](mailto:info@dcmp.org)> or by phone at 1-800-237-6213.

### **Sibling Slam Book Is Here!**

*Abstract: Woodbine House announces the publication of Donald J. Meyer's Sibling Slam Book, available in January 2005.*

*Key Words: News & Views, sibling, special needs youth, disability, Donald J. Meyer, Slam Book*

Give teenagers a chance to say what's on their minds, and you might be surprised by what you hear. That's exactly what Don Meyer, creator of Sibshops and author of *Views From Our Shoes* did when he invited together a group of 80 teenagers, from all over the United States and abroad, to talk about what it's like to have a brother or sister with special needs. Their unedited words are found in *The Sibling Slam*

*Book*, a brutally honest, non-PC look at the lives, experiences, and opinions of siblings *without* disabilities.

Formatted like the slam books passed around in many junior high and high schools, this one poses a series of 50 personal questions along the lines of:

- “What should we know about you?”
- “What do you tell your friends about your sib’s disability?”
- “What’s the weirdest question you have ever been asked about your sib?”
- “If you could change one thing about your sib (or your sib’s disability) what would it be?”
- “What annoys you most about how people treat your sib?”

*The Sibling Slam Book* doesn’t “slam” in the traditional sense of the word. The tone and point-of-view of the answers are all over the map. Some answers are assuredly positive, a few are strikingly negative, but most reflect the complex and conflicted mix of emotions that come with the territory. Whether they read it cover to cover or sample it at random, teenagers will surely find common ground among these pages and reassurance that they are not alone. It is a book that parents, friends, and counselors can feel confident recommending to any teenager with a brother or sister with a disability. For information go to <<http://www.woodbinehouse.com>>.

## **C L A S S I F I E D**

Mail or e-mail your new classifieds to Carolyn Perkins:  
TSBVI Outreach, 1100 West 45th St., Austin, TX 78756, or  
carolynperkins@tsbvi.edu.

An up-to-date Statewide Staff Development Calendar is  
Posted on TSBVI's website at <www.tsbvi.edu>.

### **2005 TAER Annual Conference Together We Can...Open New Lives**

April 7-9, 2005

Renaissance Houston Hotel, Houston, TX

This year's theme on coming together in Texas to open new lives echoes AER's national recruitment materials. TAER was the winner of AER's special membership drive contest last year, and we're eager to welcome those 19 new members as well as others who joined later this year. We're also eager to have TAER take up the challenge of *Operation One*, the resolution the membership passed at last year's business meeting of each member bringing in one new AER member, bringing back one absentee colleague to the conference, and bringing one new person into our dynamic field.

The conference will be held at the Renaissance Houston Hotel, conveniently located in the heart of Houston in the Greenway Plaza corporate complex. In grand tradition, the conference will kick off at noon on Thursday, April 7, and conclude at noon Saturday, April 9, 2005. If you're new to TAER, we promise you 48 hours filled with great exhibits, the President's Reception, an inspiring Awards Luncheon, informative presentations, and our infamous Silent

Auction. You'll receive invaluable information, well-deserved recognition, and lots of great networking opportunities.

We look forward to your participation in the 2005 TAER conference and hope you will encourage your colleagues to join you in opening new lives. Registrations can be downloaded at <[www.tsbvi.edu](http://www.tsbvi.edu)> or you may contact:

Edgenie Bellah, Conference Chair.  
Texas School for the Blind & Visually Impaired  
1100 W. 45th St., Austin, TX 78756  
(512) 206-9423, <[edgeniebellah@tsbvi.edu](mailto:edgeniebellah@tsbvi.edu)>

**Josephine L. Taylor Leadership Institute**

March 11-13, 2005

Boston Marriot Long Wharf Hotel,  
Boston, Massachusetts

The purpose of the Josephine L. Taylor Institute is to improve the quality of programming and services to blind and visually impaired children, adults, and their families.

Sessions include:

- SURVIVAL! Shape the Future of Your Public Policy Before Somebody Else Does
- Innovative Strategies to Market Programs and Expand Audiences
- Winning Collaborations for Fundraising Success

- Current State of Available Research in the Field of Blindness and Low Vision
- The Role of Information Dissemination in Leadership

Registration fee: \$345--<[www.afb.org/jltli.asp](http://www.afb.org/jltli.asp)>  
For more information contact: Carrie Fernandez  
(212) 502-7674 or [cfernandez@afb.net](mailto:cfernandez@afb.net)

**Texas Focus 2005:  
The Emotional Well Being of  
Children with Visual Impairments**

June 9 &10, 2005

Tentative location : Austin, Texas

More Information coming to <[www.tsbvi.edu](http://www.tsbvi.edu)> January 2005

**The 7<sup>th</sup> International CHARGE Syndrome Conference**

July 22-24, 2005

Wyndham Miami Beach Resort, Miami Beach, Florida

For more information go to: <http://www.chargesyndrome.org/miami.htm>

**Congenital Rubella Syndrome Symposium  
“The Many Faces of Rubella”**

March 14-16, 2005

Helen Keller National Center

Keynote Speaker: Dr. Paul Parkman,  
Co-developer of rubella vaccine

**CLASSIFIED**

**2005 Intervener Training Opportunities**  
**Introduction to the Intervener Model**  
(tentatively scheduled for June 2005)

This is an introductory–level statewide training for Interveners and a team member who have not attended previous general intervener training. 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)

**Orientation and Mobility for Individuals with Low Vision**

February 28, 2005

Region 10 ESC—Richardson TX

Presenter: Richard Ludt,

Orientation & Mobility Intern Coordinator

Western Blind Rehabilitation Center, Palo Alto., CA

Contact: Kitra Gray, [Grayk@esc10.ednet10.net](mailto:Grayk@esc10.ednet10.net)

**Spotlight on Technology:**

**What's New from American Printing House for the Blind**

Event 5597-32208

March 31, 2005

Keep up-to-date with current technology advances for students with visual impairments. New and updated products from American Printing House for the Blind will be shown and demonstrated in this presentation. Hands-on exploration will include using the Book Port, APH Font, educational and recreational software, such as, Math Flash and Termite Torpedo. Participants will have an opportunity to analyze

these products and explore educational options for student use. For more information contact: Cecilia Robinson, Region IV PDC 713-462-6379 or email <crobinson@esc4.net>.

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

### **ESC Region 14**

#### **Abilene, TX**

February 15 & 16, 2005

March 29 & 30, 2005

April 28 & 29, 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

## **Distance Broadcasts on TETN**

Broadcasts are from 1:30-3:30 P.M. Central Time.

Sorry, these broadcasts are not available outside of Texas.

**April 20** - Transition issues for students

With visual impairments

## **SEE/HEAR**

Published quarterly: February, May, August, and November

Available in Spanish and English

on TSBVI's website at <www.tsbvi.edu>

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

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

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December 1st for the Winter edition

March 1st for the Spring edition

June 1st for the Summer edition

September 1st for the Fall edition

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News and Views

Beth Dennis (512) -377-0578

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

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

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