

# SEE/HEAR

A QUARTERLY NEWSLETTER ABOUT VISUAL IMPAIRMENTS AND DEAFBLINDNESS

FOR FAMILIES AND PROFESSIONALS

A COLLABORATIVE EFFORT OF THE TEXAS SCHOOL FOR THE BLIND AND VISUALLY IMPAIRED  
AND TEXAS COMMISSION FOR THE BLIND

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**Kate’s Corner**

What a busy, fun fall we have had here in TSBVI Outreach. Two events that were especially energizing for me were the “Power of Touch” workshop and a training by Dr. Jan van Dijk on child-guided strategies for assessing children who are deafblind. In September, six families and their children with deafblindness came to TSBVI for a different kind of workshop. The intent of the training was to teach the families about the critical role that touch plays for the child with deafblindness. This relates to both the type of touch the child receives from those around him and the way he uses touch primarily through his hands as eyes, ears, a voice and as tools. Gigi Newton from Texas Deafblind Outreach taught parents how to use massage with children and the benefits of a regular massage routine. Barbara Miles, co-author with Marianne Riggio of the book *Remarkable Conversations*, presented information on why developing the use of hands is so important. She also taught specific strategies for improving interactions with the child through touch. Both presenters used videotapes the families made prior to the workshop, and individual consultations with the families during the workshop, to personalize the information related to each child. Gigi and Barbara also had parents practice skills with their children immediately after they had been discussed and demonstrated.

This workshop occurred just days after the attacks on the World

Trade Center and the Pentagon. Perhaps it took on special meaning for all of us who were involved, because we were all reminded of how precious life is, especially our children's lives. These children have much to tell us and to teach us if we can learn to be receptive to them, to slow our pace and to just focus together without hurrying through the small things in this world.

Equally powerful was the presentation by Dr. van Dijk, in collaboration with members of the TSBVI staff and the parents of a young girl who is deafblind. Over a two-day period they conducted an arena assessment that a larger group of observers was able to watch from another location, through the miracle of video conferencing. Dr. van Dijk utilized an assessment process described in a new CD-rom product he developed with Catherine Nelson from the University of Utah, titled "Child-Guided Strategies for Assessing Children who are Deafblind or have Multiple Disabilities." In the next issue of *SEE/HEAR*, Dr. van Dijk will write about this assessment. In the meantime, if you are interested in purchasing a copy of the CD-rom, send a \$50 check or money order to: Dr. Jan van Dijk, c/o Joe Franken, 4619 Spyglass Drive, Dallas, Texas 75287. "Pay to the order of" Joe Franken. After his time in Austin, Dr. van Dijk traveled to Lubbock and presented at the Distinguished Lecturer Series sponsored by The Sowell Center of Texas Tech University. We learn so much each time we have the privilege to hear Dr. van Dijk speak and watch the way he interacts with children. We're always grateful for the time he is willing to give us that takes him so far away from home.

Finally, I must mention a family that I have known for quite a number of years and an honor they received in the beginning of the summer. Lee Ann Bryan and her family, who live in Amarillo, were the recipients of the 2001 Self Help for Hard of Hearing People

(SHHH) Family Involvement Award. All of us who are lucky enough to know the Bryans agree that this family is most deserving of this honor. We are very proud of you Jackie, Everett and Lee Ann! The Bryans will be featured in a future issue of *Hearing Loss*, the magazine published by SHHH.

## **The Story of These Chocolate Chip Cookies**

By Ellen Oestreich, Parent, Humble, Texas

*Editor's note: Kate Moss was recently invited to participate in a wonderful parent support meeting in Humble, Texas, near Houston. When she arrived at the school where the event was to take place, she was given a basket of goodies. Among the goodies was a canister of cookies and this little story. She felt that the story was worth sharing with our readers; so here it is. The cookies were worth sharing as well, but she didn't seem inclined to want to share them.*

As is usually the case in our lives, we got home a little later than I planned. After the day's activities, I was looking forward to baking cookies with my daughter. We arrived home to a HOT house. We quickly changed into our "baking attire" and began measuring, pouring and mixing. In an effort to speed up the process I threw the butter into the microwave and began to "NUKE" it until it was fully melted. (What I had forgotten was that it would have melted in mere seconds just sitting on the counter of the HOT kitchen.) We cheerfully added the dry ingredients. Flour, sugar, brown sugar, salt, etc. Little grains of ingredients were flying everywhere and creating smiles. Mixing took place next and then adding the eggs and vanilla. The final and key ingredient ...the chips...went in last.

As we stirred and munched on the few remaining chips in the bag something was happening to the dough. HMMM...it is much darker

than usual! As you may have guessed by now the coveted chips were melting and giving this chocolate chip cookie dough a look all its own. Oh well ...cookies are cookies to this family, so we baked and watched and baked some more. After licking the bowl we enjoyed a glass of milk with our fresh baked treat. While they looked different and were not quite what was expected, they none the less hit the spot and provided smiles for this mom and her daughter.

I decided this cookie experience was God's way of reminding me that the unexpected can bring life and laughter to any day. It is all in the perspective! While I was planning for a typically developing chocolate chip cookie, something special happened to the mix. The look and texture was different, but the enjoyment of a warm cookie and a glass of milk shared with a precious child was the same. No chocolate chunks to bite into, but the wonderful chocolate flavor spread throughout the whole cookie. Our "chocolate melt" cookies were yummy!

Now realizing I had committed to baking cookies for visitors, I whipped up another batch after Caitlyn was asleep. The new batch was filled with "typically developing" chocolate chip cookies. They looked like the cookies I have always baked. They smelled like the cookies I have always baked, and, yes, they tasted like the cookies I have always baked. What was missing with these cookies? I had no partner in crime. I missed the smile and peace I felt when I watched Caitlyn grinning and eating and even drooling a chocolate drool. It did not matter to her how the cookies looked, only that they were cookies and she could enjoy them before bed.

I suppose this is a lot like life. It is easy to get caught up in standard expectations and forget that sometimes the best things

come from the unexpected. There will be some people in this life who cannot deal with the unexpected. There will be some people who deal with it but will be uncomfortable. There will be some people who accept it and look at it as a golden opportunity. Each and every one of us has the right to be who we are and deal with things the best we can. I hope that I can learn from my child how to appreciate the unexpected. If I can spend more of my time looking for the unexpected, no two days will be the same, and life will never be dull or boring.

On that note, there are both varieties of cookies to enjoy. Remember: they are both cookies; they were both made with the same ingredients and love; and they both taste great with a glass of milk and a favorite partner in crime! Our hope for you is that you will be the best you can be today and that your life is rich and full of ordinary and extraordinary.

Peace, Ellen and Caitlyn

### **Accepting Help**

By Gina Meadors Ortiz, Parent, Bryan, Texas

After twelve years of marriage, our little angel, Gabriela, was born. Soon our joy turned to disbelief and a sea of unanswered questions. While most parents were beaming with pride at each new milestone, we were dealing with diagnoses such as “severe developmental delay,” “legally blind,” “mentally retarded,” and “seizure disorder.”

The first years of a child’s life should be full of beautiful memories. For our family, all we remember are the seizures, the doctors, and the unanswered questions. Instead of playgroups, we had sessions with physical therapists, occupational therapists, vision therapists and speech therapists.

In the beginning, I cried a lot. Then realizing I had to “be strong for Gabriela,” I quit crying and threw myself into the job at hand. The first two years went by very fast. I thought I was in control of my emotions. After all, I no longer cried every time my little darling had a seizure.

One day Bettye, our caseworker for the Texas Commission for the Blind, stopped by for a home visit. I must have looked a mess! I know my house was dirty. I couldn’t remember the last time I had vacuumed. Though I forced myself to cook for Gabriela, everyone else fixed sandwiches if they wanted to eat. I guess you could say I was depressed. Bettye recognized I was in trouble. Not giving me time to decline, an appointment with a counselor was set for the next day.

I had been raised to “fix your own problems.” Talking about your problems was a waste of time and did nothing to solve it. If something is wrong, do something about it. But this did not include talking to a stranger! My counselor, Lois, was wonderful. I opened up to her. I told her secrets I had told no one.

Though my feeling of depression was based on my daughter’s disabilities, I did not realize how my past years still affected me. Through the hours of tears and soul searching, I learned much about myself. I learned to accept my daughter as she is. I also learned to take time out for myself. At least every once in a while!

Opening up to a stranger is difficult. You know what you say is confidential, but it’s a feeling of vulnerability to open your life for examination. Keep a box of Kleenex nearby; you’ll need them!

With the help of counseling, I have grown in so many ways. No longer am I intimidated by staring strangers. No longer do I stand by

while young college kids use Grandma's handicapped sticker park in one of the few handicapped parking spaces. (I guess their disability is wearing three-inch heels!)

A counselor cannot "fix it" for you. They listen. Believe it or not, the answer lies within yourself! We just need help in getting to the answers.

I love my daughter with all my heart. If you only looked at the diagnoses, you would miss the beautiful blue-green eyes that are full of expression. You would miss the cuddly little girl whom everyone falls in love with. You would miss the little girl who loves to be held and hates to be left by herself. If you look beyond the diagnoses, you will see a little girl, four years old, who enjoys going to school, riding horses and the feeling of wind in her face. You will see a little girl who is the apple of her daddy's eye!

### **Sharing Your Gifts**

By Paige Parrish, Parent, Tyler, Texas

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My daughter Alexandria is losing her vision due to a rare congenital retinal disease. She is a socially aware nine-year-old who is inquisitive beyond her years. She possesses the ability to push past the societal boundaries frequently imposed on the blind.

Her passion for Africa began through several friends who, due to business or medical missions, lived in Africa. While visiting their homes, she tactually explored a genuine tribal mask and zebra skins. She also was intrigued by a life-size bronze African dancer who was in the exact ballet position, "posse," that she was trying to master in her ballet class.

Alexandria's love for Africa was cultivated during a visit to our local zoo. This was no ordinary day at the zoo, for I had contacted the zoo owner, Hayes Caldwell, to inquire about a "hands-on" experience. He graciously accepted my unusual request. This experience would shape and forever change Alexandria. As she scaled a giraffe's neck she had a moment of absolute clarity - a concept that would be forever ingrained in her visual memory. (See "Out of the Mouths of Babes" *SEE/HEAR*, Summer 2001.)

Upon returning home from our adventure, Alexandria wanted to find out everything she could about Africa and its inhabitants via the Internet. With my assistance, our first inquiry about blind Africans led us to an emotional photo essay. The first photo to appear on the screen was that of a blind villager who had been robbed of his ocular function by having a parasitic worm in his system. He was using what appeared to be a gnarled branch for a mobility cane. Alexandria was brought to tears as she pressed her nose to the magnified image of someone not so different from herself. She did not understand why he did not have the proper equipment to navigate around in his environment as she did.

The next photo to emerge was of yet another man who was blind, and he was wandering aimlessly around his village with his shirt on wrong-side-out and backwards. No one would assist him in getting where he needed to go.

Further reading brought out disturbing findings - this culture views blindness as a curse. It is believed that people of Africa are stricken blind for their wicked deeds; therefore, they are discarded by society. The children of blind parents lose their childhood and any opportunity for an education because they become sighted guides for their blind parent.

Alexandria quickly began to devise a plan to relinquish her out-grown mobility canes and get them into more needy hands. As a mother, you can imagine that I am bursting at the seams with pride. The next step was to follow a link to Helen Keller International <<http://www.hki.org/>>, and they were more than willing to assist us with our desire to help. As we were getting ready to ship the canes, Alexandria decided to add a Braille label in Swahili. The label read, “Chechesha kwa itikada wala mandhari.” This means, “Walk by faith and not by sight.” This Bible verse has become her way of life.

The shipment is on its way to Helen Keller International in New York and the canes will be disbursed in various parts of Africa according to need, as determined by a field officer. And so, as I watch my daughter’s vision diminish, I am seeing it replaced by a spiritual and world vision that is 20/20.

If you are interested in helping Alexandria in her quest, you can purchase a new cane for \$10. Contact Angela with Maxi-Aids, at (800) 522-6234. She is coordinating canes donated in Alexandria’s name. These gifts will be included in Helen Keller’s annual report.

### **Abraham Has a Friend**

By Olivia Cruz, Parent, Houston, Texas

Abraham started school last year at the Texas School for the Blind and Visually Impaired. After searching for different programs and options, we made the decision to send him to Austin. He has so few communication skills and so I was afraid for him to be all alone with strangers. Who, and how quickly, would someone be able to understand my son’s needs? I asked myself those questions a lot. Abraham and I have lived together all his life. I thought I was the only one who understood every little gesture or sound my son

made. I knew when he was sick, happy or sad. I was so worried that I hardly slept for weeks. But, Abraham adjusted to his new life and learned his routines. After a few weeks everyone started noticing the positive changes in him.

Jared McGee, Abraham's roommate, has the same abilities as Abraham, but more communication skills. Jared learned to say Abraham's name and called his name all the time, even when he went home on the weekends. The school year ended sooner than we expected. On the last day of school I took a picture of Abraham and Jared for my memory book. This was to help us remember Abraham's first roommate. As we packed Abraham's things, we said goodbyes and wished each other the best. Abraham hugged Jared and said, "Adios." This is Abraham's way of saying goodbye. Abraham and I left to have a busy summer, and before you knew what happened, it was time to go back to school.

After ten weeks of summer vacation, there we were at the registration area. It was crowded with students, parents and staff. Jared walk into the area and called Abraham's name. As Abraham heard his name, he lifted his head and his face lit up as he recognized Jared's voice. With a big smile on his face Abraham said, "AAAH!" Jared called him again, and Abraham answered, "AAAH!" I told him to go and find Jared. Abraham walked with no problem about 12 feet, straight to Jared who was in the middle of that crowd room. With a big scream and a big hug they both welcomed each other to a new year of school. The scene was beautiful.

That was the moment when I realize that all those sleepless nights and tears had paid off. Abraham had a friend! Abraham had made a friend all by himself, without mom's intervention. Abraham surprised me one more time. I am so happy! My son has a friend!

## The Smallest of Gestures Can Declare Independence

By Sarah Barnes, Parent, Austin, Texas

Reprinted with permission from  
the *Austin American-Statesman*, July 30, 2001

*Editor's note: Sarah Barnes writes occasionally in the Life & Arts section about the joys and challenges of raising a child with special needs. You may contact her by e-mail at <adifferentroad@aol.com>.*

The first time I took my daughter Meredith to Rosedale School, it quite literally took my breath away. The more I looked around, the more difficulty I had breathing. I was just barely willing to accept the news that my baby daughter would be developmentally delayed, so I certainly wasn't ready for this special school.

As I walked in, an empty pink wheelchair belonging to a little girl not much older than mine sat in the hallway. Large therapy balls and special chairs with extra straps seemed to fill the corners of every room. At the school's entrance, a bulletin board displayed more than a dozen memorials to students who had died.

By the time I got to Meredith's classroom, I was breathless with anxiety. No matter how compassionate the teachers, I simply couldn't get grounded in the possibility that this would be my daughter's world.

That was 3 and a half years ago. We have since graduated from Rosedale, but Meredith comes back for summer school. I still notice the therapy equipment, but only because it is helping Meredith learn how to walk and talk. The wheelchairs don't stand out to me anymore because I'm focusing on the children in them who are friends with Meredith.

Here, I've learned, progress is measured one centimeter at a time.

This was never more apparent to me than at the school's recent Fourth of July parade. Normally an unassuming little building on West 49th Street, Rosedale was transformed into Yankee Doodle headquarters, including a parade leader dressed in full patriot attire. Following him around the school's circle drive were staff and students waving flags and glittery signs. Even April, the therapy dog, was doing her best to look stoic in a basket on wheels, hat cocked to one side. Most of the students joined the parade using their wheelchairs, while others were pulled along in red wagons, including my daughter. Though few could march, this didn't change the spirit. At Rosedale, if there is a day for celebration, it is seized.

As the music started, my eyes followed Meredith around the circle to see how well she was interacting with everyone. I thought about her first year in the parade and how she couldn't sit up very well in the wagon and couldn't spot me in the crowd. She looked so different now. This year, I was hoping she would wave.

When her wagon, got closer, I shouted in my best soccer mom voice, "Wave, Meredith!"

She looked at me, smiled, but ultimately was too overwhelmed. She came around again and her teacher, Robin said, "Look at your mama, Meredith. Wave." She beamed, but no wave. By now everyone was starting to sweat, and even April looked hot. They marched on.

The next time, as her wagon neared, I moved to the very edge of the curb, toes hanging off. I didn't say anything because Meredith looked as if she was too busy trying to process the chaos of the

music, sparkling colors and crowd. But, in my heart, I really wanted her to get the waving part. She was almost past me. Then, at the last possible minute, her eyes found me. I waved. And her little arm very slowly started to rise and she managed a small fluttery wave back at me.

My heart flipped as I put my sunglasses back on, not really wanting people to know I was getting teary-eyed over something so silly. Nearby, friendly drivers were honking at the colorful parade and I wanted to yell to them that the little girl in the front wagon was my daughter and she just waved.

After the fifth or sixth go-round, the parade began to wrap up. We all filed back into the school, past the sign that reads “Independence Taught Here.”

Inside, I had that old feeling of breathlessness again. But this time it wasn’t from any anxiety attack. It was from my all-too-happy heart that could see Meredith is figuring out her world one Independence Day at a time.

## **My Experiences in the TSBVI Summer Programs**

By Sam Barnes, Student, Houston, Texas

My names is Sam Barnes, and I live with my parents, Theresa and Bill Barnes, in the Houston area. This fall I will be going into 9th grade at Cypress Creek High School.

I like video games, speech and debate, chess, computers, and photography. I am a Life Scout (the rank before Eagle) in the Boy

Scouts of America. I plan to be a meteorologist after I get out of college. I have a lot to learn between now and then.

I have learned much by coming to the Introduction to Work program at the Texas School for the Blind and Visually Impaired during their summer school. I think learning to fill out an application for a job has really helped me. I now know more about how to get a job and how to survive in the work world.

Overall, this program has prepared me for work both in high school and later in life. I really enjoy the summer programs here. I apply every year.

I went on lots of trips both with the dorm residents after classes and during the school day. I also did a lot of cool stuff on campus. In 1994, I contributed a journal to a time capsule, which is now buried across from the main building. It contained things like what I wanted to be when I grew up and my favorite activities. Later, during the 1996 elementary summer program, I went to Natural Bridge Caverns in San Antonio. I had a lot of fun looking at all of the rock formations. I also did lots of art projects such as painting and drawing.

Now that I am in the Introduction to Work program, I am working in the Technology Services department. I am learning how to write websites. I am getting a lot out of this program.

After two years of regular school at TSBVI, as well as four years in various summer programs there, I can tell you that I gained knowledge by coming to TSBVI. I also have a lot of happy memories of my time in Austin.

## What Do You Do When...

### You Need Help But Don't Live in Utopia?

By Winifred Downing, San Francisco, California

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(800) 860-4224 and at <[www.blindskills.com](http://www.blindskills.com)>

Utopia for most blind and visually impaired persons would be a place where they could find a ready supply of volunteers to help them with all sorts of shopping, provide transportation to doctors' offices and opportunities for recreation, read any amount of material, and generally perform all the tasks that are difficult, if not impossible, for us to do for ourselves. I suspect that the individuals who find themselves in this fortunate situation are unique in a number of ways. They probably live in communities of a slightly slower pace than that in large urban areas, are well known by their participation in news-making and dramatic events, have the wherewithal to be well dressed and attractive in appearance, perhaps have an appealing home of their own, and in every way provide volunteers with a real sense of status because of their efforts.

That such a situation exists is no criticism either of the lucky people who so easily get the help they need or of the individuals who gladly provide that assistance. What that situation does, though, is to explain why similar opportunities are not available to most members of the blindness community. Sighted persons in bustling urban areas are called upon to participate in countless volunteer activities in connection with their student life, employment, the schools their children attend, their churches, and many philanthropic activities.

The blind or visually impaired person may be an SSI recipient who lives in a small apartment in a congested area where parking is found to be difficult or impossible by a would-be volunteer. The needy individual may also be like the 85-year-old woman who called last week needing help with just about everything but so traumatized by her new experience with vision loss, plus the normal problems of aging, that she would be almost frightening to someone not trained in assisting such persons. The ordinary individual who finds himself called upon for that kind of aid would, in fact, probably be terrified at the realization that he himself might face similar difficulties in his own later years and might instinctively avoid getting involved just for that reason. No community accolades are bestowed on people who snatch a couple of hours a week to help someone shop for ordinary groceries, read through a half carton of junk mail, or deliver someone to a long line in a clinic.

There are also wide differences in how one feels about help. I have read articles by blind persons who maintain that they can fly to a busy airport, deplane and find their own way to the luggage area, pick up their own baggage by touching the luggage as it goes around on the carousel, find the courtesy phone themselves, and leave for the area of pick-up outside. Now I don't believe these stories, but the thirst for independence and self-sufficiency breeds them. These are the types of individuals who maintain that blindness is nothing more than a nuisance.

Asking for assistance, particularly for people who have been able to meet their own needs all their lives until their visual problems occur is often a devastating experience. An effort was made in a church group I belonged to some years ago to force the participants (all young and physically capable) to learn to ask for and accept help from others. Each was required to request some kind of assis-

tance in the next two weeks and report on what happened. For most persons, it was a humbling experience that they had a hard time accepting. How, then, should we approach this difficult necessity? The first task is to decide what help is really necessary. In spite of the fact that some things might be a lot easier with sighted assistance than they are without it, it seems to me that we should do for ourselves all that we can just because we have other areas in which we can't function alone. We need to expend the necessary effort to organize our own clothing, groceries, mail, phone numbers, and other details of life and to develop the necessary mobility skills to travel alone when appropriate, so that we don't need to uselessly bother other people. That means attending orientation centers, classes in daily living skills or chapter meetings of blind persons who have had a variety of experiences; taking courses from a place like the Hadley Correspondence School; and reading books on related subjects. It means familiarizing ourselves with whatever community resources are available such as services for the aging, paratransit opportunities, and programs offered by agencies serving disabled people.

When all these avenues have been accessed, though, we still may need assistance that just isn't available in the area in which we live or in sufficient supply to meet the needs of those who wish to have it. Sources for advertising are local high schools, senior citizens centers, and the bulletin boards at churches, community centers, and YMCAs. If you can offer some monetary incentive, your chances are, of course, enhanced. It is absolutely necessary, in my view, to reimburse for gasoline and tolls charged by bridges and highways.

If the volunteer is coming to your home, especially if you live alone, a fairly extensive telephone interview is a safety necessity. In addi-

tion, the presence of a family member or friend at the time of the first visit provides great assurance if it can be accomplished.

Retaining a volunteer once one is found requires consideration. Don't ask him to do something other than the tasks for which he or she volunteered. If shopping is the goal, don't introduce reading the mail. Just stick to the original subject unless you have an opportunity to ask the individual about an added task. Don't exceed the time period for which the individual applied, and have everything in readiness so that maximum use can be made of the time allotted. Have the shopping list at hand and the grocery bags assembled, the mail together in one place and already opened, the directions clearly in mind for reaching the doctor's office, etc.

Lastly, make the occasion as rewarding for the volunteer as possible by taking an interest in that person's life, identifying with his or her problems and joys, remembering occasions of importance to that person, and giving small gifts when that is possible - maybe something you have baked or written, loan of a CD that might be of interest, or a phone call to check on health or the result of an important interview. Too often we are so involved with trying to get our own needs met that we forget those of the people in our lives.

So Utopia is not available to many of us. But there are ways out of our problems that not only solve them but also provide us with opportunities for meeting some wonderful people, thus enriching both our lives and theirs.

## **Thinking About Employment Issues for Our Children Who are Blind or Have Vision Impairments**

By Kris Kiley, Region 2 NAPVI Representative, Virginia

Reprinted with permission from the

Spring 2000 issue of *Awareness*

National Association for Parents of Children  
with Visual Impairments (NAPVI)

My son Patrick turned 15 last February and his thoughts turned to how he would spend the summer. He had gone to camp for many years, but he felt he needed something different this year. He probably would have benefited from an academic program to boost his skills, but he had worked exceptionally hard during the school year and felt like he needed a break from the classroom.

Patrick was lucky enough to be invited to a mission project with his church youth group. The Jeremiah Project in rural Virginia teams up teenagers with an abundance of energy and promise with people who need projects done around the house. They painted homes for elderly residents, built wheelchair access ramps, and stacked firewood. They also visited with people who enjoyed hearing about the lives of young people and wanted to share stories of their own lives. There were also spiritual components and singing as well as time spent with devoted youth group leaders. This was a project for typically developing teenagers, and Patrick was the only student with a vision impairment.

As part of Patrick's transition plan for school, we started thinking about life goals and how to prepare for the workforce. At 15, he has a couple of general clusters of goals in mind. He is interested in food service and building. During the school year, he had the opportunity to "shadow" a caterer for a day. He helped prepare soup

and bake bread and work in the restaurant-size kitchen. He loved the atmosphere as well as the actual work. Over spring break we contacted a local restaurant to see if they would let Patrick volunteer there for several weeks during the summer.

A local seafood restaurant, The River's Inn, in Gloucester Point, Virginia, was kind enough to give Patrick his first opportunity in subsidized employment. Patrick was "hired" to be a busboy. His responsibilities included setting and clearing tables, filling water pitchers, and doing any other task requested by the customers or servers. He seemed to learn quickly and loved waiting on customers and making them feel comfortable. Most of all, he loved feeling like part of a team of people who were working together to keep the customers happy and well fed. The restaurant has an excellent reputation, and Patrick felt like he had to work hard not to let down the owners, chefs, hostesses, and servers in their mission to provide a warm atmosphere and wonderful meal. The job also provided the opportunity for Patrick to increase his self-esteem. When we told friends and relatives that he was working at The River's Inn, they were very impressed and expressed admiration for The River's Inn for taking a chance on Patrick and on Patrick for stretching himself by working there.

We did face some barriers. We had to locate a business that was close by, so that Patrick's dad and I could get him back and forth to work. Not being able to drive is one of the biggest hardships faced by people with low vision. At this point, we don't know if Patrick will be able to drive. If he can get a license, it will be with bioptic lenses and restricted to daylight hours. So, location is important. Patrick needed a few accommodations. He was not able to carry the tray "waiter style," using one hand, and holding it over his head. He had to carry it in front of him, using two hands, and that is not the pre-

ferred way to carry a tray in a restaurant. He also had some difficulty hearing and following verbal directions in the background noise of clanging eating utensils and noise of the busy kitchen. His coworkers and customers seemed very understanding. Many people have a friend or family member who has special needs, and the public seems very understanding of a young person who is making every effort to become a taxpayer.

Our children who live with disabilities need to feel the satisfaction of contributing to society and becoming productive citizens. They have individual needs as well as abilities. Perhaps you are not able to envision your son or daughter (or grandchild) in a situation like Patrick's, but help them find their own dreams and then make a plan and begin the process of reaching their goals. By letting your child know that you think this possible, it will help them create their own dreams. I did not say this first, but I say it often: "First we give them roots, then we give them wings."

We don't have time to wait for agencies to take this on...the students are only teenagers once, and we need to make the best use of the time we can. Agencies can help you in the process, but taking an active role is just another aspect of parenting. Sometimes an agency can help find a job and sometimes they can provide a stipend. I was successful by asking if the business could take Patrick as a volunteer, and secured the funding later.

We are very appreciative of The River's Inn for going out on a limb and giving Patrick the opportunity to work. The Virginia Department of the Visually Handicapped and the JTPA (Job Training Partnership Act) provided a stipend and support for Patrick. He used the money he earned to put toward the laptop computer we purchased to assist him in mainstream classes as he started ninth grade. I feel like it

was a win-win situation all around. Patrick had a good experience, grew both emotionally and in tangible employment skills, and earned some money that he put to good use. The Commonwealth of Virginia has helped a citizen become a little closer to independence, and the employer got the services of a busboy and was able to contribute to the success of a future taxpayer.

*Editor's note: The Transition Program of the Texas Commission for the Blind offers similar assistance for teens and their families.*

### **Looking at Self-Stimulation in the Pursuit of Leisure or I'm Okay, You Have a Mannerism**

By Kate Moss, Family Specialist  
and Robbie Blaha, Teacher Trainer  
TSBVI, Texas Deafblind Outreach

This article first appeared in the July 1993 edition of *P.S. NEWS!!!*

*Editor's note: This article has been reprinted once, but a renewed discussion on the topic seems important. In light of the many questions we have had from parents and professionals about self-stimulatory behavior, we felt that it was time to reprint this article again.*

*I would like to thank Jim Durkel, Craig Axelrod, Gigi Newton, David Wiley and Stacy Shafer for taking their time to discuss the topics of leisure and self-stimulation with Robbie and me when we first set out to write it. I began with the intention of writing a simple article on leisure. I had no idea I would end with an article on self-stimulation. I hope this article shows some of the prejudice that seems to exist in our thinking about this topic. We have to understand what a normal human activity self-stimulation is and address these behaviors accordingly. Because this topic is so complex I hope to provide more information about self-stimulation in a future edition.*

*I would also like to thank Gretchen Stone, Ann Silverrain, and Barbara Bellemo-Edusei for their contributions to this work. These women, along with Robbie, formed a study group back in 1985 after attending a conference in Tallahassee conducted by Dr. Jan van Dijk. Challenged by both the information and the values conveyed by van Dijk in discussing children with deafblindness, they worked to digest rather complex information about the human brain, the nervous system, and the implications this information has in teaching children with deafblindness. Their discussions, and the papers generated as a result of this study group, were invaluable to me in beginning to understand the effects of sensory deprivation on the central nervous system and how it relates to the way children with deafblindness respond to the world.*

Leisure time, the time free from work or duties, is important to all human beings. Leisure time is the time for doing something that will relax us or energize us, so that we can renew ourselves to face the demands of our lives. It is something we require as much as food or sleep to stay healthy and sane.

We all have different ways of spending our leisure time. What might be a leisure activity for me (reading a mystery) might not be leisure to you. We know and accept this about each other. When considering “leisure skills” for children with deafblindness, however, we often focus on activities which do not relax or positively energize them. We spend their time getting them to participate in “play work” as one young man with deafblindness terms it. Learning to play games, participate in arts and sports activities, or other pursuits as a part of their educational programming may be beneficial for children in many ways, but these activities don’t necessarily meet their needs for “leisure”.

The type of activities that often do provide relaxation or amusement for these individuals includes behaviors that we find unacceptable: flicking your hand in front of your eyes, pulling threads out of your clothes, making repetitive sounds, etc. These behaviors are considered self-stimulation, and as such, are often perceived negatively because they do not look “normal,” may interfere with learning and can often become self-injurious. Yet these behaviors serve a positive purpose for these individuals as well.

Changing our perception of these self-stimulation behaviors may be the most reasonable course to take in addressing this issue, especially if this change of perception also helps us find ways to give more information to the child who is deafblind and consequently reduce his need to find stimulation on his own. These behaviors may also hold the key to information about his/her personal preferences, which we may tap into to select more appropriate choices for typical leisure options.

## STIMULATING EXPERIENCES

Most of our “leisure activities” are nothing more than self-stimulation behaviors that have become highly ritualized over time and made socially acceptable. There is nothing intrinsically valuable or reasonable about leisure pursuits such as bungee jumping, playing cards, dancing, playing video games, listening to music, smoking, etc.

People participate in these different activities because they find them to be pleasurable and because the activities alter their physical state. Each activity provides us with a particular type of sensory input (**Chart - pages 28-29**). There is not necessarily a great difference in so-called self-stimulation behaviors and some of these activities, beyond the fact that some are more socially acceptable and

“normal” in appearance than others. For example, what is really so different about banging a table and banging a drum, rocking to music and rocking to silence, making repetitive sounds and imitating bird calls, spinning for no apparent reason and spinning in a ride at the amusement park?

Each day, a good portion of our energy is spent in self-stimulation. Just look at the people around you. You are in a room with your family watching television or at a meeting with a group of co-workers. Although you are seemingly engaged in the same activity, your daughter or colleague is playing with her hair. Your son or your office-mate is shaking his leg and tapping out rhythms on the arm of the chair. Your husband is flipping channels with the remote or your boss is flipping papers. If you ask them what they were doing, they would likely reply that they are watching television or having an important meeting. They would be less likely to say they were channel surfing, twirling their hair, practicing the drum part for “Wipe Out,” or fanning their papers.

Each of us, even those of us with more intact central nervous systems, tolerates differing degrees of stimulation. Look at the difference in the preferred musical tastes (and intensity levels) between the teenager and the forty-year-old. Although most teenagers enjoy megawatt rock concert with all the trimmings, most adults are more inclined to seek out softer music or silence in a dimly lit room. In the same way, children with deafblindness vary in the amount and intensity of stimulation they need.

If we come to accept that self-stimulation is an important and valid activity for individuals without disabilities, then we must begin to revise our thinking about addressing self-stimulatory behaviors in individuals with deafblindness.

## **CAN THIS BEHAVIOR BE STOPPED?**

In looking for the answer to this question, first take a look at yourself. Try this little exercise. Identify one of your own deeply cherished self-stimulatory behaviors such as cracking your knuckles, humming, sliding a charm on your necklace, etc. Try to keep track of how many times during the course of a 24 hour period you engage in this behavior. Then spend the next 24 hours refraining from this behavior. If you succeed, then try to extinguish that particular behavior for a year. Stop this behavior under all kinds of circumstances: times of stress, times of idleness, etc. Once you have completed this exercise, answer the question for yourself. Your answer will either be a resounding “no” or a “maybe, if” depending on your particular success in completing the exercise.

Children with deafblindness (just like you and me) participate in self-stimulatory behavior to calm, to energize, to get feedback, etc. Most of the time you can't completely extinguish the behavior, and perhaps you shouldn't, because it does serve a purpose.

## **CAN THIS BEHAVIOR BE REDIRECTED?**

Most parents find that their child is more likely to participate in self-stimulatory behaviors when he/she is idle or stressed. Interacting with your child in some way may break up the self-stimulation. If the behavior appears in response to stress, finding ways to help him relax (e.g., massage, being wrapped up in a quilt, etc.) may reduce the amount of time spent in the behavior you find inappropriate or harmful. If your child is left alone, however, it is likely he/she will re-engage in this activity as soon as the opportunity presents itself.

## **CAN THIS BEHAVIOR BE “CONTAINED” BY ALLOWING IT IN CERTAIN LOCATIONS OR AT CERTAIN TIMES?**

Some behaviors may present problems because they are consid-

**Chart** - *Our brain seeks out stimulation through the channels of our senses. Each of us seeks out this stimulation in a variety of ways. Society accepts some of these behaviors without question, yet feels very differently about others. In some cases this acceptance seems to be arbitrary. The chart shows examples of how individuals typically fulfill this craving for stimulation and how some self-stimulation behaviors of children with deafblindness parallel these behaviors.*

**PROGRAMMING**

**Sensory Channels**

**Miss Manners' Guide to Appropriate Self-Stimulation**

**Creative Variations Which May Plug You Into a Written Behavior Plan**

*Tactile:* Information received by touch (throughout body surface) includes sensitivity to light touch, pressure, pain, and temperature.

Twirling hair, drumming fingers, playing with condensation on a drinking glass, fingering fabrics, rubbing eyes, pulling on beard

Pulling hair, lying in front of the air vent, slapping face/ear, playing with spit, rubbing head

*Proprioceptive:* Information about the relative positions of parts of the body. This information comes through sensations arising in the muscles, joints, ligaments, and receptors associated with the bones.

Snuggling in quilts, cracking knuckles, jiggling/crossing legs, sitting on your leg

Burrowing into furniture, wrapping arms inside tee-shirts, wrist flapping

*Visual:* Information received through the eyes/seeing.

Gazing at your fingernails, hands and rings, watching television without the sound, window shopping, flipping through magazines, eye pressing 28

Flicking hand in front of eyes, flipping pages of books, light gazing, playing with transparent or shiny objects, eye poking

Sensory Channels	Miss Manners' Guide to Appropriate Self-Stimulation	Creative Variations Which May Plug You Into a Written Behavior Plan
<i>Auditory:</i> Information received through the ear/hearing.	Humming/whistling, tapping a pencil on a surface, playing background music	Vocalizing or making sounds, banging on objects, tapping objects together next to ear
<i>Olfactory:</i> Information received through the nose/smelling.	Wearing perfume, sniffing magic markers, scratch and sniff stickers, burning incense	Rubbing feces on the body and smelling, smelling other peoples' hands or shoes
<i>Gustatory:</i> Information received through the tongue/lips, tasting. Closely tied to the sense of smell.	Chewing flavored toothpicks, sucking on mints/hard candy, smoking, chewing on hair, sucking on pens/jewelry	Mouthing objects, chewing on hair, sucking on fingers, licking objects
<i>Vestibular:</i> Information received through receptors in the inner ear which enables us to detect motion, especially acceleration and deceleration. Closely tied to the visual system which provides information to the vestibule located in the inner ear.	Rocking in chairs or rocking body, amusement park rides, dancing, twisting on bar stools, skating, sliding	Rocking body, spinning, twirling in swings, head rocking

ered socially inappropriate. Those of us who are smokers have learned to refrain from our favorite self-stimulation behavior on flights, but we all know exactly where to go in the airport for that last cigarette before the flight leaves.

With some effort, many children can learn to remove themselves to their bedroom or a private place when engaging in self-stimulation that is not considered socially acceptable. Using calendar symbols to represent this favored activity and scheduling the activity as part of the child's day may help the child refrain from this particular self-stimulation behavior for increasingly longer periods of time and stay involved in other kinds of activities.

### **CAN THIS BEHAVIOR BE MODIFIED OR EXPANDED INTO MORE "SOCIALLY ACCEPTABLE" SELF-STIMULATORY BEHAVIORS?**

Self-stimulatory behaviors are valuable because they tell you how your child takes in information. If your child likes to burrow down inside the cushions of the couch, be held or hugged a lot, enjoys massage, etc., you can assume that he is motivated by information he receives proprioceptively. If your child likes to vocalize, listen to music, or bang things together next to his ear, you can assume he is motivated by information he receives auditorially.

These behaviors can be used as a way to explore the individual's preferred sensory channels for receiving information from the world. With this information we may identify preferred sensory experiences around which we can develop more "mainstream" leisure activities that our children will also come to view as "leisure." For example, if a child enjoys the visual sensation of lights we can find age-appropriate toys that might be motivating to him. In addition to familiar toys such as Lite-Brite, consider lava lamps, continuous wave ma-

chines, lighted drafting tables for drawing, and even some Nintendo-type games. You might also consider extracurricular events such as visiting arcades, decorating with lights for appropriate holidays or lying in a hammock under a tree watching the play of light through the leaves.

Take time to observe the types of self-stimulation that your child participates in and when this behavior occurs. Watch him/her and make notes about what you see and when you see it. Then try to see if there is any pattern to these behaviors that would give you insight to the type or types of stimulation he/she prefers and the purpose it serves. At the same time note what types of activities he/she finds aversive.

When you have a good understanding about his/her preferences, begin to brainstorm ways that you can offer other stimulatory activities, modify or expand on the preferred self-stimulation. Ask for help from your child's teacher, physical therapist, occupational therapist, and others. Look at children of the same age, and try to find toys or activities that may make the self-stimulatory behavior appear more "normal."

Sometimes your child's favorite self-stimulation activity can be modified or expanded in a way that will make it more socially acceptable. For example, everyone knows the "nail-biters," but do you recognize them when they become "the manicurists?" Several of my friends substitute the more acceptable behavior of nail care for their favorite activity of nail biting. They carry a complete manicure set with them at all times and can often be seen in meetings quietly filing or clipping a nail. They buff, cream, and polish. They examine their nails for chips, snags, splits. They are rewarded by others who admire their efforts instead of being held in low esteem as nervous nail-biter types.

You should realize, however, that generally your child will need support from you to seek out these more acceptable behaviors. Their first preference will usually be for the behavior they have developed on their own.

Can the environment be engineered to make this behavior safer if the behavior is detrimental to the child or those around him/her?

People who like to jump off things are great examples of engineering the environment to make a dangerous self-stimulation behavior safer. These folks (skate-boarders, skydivers, skiers, etc.) have developed elaborate ways of placing themselves in extremely dangerous activities and surviving. We have industries based on protective clothing and equipment that will allow them to hurl themselves through space and make a safe landing.

PROGRAMMING

Frequently, the best you can do is provide protection for children who put themselves in danger of bodily harm by participating in self-stimulation activities that are excessive to the point of creating physical danger to themselves or others. Splints, helmets and other devices sometimes must be used temporarily to protect the child and others around him/her.

In addition to providing protection from the effects of the behavior, it is important to look at the cause of the behavior. Often times these behaviors erupt in response to real physical problems that the child is not capable of communicating to you. These behaviors might indicate pain or decrease of sensation, as in the case of retina detachment or ear infections. It's very important to the health and safety of the child to seek out appropriate medical examinations when this type of behavior emerges or escalates.

Emotional and environmental conditions may also provoke in-

creases in self-injurious behaviors. One individual I knew exhibited a dramatic increase in self-stimulatory behavior after the death of her father. The amount and intensity of the behavior posed concerns for her safety and the safety of others. Since there was no physiological basis for her behavior, the family spent a lot of time with her looking at pictures of her dad, going to the cemetery, and trying to participate in activities that were associated with her father. After a period of time, the behaviors decreased to levels that were comparable with the period before her father's death.

Changes in schedules, moves to new environments, and so forth, can also bring about increases in self-stimulatory behavior. Helping the child anticipate these changes, and providing as much consistency as possible through familiar routines during times of change, may help reduce this type of behavior.

## **CONCLUSION**

Like you and I, children with deafblindness have a need to participate in self-stimulatory activities. Because their behaviors appear very different from our own and can interfere with learning or become dangerous, they are viewed negatively by many people. Changing our perception about these behaviors may help us respond to them in a better way.

There are a number of ways to intervene. Keep the child involved with others during the course of the day. Help him/her contain the behavior, or engineer the environment to make the behavior safer. Schedule times in the day for your child to engage in the preferred activity. Look at ways the behavior can be adapted, so it will appear more "normal." Use the information these behaviors tell you about your child's preferred channels of sensory input, to develop recreational and social pursuits that may be enjoyable for him/her, even if

these activities will not entirely meet his/her “leisure” needs. Finally, accept that you will probably never completely extinguish the behavior without having it replaced by another self-stimulatory behavior. Self-stimulation is common to all humans and serves an important purpose.

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# Planning and Supporting a More Active Life at Home

By David Wiley, Transition Specialist  
TSBVI, Texas Deafblind Outreach

*Editor's note: While David's article is written about people with deafblindness, the ideas he discusses are relevant for a much wider population.*

Helping a young person with deafblindness develop an active lifestyle is one of the important issues to consider when planning for the future. People with deafblindness, especially those with additional disabilities, may develop a routine of remaining passive and uninvolved with basic life activities around the home, and experience an unsatisfying use of free time. Families, educators, and any others who work with a young person, all have a role in planning and supporting a more active life at home.

## WHY AN ACTIVE LIFE IS IMPORTANT

It is important that kids develop the expectation of being actively involved in home life. Without this expectation, children are at risk of developing a "learned helplessness" that can continue throughout the adult years. Most people feel that being actively involved in everyday activities leads to a higher quality of life. A person who is actively involved in common daily activities, such as taking care of the home and personal care, has several advantages:

1. Active participation allows a person to avoid boredom and inactivity.
2. Active participation allows a person to gain a sense of competence and accomplishment.

3. Active participation allows a person to have a greater sense of control over the circumstances of his or her life and more influence over the way things are done.
4. Active participation allows a person to have more opportunities for making choices and expressing preferences.
5. Active participation allows a person to have a better understanding of how everyday things happen (e.g. how long it takes for meals to be prepared, or how clean laundry gets back into drawers).
6. Active participation supports communication development by providing a person with more topics to use in interactions with others.

## **CREATING OPPORTUNITIES FOR MORE PARTICIPATION**

When individuals are able to complete activities around the home independently or with minimal supervision, they should be given opportunities and support to do them. This may involve:

1. Giving him or her responsibilities and chances to use current skills in regular household activities.
2. Teaching new skills so he or she can take responsibility for regular household activities.
3. Creating new household routines as opportunities for the person to use his or her skills (e.g. create a garden, get a fish tank, or start recycling).

Partial participation in activities is a way to encourage a more active life for individuals who are not very independent. Even when a person is not able to fully complete an activity, he or she should be

given the opportunity to participate at a level in keeping with his or her capabilities. No one should be left out.

Partial participation can involve selecting those steps within an activity routine that a person is able to accomplish independently, and providing a chance for him or her to complete those steps while someone else completes the rest. Activity routines should be “task analyzed,” by breaking them into small steps and identifying those steps the person can complete.

When steps cannot be completed independently, people should be allowed to participate in a wide variety of activities with the support of prompts or physical assistance from another person. Once a person is actively involved in a routine, the level of participation and independence can be increased over time, by reducing prompts, adding more steps, or fading the level of support.

Adapting materials and the environment can allow a greater level of participation. Adapted materials may include things such as tactile markers on appliance dials, a non-skid surface on a countertop, an electric razor, or a food processor to cut and stir. Adaptations to the environment include things such as storing materials in consistent locations, reducing clutter, and defining work spaces clearly.

## **CREATING NEW EXPECTATIONS**

It is not unusual for someone to initially protest when asked to join in new activities. Because daily routines are familiar, any person might become upset when these routines are disrupted. People may have a sense of uneasiness when they skip their morning coffee, miss the evening news, or alter some other routine activity. The difficulty of starting new routines is very evident to someone who attempts to change diets, stop smoking, or begin an exercise program.

Being accustomed to a routine of inactivity may cause a young person with deafblindness to initially resist more active participation. This is to be expected, even when the new activities are enjoyable, as would be the case if any routine is replaced by another. Once an individual becomes familiar and comfortable with new expectations and opportunities to be more active, however, the new routines will gradually take the place of inactivity. When that happens, the person will more easily grow to accept and enjoy new chances to participate.

Of course, if someone continues to resist a particular activity over a period of time, there comes a point when this must be accepted and honored as the communication of a preference. Before giving up, however, the person must have had enough opportunities to participate and fully understand the activity.

**FREE TIME CAN PRESENT A CHALLENGE**

A significant portion of every person’s time at home is spent with self-directed leisure. Leisure can be defined as unobligated time in which people perceive themselves to be free to choose activities they find meaningful, enjoyable, and intrinsically motivating. During free time, a person may be given the opportunity to “do anything he or she wants to do.” But what does it mean to “do anything you want?” There are many steps that must be successfully completed before a person can initiate a leisure activity:

1. The person must know how to do a number of activities from which he or she can choose.
2. The person must understand the concept of free time, and know that it represents a time to choose for oneself.
3. The person must know how to make a choice.

4. The person must be able to think of, or have a reminder of, the activities he or she is able to do, and from which he or she is able to choose.
5. The person must know when the free time will end, and how it fits in with other daily activities and events, as well as what activities are appropriate within that time frame.
6. The person must be able to locate and get the materials needed to participate in an activity.

If any of these steps cause a problem, the person needs more support during free time, just as during self-care or other tasks. When given no support, many people with deafblindness may be unable to successfully initiate a leisure activity. This can be recognized when someone consistently chooses sleeping, sitting idly, or engaging in problem behaviors during free time.

## **HOW DEAFBLINDNESS AFFECTS THE LEVEL OF ACTIVITY**

Some problems experienced during leisure time are directly related to deafblindness. For example:

1. People who are deafblind with multiple disabilities are often unable to enjoy many “old standbys” - simple, common leisure activities that people often fall back on (e.g. TV, music, books, conversation, sight-seeing and board games)
2. Most people are motivated to try new activities they hear about or see others doing, and consequently build a repertoire of leisure choices. People with deafblindness often receive less information through modeling and other sources in the environment. As a result, they may not have many leisure options from which to choose.

3. People with deafblindness receive fewer natural environmental cues that prompt self-initiation and independent participation. Most people observe these cues and are reminded of the activities they might want to select when they have free time.
4. People who are not strong communicators may be unaccustomed to making choices, and unable to easily communicate preferences. They may not be good self-advocates either.
5. Sensory stimulation often takes on great importance. Activities that do not provide sensory stimulation may not be as motivating.

## **HOW TO HELP SOMEONE HAVE A MORE ACTIVE LIFE**

Enhancing participation and increasing self-initiation is beneficial for a higher quality of life. These steps can help a young person become more active:

1. Create and practice consistent routines that increase participation around the house.
2. Develop and communicate a daily schedule, so the person will have expectations of what will happen. (Include both “chores” and leisure activities.)
3. “Label” the concept of free time and support concrete choice-making.
4. Support the person in learning about self-determination and self-advocacy.
5. Arrange a system that reminds the person about possible leisure activities.

6. Assess the person's interests, and plan new experiences for him or her to try.

## **ASSESSING AND PLANNING NEW EXPERIENCES**

In assessing interests and planning new experiences, consider the following:

1. The person's past experiences.
2. The person's preferences and attitudes.
3. The expectations and interests of friends and family.
4. Opportunities available in the person's home.

After gathering this information, support the person to become more active. Enjoyable and familiar preferred activities should be balanced with new things a person can learn more about. Honor the person's choices when possible. When it is not practical to accept a person's preference, because it is inappropriate for some situations, frustrating to the person, or potentially harmful, help the person by adapting these preferred activities to make them more appropriate. New skills should also be taught for specific activities, to increase the number of options the person has, and to provide a larger array of opportunities to choose from.

The Activity Planning Sheet (page 44) can be used to "brainstorm" new activity ideas. By knowing the young person's preferences and abilities, and working together to encourage a more active life at home, everyone involved can help a young person with deafblindness have a more productive and satisfying lifestyle, now and in the future.

# THE PROCESS OF PLANNING AND SUPPORTING A MORE ACTIVE HOME LIFE

## TEACHER'S ROLE

1. Talk to the family and work as a team to determine what routines might work well at home for the student.
2. Work on similar routines at school, and communicate with the family to create as much consistency as possible.
3. Make sure daily living and independent leisure activities are routinely discussed during IEP and ITP development.
4. In order to plan effectively, find out about the activity level and typical support available to adults with deafblindness in their homes.
5. Document both proficiency and preference, and make a list of activities the student has tried in the past. Documentation can be written and/or videotaped.
6. Remember that the family has obligations in addition to supporting the student's active home life. Work, doctor appointments, other children, home maintenance, meal preparation and relaxation are only a few of the competing priorities families face.

## FAMILY'S ROLE

1. Make your child's active participation a regular and expected part of family life. Try to be as consistent as possible.
2. Give your child chores, or find ways to include your child in household duties, even if only in a small way.
3. Consider all the regular routines that involve your child, and discover some active role for your child in each.

4. Use a calendar or other way to let your child know what is expected every day.
5. Help your child make satisfying and productive choices during free time.
6. Develop new ideas with your child's teacher or care providers, and be consistent across different settings.
7. Remember your other family obligations, and find a way to support your child consistently without placing too much stress on other aspects of family life.

#### **OTHER CAREGIVER'S ROLE (GROUP HOME STAFF, MEMBER, RESPITE CARE WORKER, ETC.)**

1. Work with the individual and family as a team to determine what routines might work well at home.
2. Make active participation a regular and expected part of the young person's life. Be consistent.
3. Do things with, not for, the person you are supporting.
4. During free time, help him/her make choices and participate in satisfying, productive activities.
5. When necessary, schedule activities with or for the person. Keep in mind the appropriate level of support and his/her preferences.
6. Use a calendar or other way to let him/her know and anticipate what to expect throughout the day.
7. Document both proficiency and preference in making a list of activities the student has tried in the past. Documentation can be written and/or videotaped.

# Activity Planning Sheet

## Developing and Adapting Activities to Improve or Expand Options at Home

PROGRAMMING

1. What does the person currently enjoy doing or show an interest in?
2. What might be motivating about this activity?
3. Does this activity currently create such a problem that it needs to be changed? If not, skip ahead to Question 5.
4. If so, answer the following three questions:
  - If this activity's location creates the problem, how could changing the setting make the activity better?
  - If the materials used in this activity create the problem, how could changing the materials make the activity better?
  - If the person's inability to finish this activity completely or correctly creates the problem, how could changing the expectations or level of support make the activity better?
5. What are five new activities that could be motivating or interesting to the person, based on the qualities listed in Question 2?

Worksheet accompanying article "Planning & Supporting a More Active Life at Home"  
by David Wiley, Texas Deafblind Outreach

## **A Personal Journey to Literacy**

By Jeff Moyer, Highland Heights, Ohio  
<[www.jeffmoyer.com](http://www.jeffmoyer.com)>

*Editor's note: Jeff Moyer is a true renaissance man – songwriter, author, passionate public speaker, publisher, and champion of the dignity of all people. His unique blend of humor, music, and powerful ideas has been heard by audiences in 46 states, in Australia, throughout Canada, and in the Virgin Islands. Moyer's published books of classroom activities and his new musical How Big Is Your Circle? are at work in schools and communities worldwide, promoting acceptance of difference, genuine community, and overcoming exclusion, ridicule, and violence. Jeff's six albums of recorded original music span many styles, themes, and forms, but share the common attribute of lifting high the dignity of the human spirit and showcasing the thought, depth, and heart of this talented and versatile musician. His entertaining, moving, and uplifting keynotes make him a popular and sought-after conference presenter for diverse audiences at both national and international meetings. Texans may remember Jeff as the keynote speaker at last spring's TAER conference, or from the Future Horizons family workshop in Galveston. Outreach spoke with Jeff at TAER about his experiences with different media and his definition of literacy. If you would like to know more about Jeff, visit his website at <[www.jeffmoyer.com](http://www.jeffmoyer.com)>.*

### **1. TELL US ABOUT YOUR TRANSITIONS INTO DIFFERENT LEARNING MEDIA AND WHAT YOU USE NOW.**

I had full vision until I was five years old. I remember studying print wherever I saw it, and I eagerly awaited the day when I could master the ease and wonder of reading. When the day came to enter kindergarten, I brimmed with excitement. Throughout the school there was printing on bulletin boards, classroom blackboards and

books were everywhere. By first grade, when print reading and writing was introduced, however, the early deterioration of my retinas was beginning to impact my ability to see detail. I remember being unable to see the print in the giant *Dick and Jane* reader that sat on the table in the front of the classroom, and the necessity of holding my reader closer than anyone else in order to read. When my parents observed, after a life-threatening bout of measles, that I was not seeing normally, they were told by an optometrist that I wanted to wear glasses, and that there was nothing wrong with my vision. My father insisted that I not pretend, and I would snap the funnies to normal reading distance when he entered the room. In second grade, I was taken to an excellent ophthalmologist who began seeing me twice a year.

The grim march of vision loss continued with devastating results on my ability to read normally or easily. Throughout elementary school, the twin forces of increasingly smaller print and greater volume of reading, and my slowly eroding vision made schoolwork difficult, frustrating and disheartening. My dad bought every drug store magnifier he could find, I was prescribed bifocals that did very little good, and I felt like a drowning swimmer. The perplexed ophthalmologist scratched his head about the cause, but validated and documented the death of my retinas.

At age 11, I had crossed the magic threshold of legal blindness and two powerful things occurred. First, I was seen at a low vision clinic where I picked out a powerful magnifier for books and a telescope with which I could read the blackboard. These tools were wonderful and I remember my elation sitting in the clinic learning to use them. But using devices that look strange and are not understood by other students kept me from using them under anything but required circumstances. I can still feel the flush of embarrass-

ment as I pulled the opera-glass monocular out of my gym bag to read the board from the front row or read a test with my thick magnifier. My reading was now possible but slow, fatiguing and even painful, and I realized that creeping along with my magnifier was not going to get me through the volume of reading ahead of me.

My mother stepped in and began to read to me: a very welcome relief. At the same time, I was enrolled in the Talking Book program, and the world of easy, effortless, and boundless reading opened to me like a prairie. I would spend Sunday afternoons and many evenings reading book after book, and I relaxed and read and read.

That same year, I was pulled out of my local elementary school and placed in another district with a resource room and a special education teacher. Braille was introduced, and I remember the shame and pain that accompanied that year. No counseling or support was offered concerning the trauma and grief of losing vision, and my fear of blindness kept Braille at bay with steel cables of complete resistance.

Despite the best efforts of dear old Miss Stone, my Braille teacher, I refused to genuinely apply myself to the work under hand. The judgment of Miss Stone, a social worker and my parents was that I was not “ready” for Braille. In retrospect, the reality was that there would never again be the opportunity to learn Braille under the instruction of a teacher and with time committed to surmount the learning itself.

The school did have large print books, which I despised. The books were oversized, and I read smashed to my magnifier flat on the page. It was impossible to maintain a comfortable posture while reading the wide and long pages of the books. Reading with my

magnifier always caused neck and back pain and ultimately chronic postural strain.

Miss Stone did teach me to type, and I took to the old Royal mechanical typewriter like a serious student of old Master QWERTY. After that one year in sixth grade, I never read a large print book again, but I sure started typing and never looked back. I typed on my large print typewriter and found it better than small print. Reading a page or so of typing was just another slow and glacial reading task. In any case, I think we got rid of that old beauty when I was in high school, and I traded the large print machine for a trim portable manual with regular type. I would check my place and make corrections with a high power magnifier which was needed, in any case, to read large print.

I was returned to public school and fellow students were paid to read to me at school and at home, and the accommodation of having certain tests read aloud to me at home or in a teacher's office. Actually, I use readers at least some of the time to this day.

By tenth grade a reel-to-reel tape recorder sat on my desk in my room and I listened to all my textbooks, read by the National Braille Press. Stronger and smaller magnifiers allowed me to read for short periods, and I even took timed tests, but not very successfully without accommodation.

During my college career, cassettes became a part of my reading world and have stayed a constant companion, initially supplementing, and then replacing, reels of tape and records.

I began using CCTVs in the early seventies, and was blown away. I could see easily to read and write, although not for bulk reading. I

had hoped that those amazing devices would free me to jump onto print and finally read effortlessly. I even convinced the State of California Department of Rehabilitation to buy me a system for college. I presented a cost/benefit analysis showing how much money would be saved over reader service. Alas, with the magic box I was still not able to read volumes of text, but I was able to read my notes without effort and study without postural strain and discomfort. After school, I continued to use CCTVs on the job, including two camera systems for monitoring typing and reading simultaneously.

I worked for several years at Telesensory Systems Inc., and while there I became one of the first individuals to use a computer that generated enlarged characters. The engineering department where I worked doing human factor studies on new technology used a massive development computer, that included programs for word processing and an intriguing computer game called Dungeons and Dragons. A friend wrote a program that “painted” the screen with greatly enlarged characters. This gave me access to writing and even to the addictive adventure game. I didn’t know the program code, so my writing was not editable, but I certainly did use the capacity. I would give the print command to the computer and printer in another room and then go and retrieve the grants, reports, teaching materials or whatever I was working on, tear off the sheets, and give them to my secretary to re-type on an electric typewriter. Talk about repetition!

In 1984 I obtained a new portable computer called The Viewscan. It was a wonderful system, with a right to left scrolling orange on black computer screen. Many presentations were written and read using that magic box. But my retinas were losing the battle against slow death and within a few years the system became unusable. I still kept a CCTV on my desk and would use it for straining to see

very limited text, but my desktop computer use had morphed into voice output, augmented by enlarged characters.

In 1988 I obtained a Keynote, a highly portable word processor with voice output. For the first time, I could write and read my work without effort. I am a songwriter and poet. At the time I was also writing many grants, articles for publication, and the other sorts of business communication required of an ambitious young administrator. Books were mine through cassettes and the elegant little players that had evolved. But for me, reading is as much about reading my own writing as it is reading books. So computers that gave me the ability to freely write and edit, review and refine, were a dramatic boost to my overall literacy. The technology has changed for me, but I still use voice output computers exclusively and love the freedom and power they provide.

Ten years ago I severely damaged my hands through overuse, typing, guitar playing, and carrying my portable computer back and forth from work. Repetitive strain injury is the leading workplace injury these days, and I found myself with very painful, limited hands. I can't type on a regular keyboard, lift a suitcase, shake hands, clap, or do anything else that requires much finger grip and articulation. I moved to a Braille 'n Speak and now a Voicenote due to the Braille keyboards that require less finger torque and range of motion. Technology saved me once again.

Several years ago I began using the Kurzweil Voice for input into my desktop computer. This has proven to be an excellent, albeit tedious, method for input and data retrieval, and is a great step forward when paired with a screen reader and voice synthesizer.

## 2. DO YOU CONSIDER AUDIO INPUT AS A LITERACY MEDIA?

Absolutely. One needs to know how to write, spell, think critically, digest, and absorb the written word, but I have been reading through listening for over 40 years. From sixth grade through graduate school and throughout my busy and varied career activities, live readers, tapes, computers and scanners have been my key to the wondrous world of ideas and communication. I have listened/read avidly since childhood and have been a writer of one sort or another throughout my life. The fact that my Braille skills are limited to Grade One input and the labeling of items in short, simple notes is beside the point.

Literacy should include the ability to read and write. Thanks to technology, those of us who did not have a solid education that included Braille instruction can still compete and share in the discourse between people. Across time, that is the hallmark of literacy.

I do believe that children need to be taught a literacy media that is portable and efficient. Today's technological tools have provided the means through which we can now easily write and read using small portable systems that generate refreshable Braille, synthetic speech or enlarged characters. As long as one is competitive, actively learning and gaining independence and learning skills, does it matter if a tool is used? Some might argue that reliance on technology is not literacy. Is reliance on a wheelchair not mobility?

Braille and print rely on literacy through the fingers and eyes. I am a highly literate person, relying on literacy through the ears.

## I'm Reading with my Ears

I'm reading with my ears you know,  
I'm reading what I hear  
The words I read fulfill my need.  
They make ideas clear  
I'm grateful for the faculty communication here,  
I'm reading what I'm hearing, yes I'm reading with my ears.

I'm listening with my eyes you know,  
I'm hearing what I see  
The signs and faces of my friends  
Make it quite clear to me  
I'm listening with my eyes to all the language that I see  
I'm listening with my eyes, your hands are speaking right to me.

I'm looking with my hands you know,  
I'm seeing what I feel  
When I can touch it means so much, it makes concepts come real.  
I'm seeing with my hands - all that I touch I really see Ideas rush.  
It makes sense to touch.  
It makes it clear to me.

I'm living my own life.  
You know, I'm living my own way  
The differences in how I do don't need get in the way.  
The only blocks I face are those within some people's minds  
I'm living free inside of me.  
I've left my fear behind.

(c) Jeff Moyer 1996

## Whatever Works

By Peggy Brisco and Jeri Cleveland, Special Programs Teachers  
Texas School for the Blind and Visually Impaired

*Editors' note: We asked Peggy Brisco and Jeri Cleveland, Special Programs teachers, to give their definition of literacy. They have been classroom teachers at TSBVI, and now are the teachers who work with students who come from districts across Texas to attend one-week short-term programs.*

One aspect of the conventional view of literacy is that readers and writers must be able to directly access print or Braille with eyes or fingers. This traditional perspective also defines parameters for spelling, grammar, rate and grade level. Our opinions have evolved over the past twenty-five years of combined experience teaching children with visual impairments. We now believe that the established view of literacy is far too constraining. By limiting the media and the senses employed, we ignore the fact that a large part of literacy is the ability to create, manipulate and synthesize symbolic language. Also implicit are the ideas that people who cannot use print or braille are less intelligent and that functional literacy activities are less valuable than more academic ones.

This narrow focus does not honor or facilitate the associations among language, literacy, intelligence and functionality. Working with students who struggle with literacy learning, we discovered that concentrating on functional tasks and accepting auditory input and output as a literacy medium were the most successful strategies. We were able to give students credit for the intelligence and vocabulary to create and understand written information, even when they couldn't access it in traditional ways.

The term "functional literacy" carries a load of negative stereo-

types that need to be dropped. We tend to see it as the last resort in education, and this implies that the parents, teachers and students have failed. Educators tend to focus exclusively on academic literacy and leave students to figure out how to use the skills to do functional tasks on their own. Actually, functional literacy is the basis of all literacy. When we make it the core of literacy instruction, there are some very useful natural outcomes.

Chief among these outcomes is that students make connections between literacy and everyday life. When those connections are in place, students can often progress farther and faster in literacy learning. We have found that when students become functionally literate and learn to value those skills, they are often able to move more successfully into academic literacy.

We have observed these positive outcomes repeatedly among our students. One young man came to us at the age of twelve, knowing how to type Braille letters using a brailier. He had not made the connection between sound and symbols, nor could he identify the letters he typed. He felt that he had failed in literacy learning, and he detested any and all literacy activities. In other ways this young man was an avid learner, full of curiosity and questions. We introduced this young man to a Braille 'n Speak classic, a very simple portable word processor with voice output. In the interactive mode, this device will speak the words typed when the space bar is pressed. For the first time this student was able to understand the connection between the symbols (he felt he was being "tortured" to learn) and words. He became an excellent inventive speller. In a very short time with the aid of the Braille 'n Speak's "read by line" function, this student grasped that written words could actually be put together into ideas. After this there was literally no stopping him. By winter break he had independently written a short story that

he was downloading into the devices of other students. He was also using his Braille 'n Speak to access the Internet for information and e-mail. He soon found that phonetic spelling was not adequate for doing Internet searches, and that is when he recognized the need to learn standardized spelling. Suddenly the world of information technology was open to this student and he was able to independently satisfy his curiosity. This also helped improve his social acceptance, because he was no longer constantly asking questions of the people around him. Years later this student is still able to read just a few braille sight words with his fingers. Yet, with his abilities to access and relay information using the written word, can we really classify this young man as illiterate?

A more inclusive definition of literacy incorporates the following ideas:

- Print, braille, recorded materials, adaptive technology and tactile, visual and auditory symbols are all valid literacy media.
- Literate people use these media at a variety of levels of abstraction and fluency.
- Literacy involves the ability to use specialized skills and tools to access and relay information, and to communicate with oneself or others.
- Literacy facilitates our ability to perform necessary tasks of daily life and participate in recreational activities (including reading and writing for pleasure).

Many people are using technology and recorded texts to accomplish literacy tasks at both functional and advanced academic levels. Clearly, Jeff Moyer is a literate person, who uses a personalized

combination of media and tools to perform a wide range of literacy tasks (see previous article). Choices of media and tools are highly individual and will probably change with time, setting and activity. It is the educator's job to help students reach the highest degree of literacy possible, and find the optimal combinations of tools and media. This involves a great deal of creativity, experimentation and flexibility on the part of both teacher and student.

Adopting a broader view of literacy facilitates, rather than threatens, the development of literacy skills. Acquiring literacy involves a continuum of skills that range from the fundamental connection of language and symbols to fluent reading and writing. More than being a hierarchy of skills, we believe this continuum contains an important array of literacy tools and media that remain useful across time and circumstance. This array of literacy options is akin to a menu that we make selections from, depending on the task at hand. A fluent reader continues to use basic symbols and labels to mark appliances, organize the pantry, identify personal possessions, etc. If you stop and think about it, most of the literacy tasks that adults do in the course of a day are simple, functional activities like lists, labels, short memos to self and others, recipes, directions, schedules, calendars, and so on. By expanding the definition of literacy we give educators and learners permission to use all available tools, methods, skills and abilities. We also acknowledge the value of all literacy skills, at whatever level students are able to master them.

## **New Technology for Blind and Visually Impaired Students**

By Holly Cooper, Technology Consultant, TSBVI, Outreach

One of the things we do here at Outreach is learn about new technology products, and try to share that information with parents and professionals. There are currently some new note takers,

CCTVs and software available on the market we thought might be of interest to our readers. Most of these new devices are designed for academic students. There is, however, one software product that is also useful for students with additional and more severe disabilities.

**BrailleNote:** There has been an explosion of new devices and new revisions of existing devices in the world of notetakers. The newest of the note takers is a completely new family of products available from Pulse Data International. These include BrailleNote QT, BrailleNote BT, VoiceNote BT and VoiceNote QT. All of these devices are built on the Windows CE operating system, and include a built-in modem, standard computer ports, type II PCMCIA slot, support for standard POP3 e-mail services, and Active Synchron. For the first time, students can send and receive e-mail (including MS Word attachments) with their note taker. Another notable feature is Active Synchron, which allows the user to easily share files between note takers and computers. For more information, see <[www.humanware.com](http://www.humanware.com)>.

**Blazie:** Significant revisions to existing Blazie products are now on the market. These note takers continue to support familiar features such as spell check and word processing. They now, however, also include a built-in modem for POP3 e-mail and internet access, programmable scrolling wheels, and a backspace and enter key. The programmable scrolling wheels are designed to allow the user to scroll by line, sentence or paragraph. Both the BrailleLite Millennium 20 and 40 now come with software called Connect Outloud. Connect Outloud is a product of Henter-Joyce (the manufacturer of JAWS) which allows Internet access using MS Internet Explorer and e-mail. Connect Outloud works with the built in Microsoft Outlook Express e-mail client. The software also has a

built in word processor. All of these features include the Eloquence speech synthesizer usually found in JFW (JAWS). For more info, see <[www.freedomsci.com](http://www.freedomsci.com)>.

**Flipper:** The Flipper, manufactured by Enhanced Vision Systems, is a small CCTV with a camera size of about 2 by 3 inches and a small, lighted microscope-like stand. It has the ability to focus on both a desktop and chalkboard with the flip of the camera. The Flipper can be hooked up to any TV monitor, but requires an adaptor for connection to a computer monitor, which entails additional cost. For a photograph and additional information, see <[www.lvproducts.com](http://www.lvproducts.com)>.

**Clarity:** The Clarity Classmate CCTV is a comparable small CCTV made by Clarity Solutions. Connecting the camera to the stand is more difficult with this device, and a special lens must be slid over the camera to change from near to distance viewing. The Clarity, however, does not require a special interface to connect with a computer monitor. For additional information and photographs, see <[www.clarityaf.com](http://www.clarityaf.com)>.

**Clicker 4:** Clicker 4 is a software product developed for the general education population that is also very useful for single-switch blind and low vision students. The software is advertised as a multimedia word processor, and it is similar to an onscreen version of Intellitools. Clicker 4 can be used in an auditory scanning mode with a single switch user. Using teacher-made and parent-made “grids,” the student can write stories, access talking books, and write e-mail. It can be used as a simple, computer-based augmentative communication device. This product is very exciting, and it has potential for use with VI students who have additional multiple disabilities. TSBVI Outreach will be offering training to interested new users.

Clicker 4 is available in Mac and Windows versions. See <[www.cricksoft.com](http://www.cricksoft.com)>.

**Connect Outloud:** Connect Outloud by Henter-Joyce is a simplified version of JAWS. It can speak in English or Spanish. It works only with MS Internet Explorer, MS Outlook Express (e-mail), and built in word processors. The most exciting things about this program are its simple to use interface, inexpensive price, and its similarity to JAWS. This allows for ease of transfer of skills, as student's educational needs change. See <[www.freedomsci.com](http://www.freedomsci.com)>.

### **Otosclerosis: The Silent Thief**

Juanita Fletcher, Children's Caseworker  
Texas Commission for the Blind, Victoria, Texas

*Editor's note: I would like to thank Juanita for sending us this article. Although this disease does not usually occur in children, we felt it might be of interest to our readers. Typical age of onset of the hearing loss associated with otosclerosis is between 30-50 years of age, according to Bobby Alford with the Department of Otorhinolaryngology and Communicative Sciences on the Baylor College of Medicine website <<http://www.bcm.tmc.edu/oto/otologyprimer/otosclerosis/Otosclerosis.html>>.*

I have otosclerosis. Otto what?

Like most people, I had never heard of this nasty but very common little disease. I did know that I had terrible earaches for years, but when I'd go to the doctor, they would say there was nothing wrong. I also knew I lost my balance easily, fell off ladders, and sometimes seemed to sway or stumble when I walked. I had unexplained dizzy spells.

People said I didn't listen. But how could I listen, when I couldn't hear? They'd laugh at me when I mispronounced words and ridicule my incredibly poor spelling. How could I pronounce and spell words properly when I couldn't hear part of the sounds?

Interestingly, all of these supposedly unrelated problems are caused by the same nasty disease - otosclerosis.

Otosclerosis does a lot of damage in a number of different ways. Cochlear otosclerosis causes the tiny filaments in the cochlea that transmit sound to the auditory nerve to harden and die. Stapedial otosclerosis causes a spongy, bony growth to take over the ear cavities thus locking one or all of the three tiny bones that vibrate to produce sound waves - the stapes, incus, and malus. Unfortunately, even when the growths are surgically removed, they can come back.

SYNDROMES/CONDITIONS

Otosclerosis sneaks up on you because the hearing loss is so gradual. Like a lot of people who have otosclerosis, but don't know it, I learned to informally lip-read and use facial expressions and context to help me figure out what people were saying. I did pretty well as long as the person was speaking in a moderately normal tone of voice and directly to me. If, however, they talked softly, turned away or talked behind my back, I heard nothing but random sound.

Unfortunately, just as glasses cannot correct colobomas or severe visual field loss, hearing aids can't completely correct all hearing losses caused by otosclerosis. Just as no amount of magnification will provide sight in those gaps caused by a visual field loss, amplification won't enable people like me to hear all of the sounds lost to cochlear otosclerosis. Hearing aids do help but, like glasses, they are not perfect.

To give you an idea of what it is like to be hearing impaired, here is what I might hear if a soft-spoken person said this sentence, or said it behind my back:

*“Tu gi o e ida ov wat it iz lk to be erin impard, er iz wat I mit er iv a oft-oken peron er to ay tiz entnz er wr tu ay it bhnd mi bak.”*

Because otosclerosis can strike at any age, it’s important to recognize the warning signs and get treatment as soon as possible.

Children and adults who complain of frequent ear infections when none are apparent, may well have otosclerosis. Balance problems or unexplained dizziness are other indicators of the disease. And surprisingly, those terrible, rude people who just don’t listen, and kids who disrupt the classroom when they’re sitting in the back and you’re talking to them from the front, may not be rude or terrible after all. They just might not be able to hear because this nasty spongy stuff is growing in their ears.

Early diagnosis and treatment is crucial. Fluoride can retard or slow the damage done by cochlear otosclerosis. Surgery can remove the growths. The incus, malus, and stapes can be repositioned or replaced. Hearing aids, phone amplifiers, and other devices can help restore some hearing. Organizations like the Texas Commission for the Deaf and Hard of Hearing, and Self Help for the Hard of Hearing, provide a wealth of information about resources and support.

The most important thing is to know is that this nasty little disease exists. When a doctor tells you there is no reason for your earaches, your balance problems or your minor hearing loss, insist that he/she find a reason or find another doctor. Had I done so years ago, I’d likely have a lot more hearing than I do.

## **Cytomegalovirus - Parent to Parent Support**

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

In looking at the 2001 Texas Deafblind Census, I became aware that twenty-seven (27) children on the Census were identified as having become deafblind as a result of Congenital Cytomegalovirus or CMV. This often benign infection which results in mild flu-like symptoms for most individuals, can have devastating consequences for the child who contracts the disease in utero. I recently became aware of a great website provided by the National Congenital CMV Disease Registry in Houston. This website can be found at <<http://www.bcm.tmc.edu/pedi/infect/cmv/index.htm>>. One of the features of this website and organization is a Parent to Parent connection service. This contact is meant to help parents by facilitating information exchange and general support. Anyone who is interested may join this group of parents. You simply need to visit the website and complete the information request form, or you may write to:

SYNDROMES/CONDITIONS

National Congenital CMV Disease Registry  
Feigin Center, Suite 1150  
1102 Bates Street, MC 3-2371  
Houston, Texas 77030-2399

The National Congenital CMV Disease Registry also provides a variety of other services families might want to know about, such as fact sheets and interesting articles on CMV, questions and answers, a newsletter, links to other resources and information on current research.

If your child has been disabled by congenital CMV infection, you

may want to connect with this organization. If you are a professional working with children who have CMV infection, visit the website to learn more about this disease.

## **Update on Short Classes at TSBVI**

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

Short Classes at TSBVI are off to a running start this year. These one-week classes are designed for academic, visually impaired students who attend school in their home district, but would benefit from intensive, individualized instruction on certain IEP objectives. TSBVI staff provide one-to-one instruction in any area related to the expanded core curriculum for the visually impaired. Tutoring on homework is provided to prevent students from falling behind while attending classes.

Due to large enrollment during our first year, the Texas legislature provided funding to add a third teacher, a teacher aide, and additional program funds. The classes for the current school year are listed below. We fill the classes on a first come, first served basis, beginning as early as the spring of the prior school year. Please call me at (512) 206-9119 to discuss programming for your student.

### **1. Disability-specific workshops with a pre-determined curriculum**

- *Independent Living Skills* Two programs - each scheduled for two 3-day weekends

High School Students (ages 16-22)

September 6 - 9

October 4 - 7

Middle School Students (ages 12-15)

March 21 - 24

April 25 - 28

- *Technology Weeks* (secondary students) Each program is one week in length  
Fall: November 11 – 16, Braille ‘n Speak  
Spring: February 3 – 8, JAWS
- *Math Week* (students going into algebra or geometry) - November 25 - 30
- *Issues in Low Vision* (described below) - May 1 - 5

**2. Instruction on Student’s IEP objectives, selected by LEA & TSBVI**

- September 16 - 21      High School
- October 21 - 26      Middle School
- December 9 - 14      Elementary School
- January 13 - 18      High School
- February 24 - Mar 1      Middle School
- April 7 - 12      Elementary School

**NEW CLASS IN LOW VISION**

If we can get enough students, we would like to add a new class from May 1 - 5 for secondary students with low vision. This class was inspired by last summer’s Texas Focus conference, which addressed the special needs of students with low vision. The class will address issues such as: self-advocacy, classroom modifications, choices in low vision aids, issues regarding reading medium, unique

mobility issues, driving issues, understanding and explaining your vision, and social-emotional issues. If you are interested, please call as soon as possible, so we will know if we have enough students to develop this class.

## **What Does This SBOE (State Board of Education) Rule Mean?**

By Jean Robinson, Family Specialist, TSBVI, VI Outreach

### **§89.1096. PROVISION OF SERVICES FOR STUDENTS PLACED BY THEIR PARENTS IN PRIVATE SCHOOLS OR FACILITIES**

- (d) Parents of an **eligible student ages 3 or 4** shall have the right to “dual enroll” their student in both the public school and the private school beginning on the student’s third birthday and continuing until the end of the school year in which the student turns five, subject to the following.
- (1) The student’s ARD committee shall develop an individualized education program (IEP) designed to provide the student with a FAPE in the least restrictive environment appropriate for the student.
  - (2) From the IEP, the parent and the district shall determine which special education and/or related services will be provided to the student and the location where those services will be provided, based on the requirements concerning placement in the least restrictive environment set forth in 34 CFR, §§300.550-300.553, and the policies and procedures of the district.
  - (3) For students served under the provisions of this subsection, the school district shall be responsible for the employment and supervision of the personnel

providing the service, providing the needed instructional materials, and maintaining pupil accounting records. Materials and services provided shall be consistent with those provided for students enrolled only in the public school and shall remain the property of the school district.

These provisions state that when two-year-olds leave ECI programs, their parents and school districts have the option of considering alternative settings to the Preschool Programs for Children with Disabilities (PPCD) classrooms. Typically, your child's peers don't attend a PPCD class unless they have a developmental delay. Therefore, the natural environment for your child may be a Parent's Day Out at your church, a Head Start or Early Head Start program, a private nursery school, or a child care facility. Your child can receive vision services, along with other special education services, in this alternative setting. Your child does not have to attend a school setting five days a week, but you can consider a combination of PPCD and private child care. Many toddlers with low vision or blindness benefit from playing with their typically developing peers. The child care staff can receive disability-specific training and materials if needed.

CCMS (Child Care Management System) provides funds for low-income families if a parent is actively working, in training, or attending school. This community-based program is funded by the Texas Workforce Commission. You must contact your local child care facility or local Texas Workforce Commission office to apply for CCMS funds.

## Lessons from Geese

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

It was 103 degrees “warm” in Austin yesterday in my backyard. I’m ready for August to end, so I’m taking today to write my fall article for *SEE/HEAR*. Just the thought of fall makes me feel cooler. Fall is a time of refreshing change and movement. By the time this gets published, classes will be full of new faces, parents will be juggling their work schedules with school activities, nature will be preparing itself for winter, and TCB will have launched itself into its new fiscal year plans.

While looking around for some inspiration for a planning meeting a while back, I came across an article a colleague sent me entitled “Lessons from Geese” - which I’ve borrowed for my own use today. It’s a short article that made its rounds in leadership development circles in recent years. Most sources attribute the work to Milton Olson. Inspired by migrating geese late one fall, Olson says that humans can learn a lot by studying our feathered friends’ interrelationships during their annual pilgrimage. The article includes a list of facts about geese and lessons for us. Fact One and its coupled lesson are my favorite:

Fact One - As each bird flaps its wings, it creates an “uplift” for the bird following. By flying in a “V” formation, the whole flock adds 71% greater flying range than if the bird flew alone.

Lesson - People who share a common direction and sense of community can get where they are going quicker and easier because they are traveling on the thrust of one another.

That last phrase could be an action motto for the Texas Commission for the Blind and our partners and allies in the field of rehabilitation and blindness. “Traveling on the thrust of one another” is such a vivid, accurate way to describe the value of these relationships.

Case in point: The Commission and the Texas School for the Blind and Visually Impaired are preparing to “fly” together on an important project soon. We plan to initiate a joint program to provide educational and vocational training for those blind high school graduates who still need intensive remediation in order to cultivate the skills, attitudes and opportunities necessary to meet the demands of adult living.

In our August board meeting, Dr. Phil Hatlen, TSBVI Superintendent, spoke to TCB’s Board members about the program from TSBVI’s viewpoint. Dr. Hatlen stated that an estimated 500 blind or visually impaired students graduate from high school across Texas each year. For varying reasons, some of these graduating students have not had the opportunity to receive an expanded core curriculum that included social, independent living and vocational skills. In addition, for some students, academics may not have been stressed as intensely as they should have been. The program will target these students who need to be better prepared, both academically and experientially, in order to be successful when venturing out into the world of work and the community.

From our viewpoint, studies have shown for years that students with visual impairments have traditionally been at risk for failure in securing employment right out of high school. One study I read a couple of years back reported the dismal statistic that only 30% of graduating students were working in a two-year period following school. To get the program off the ground, the Commission is work-

ing out the final details for selling some property we are no longer using for consumers because of its age and upkeep costs. Funds received from the sale would allow four apartments to be built on property owned by TSBVI on 49th Street in Austin.

The dual goals of the program are to provide students with training in the specialized skills of blindness and to remediate academic deficiencies. Skills training will focus on areas such as travel, communication, independent living, personal adjustment, career development and the acquisition of support systems. These components reflect the minimum expectation of competency held for all participants, and are necessary to confidently meet the challenges of adult living. Students will be expected to have the opportunity to live independently, manage their budget, do their own shopping, and access needed community resources - all within a supportive environment which facilitates and encourages self determination and team work. Individualized goals will be developed through assessment, exploration, and experiences which incorporate each student's individual strengths, interests, and abilities. Overall, this program believes in the potential of students who are blind, and with the proper training, philosophy and expectation, dreams are conceived, achieved and believed.

The proposed program received unanimous support from TCB's Board in August, and we're looking forward to the flight with TSBVI. Look for details in future *SEE/HEAR* articles.

## **When Need and Opportunity Meet**

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

So many times in our lives, a need exists, but there is little or no opportunity to meet that need. At other times, the opportunity to do something is there, but there is no apparent need. These are, at best, frustrating experiences!

We now have a situation in which a need has been identified, and the opportunity to do something about it exists. Pretty exciting, isn't it? The Texas Commission for the Blind (TCB) and the Texas School for the Blind and Visually Impaired (TSBVI) have begun serious discussions regarding the initiation of a post-secondary program for blind young adults. These young people, between the ages of 18 and 22, are often ill-prepared to move from school and family to community, independence, and employment. Often they are in need of remedial academic education, of additional orientation and mobility instruction, of independent living skills, of social skills, and of vocational preparation. A unique marriage of the skills available from TCB and TSBVI seems a perfect match for the potential needs of these young adults.

This is a dream that I have carried from California to Austin. Many years ago, my colleagues and I in California noted that many blind and visually impaired young people who were graduating from high school did not seem to be able to make the move from parent's home into the community. Further, they seemed to lack skills in daily living and social interaction that were basic to assimilation into the community. I'll never forget sitting at a table in a restaurant in Berkeley, California, in 1969, with two colleagues. We were all wondering why the bright and capable blind students, graduating from

local high schools in record numbers, were not moving out into the community, making social contacts, becoming employed. It didn't take us long to figure out that the early local school programs did a good job in most academic learning, but generally neglected the disability-specific needs of these young people. They were not capable of living independently, they had no job knowledge, nor skills, and while their academic skills were sometimes good, they didn't know how to apply academic learning to real life. So, they sat at home, waiting for the next agency to save them.

In 1972 the Living Skills Center for the Visually Impaired opened in San Pablo, a suburb of the San Francisco Bay Area. Recent high school graduates who were blind moved into apartments and began a transition program before the word "transition" was heard in special education. They received academic instruction when needed, living skills, orientation and mobility, social skills, and vocational instruction in a real-life setting. Suffice it to say that this program has been a tremendous success over the years, and is still offering one of the most effective, unique post-secondary programs in the country.

At last we have an opportunity to bring a similar program to Texas. Funds from TCB and from TSBVI are being used to build a four-unit apartment building at the back of the TSBVI property. A committee with representatives from both organizations is currently meeting to develop program and curriculum. The Boards of both organizations have enthusiastically endorsed this new endeavor. At last the newly graduated blind young person will have someplace to go that will address her/his unique needs as a congenitally blind person. At last this young person will have the skills and confidence to move into the community, and the self-esteem to become a part of the social and economic structure where she/he lives.

There is much work to be done on the program and on a funding pattern. We expect ground-breaking on the apartment building in early October, with a completion date in the Spring. We may be ready for the first participants in late Spring or Summer. It finally looks like opportunity and need are meeting, and blind young people will be the beneficiaries.

### **Legislative Update**

By Cyral Miller, Director of Outreach,  
Texas School for the Blind & Visually Impaired

Every two years, the Texas Legislature creates new laws and modifies old ones. Although several bills generate public comment and publicity, the majority are passed without fanfare. Below is a sampling of a few legislative initiatives you may not have heard about, with implications for persons with disabilities. If you would like more information, a great source is the Texas Legislature Online, on the web at <<http://www.capitol.state.tx.us/>>. You'll find information there on legislators, legislative action in general, the entire text of each bill, an analysis of its meaning and many related resources and links. Much of the information for this article came from this source, as well as the Texas Governor's Committee on People with Disabilities website at <[http://www.governor.state.tx.us/the\\_office/gcopd\\_div/main.htm](http://www.governor.state.tx.us/the_office/gcopd_div/main.htm)>.

**SB1196** addresses school discipline and has new language about enforcement of behavior plans and special education students. This bill amends the Education Code, to prohibit placing students alone for any period of time in a confined area without the ability to leave.

**SB 1735** also amends the Education Code, to ensure that disci-

iplinary actions for students with disabilities involving change of placement receive review by the ARD committee, and are in line with federal law and regulations for students in special education. Sec. 29.017 of this bill addresses the transfer of parental rights to students with disabilities who are 18 years old or older. These students have the same right to make educational decisions as a student without a disability, except that the school district is required to provide notices to both the student and the parents.

**HB 1144** establish new rules regarding the state educational accountability system, and establishes a new master mathematics teacher certification program, to be created not later than January 1, 2003. The bill requires the Commissioner of Education to develop and make available professional development resources to assist mathematics teachers. The bill also addresses end of course assessment instruments for Algebra 1. The Admission, Review, and Dismissal committee of a student in a special education program must determine whether allowable modifications are necessary for the student to take the assessment, or whether the student should be exempted.

**HB 477** establishes a pilot program for coordinating case management services. There is a concern that recent changes, requiring time-limited benefits along with work requirements, have helped those with minimal barriers into work, but left those with more significant needs behind. The bill requires the Texas Department of Human Services and the Texas Workforce Commission to develop a plan for clients with higher levels of barriers to employment and provide them with coordinated services.

**HB 2510** and **SB 1456** both address the growing incidence of diabetes in our nation. They create a new Diabetes Research Center at the Texas Tech University campus in El Paso, and a Pediatric

Diabetes Research Working Group in the Department of Health.

**HB 2345** modifies provisions regarding the program run by the Texas Commission for the Deaf and Hard of Hearing that provides vouchers for specialized telecommunications equipment, and removes the \$35 fee that is required for an individual to receive a voucher.

## **Deaf-Blind Multiple Disabilities Medicaid Waiver Update**

By Stephen Schoen, Program Consultant

Deaf-Blind Multiple Disabilities Medicaid Waiver Program

Texas is the only state in the U.S. to have a Medicaid Waiver Program specifically for persons who are deaf-blind with multiple disabilities. The waiver program had its roots in a deaf-blind program that began in 1984 as a result of self-advocacy by parents of children who were deaf-blind with multiple disabilities due to Rubella Syndrome. As their children graduated from public special education, parents realized there would be no specific program that could serve their grown children. The parents advocated to the Legislature for the development of a residential program tailored to meet the needs of adults with deafblindness. The Texas Commission for the Deaf and Hard of Hearing first administered the program in three group homes located in Houston, San Antonio, and Dallas. After one year, the Texas Rehabilitation Commission (TRC) took over administration duties. Under TRC's direction, the program expanded service area to many more areas of the state. In 1995, TRC converted the program into the Deaf-Blind Multiple Disabilities Medicaid Waiver program, which expanded the number of people served and the types of services delivered. In 1999, the Legislature moved the program to the Texas Department of Human Services (TDHS). The program is currently serving 110 individuals and by the end of August, plans to serve 145 individuals.

## FREQUENTLY ASKED QUESTIONS

### 1) WHAT IS A MEDICAID WAIVER?

A Medicaid Waiver is a long-term care program, which provides services in order to prevent people from being institutionalized.

### 2) WHICH WAIVER SHOULD I CHOOSE FOR MY SON OR DAUGHTER?

There are 4 major waivers operated by the Texas Department of Human Services (DHS) and 3 waivers operated by Texas Mental Health and Mental Retardation (MHMR). The DHS waivers are Community Based Assistance (CBA), which is for adults eligible for nursing home care; Medically Dependent Children's Waiver Program (MDCP), for children eligible for nursing home care; Community Living Assistance & Support Services (CLASS), for people of all ages who have developmental disabilities other than mental retardation; and the DB-MD waiver for people who are deaf-blind with multiple disabilities. The Home & Community Support (HCS), Mental Retardation Local Authority (MRLA), and Home & Community Support OBRA (HCS-O) Waivers operated by MHMR all serve people who have mental retardation. A "Consolidated Waiver" combining all of the above-mentioned waivers will be piloted in the San Antonio area in the very near future. Frequently, people who are eligible for the DB-MD Waiver are also eligible for some of these other waivers. Factors in making a choice include: your number on the waiting list, private provider choice in your geographic area, and services available from each waiver. One thing is clear: Most people are better off *with* waiver services than *without*. I would advise people to get on all interest lists for which they may be eligible. Before making a choice of waiver, I would talk to professionals from school, public agencies, advocacy groups such as the Deaf-Blind Multihandicapped Association of Texas (DBMAT), and other parents.

### **3) WHO IS ELIGIBLE FOR THE DB-MD WAIVER?**

Consumers must be age 18 or over and have a disability of deafblindness with a third developmental disability such as mental retardation or autism. This disability must result in a need for long-term care to prevent institutionalization.

### **4) HOW ARE SERVICES PROVIDED IN THE DB-MD WAIVER?**

Services are provided by private vendors who contract with the Department of Human Services to provide all services from a menu of services.

### **5) WHAT CHOICES ARE AVAILABLE?**

Within the DB-MD Waiver, individuals have a choice of private providers, type of residence, type of support service received, and location of delivered service. Providers are available in all major Texas metropolitan areas and in many rural areas.

### **6) WHAT SERVICES ARE AVAILABLE IN THE DB-MD WAIVER?**

Services include: assisted living (24 hour care); residential habilitation (support to help individuals do activities for themselves); intervenor (a person who assists the individual in relating to other people and the community); orientation and mobility (training to navigate more independently); therapies (including occupational therapy, physical therapy and speech therapy); and behavior communication specialist (consultation with specialists in the field of deafblindness).

### **7) WHERE ARE THE INDIVIDUALS SERVED?**

Individuals can be served in the home of their parents or guardians, an apartment, or a group home with six or less people.

**8) ARE THERE OTHER SERVICES PROVIDED BY THE DB-MD WAIVER?**

The DB-MD Program provides an annual summer week-long camping experience for people who are deaf-blind. It also partners with the DBMAT and other Texas state agencies to conduct an annual family conference, which is usually held in early October.

**9) HOW LONG MAY A PERSON RECEIVE SERVICES FROM THE DB-MD WAIVER?**

Services from the DB-MD Waiver program may last for a person's lifetime.

**10) WHEN SHOULD A PERSON APPLY FOR THE DB-MD WAIVER?**

A person should put their name on the DB-MD Interest List immediately. Even though the waiver only serves individuals who are 18 years old and over, we encourage children who are younger to be on the Interest List so we can plan for future services.

**11) HOW LONG WILL I NEED TO WAIT IF I PUT MY NAME ON THE INTEREST LIST?**

At this moment, the DB-MD Waiver has contacted all individuals on the Interest List who are over age 18 to offer them services. If a person over age 18 applies today, they would be able to begin services as soon as eligibility is established. When the number of served individuals reaches 145, new referrals will again need to wait for services.

**12) I'M ALREADY IN ANOTHER MEDICAID WAIVER (OR INTERMEDIATE CARE [ICF] GROUP HOME). CAN THE DB-MD WAIVER ALSO PROVIDE SERVICES?**

No. All Medicaid Waiver or ICF services are delivered using the same type of Medicaid Long Term Care funding. A person can only receive one of these types of programs at any time. A person can switch from one waiver to another as long as he is eligible. But, he must realize that he will be subject to a long waiting list if he tries to switch back.

**13) MY CHILD RECEIVES SERVICES FROM TEXAS COMMISSION FOR THE BLIND (TCB), AND/OR THE SCHOOL SYSTEM. CAN SHE ALSO RECEIVE SERVICES FROM THE DB-MD WAIVER?**

Yes. Programs from the TCB and the DB-MD Waiver can supplement each other to the benefit of consumers. For example, job placement and supported employment may be provided by TCB while long-term support is provided by the DB-MD Waiver.

**14) HOW DO I APPLY FOR OR GET MORE INFORMATION ABOUT THE DB-MD WAIVER?**

Call me, Steve Schoen, the Program Consultant for the DB-MD Medicaid Waiver, at (512 ) 438-2622 or send an e-mail to <stephen.schoen@dhs.state.tx.us>. I will send you a brochure and Interest List Survey Form. Once I receive your completed survey form, your name will be placed on the DB-MD Interest List.

# **CLASSIFIED**

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

**November 27, 2001**

## **Making a Difference in the Lives of Students with the Most Severe Disabilities**

Focuses on the best practices for students with profound impairments. Participants will learn to identify a range of arousal states and will practice an observational assessment procedure for identifying desirable states and techniques for modifying undesirable states. The relationship of arousal states to learning and instruction will be emphasized.

Region XVIII ESC, Midland, TX  
Contact: Fred Martinez, (915) 563-2380

**November 29, 2001**

## **Communication & Cognitive Development: Assessment and Intervention for Children with Multiple Disabilities**

A program of comprehensive instruction for professionals working with nonverbal children who have complex or multiple disabilities, including severe cognitive limitations, deafblindness and autism spectrum disorders. Includes both instruction and practical exercises to help participants learn how to help students interact with social and physical environments.

Region XX ESC, San Antonio, TX  
Contact: Britt Green, (210) 370-5431, E-mail: britt.green@esc20.net

**November 28, 2001**

**SEEK: Successfully Educating Exceptional Kids**

SEEK is a program for students with autism or pervasive developmental disorders. This workshop will focus on how to use structured teaching activities for students with autism. Other topics will include assessment, sensory integration, the picture exchange communication system (PECS), and the grief process.

Region VI ESC, Huntsville, Texas  
Contact: Anissa Barton, (936) 435-2155

**November 30, 2001**

**Speech Therapy Series: Speech Diagnosis and Treatment of Students Who Are Deaf and Hard of Hearing**

This session provides opportunities to explore the assessment, IEP development, and intervention processes necessary to successfully support students who are deaf and hard of hearing. Participants will examine general language intervention strategies, models for teacher prompting, and principles of “focused stimulation.” The session will include the sharing of game ideas and commercial resources.

Region XX ESC, San Antonio, Texas  
Contact: John L. Bond, (210) 370-5418 (v/tty)  
E-mail: john.bond@esc20.net

**December 3, 2001**

**Correlating O&M Goals and Objectives with the  
Texas Essential Knowledge and Skill**

O&M Specialists will be guided through correlating their goals and objectives with the state curriculum - Texas Essential Knowledge and Skills. The presenters will facilitate the group through the TEKS for alignment and implementation of strategies in orientation and mobility. Participants will gain a deeper understanding of the connections between TEKS and orientation and mobility strategies to improve student performance.

**Designing Curriculum for Divergent Learners**

The reauthorization of the Individuals with Disabilities Education Act of 1997 calls for providing access to the general education curriculum as a means for improving education for students with disabilities. Skip Stahl will focus on how to redesign the general curriculum to meet the needs of students with physical, emotional, sensory, and cognitive disabilities. He will also present the latest research data on effective practices for increasing access to the general curriculum.

Region XI ESC, Fort Worth, Texas  
Contact for both workshops:  
Olga Uriegas, (817) 740-3619

**December 4, 2001**

**Training with Low Vision Devices**

This presentation will demystify low vision devices by defining categories, describing idiosyncrasies and demonstrating the appropriate uses of these devices. Basic optics, as they relate to the use and understanding of reading lenses and telescopes, will be presented.

Region VI ESC, Huntsville, Texas  
Contact: Gwynne Reeves, (936) 435-2155

**December 4, 2001**

**Treatment and Education of Autistic  
and Communication Handicapped Children**

This is an overview of the TEACCH program. TEACCH cannot be reduced to a technique, a set of techniques, or even a method. It is a complete program of services for people with autism and other severe communication disorders, which makes use of several techniques, depending on the individual's needs and emerging capabilities. The main goal of TEACCH is to help students attain maximum autonomy as adults. This includes helping them understand the world that surrounds them, acquiring communication skills that will enable them to relate to other people and giving them the competence to make choices concerning their lives. The major thrust is toward improving communication skills, and is not for participants who will attend TEACCH team training on Dec. 5-6.

Region XVII ESC, Lubbock, Texas  
Contact: Jill Watkins (806) 792-5468, ext. 870  
E-mail: [jwatkins@esc17.net](mailto:jwatkins@esc17.net)

**December 5, 2001**

**F.A.C.E.S.**

**Functional Academic Curriculum for Exceptional Students**

In this second of a two-day training, discover the value of F.A.C.E.S. - Functional Academic Curriculum for Exceptional Students, a curricular framework aligned with the TEKS. This curriculum covers Math, Science, Social Studies, Physical Health and Vocational skills (elementary to high school) for students with moderate to severe disabilities.

Region VI ESC, Huntsville, Texas

Contact: Noyda Thornton, (936) 435-2195

**November 29, 2001**

**IntelliTalk II**

Presenter: Patti Rea, Independent Consultant - Celina, Texas

**December 7, 2001**

Writing Alternatives and AT Consideration:  
A Decision Making Process

Presenter: Denise DeCoste, Independent Consultant - Potomac, MD

**January 30 - 31, 2002**

Evaluating Technology Needs of Students with Visual Impairments

Presenter: Ike Presley, AFB - Atlanta, Georgia

Region IV ESC, Houston, Texas

Contact: Karen Crone, (713) 744-6324

**December 7, 2001**

**Discrete Trial Training for Students with Special Needs**

Participants will become familiar with the fundamental aspects of Discrete Trial Training. This technique breaks down a skill into small tasks that the educator teaches in parts, or “trials” to the student. Each trial consists of an instruction, a prompt, a response, and feedback. Participants will be able to define what discrete trials are and what they are not, including the relationship of Applied Behavior Analysis (ABA) and discrete trial. Behavior concepts such as shaping, chaining, and modeling will be demonstrated. Participants will also learn how to construct and conduct trials and how to collect data for IEP documentation and behavior plan documentation.

Region VI ESC, Huntsville, Texas  
Contact: Anissa Barton, (936) 435-2155

**December 13, 2001**

**Communication & Calendar Systems for Students with Severe Cognitive Disabilities**

Participants will learn about the importance of routines as an organizational approach for teaching this population of students and will practice the routine-development process. Participants will examine a communication model that draws from several methodologies, including Dr. Jan van Dijk’s, and incorporates the use of individual calendar systems.

Region XX ESC, San Antonio, Texas  
Contact: Deborah Thompson, (210) 370-5433  
E-mail: [deborah.thompson@esc20.net](mailto:deborah.thompson@esc20.net)

**January 24, 2002**

**Augmentative Communication, Technology,  
and Special Devices for the Classroom**

Participants will be shown how to set up a classroom for communication and accessibility, using simple speech devices, picture communication symbols, adaptive keyboards and switches. Overlays will be made for the devices and programmed for use in many different classrooms and settings. Participants will have hands on experience in adapting battery operated devices for switch accessibility. (Participants will be provided with one battery operated device, such as a tape recorder or toy.) A variety of easily accessible software in the areas of telling time, cause and effect, art and concrete math manipulatives will be demonstrated.

Region VI ESC, Huntsville, Texas  
Contact: Nodya Thornton, (936) 435-2155

**April 8, 2002**

**Autism in the Visually Impaired Child**  
Presenters: Terese Pawletko & Lorraine Rociassano

Region X ESC, Richardson, Texas  
Contact: Kitra Gray, (972) 348-1580  
or grayk@esc10.net

Handouts from these presenters' session at AER 2000  
can be found on the TSBVI website at  
<<http://www.tsbvi.edu/Education/vmi/index.htm>>.

## **TSBVI Outreach Video Conferences**

Sharon Nichols and Holly Cooper of TSBVI Outreach will be offering a number of video conference workshops for the 2001-2002 school year. All broadcasts will be held from 8:30 - 10:30 a.m. (CST). From 10:30 - 11:00 a.m., participants will be able to ask questions about the specific technology discussed that day, as well as any questions about any piece of technology. If possible, participants should bring to the training the piece of technology being discussed.

These workshops can be accessed by anyone who is part of the TxED (formerly known as ESCONETT) network and up to five sites that are not part of that network. To get connected, please contact Scott Wimpres at [ScottWimpres@tsbvi.edu](mailto:ScottWimpres@tsbvi.edu). Videotapes of the session will be available. Any other questions can be sent to:

[SharonNichols@tsbvi.edu](mailto:SharonNichols@tsbvi.edu),  
[HollyCooper@tsbvi.edu](mailto:HollyCooper@tsbvi.edu) or  
[JimDurkel@tsbvi.edu](mailto:JimDurkel@tsbvi.edu).

**December 12, 2001** - JAWS and Internet Access

**January 16, 2002** - ZoomText Xtra! Document Reader

**March 20, 2002** - Braille Lite, Braille 'n Speak & Type 'n Speak

**April 10, 2002** - Home Page Reader and Internet Access

**May 9, 2002** - Matching Technology to the Student

**Texas School for the Blind and Visually Impaired**  
is pleased to announce a new product:

**Elementary Concepts** for Students with Visual Impairments  
by Brenda O'Sail, Nancy Levack,  
Linda Donovan and Debra Sewell

This curriculum is written for students younger than twelve years of age who have visual impairments and are not yet reading, writing, or doing math at a first grade level. It is based on a thematic approach to teaching. Specific units of study have been included and unit activities include concept development, math readiness, reading and writing readiness, music and games, arts, cooking and eating, pretend play, story time, and extended discussion or activities. Infused skills in cognition, communication, sensory and motor skills, readiness, work skills, and music skills are taught through the themes.

Elementary Concepts, Order #59435ECC, sells for \$105.00,  
and may be ordered by contacting  
Trudy Ross at (512) 206-9215, or [TrudyRoss@tsbvi.edu](mailto:TrudyRoss@tsbvi.edu).

**April 3 - 7, 2002**  
**Council for Exceptional Children's**  
**Annual Convention and Exposition**  
New York, New York

Contact: Division on Visual Impairments, The Council for  
Exceptional Children, (888) 232-7733  
or [www.cec.sped.org](http://www.cec.sped.org)

**April 4 - 6, 2002**

**Conference for TAER**

(Texas Chapter of the Association for Education  
and Rehabilitation of the Blind and Visually Impaired)

Harvey Hotel, Richardson, Texas

Contact: Neva Fairchild, (214) 688-7007  
or [nevaf@tcb.state.tx.us](mailto:nevaf@tcb.state.tx.us)

**SEE/HEAR**

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**NEWSLETTER CONTRIBUTIONS**

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

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

**DEADLINES FOR ARTICLES**

December 1st for the Winter edition  
March 1st for the Spring edition  
June 1st for the Summer edition  
September 1st for the Fall edition

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

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

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